

#MyAccessMatters

OSTOMY STORY

Your name here
(Your photo here)

Sample story:
Your story would go on these pages.

This is only a sample story. You would describe your situation or story on these page. For example: Until I was able to find an ostomy appliance that fit properly, stool was constantly leaking out of my appliance and I suffered from skin infections. I had to change my pouch completely multiple times a day, exceeding what Medicare considers a reasonable and necessary quantity of supplies. Even with multiple pouch changes, my skin was excoriated and bleeding, because stool that leaves the body from the ileum still contains the digestive enzymes that eat away at skin. For this reason, stool cannot be left in contact with my skin. Once this occurs, the digestive enzymes start breaking down the skin layer by layer.

What is left can vary depending on severity, but may resemble severe sunburn or a full thickness wound.

I was unable to leave my house...

because my pouch was constantly leaking stool. I would even wake up lying in a pool of it. Imagine trying to live your life if you were incontinent 24/7 and your skin was worn away and bleeding. For me, the correct appliance was a rigid wafer with convexity and specialized adhesive and seals.

Advocates for a Positive Change

www.ostomy.org 1.800.826.0826



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Flash forward a few years to different problems:

My ostomy and my supply needs having to be adjusted. My stoma inverted causing leakage and skin breakdown once again. Since there were no out-patient ostomy clinics or nurses where I lived, I suffered severe complications for months until I was readmitted to home care to see an ostomy nurse to treat my wounds and ostomy problems. This was **not** cost effective.

Through trial and error of various products...

an ostomy home care nurse was able to help me find a pouching system that fits properly and meets my individual needs. I have returned to a normal life and have rejoined the workforce, and am no longer dependent on government assistance programs. To avoid encountering further leakage, infections and subsequent expenses for wound dressings and wound specialist appointments, I must use this exact prescribed pouching system.

"If you could say one thing to a policymaker about the importance of access to the ostomy supplies that have been specifically prescribed for you, what would it be?"

When I show up in the emergency room because I have a wound under my ostomy appliance due to wearing the inappropriate appliance, I will make sure it is clearly documented who is responsible for this wound. It will not be myself, or the hospital or the doctor or even the supply company. You, my elected official, will be responsible for my wound and the costs associated with it, because you are voting to knowingly put hundreds of thousands of people in a position where we are forced into wearing a product that neglects to take into account individual needs of individual bodies.

There is a reason why thick catalogs of ostomy supplies exist; everybody is different.

Please respect my ability and my certified ostomy nurse's ability to know what works for my body. I have lived with this ileostomy for 15 years. I want nothing more than to return to work, and I am on the cusp of succeeding. Please don't take this away from me. Please don't sell my future to the lowest bidder.

Do not include ostomy supplies in Medicare's Competitive Bidding Program.

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