

Dave

Your ostomy is what you have, not who are.

My surgery was forty two years ago. I was an eighteen-year old and I remember that the first time I looked at my stoma after my surgery, I basically passed out. I had seen pictures but until you actually face it and see it for yourself, it's just a picture, it's not real. This brought the reality to me and I realized that this can't happen again. I need to get a grip, understand what I have and start dealing with it because there wasn't going to be anybody else that was going to do it for me. So I had to rely on myself and learn to deal with it. The surgery was done between my freshman and sophomore years of college.

I went back to school for my sophomore year, about six weeks later and told my roommates right up front that I now am connected differently so to speak and swore them all to secrecy. I was mortified by the way I looked. I was an eighteen-year old. I was starting to date. Women looked good, things started happening and I didn't want anybody to know because I didn't know how to bring it up. I didn't know how to discuss it. I told my roommates that if they breathe the word of this, I would slit their throat in the middle of the night. They all thought I was absolutely nuts and they basically said, "We don't care." I said, "That's good because I just want you to know that I'm very serious."

School started, classes started, et cetera, et cetera and relationships started. I met a variety of girls and we started becoming friends. The friendships grew and at one point, things became, so to speak, it was do you move on or do you run away? I didn't know how to bring up the discussion as to ... well, I don't want you to be afraid of what you're about to see so I really didn't say anything because I didn't know what to say. We got ready so to speak and she freaked out. She ran out of the room and I basically thought, "Okay, this is going to be my life from now on." I was, in my own mind, somewhat of a freak and I needed to learn how to deal with it.

One of the popular TV shows at that time was called the Six Million Dollar Man. It was about an astronaut who had been involved in a crash and scientists had put him together better and stronger than he was before. Well, that's similar to what happened to me but I wasn't convinced that I was better or stronger. I was convinced that I was just very, very different than I was before, but again, I was eighteen, I didn't know how to handle it. I didn't know what to say and I couldn't wrap my head around it. A year later, I transferred back from college to the city because my father had passed away and went on to get my bachelor's degree and my master's degree.

I met a woman and I promised myself that from the beginning, I would tell her immediately upfront because I wasn't going to waste any time. I basically told her, "Look, this is what I have. If you can deal with it, fine. If not, hit the road." She looked at me and she said, "I can deal with it. Can you?" People know me, I'm usually not one to be caught off guard and not have a response. I had no response. I was stunned and flabbergasted but then I realized that she was right and I needed to start learning to deal with this and get over it so to speak. Well, we eventually got married, had children. Unfortunately many years later, that led to a divorce.

I am now happily re-married to a wonderful woman but I didn't get involved in organizational things for years and years because I didn't think that was for me so to speak and I didn't really know what I could provide to someone else. When I turned thirty five, I started reevaluating my life and I said, "If I'm old enough to be the president, I'm old enough to get over these fears and issues that I have about myself." I decided to look up the local activities and I first looked up the CCFA and I found that there was a chapter literally six blocks from where I lived. I also got involved in a UOAA chapter with the local hospitals in my area.

I walked in and I remember thinking about being asked, "Oh, so you're a new person. How long have you had your surgery?" I went like, "Seventeen years" and they said, "Oh my God, where have you been?" I said, "You know, I could never bring myself to do this because I had issues that existed between my ears that I couldn't get over. Now as I'm older, I need to deal with these issues and get over it."

I started serving on the board of CCFA, started serving on the board of UOAA and the lovely woman that I first met at CCFA is now my current wife and lifetime partner. She was one of the first people that really got me to start looking at myself beyond the ostomy. For years, when people would ask and I would speak to them, when they would say, “Well, tell me something about yourself,” I would say, “Well, I’m X years old and I happen to have had surgery. I’m an ostomate.” I was once stopped by somebody who said, “I’m not interested in what you have. Tell me who you are,” and I paused and I went, “Wait a minute. You mean I’ve been defining myself by my surgery for all these years?”

They said, “That’s correct. Tell me that you like music. Tell me you like to play sports. Tell me you’re a basketball player. Tell me you’re a reader. Your ostomy is what you have. It is not who are.” When I heard that phrase years ago, that phrase became my mantra because for so many years I have defined myself by that surgery, by that pouch and it took somebody to wake me up to realize that it’s just something I have. It’s not the essence of who I am and that was an extremely emotional, enlightening opening to me to where now, whereas many years ago I would never talk about this openly. I would only talk to certain groups or “face groups,” other ostomy groups, maybe some CCFA groups, et cetera.

Now, I talk to anybody who’s willing to listen and even to some people who aren’t willing to listen. For people who don’t know my nature. to the extent that I will get in people’s faces to let them know what the surgery is about. One of the perfect examples of that is, a couple of years ago at one of ostomy conferences, I think the one in San Antonio. We were exhibiting in our UOAA booth and some colorectal surgeon stopped by and I happened to see one turn the corner and he looked up and he saw our poster and he kind of shuddered and took a step and I saw that and I literally called him out.

I said, “You over there, come here. I saw what you did.” He walked over to the booth and he said, “What are you talking about?” I said, “I saw what you did. You came around the aisle, looked up, saw United Ostomy Associations of America and you stopped and you kind of shook and you

were going to turn the other way.” I said, “What do you do for a living?” He said, “I’m a colorectal surgeon.” I said, “And do you apologize to your patients before you do your surgery?” He went, “Well.” I said, “You do, don’t you?” I said, “Shame on you.” I said, “You’re the kind of people that we’re fighting against. You’re the people that create the stigma that exists often with us who have had surgery.”

I said, “You need to tell the people that they’re going to be healthy and they’re going to live full, wonderful lives and they’re going to be able to do things and they’re not going to be tied to the bathroom or have to know where every bathroom is on a six-mile journey to the grocery store and back.” As I said, I’ve had mine for many, many years. I fought against stigmas, I fought against ignorance and stupidity and I’m determined to correct it in every situation I can. We basically tell people that the surgery can be curative. You may have Crohn’s versus UC versus cancer, they’re all different things but in many cases, the surgery can be one hundred percent curative.

It can open up a full healthy life for the person. It can expose you to the most wonderful people you have ever met within the UOAA, which has been my blessing. I have met and made some of the greatest friends I have within the organization and within our sister organization in Canada. These are people I feel like I can call in a moment’s notice with an issue, discuss it with them and get true, honest answers because these people don’t sympathize with me. They empathize. They have lived the similar life as what I do and when I tell a new patient or somebody who is thinking of undergoing the surgery, I say, “If you’re looking for sympathy, you will not get it from me. I can empathize with you.”

As my phrase goes, if you’re looking for sympathy, look between shit and syphilis in the dictionary. I will empathize with you. I say, “I will empathize with you because I have walked your steps. I have walked your path and I am probably further along in that path than you are. If you want, I will guide you along the way. I will hold your hand along the way and walk with you on that way so that you can get to the other side so to speak and you can see what a whole productive, healthy life you can live after the surgery.”

Now, are there any restrictions that you have because you have an ostomy? I think the answer is, it's specific to the individual. For example, after ostomy surgery some people can still eat absolutely anything they want. Some people can eat anything but one item. Some people can eat anything but two items. Some people can do absolutely everything. There may be certain activities some people can't do because of the surgery or because of the placement of a stoma. It's very specific but in general, I would say, if you ask does ostomy surgery restrict a person in any way? The answer would be no. A person's specific surgery may restrict that individual in certain cases, but in general, no. Ostomy surgery does not restrict the person at all.

As a matter of fact, it opens up more possibilities. After ostomy surgery, I have gone swimming with the dolphins down in the islands. I have done a 5K walk. I play sports. I'm very active in the community. I still have a wonderful love relationship with my wife, so there are no restrictions.

Now, I think one of the most important things for someone after ostomy surgery is to connect with their local support group. People may say why, my answer is, the surgeon does a great job at surgery. Your WOCN nurse does a great job of showing you how to care for yourself and how to manage on a day-to-day basis. Now you've been given most of the tools but what I found most often is this: "But I still have issues between my ears. I still have questions. I still have thoughts. I still have fears. The doctor can't help me with those. The nurse can't help me with those." And my answer is, "That's right. We, the UOAA, the local affiliated support groups and the national UOAA can help you."

Why? Because we've been there, we've done it. Go find a local support group in your area, go to that group. Talk to the people there. Now, the people there may be twenty, thirty, forty years older than you. That's fine but that person who's forty years older than you may have had his or her surgery at the exact same age as you did so now, you're talking to a person with forty years experience who was eighteen just like you when they had the surgery and now they're fifty eight. That's forty years of experience you can lean on and you can get tremendous insight from. One of

the things I do, I talk to younger people because I've been doing this forty two years. I know what it's like as an eighteen-year, as twenty-year old, as a twenty five-year old.

The local support groups are vital to the psychological rehabilitation of a patient so to speak. Now, can people do it alone? Yes, but it's tougher. It's harder and why bother if a group is there that you can connect with. Connect with those groups. They can only help you and then the national organization oversees all the local support groups and we put on conferences every few years. We put on regional conferences, national conferences. We have all the information that a person with an ostomy can need, can use.

One of the examples is many of us travel. Well, when we travel and we go through the airports, you know you got to go through the detectors at the airports. Well, when you put your hands up and go through those detectors, they're going to notice that you're wearing something, so many people are terrified to travel because they don't want to be seen going through the processor and asked the question, "What is that on your belly?" The national organization has a card that a traveler can get that says, "I am a person with an ostomy. I have this device on me." If you want me to swab it for explosive so to speak, we can do that but know that when I'm going through, you will notice something.

Now, one of the things I always joke about is TSA always says, "Well, we need to swab your hands for explosive." As an otomate, the last thing I would ever do would be to put explosives in the pouch because what would happen if that thing explodes? There is a huge mess all over wherever it explodes from. I joke to the TSA agents when I travel. "This is the last place I'd put explosives, trust me."

I think the national organization is a spokesman for people with ostomies all over the country. Last year, there was an instance that the Cincinnati Police Department had experienced ... crime was up in Cincinnati and they were trying basically a Scared Straight policy where they basically try to put the fear into gangbangers that they need to get in line or else. What did they do?

They showed them pictures of people with ostomies and said, “If you continue to be a gangbanger, you can end up like this” and they showed people with pouches and bags, et cetera and I took tremendous offense to that. We as an organization protested. We put it all over Facebook and basically, I told the police department, “Would you do the same thing to women with mastectomies or amputees that have lost limbs? Would you say, ‘Oh my God, you’re disgusting, you’re gross?’” I said, “Do you know what would happen if you would do that?” The amputee community and the breast cancer community will shut you people down in a heartbeat.” I said, “If you think that I’m going to give you a pass, you’re out of your mind.”

Well, we went back and forth. We got a reporter in Cincinnati to publish the story and within about a week-and-a-half, after the Cincinnati police got hundreds and hundreds of phone calls protesting this, we got a written letter of apology that was read at our national conference in Jacksonville, Florida last August apologizing to the organization. I’ve been an ostomate for forty two years. I am going to be damned if I let some ignorant person out there get away with making false, ridiculous, disparaging statements regarding the ostomy community. Get educated, get the knowledge and talk with some common sense.

It wasn’t easy as a twenty-year old or nineteen-year old or twenty one-year old when I was down in college and I remember even going years ago to my first CCFA meeting and stood I up and I said, “Well, I’m a person with an ostomy” and there was this hush over the audience and I said, “Okay, put down the cross and the garlic, folks. Let’s just realize that I get that none of you want to be like me. I understand that, but statistically if you look at the history of medicine, twenty five to thirty percent of you will become just like me so at least open your ears and hear the information that I have. Hopefully, you’ll never have to use it, but just in case you do, you heard it here first and you can come back to me with more questions in case it’s you that gets the next ostomy surgery.”

Finally, one of the most important things is don't do it alone. Get connected because all of a sudden, you're looking up and you see five of your friends or five new people who'd done it and go, "Yeah, we can help you. Walk with us. Not in front of us, not behind us but with us."