Preface

An Open Letter to Surgeons from an Ostomate

Kenneth W. Aukett¹¹ United Ostomy Associations of America

Clin Colon Rectal Surg 2017;30:155–156.

When invited to write a preface to this issue in *Clinics in Colon and Rectal Surgery*, I was asked to provide a patient perspective about the holistic impacts of having a stoma. So that the reader may understand my perspective, I have had a stoma for over 40 years. I continue to live a fulfilling, busy, and dynamic life. I am still an active participant in my building maintenance business. As a cofounder of the United Ostomy Associations of America (UOAA), I actively advocate on behalf of ostomy surgery patients regarding quality of life issues.

Recently, I met a most engaging woman and found that we shared many common interests. Shortly thereafter, we enrolled in a Zumba dance class. She appealed to the dance and I enjoyed the cardiovascular workout. Now this may not seem unusual, but when you consider that she is 68 years old and I am 76—and that she has had her ileostomy for 8 years and I have had my ileostomy for 43 years—our actions might be viewed in a new light. To feed our wanderlust, in several months we will vacation in a remote United Nations Educational, Scientific and Cultural Organization (UNESCO) world heritage archipelago off the coast of northern Brazil. This may seem a long way to travel for Brazilian barbeque and stunning snorkeling around the island of Fernando de Noronha, but the trip afforded us both the opportunity to cherish the quality of life that ostomy surgery has provided us. Not only are we able to live this amazing life, but also our stoma makes adventures not only possible for us to share but also most enjoyable.

For the longest time, ostomy surgery has been referred to as “the most secret surgery” because bowel and urinary bodily functions are not normally discussed around the dinner table. In this silence, many myths, stigmas, and misconceptions have remained unchallenged. To the general public, the thought of having a piece of intestine that protrudes from your abdomen and drains into the infamous “colostomy bag” was the target for many unbearable, tasteless comedic references. What is overlooked is that the surgeon in making this stoma has performed a lifesaving act—a surgical procedure that will give the patient a second chance to live a full life!

Prior to ostomy surgery and in the early postoperative period, the patient will have questions about their new plumbing system. For example:

- “Is there a special diet that must be adhered to?” There is no “ostomy diet” and any restrictions are those dictated by common sense or other medical conditions.
- “What about the clothes I will wear, will they be baggy and lacking in style?” Nope! Designer jeans, no problem.
- “When I enter a room, will people smell me before they see me?” No way. Thanks to today’s ostomy product manufacturers, the unpleasant odors associated with a fecal stoma are a thing of the past.
- “Can I still engage in sporting activities?” Absolutely. Tennis, golf, swimming, running, most certainly. I even have a friend with an ileostomy who is an amateur boxer and another who climbed the Seven Summits, the highest mountain peak on each of the seven continents.
- “Will I be able to return to my job as a policeman or will I be restricted to a sedentary life?” People with ostomies serve on police forces, as firemen, and in the military flying a Blackhawk helicopter; there is really nothing you can’t do!
- “Can I have sex and intimacy?” Sexual activities are indeed possible and a stoma doesn’t necessarily keep a woman from pregnancy and enjoying motherhood.
- “What will my spouse, family, and friends think of me?” People will react to you in the same way you react to yourself ... they will see what you see when you look into a mirror ... if you are upbeat and can go with the flow, then that is the way you will be perceived.

Yes, an ostomy will change a person’s life, but the medical problem that necessitated this surgery has been addressed, it is behind them, and now it is up to the patient to take the first positive rehabilitative step ... that of self-acceptance. Playing the “why me” card is a nonconstructive waste of time. What is different between the preoperative person and the person with an ostomy? A bodily function that was once behind them is now up front. No big deal! People do not judge you by how you go to the bathroom! You are judged by whom you are,

Address for correspondence
Kenneth W. Aukett, Co-Founder
UOAA, United Ostomy
Associations of America, P.O. Box
525, Kennebunk, ME 04043-0525
(e-mail: kenwaukett@gmail.com).

Issue Theme Intestinal Stoma;
Guest Editor: Michael F. McGee,
MD, FACS, FASCRS

Copyright © 2017 by Thieme Medical
Publishers, Inc., 333 Seventh Avenue,
New York, NY 10001, USA.
Tel: +1(212) 584-4662.

DOI <https://doi.org/10.1055/s-0037-1598154>.
ISSN 1531-0043.

how you react to your surgery, and the manner in which you view yourself. It is important for the patient to understand that X-ray vision does not exist and no one needs to know about their ostomy unless they choose to tell them. We do not wear signs that state “I do #1 or #2 in a bag”!

It is important for the surgeon to thoroughly answer all questions about stomas prior to surgery. Don't gloss over your responses. Small issues to the medical professional can be very big to the patient. I also recommend seeking counsel from a local ostomy support group that is affiliated with the UOAA (www.ostomy.org). There are more than 350 such groups throughout the United States. UOAA is recognized by both the American Society of Colon and Rectal Surgeons and the Wound, Ostomy and Continence Nurses Society. These affiliated support groups feature ostomy patient visit-

ing programs that provide certified visitors and trained well-matched volunteers who have an ostomy themselves, who can meet with your patients and their care-givers to discuss bowel or urinary diversion quality of life issues. The name of the visitor may be forgotten but the image of the confident, well-adjusted person they talked with will be a permanent inspiration. Physicians have reported that when an ostomy visitor is included as part of the multidisciplinary team involved in the patient's postoperative care, the length of the patient's rehabilitation period has been significantly reduced.

In conclusion, I want to thank you for giving us a second chance at life and for caring about the quality of the life that you gave back to us, even if it meant having “the bag.”