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Living With an Ostomy

An ostomy (or stoma) is a surgical opening made in the skin when a problem is not allowing a part of the body to function well. A tracheostomy is done for breathing problems, while an abdominal (belly) ostomy can allow wastes to leave from the intestines (ileostomy or colostomy) or from the bladder (urostomy). Get practical tips for managing a tracheostomy, colostomy, ileostomy, or urostomy.

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Talking to People About Your Ostomy

You might be worried about talking to others about your surgery and ostomy. Or maybe you're worried about how others will accept you and how your social life may change.

Your friends and relatives may ask questions about your operation. Tell them only as much as you want them to know. Don't feel as if you have to explain your surgery to everyone who asks.

Who to tell first

When you're deciding who to tell about your ostomy, it's best to first talk to the people who need to know. These people include your health care team, your spouse or partner, and friends and family who will be involved in helping you recover from surgery. Besides the people you talk to first, you can decide who to tell. Don't feel that you have to explain it to everyone. But telling your story can help educate others and help them understand how you have been affected by your surgery.

If you have children

It's best to answer their questions simply and truthfully. A simple explanation is often enough for them. Depending on what type of stoma you have, they may ask questions about it and want to see it. Talking about your surgery in a natural way will help get rid of any wrong ideas that they may have. They will accept your ostomy much the same way you do.

If you're single and dating

You might be able to choose when to tell a new partner, depending on what type of stoma you have. Stress the fact that this surgery was necessary and managing your ostomy does not affect your activities and enjoyment of life. This not only lessens your anxiety, but if there is an issue that cannot be overcome, the letdown is not as harsh as it might be later. Do not wait until intimate sexual contact leads to discovery.

If you're in a relationship, married, or considering marriage

Talk with your partner about life with an ostomy and its effect on sex, children, and your lifestyle. This will help reduce stress about the situation. Going to an ostomy support group meeting together may also be helpful. Talking to other couples in which one partner has an ostomy will give you both an experienced point of view. See [Intimacy and Sexuality When You Have an Ostomy](#)¹ for more on this.

If you don't feel like talking

Learning to talk openly about an ostomy may feel like a big challenge, but it will get easier over time. Just as with any life change having a positive outlook, patience, and a sense of humor are key. There may be times after surgery when you feel discouraged. You may feel alone and isolated. Because the whole experience is so new to you, you may feel awkward, frustrated, and uncertain. Feeling discouraged is real and normal. You might cry, be angry, and react in ways that are unusual for you. Talking to a trusted friend, nurse, clergy, and certainly another person with an ostomy may help you work

through those feelings.

Hyperlinks

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If You Need Medical Care and Have an Ostomy

You probably have different health care teams that help care for you. Let them know about your ostomy. If you need to go to the hospital, take your ostomy supplies with you. The hospital might not have the same type you use.

Do not assume that all hospital staff know a lot about ostomies. Depending on the type of ostomy you have, you may need to do some explaining and teaching. Remember it might be a hospital where ostomy patients are rare, or you might need care for problems not related to your ostomy. Do not let the hospital staff do anything you think

may be harmful. For example, if you have a tracheostomy, make sure they know the specific types of equipment you use. Or, if you have a colostomy or ileostomy, do not let them give you laxatives, give an enema through your stoma or rectum, or use a rectal thermometer. If you're in doubt about any procedure, ask to talk to your doctor first.

Also ask to have the following information listed on your chart:

- Type of ostomy you have
- What part of your body has been removed (if any has)
- Details of your management routine and the equipment and products used
- Procedures to be avoided

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Working, Staying Active, and Traveling When You Have an Ostomy

Know what's safe for your type of ostomy

Everyone needs daily exercise to stay healthy and for the body to function well. An ostomy should not keep you from exercising and playing sports. In fact, people with ostomies are distance runners, weight lifters, skiers, swimmers, and take part in most sports. But it's important to know what activities may not be safe for your type of ostomy. There are safety measures you may need to think about. For instance, many doctors recommend avoiding contact sports because of possible injury to the stoma from a severe blow. But special protection may be able to help prevent these problems. Talk to your health care team about any limitations you may have.

If you have a tracheostomy, you may have more limitations than people with other types of ostomies. This is because a tracheostomy stoma is your airway. You will need to be careful when doing activities that involve water. You will also need to guard your stoma from other things that are harmful, such as certain particles, objects, or substances in the air.

Most of the hints and tips below are for people who have an ostomy in their abdomen (belly), such as a colostomy, ileostomy, or urostomy. People with these types of ostomies sometimes wear longer shirts or exercise pants and shorts with higher waistbands, depending on the location of the stoma.

Swimming and water sports

People with a tracheostomy should ask their health care team about precautions related to swimming and water sports. People with abdominal ostomies can swim with a pouching system in place. For sanitary reasons, use a stick-on pouch when you go swimming in fresh water or in the ocean. Remember these points:

- If you use a support ostomy belt, you can leave it on if you want to.
- You may want to protect the barrier by taping the edges with waterproof tape.
- Before swimming, empty your pouch and remember to eat lightly.

Choosing a swim suit

You may want to choose a swim suit with a lining for a smoother profile. Dark colors or busy patterns can also help hide the pouching system.

For women:

- Consider a suit with a well-placed skirt or ruffle.
- You may also wear stretch panties made especially for swim suits.

For men:

- Try a suit with a higher waist band or longer leg.
- You may also wear bike shorts or a support garment sold in men's underwear departments or athletic wear departments under your bathing suit.
- Some men may prefer to wear a tank top and trunks, if the stoma is above the belt line.

Traveling when you have an ostomy

All methods of travel are open to people who have ostomies. Many people with ostomies travel just like everyone else; this includes camping trips, cruises, and air travel. Here are some travel tips:

- Know your limitations for activities and type of travel, if any.
- Take along enough supplies to last the entire trip plus some extras. Double what you think you may need, because supplies may not be easy to get where you're going. Even if you don't expect to need them, take along everything you need. Plastic bags with sealable tops may be used for pouch and equipment disposal, but local areas may have certain laws for medical waste that involved body fluids.
- Leave home fully prepared. Find out if and where you can get supplies before a long trip. A local ostomy support group may be able to help you find ostomy supplies and local medical professionals.

Traveling by car:

- Seat belts will not harm abdominal stomas when adjusted comfortably.
- Keep your supplies in the coolest part of the car. Avoid the trunk or back window ledge.

Traveling by plane:

- Remember that checked-in luggage sometimes gets lost. **Carry extra supplies on the plane with you.** Small cosmetic bags or shaving kits with plastic linings work well. These should be kept in your carry-on bag.
- Air travel security will generally let you carry on all medical supplies. You may want to review the Transportation Security Administration's information at: www.tsa.dhs.gov/travelers/airtravel/specialneeds/index.shtm¹

Traveling abroad:

- To avoid problems with customs or luggage inspection, **have a note from your doctor stating that you need to carry ostomy supplies and medicine by hand.** Further problems might be avoided by having this information translated into the languages of the countries you are visiting.
- Be aware of any special provisions your insurance coverage may have should you need care while you are away. If you are traveling abroad, **get a current list of English-speaking doctors in the areas you'll be visiting.** The International Association for Medical Assistance to Travelers (IAMAT) at 716-754-4883 or www.iamat.org² publishes lists of English speaking doctors who were trained in North America or Europe and are available in many countries around the world.
- Traveler's diarrhea is a common problem for tourists in foreign countries. The most common cause of diarrhea is impure water and/or food. It may also be caused by changes in water, food, or climate. Don't eat unpeeled fruits and raw vegetables. Be sure drinking water is safe. If the water isn't safe, don't use the ice either. Bottled water or boiled water is recommended, even for brushing your teeth. **Note for people with ileostomies:** your body may lose water and minerals quickly when you have diarrhea. For this reason, you may need medicine to stop the fluid and electrolyte loss. Your doctor can give you a prescription to control diarrhea. Get it filled before you leave so that you can take the medicine with you just in case you need it.

Hyperlinks

1. <http://www.tsa.dhs.gov/travelers/airtravel/specialneeds/index.shtm>
2. <http://www.iamat.org>

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Intimacy and Sexuality When You Have

an Ostomy

Sexual relationships and intimacy are important and fulfilling aspects of your life that should continue after ostomy surgery. But there is a period of adjustment after surgery, and some ostomies can affect intimate relationships more than others. Communication is a key factor in re-establishing sexual expression and intimacy.

Ostomy surgery may present more concerns for single people. When you choose to tell that someone special depends on the type of stoma you have, and the relationship you have with the other person.

If you have a tracheostomy, you may want to clear secretions in the tube or stoma before having intimate contact.

If you have an abdominal ostomy, you may want to empty the pouch beforehand.

Discuss any sexuality concerns you have with your partner. A stoma is quite a change in how you look and can make you feel anxious and self-conscious. It's likely that your partner will be anxious about sex, too, and may be afraid of hurting your stoma or dislodging the equipment. Talk to your partner about the fact that sex is not likely to harm the stoma. Try to be warm, tender, and patient with each other.

For people with abdominal ostomies, sexual function may or may not change. Women could sometimes have pain during sex. Men may have trouble getting and keeping an erection. Their sexual potency may sometimes be affected for a short time. These problems usually get better with time.

Body contact during sex will usually not hurt the stoma. People with a tracheostomy need to be sure the tube is secure and protected, and may need to try different positions. People with abdominal ostomies can also vary positions if the pouch or stoma is in the way.

For people with abdominal ostomies, the type of intimate clothing that is worn may need to change. For example, women may consider wearing open panties, "teddies," intimacy wraps, or a short slip or nightie. Men may consider wearing a wrap or cummerbund around the midsection to secure the pouch. You can buy many types of pouch covers or you can make your own.

For more detailed information, see [Sex and the Man With Cancer](#)¹ or [Sex and the Woman With Cancer](#).²

Pregnancy with an ostomy

Pregnancy is possible for women who have had ostomy surgery. The ostomy itself is not a reason to avoid pregnancy. But before you plan to get pregnant you should talk about it with your doctor. If you are healthy, the risk during childbirth appears to be no greater than for other mothers. Of course, any other health problems must be considered and discussed with your doctor.

Hyperlinks

1. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects/sexuality-for-men-with-cancer.html
2. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects/sexuality-for-women-with-cancer.html

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For Parents of Children With Ostomies

If your child has an ostomy, you probably have many questions and concerns. When the surgeon said your child needed this surgery, your first reaction may have been, “Is this the only choice?” Your doctor no doubt assured you that the ostomy was needed to save your child’s life. You may have felt shock. You may have asked yourself, “Why did this happen to us?”

It helps to talk to a good friend, the doctor, clergy, an ostomy nurse, or the parents of a child who has an ostomy. This will prepare you to help your child adjust to the ostomy. Deal with your own feelings first, then you’ll be better able to give your child the emotional support he or she needs.

Your child’s health care team will teach you and your child on how to care for your child’s ostomy. They will be sure you have the training and supplies you need, along with support for any problems that come up or questions you may have.

Psychosocial issues

As your child begins to recover from ostomy surgery, there are many ways you can be a source of strength and support:

- **Acceptance is key.** Your child may be afraid that young friends and relatives won’t want to be around them. Encourage your child to talk to you about these feelings. If you are open and natural about the ostomy, he or she will be, too.
- **Empathy.** Your child needs to feel that you understand what it’s like to have a ostomy. It’s hard not to overprotect and pamper a child who is recovering from major surgery. Listen, try to understand feelings, be encouraging, and be tactful.
- **If your child is very young,** he or she will probably accept the ostomy more easily than you. Your child will grow up with it and it will become a natural part of them.
- **If your child is a teenager** who is facing all the problems that come with puberty and adolescence, this surgery comes at an especially difficult time. The changes in body image caused by the ostomy may make the stresses of adolescence worse. Your teenager may feel unattractive, rejected, and different because of the ostomy.

If problems such as changes in behavior, falling grades, irritability, or loss of interest in activities persist, talk with your child’s doctor or ostomy nurse about getting help from a mental health professional. There are online resources that may be helpful.

Your child's ostomy care

Even a very young child can be taught to care for an ostomy. An older child can get supplies together and learn the steps of caring for the ostomy until the whole process can be done alone. You may want to use a teaching process that begins with your child helping you. Later on you can help them, then over time, stand by to help only if you are needed.

A tracheostomy involves your child's airway and will require very different care than other types of ostomies. You will probably have a home care nurse to help once your child is at home. For children with abdominal ostomies, you'll work with your health care team to help your child learn to take care of the ostomy and pouching system on his or her own. Your child may need some help and support at first. He or she may be unsure about how to use the new supplies, feel physically weak, and tire easily. A sense of humor and a positive attitude will help you and your family through this time.

It's very important that your child have support and help from an ostomy nurse. This person has special training in ostomy management and the emotional needs that may come at this time of change. To find an ostomy nurse in your area, call the Wound, Ostomy and Continence Nurses Society at 1-888-224-9626 or visit their website at www.wocn.org¹.

Be prepared for trial and error in caring for, or helping to care for, your child's ostomy. There are some changes that will happen in the beginning that won't happen later. There may be diet adjustments, skin problems, pouching problems, and more. The important thing to remember is that all of these changes will become more comfortable over time.

Going back to school and everyday living

Be flexible as your child adjusts to school and everyday living. Children with a tracheostomy will require different care during school and activities than children with abdominal ostomies.

Have a plan in place in case there are problems. The school nurse should be aware of your child's ostomy and how to care for any problems that come up.

Keep supplies available at school and activities. Ostomy care supplies should include everything you use when you're at home. For example, for children with abdominal ostomies, have supplies available if the pouch leaks at school. If that happens, your child can go to the school nurse. Or you might pick up your child for a

pouching system change at home, then take them back to school. One youngster tells this story: he noticed that his pouch was leaking and had stained his pants. Instead of rushing out of the class with everyone else, he calmly waited until everyone had left the room. This way, he was able to avoid embarrassment and called home so that his mother could pick him up. You may want to visit the principal, the classroom teacher, the physical education teacher, and the school nurse to explain your child's needs.

Talk about what can be done if any problems come up while your child is away from home. A child with a tracheostomy will have different limitations than a child with an abdominal ostomy. Depending on the type of ostomy and age of your child, they can usually take part in most sports, go on overnight trips, camp, and, enjoy the same activities as before. At first, it may be hard to let your child go away on his or her own. If you can help your child know how to best handle any problems that may come up, he or she won't need any "special" treatment or seem different from any other children.

Talk with your child about how they'll tell others. He or she may want to tell close friends and loved ones. Naturally, people will be curious. Once the surgery is explained, chances are your child will be accepted as before. Your child is likely to repeat what you say. If you talk about the surgery in a natural way with others, your child will too.

Remind your child to think about others. For example, children with a tracheostomy may need to clear secretions often, especially if they are in close contact with other children. For children with abdominal ostomies, cleaning up the bathroom after ostomy care is important. You and your child are facing a new situation in your lives. If it's approached with openness, firmness, and a sense of humor, you'll find that a ostomy won't stop your son or daughter from taking part in life's everyday activities.

Be around other kids with ostomies. This can be a great help. There are summer camps for children with ostomies.

- The Youth Rally is a camp for young people ages 11 to 17 who have abdominal ostomies or any other bowel or bladder changes. Planned learning sessions on self-esteem, body image, hygiene, and ostomy issues, plus discussion sessions, craft projects, tours, and sports are offered. Visit www.youthrally.org² for more information.
- Champ Camp is a camp for children who have tracheostomies and children who need respiratory (breathing) assistance. Campers can have full participation in camp events, including outdoor activities and sports. Visit www.champcamp.org³ to learn more.

Hyperlinks

1. <http://www.wocn.org>
2. <http://www.youthrally.org>
3. <http://www.champcamp.org>

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Getting Ostomy Help, Information, and Support

There are many ways to better understand and manage life with a ostomy. Your doctor and ostomy nurse are important sources of information and support. A lot of information can also be found on various websites, such as those listed here.

Talking with someone who has gone through the same experience can help, too. Look for an ostomy visitor program in your area. This is a program that matches you with a volunteer who, like you, has a ostomy. They can answer many of your questions about day-to-day life.

An **ostomy support group** can also be very helpful. It allows you to share your feelings and ask questions as you learn to live with your ostomy. It also lets you share your successes with others who may need the benefit of your experience. Most ostomy visitor programs and support groups are sponsored by local chapters of the United Ostomy Associations of America (UOAA).

Cancer centers have **ostomy rehabilitation programs** which include all types of ostomies, whether or not they are caused by cancer. Ask about services that may be available, such as educational pamphlets, and ostomy supplies for people without insurance coverage. You can also contact the American Cancer Society (1-800-227-2345) for information on ostomy support groups.

Other organizations and websites*

Wound, Ostomy and Continence Nurses Society (WOCN) Toll-free number: 1-888-

224-9626 Website: www.wocn.org¹

The WOC nurse is a specialist in ostomy care and rehabilitation. These nurses care for and teach people with ostomies, coordinate patient care, teach nursing staff in hospitals and clinics, and work closely with the nursing and medical professions to improve the quality of ostomy rehabilitation programs. The WOCN Society can help you find a WOC nurse in your area. The “Patient Information” section of their website contains resources for patients and families.

United Ostomy Associations of America, Inc. (UOAA) Toll-free number: 1-800-826-0826 Website: www.ostomy.org²

For local support group information; the interactive website includes discussion boards and online support groups

International Ostomy Association (IOA) Website: www.ostomyinternational.org³

Advocates for and outlines the rights of ostomates worldwide

ConvaTec Great Comebacks Community

Website: <https://www.convatec.com/ostomy/meplus-community/>⁴

A non-profit organization that accepts donations of unused ostomy products and provides products to uninsured people for the cost of shipping and handling.

Global Tracheostomy Collaborative Website: <http://globaltrach.org>⁵

A non-profit organization that has patient and family resources, including support groups, discussion forums, and education materials.

Centers for Medicare & Medicaid Services (CMS) Toll-free number: 1-800-633-4227 TTY: 1-877-486-2048 Website: www.cms.hhs.gov⁶

Ostomy care and supplies are covered under part B of Medicare. These same supplies and care may be covered under Medicaid (this is state regulated and varies). Check with an ostomy nurse about which health department or other agency in your state may be able to help you.

**Inclusion on this list does not imply endorsement by the American Cancer Society.*

Hyperlinks

1. <http://www.wocn.org>
2. <http://www.ostomy.org/>
3. <http://www.ostomyinternational.org>
4. www.convatec.com/ostomy/meplus-community/
5. <http://globaltrach.org/collaborate/patients-families-portal/connect-with-other-patients-families>
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