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Living with an Ostomy

Talking to People About Your Ostomy

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

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

1. <file:///C:/ssLINK/colostomy-sex>

References

In its original form this document was written by the United Ostomy Association of America (1962-2019). It has since been modified and updated by the American Cancer Society using the following sources.

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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

References

American Thoracic Society. Living with a tracheostomy. *Am J Respir Crit Care Med*.

United Ostomy Association of America (UOAA). *Living with an ostomy: FAQs*. Accessed at <https://www.ostomy.org/living-with-an-ostomy/> on October 2, 2019.

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

- [Know what's safe for your type of ostomy](#)
- [Swimming and water sports](#)
- [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

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

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. www.tsa.gov/travel/special-procedures
2. 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.

- [Pregnancy with 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

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Hollister. *Caring for your loved one with a colostomy*. Accessed at https://www.hollister.com/~media/files/pdfs-for-download/ostomy-care/caring-for-a-loved-one-with-ostomy_923058-0318.pdf on October 2, 2019.

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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?”

- [Psychosocial issues](#)
- [Your child’s ostomy care](#)
- [Going back to school and everyday living](#)

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 they need.

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, they 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,** they 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

activities as before. At first, it may be hard to let your child go away on their own. If you can help your child know how to best handle any problems that may come up, they won't need any "special" treatment or seem different from any other children.

Talk with your child about how they'll tell others. They 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 them 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. www.wocn.org
2. www.youthrally.org
3. 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.

- [Other organizations and websites*](#)

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

5. globaltrach.org/collaborate/patients-families-portal/connect-with-other-patients-families
6. www.cms.hhs.gov

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