

Emergency Preparedness for Urostomates

[00:00:00] Hello, and welcome back to Leaks, Laughs and Life with a Urostomy, Resources for Urostomates. I'm Dawn, and I'm so glad you're here.

If you are new here, my mission is simple. I want to help you replace fear with knowledge, uncertainty with confidence, and isolation with hope as you navigate your new life with the urostomy.

Because while we spend a lot of time discussing the actual surgery process with our surgeons, there's a whole other side to the surgery that doesn't get talked about, the living life after surgery part. The part where you go home, the part where you learn how to sleep, travel, work, choose clothing, manage relationships, build confidence, and everything else that comes after you leave the hospital.

The part where life happens, and sometimes the part where life decides to throw you a curveball or a plot twist, as I call them.

Before we get started, I want to remind everyone that I am [00:01:00] not a physician, a nurse, or a medical professional. I'm only sharing my own personal experiences as a urostomate, along with information and practical tips that I have learned along the way. You should always follow the recommendations of your own healthcare team, who know your personal medical situation best.

And with that being said, let's talk about something I never thought I would become passionate about, emergency preparedness.

And how this resource came to be was, as some of you know, over the last few weeks, our community suffered through the Aspen Acres fire, seventh-largest fire in Colorado history.

And thankfully, we are all safe. I do have friends that lost everything and family members that were displaced for almost three weeks. But we are so thankful to all the firefighters and emergency response crews that worked so hard to protect our [00:02:00] area. You did an amazing job, and we appreciate everything you did and are still doing to keep us safe.

But for a few days there was a lot of unknown. And if you know, you know that feeling when you are constantly looking at your phone, waiting for that update, hoping that the next notification doesn't say you need to evacuate now.

Well, if and when that waiting game ever happens to you, when reality starts to sink in, when you suddenly have minutes to make decisions, the last thing you want to worry about is how much urostomy stuff you have access to.

Where did I put my spare bags? Do I have enough barrier strips? Did I refill my meds? Stress does crazy things to us. It can make the smartest people forget things that are so obvious, like a toothbrush or underwear. And believe me when I say that because I speak from experience. As someone who is not the most organized person by [00:03:00] nature, if you are one of those people, has everything labeled, sorted, and prepared for an emergency ahead of time, good for you.

Kudos to you. Honestly, I admire you. That is not me. I tend to fly by the seat of my pants, and I figure it out as I go most of the time. And although we have been through the emergency drill several times before, it had been about 18 years, and that is exactly why this past fire was such a good reminder for me.

When life throws you one of those situations,

it is not the time to try to dig through closets, drawers, and cabinets trying to find random bags and supplies, important papers, and insurance information. And if you're like me, stress will make your brain forget where you put something you just set down and walked away from five minutes ago. So preparing for an emergency does not mean that you need to be [00:04:00] hyper-organized.

It just means that you are giving yourself one less thing to worry about if something happens.

Let's start with the easiest, a grab-and-go bag, a small bag that you can quickly throw together. Think of it as your "I need to grab everything and leave the house for a couple days bag", like a backpack or a small suitcase.

Hopefully you will never need to use this bag, but if an emergency happens, you will be so glad you took the time to prepare ahead of time. Trust me, and your future self will thank you.

If you have a urostomy, your supplies are not optional. You can't just run to any store to pick up what you need.

You need to have extra supplies on hand. So try keeping a small stash of pouches, wafers, barrier rings if you use them, adhesive remover wipes, skin prep wipes, barrier strips, stoma powder if you use it, disposable bags, gloves if you use them, scissors if [00:05:00] you cut your own wafers, extra night drainage bags if you use them, connectors and tubing if needed, extra washcloths, unscented wipes.

Remember, never use to clean around your stoma. It's just to clean up around your supply area and to catch those drips down your leg. You know what I mean.

And extra clothing.

Now for medications, you're going to want to keep a list of the current medications that you take that include a list of the medication names, the dosages, how often you take them, which doctor prescribed them, and pharmacy information, and keep them separately from your medications in case something happens and they get separated.

During an emergency, it's nice to have this information readily available. Keep digital and physical copies, because remember, technology is great until your phone decides it wants to die at the worst possible moment

And as we continue on, as urostomates, [00:06:00] we are always told to stay hydrated.

Times of stress, it can be easy for you to forget to drink water. Try keeping bottled water or a big bottle or supply of water on hand, electrolyte packs, shelf-stable food like protein bars, crackers, and nuts, because trust me, emergency situations are not the time to realize you have turned into a cranky, hangry person because you forgot to eat.

Not that I'm speaking from experience or anything like that.

As for clothing, pack things that make you feel comfortable. During times of stress, you don't need to be uncomfortable in your own skin. If that means throwing in that old T-shirt that you know looks great with your pouch, do it. Comfort is key. Make sure to pack, , extra underwear, pants, shirts, socks, pajamas.

I forget those quite often. Comfortable shoes and socks, and layering pieces, like coats or jackets or sweaters if you need [00:07:00] them.

The next item on the list is documents, the documents we don't think about and we don't keep copies of, but should. So not only do you take these with you, but you make physical copies and put them somewhere else in your packing.

Your ID card, your insurance cards, medication lists, medical history, emergency contacts, your urologist information, your surgeon information, and also include your supply brand information, like the manufacturer name, the product numbers, the size you wear, where you order supplies, because trust me, when you're trying to remember the size of your wafer or what brand it was when you're stressed, it's just, it's just too much stress.

What happens when you don't know if you're coming home? What if you get that message that, "Okay, you need to evacuate," when you must leave your home with no idea when or if you will even have a home to come back [00:08:00] to? Wildfires, hurricanes, floods, major storms, these are situations where you will need a little more than just a go bag.

This is where the larger emergency tote or totes can become your best friends. Include your medical supplies, and you guessed it, extra urostomy supplies, plus any medications and medical information for prescriptions.

If you're in an area where there's going to be a fire or a hurricane, and they shut the emergency or the electricity off, make sure you take all your medication with you that you have on hand, because you may not be able to get back in, especially if you're a diabetic.

I had a friend that, that's a diabetic, and she, um, got the evacuation order to go and left all of her insulin in the refrigerator, and she wasn't able to go home for three weeks, and she got home [00:09:00] and, you know, their electricity had been off for three weeks, so not a good situation to go home to.

Some of the most forgotten items. Can you guess what the number one is? Toothbrush and toothpaste. And then second, underwear. Yep. And then you need to add like deodorant, soap, shampoo, contact solution, glasses, makeup, any items that make you feel like you will feel normal, like you'll have your normalcy with you.

Don't forget your wallet or your purse. When it comes to keepsakes, it depends on how much time you have. Try to gather as many photo albums or photos,

jewelry, electronics, your phones, phone chargers, computers and chargers, tablets, TVs if you have room.

Some emergency supplies that are really good to have on hand are flashlights, a battery lantern, first aid kit, extra blankets and pillows, [00:10:00] extra batteries, cash, copies of your important documents like insurance for your home and cars, birth certificates, marriage certificates, bank statements, financial papers, last year's taxes, credit card information, et cetera.

Because sometimes if you don't have access to internet or your computer, and you don't have access to your passwords, you might need to have some of these things in order to get information.

Some of the things that we, also pack are, camping gear. You know, like tents and cots and, our cook stove, our camp stove, our little kitchen setup that we take with us.

Just in case we don't have a place to go to, we can go camp out in the woods and, still have a place to live. So it's not the most ideal situation, but you know, in a [00:11:00] pinch it, it's great to have.

There are other type of emergencies. Not every emergency requires you to leave your home. Sometimes emergencies are like sudden hospital stays, or you need to leave because a loved one requires care, or an unexpected trip to the ER. You get the idea. These are occasions where you may want to keep a small hospital bag packed and ready to go.

You can do it like the backpack, but keep it in your car so that it's available, The only thing with keeping urostomy supplies... Let me back up a little bit. The only thing with keeping urostomy supplies in a car in a hot summer is that the adhesive can get really, really sticky and tacky. So make sure that you take your bags into the house and then take them back out to the car every time you leave.

I know it's kind of a pain, but it's really something that will give you more confidence and [00:12:00] comfort knowing that it's there. Because when you need it, you need it. So in that bag, you know, just like the to-go bag, your ostomy supplies, medication list, charger for your phone, comfortable clothing, toiletries, and something to keep you busy, like a book or your tablet.

Because waiting in hospital rooms are known for their luxurious accommodations. Okay, not so much.

Anyway, and don't store everything in one place. I have learned that it's good to have multiple backup plans. Consider having supplies in different areas, an at-home emergency kit, a travel kit, a car kit, a work kit.

The work kit especially is great if you frequently travel for work. You never want to keep living in fear of the unknown. But having multiple kits keeps you prepared if an emergency happens while you are away from [00:13:00] home. Just remember to stock them when you are back home.

Also, make sure that your pouches, the areas that fit onto the wafers do not get bent or creased. Just speaking from experience, that kind of causes some leaks, and they're very unexpected.

If there's one thing that the Aspen Acres fire taught me, it's that we can't control everything happening around us. We can't control wildfires, hurricanes, or unexpected emergencies. What we can control is how prepared we are for those emergencies.

And for us urostomates, being prepared can give us one of the most valuable tools we have, confidence.

Confidence that if something happens, we know what to do. Gives us the confidence that we have what we need, and it gives us the confidence that we can get through the next moment.

My hope [00:14:00] is that you never need this resource. I don't want anyone to use this. I really mean that.

But if you do find yourself in need of it, I hope you are happy you took the time to prepare before life decided to happen. And as always, I've created a handy little checklist to go along with this resource. You can find it in the show notes on my website at leakslaughslife.com.

Print it out, alter it, make it work for you and your family, because being prepared doesn't mean living in fear of the unknown.

It gives you the freedom to continue living your life no matter what.

Thank you so much for joining me today on Leaks, Laughs & Life with Urostomy. And remember, this journey is full of leaks, but it also gives us plenty of laughs and an unlimited amount of life.

Until next time.