

How do I talk with friends and family about my ostomy?

SITUATION 1:

After getting your ostomy, you decided to name your ostomy Tammy. Now that you are comfortable with Tammy, you and your sister decide to go on a trip. Your sister knows about your ostomy, but you do not know how comfortable she is talking about it with you yet. You know that you will have to talk about your ostomy at some point, especially if you need to get to a restroom quickly. This is the perfect time to use your ostomy's name. Instead of saying "My ostomy bag is getting full" you decide to say "Tammy needs to be changed."

Suggestion:

If you are not sure how to talk about your ostomy with people that may be uncomfortable, it might be a good idea to come up with a "code name" for your ostomy. Naming your ostomy or using a code phrase to tell people when you need to change your ostomy bag can be a good way to cope and talk about your ostomy with other people. Some people also just name their ostomy for fun!

Some ostomates have a code word for their ostomy. They use it with friends and family to secretly talk about their ostomy. "She would ask, 'How far along is the baby?' and so nine months was like-I have to go to the bathroom and empty this now." The person went on to say, "I think it made [my friend] more comfortable to talk about it." The ostomate even recommended that other people with ostomies should have a code word or nickname for their ostomy. Naming the ostomy can make talking about it more casual.

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SITUATION 2:

You were invited to a Fourth of July celebration in an outdoor space. You are worried that there may not be a place to use the restroom if you need to empty your ostomy bag. You decide to tell your friend about your concern and they respond with, “It’s OK! If that happens, we’ll just hose you down with water.”

Suggestion:

Some people use humor to cope with their ostomy or to talk to people with ostomies. Talk about your ostomy the way that makes you feel good. If you are comfortable, using jokes and humor can be a great way to talk to people about your ostomy.

Or if you are not comfortable with humor, that is OK too. You can respond by saying something like, “I’m not really comfortable joking about my ostomy like that, but I am glad you will be willing to help if I need it. I really appreciate it.”

Some people worried about repeatedly asking for a bathroom when visiting friends and family. When talking to her family member about being worried she’d get a leak, her family made her laugh by saying “Ah, we’ll just hose you down.” This helped the ostomate be less worried about the possibility of a leak.

How do I disclose that I have an ostomy?

You may tell people more information or less information about your ostomy depending on how close you are to them, how often they will be around you, and how your ostomy might affect them. For instance, your neighbor will probably need to know less about your ostomy than your spouse. This is the same for employers. Some employers may not need to know at all, whereas others may need to know about your ostomy if there are physical requirements in your job.

SITUATION #1: LOW DIFFICULTY

Imagine that you are going back to school after your ostomy surgery. You tell your teacher about your ostomy, but do not want to share much more information.

Suggestion:

"It's a surgery to help me go to the restroom."

Or if you want to share more information:

"I used to have a lot of stomach problems and got an ostomy to help"

SITUATION #2: MEDIUM DIFFICULTY

Imagine you are coming back to work after taking some time off after your surgery. Your job requires you to lift heavy objects sometimes and sit through long meetings. You want to tell your boss and coworkers that you might not be able to lift heavy things or sit in meetings without going to the restroom.

Suggestion:

"I recently had abdominal surgery, so I cannot lift heavy things yet."

Or more specifically:

"I just had surgery to get an ostomy, so I may be in and out of the restroom. If you have any questions, let me know."

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SITUATION #3: HIGH DIFFICULTY

EXAMPLE 1:

Sometimes people may not react kindly when you tell them about your ostomy. Imagine that you decided to tell a friend that you have an ostomy. After telling them about your surgery, the friend says, “Eww, aren’t those gross?”

Suggestion:

"That has not been my experience. I can see where this could be scary or different. I feel so much better since I got my ostomy and it has finally made me healthy again."

EXAMPLE 2:

Imagine that someone says something hurtful to you about your ostomy. You do not know this person very well, so you do not want to talk to them anymore. How do you get out of the conversation?

Suggestion:

"I don't feel comfortable discussing this with you. I'd like to talk about something else."

Or:

"I don't feel like talking about this right now. I'm going to go ahead and head out."

One experienced a similar interaction, and they responded, **“I wouldn’t be alive without my ostomy. So I make that crystal clear** to anybody who kind of hesitates or wants to say something about how nasty or dirty they are.”