



TEXAS

The University of Texas at Austin

SPEAKING STOMA

A communication guide for people with ostomies

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WHAT IS A COMMUNICATION GUIDE?

Talking about your ostomy will not always be easy. However, as you practice talking about your ostomy, we hope that these conversations become easier. This communication guide is meant to help you come up with ideas of things to say when you are in different situations. You do not have to use the things we say word for word. We hope this guide gives you an idea of things you could say if you are ever in similar situations.

What is a communication guide?

Each section has a big topic (ex. Leaks) and has different situations that you may experience. Each situation comes with a suggestion for what you might say to help manage the situation.

In this communication guide, we have suggestions and situations that have different levels of “disclosure”. When we say disclosure, we mean how much or how little information you want to share about your ostomy. For example, low disclosure situations mean that you would not need to share very much about your ostomy to manage the situation if you do not want to.

We present a range of experiences in this guide. Sometimes, situations may be more or less difficult than others. When something is listed as high, medium, or low difficulty, we mean how challenging people with ostomies might think those situations are to manage.

Within the guide, we often refer to an ostomy “pouch.” When we say ostomy pouch, we mean any type of ostomy appliance that might be used with your specific kind of ostomy.

All of the situations in this guide are inspired by real people with ostomies.

Helpful Tips

When you are learning to explore, travel, and socialize with your ostomy, being prepared is one of the best ways to make sure that you feel comfortable and confident. Here are some tips to help you be prepared for any situation:

1. Pack an extra set of clothes and supplies in your car or in a bag.

Sometimes you may need to change your ostomy pouch or clothes unexpectedly. Having extra supplies helps make sure that if anything happens, you have a plan in place. You might want to pack pre-cut supplies (if needed) so that your supplies are ready to go when you need them. Some other suggestions for supplies include:

- clothes
- ostomy supplies
- water bottles
- perfume
- disposable plastic container or sandwich bags for trash

2. Start small.

If you are nervous about traveling long distances, try making small goals first. Maybe walk around the block before taking a drive. After you are comfortable in the car, try taking public transportation or riding in the car for a couple hours. After you can travel for a few hours, try taking a short flight in an airplane.

3. Do not be afraid to take notes of where restrooms or private spaces might be in case you need to use them.

If you are in a new place, it might be helpful to ask where things are as soon as you arrive in the event that you need those places quickly.

What do I do when I have a leak and need quick access to a restroom?

SITUATION #1: LOW DISCLOSURE

Imagine you are at a friend's party and need to find a restroom or a private space to change your ostomy pouch. Your friend does not know that you have an ostomy pouch and you don't want to tell her at the party. In most cases, you may not need to tell people about your ostomy to get the help you need.

Suggestion:

"Can you show me how to get to the bathroom?"

Suggestion:

"Thank you so much for inviting me. I am having trouble with my ostomy pouch, so I need to leave and go home."

SITUATION #2: MEDIUM DISCLOSURE

In some cases, you may need to leave wherever you are quickly if you do not have supplies on hand. Imagine you are at the same friend's party. This friend knows that you have an ostomy pouch, but your pouch is leaking and you do not have supplies with you at the party. If you feel comfortable, you can tell your friend that you need to leave because of your ostomy pouch. For this kind of situation, you can follow a 3-step process of a greeting, disclosure, and solution.

SITUATION #3: HIGH DISCLOSURE

Special events like weddings are a fun way to socialize and get dressed up. However, there may be a time when you are at a fun event and your ostomy pouch begins to leak. Sometimes leaks at these events can be tricky, especially if you are not able to get supplies quickly enough and need to ask for help. If you have people around that can help you, especially friends or family, it is okay to ask for help finding supplies or a restroom.

Suggestion:

"Can you show me how to get to the restroom? My ostomy pouch has leaked and I need to clean up. Would you be able to find me an extra set of clothes? I really appreciate it."

How do I talk to people about food?

SITUATION: MEDIUM DISCLOSURE

Summer dinner parties can be a great time to see friends and family. However, sometimes dinner parties have foods that you may not be able to eat yet or already know that you cannot eat. You do not want to eat the food the person is serving and you also do not know if the host knows you have an ostomy or not. What do you say?

Suggestion:

"Thank you so much for inviting me. After my surgery I'm still figuring out the foods that make me feel best, so I ate before I came. Everything looks delicious!"

Or if the host asks why you did not try a certain food at the party:

"It all looks delicious. I know that (these foods) make me feel best, so I'm going to stick with the foods that I know I can eat for now."

Saying "no" to Food

Some people were embarrassed when they couldn't eat the same food everyone else is eating. It's hard to say "no" whenever someone offers you food. Some family members helped the person explain to others that they can't eat certain foods because of their ostomy. For example, one family member explained it by saying, **"Please don't take offense. She doesn't eat these things. It's not your cooking."**

What do I do when I need to use a public restroom?

SITUATION 1: LOW DISCLOSURE

Being in a public space can be hard, especially when you need to use a public restroom. Imagine you are at the theater watching a play. During the intermission, you realize that your ostomy pouch needs to be changed immediately and you are not sure you will make it. The line is very long to the restroom and you do not know what to say.

Suggestion:

"Excuse me, I have an emergency and need to get to a restroom right now."

SITUATION 2: HIGH DISCLOSURE

Imagine you are trying to use the accessible restroom at a concert. You would like to use this particular restroom because it is private and has a sink inside the restroom. As you open the door to use the private restroom, someone looks at you and says, "You don't look sick." How do you respond?

Suggestion:

"You may not be able to see it, but I have an ostomy and it is full. I need to empty the pouch as soon as possible."

"I just started breaking down and crying because the damn line wasn't moving at all. I didn't know what to do. How do I handle this? What do I do?" The woman behind her in line asked if she was okay. The person explained they had an ostomy pouch that was leaking, and they did not know if they'd make it in time. The kind stranger brought her to the front of the line and said it was an emergency. The person explained, "I would never think to do that on my own... This woman made me realize that **it's okay to [ask to go to the front of the line] when it's really an emergency.**"

How do I travel with an ostomy?

SITUATION 1: LOW DISCLOSURE

Traveling with an ostomy may be scary, especially if you have to go through security. If you are flying somewhere, a travel communication card might be helpful. Your ostomy pouch may show up on some of the security measures. If you do not want to tell people very much, the card can be useful to help you communicate.

Suggestion:

"Here's a card from my Doctor to explain what an ostomy is."

SITUATION #2: MEDIUM DISCLOSURE

Security measures like luggage checks may also be difficult. You may have supplies with you that raise questions. If you are afraid that your ostomy supplies might cause issues, it may be helpful to explain a little bit more about your ostomy supplies before the luggage check happens.

Suggestion:

"I have to travel with a few extra things because of my ostomy and I may set the machine off when I walk through. Here is a medical card from my doctor explaining why I need these supplies."

How do I travel with an ostomy?

SITUATION #3: HIGH DISCLOSURE

Flying in an airplane for the first time since receiving your ostomy can be scary. Flight attendants are there to help! Some people with ostomies choose to talk with their flight attendant before the flight takes off to answer their questions or erase any concerns.

Suggestion:

"Excuse me, I have an ostomy and I might need to sit in the aisle seat and get up to use the restroom a lot. Is that something your team can help me with? If you have any questions I can answer them for you. Thank you for helping me."

Helpful tip:

You can take an extra carry-on of medical supplies on flights without charge. Have the airline's policy available for any crew who might not know that policy. Be sure to look up each airline policy ahead of time to see how they want to be notified of your medical carry-on.

What do I do if my ostomy makes noises in public?

SITUATION 1: LOW DISCLOSURE

You are on an elevator with a few people that you do not know. All of a sudden, your ostomy pouch makes a loud noise. You do not want to tell anyone about your ostomy, but do not know what to do.

Suggestion:

It is OK to not say anything.

OR

You may feel comfortable pretending like the sound is something like your stomach growling instead of your ostomy making a noise. Try saying something like, “Sorry, I have not had lunch yet!”

Some people discussed coping with the potential awkwardness of ostomy noises in public spaces. “Sometimes, ostomy pouch can be a bit noisy. I think that sometimes that’s a hard thing for people to know how to deal with because you don’t know when that’s gonna happen. And so, **sometimes it just means ignoring it, because who’s gonna know whether it was you. Or sometimes...you can kind of crack a joke and make light of it** if the people around you know your situation, and it can be lighthearted.”

What do I do if my ostomy makes noises in public?

SITUATION 2: MEDIUM DISCLOSURE

Imagine you are in a meeting at work. During the meeting, your ostomy pouch keeps making noises. People keep looking at you, so you feel like you should say something.

Suggestion:

“Excuse me, I have an ostomy pouch and sometimes it makes noises.”

People recalled that they felt awkward when their ostomy pouch made noises in public at the beginning of their ostomy journey. It helped people to remember that no one in public knows that those noises came from their pouch. “You don’t have to say anything. How many times has someone ripped one, and everyone just looks around.” It can be embarrassing when you know the noise came from your ostomy pouch. People with ostomies have an important reminder, **“You have no control over it.”**

There may be times when you feel the need to explain the noises your ostomy pouch makes. In these cases, some people respond with, “Excuse me, I’m having stomach problems.” Some people also told the person they are with that they had intestinal surgery.

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 pouch 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 pouch 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.

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

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 pouch. 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."

How do I disclose that I have an ostomy?

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 ostomate 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.”

How do I talk about sex and intimacy?

SITUATION:

You recently met someone who you are interested in. You think that you may need to tell them about your ostomy soon before you feel comfortable having sex with them, but you do not know how to tell them. What do you say?

Suggestion:

“I have really enjoyed getting to know you. Before we continue this relationship, I need to tell you about a surgery that I had. I have an ostomy, so I have an ostomy pouch on my stomach. Everything is fine and I feel so much better now, but there may be positions that are more comfortable for me than others. Do you have any questions?”

Testimonies:

“How you approach things and how you say it, not like you’re dropping a bomb, but just saying it casually, really helps. I think it helps to put your partner at ease as well. You’re just saying this is not a big deal. It’s like you’re not saying ‘I love you’ on the first date.”

Ostomates acknowledged that it can be nerve-racking to have sex with a new partner when you have an ostomy. “When you’re having sex, it’s a very present thing. As long as you stay present, it’s a lot easier to not think about what’s going on with you. Or also, your partner is not thinking about what’s going on with you, because you’re connected.”

Helpful tip: Some people are not sure when or how to tell a romantic partner about their ostomy. There is no right or wrong time. Some people may choose to tell someone immediately, while other people might wait to tell the person until they know the person better. Your comfort is what is most important.

How do I talk to clinicians?

Positive Experiences with Clinicians

SITUATION 1: LOW DIFFICULTY

People have different preferences for how to communicate with their clinician. Imagine you are visiting a new clinician for the first time. You have heard good things about this clinician, but you have a lot of questions and want to make sure that you get all of the information that you need to understand what is going on. If this is the case, it may be helpful to set expectations to give your clinician a sense of what typically works for you.

Suggestion:

“I’m someone who might ask a lot of questions.”

Or:

“It would help me if you would write down the instructions.”

Helpful tip:

Don’t be afraid to ask for a referral to an ostomy nurse. These nurses are also called WOCN, which stands for wound, ostomy, and continence nurse. Many people find these nurses really helpful.

SITUATION #2: HIGH DIFFICULTY

While seeing your clinician, your clinician asks if you have ever thought about using a convex appliance. You have never heard of a convex appliance and do not know what the word convex means. The brand and type of supplies you are currently using seems to work fine with only the occasional issue. You are wondering if there is something else that you can do to fix those occasional issues without making too much of a change.

Suggestion:

"I don't really understand what you mean when you say this, can you explain it so I understand?"

Or if you do not want to try a new kind of appliance:

This sounds like a good option. What are some other options that I could consider?"

How do I talk to clinicians?

Negative Experiences with Clinicians

SITUATION #1: LOW DIFFICULTY

You are visiting a clinician to talk about your ostomy. The clinician asks you how often you change your ostomy pouch. You prefer to change your ostomy pouch a lot because it is more comfortable for you, but you are worried that changing your ostomy pouch a lot is not going to answer what your clinician is looking for.

Suggestion:

“I change my ostomy pouch (*say how often*), but if I had to guess, it fills up around (*say how long it takes to fill up*). Is that what you are looking for?”

SITUATION #2: HIGH DIFFICULTY

Imagine you are visiting a clinician. The clinician says that they want to perform an anal exam on you. However, you had a proctocolectomy, so you do not have a rectum for an anal exam. You tell the clinician that you cannot have an anal exam, but they insist.

Suggestion:

“I do not have a rectum, so I am not able to have this procedure. The information should be listed in my chart. Would it be helpful if I told you more about my ostomy or do you think we should talk to someone who has experience with my ostomy?”

Some people educate providers who don't know a lot about ostomies. One person's doctor asked if they had any pain or burning during urination. The person said, “If you know anything about urostomies, I literally don't feel anything when I urinate. So how can I have pain or burning during urination?”

How do I go about socializing and finding support after surgery?

SITUATION #1: LOW DIFFICULTY

Imagine that you just had surgery a few weeks ago. You are still getting used to changing your ostomy pouch by yourself and you are still not feeling well from the surgery. A friend reaches out to you and asks if you want to go on a walk with them. You have not seen this friend in a long time and it sounds really nice, but you just do not want to today. Sometimes you may not feel well enough to socialize. When this happens, you can politely decline an invitation.

Suggestion:

"I'm so glad you asked, thank you for thinking of me. I'm not feeling well today, but can we try again when I am feeling better?"

Many people talked about how the support from their family and friends helped them. After her surgery, one participant never wanted to leave the house. Her mother did not accept that. She said, "No, we're just going to walk down the street. We're gonna go to Starbucks. There's a bathroom there. By the time we get there, if you need to empty this thing, great. But we're just gonna sit there. You're gonna see these healthy people. And you're gonna just know that you can do your life." The mother knew what her daughter needed. Even though her daughter didn't want to go out at the time, she is extremely thankful now.

How do I go about socializing and finding support after surgery?

SITUATION #2: MEDIUM DIFFICULTY

After your procedure to get your ostomy, you are afraid to go out in public. What if your ostomy pouch leaks? What if you do not have enough supplies with you? What if the ostomy makes a noise? You want to try something small like going to a small restaurant and want to ask a friend to come with you.

Suggestion:

“Hi, I really want to try going to a restaurant to eat. Would you like to come with me?”

Or if you are comfortable sharing more about your concerns:

"Hi, I really want to try going to a restaurant to eat, but I am still a little nervous to go out in public with my ostomy. I am afraid the ostomy pouch might leak. Would you like to come with me? I think going with you would help me feel better."

Other participants talked about the importance of being honest with family and friends when they're not feeling positive about their ostomy. One participant said, **“I looked at it like, okay, this ostomy gave me my life back.** Even though there are times I want to throw the ostomy pouch across the room.”

Want to learn more about this communication guide?

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