LIVING WITH AN
OSTOMY

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Dedicated to Improving Ostomy Lifestyle!

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The author underwent surgery for colorectal cancer in December of 2003 at age 64 and the surgeon performed a permanent Colostomy. The Colostomy is irreversible and the following pages outline the resulting steps that were taken by Kenneth R. Schena to adapt to living life with a Colostomy. A colostomy repairs the lower digestive track or colon. An Iliostomy repairs the upper digestive track, and the output is of a more liquid consistency with a higher acid content.

The objective of this compilation is to help those who will undergo this type of surgery in the future and make life easier for those who have been living with a Colostomy or Iliostomy. All of the discoveries and trials experienced by the author have been documented in hopes of developing a guide that will help others who experience a similar surgery deal with their issues, or at least know what to expect.

Not withstanding the medical procedures required that result in a Colostomy / Iliostomy, coming home from the hospital and dealing with the mental adjustment is overwhelming. The physical adaptation of ones’ body becomes yet another barrier to overcome. When you add the servicing required to maintain the collection system, it makes for a drastic initial adjustment to life.

Having a good support system at home will help immeasurably and seeking outside support groups to learn from others is invaluable. In this day and age, the Internet can provide resources to help you achieve a more normal life again.

Another great source of helpful information is the United Ostomy Association of America (UOAA) publication called Phoenix which is published quarterly. You may subscribe by calling 949 600-7296 (I highly recommend this publication). Their web site is: www.uoaa.org

I sincerely hope readers will find the information in this booklet helpful and useful in adapting to life with a Colostomy / Iliostomy. I will be happy to speak to anyone in need of guidance and can be reached at 239 263-9957.
What is a Colostomy?

The surgeon creates a Colostomy when he removes the part of the colon that has been infected (or for whatever reason stops functioning properly). A cut is made in the abdominal wall (stomach) through which the surgeon feeds the colon and forms an opening approximately 1-to 2-½ inches in diameter and protruding ½ to 1 ½ inches. The exact size and location depends on the surgeon, but generally the Stoma, as it is called, is on the left of the belly button and just below the waist belt line.

The Stoma excretes body waste - replacing the function of the rectum. If the Colostomy is permanent, the rectum has either been removed or closed with sutures. The person must then depend on one of the available collection systems to receive and dispose of waste. There are several companies that make a variety of products to deal with excreted body waste.

The Stoma has no rectal muscle - so when the body develops waste, the Stoma deposits it in the collection system used. There is a variety of different collection systems available to choose from, and several companies that make them. I will attempt to identify the various types in order to educate the reader which should help in making a suitable, intelligent choice.

Most companies will provide samples to a user in order to promote the benefits offered by their product. Contact your local Ostomy Support Group for a listing of the various companies and their toll free telephone numbers. This can facilitate locating the right product to suit your needs.

There is also a temporary Colostomy (commonly referred to as a J-Ostomy) that can be later reversed. The temporary Colostomy is generally located on the right side of the abdomen and is attached to the ileum (small intestine). This is used for a period of about three months to allow the colon (large intestine) to heal after surgery without infectious body waste passing through. This type of Colostomy can later be reversed by re-attaching the ileum to the colon to regain / allow normal body function.

A basic knowledge is necessary to help a person with a Colostomy understand the details of what must be done to service the system created by this procedure. Mental adjustment is imperative for one to live life on a day-to-day basis.
What is an Ileostomy?

Food consumed by an individual is deposited in the stomach and then passes to the ilium in a semi liquid form that is highly acidic. This oatmeal consistency waste product passes through the ilium enroute to the colon.

The colon functions to extract other body liquids and passes them back into the body for other use. As the waste passes through the colon it becomes the stool that leaves the body via the rectum. This may be an over simplification of the process, but it may help one to understand from a lay person’s perspective, the basic function they are dealing with.

The ilium is separated from the colon and a stoma is created on the right side of the body - on the abdomen adjacent to the belly button at, below or above the waste line (depending on the doctor performing the surgery). This can be a temporary Ileostomy - allowing the colon to heal after removal of a diseased section. In such a case, the ilium is resected after the colon has had time to heal. A pouch collection system must be worn to service body waste while the colon healing takes place.

There are also permanent Ileostomies performed due to other medical problems such as colitis. In these cases, the doctor is unable to reconnect the colon to allow normal body function. The Iliostomy (much like the Colostomy) requires a collection system to receive waste excreted by the body. The Stoma created for an Iliostomy does not have muscular control so it excretes waste as it is processed by the body. A pouch collection system is required on a permanent basis to service the body excretion function.

Most Ileostomates must empty their pouch systems periodically throughout the day and evening. Generally the pouch must be emptied every two hours or so on a 24 hour basis. Having this condition makes one acutely aware of restroom locations.

This information is meant as a guide to help someone new to the subject have a basic understanding of what is taking place. This will hopefully result in the person adapting to the circumstances and mentally coping with the necessary adjustments - and allow them to live a normal life.
Colostomy Pouch Collection Systems

1. The collection pouch can be one or two piece in design.
   a. The one-piece pouch has the wafer (also called flange) permanently attached to the collection bag. It is attached to the abdomen as a unit, and replaced totally.
   b. The two-piece pouch is designed with the wafer as one piece and the bag as the second piece. There is a substantial connection joining the two that is air tight and capable of withstanding the weight of collected body waste. The wafer is attached to the abdomen and the bag later attached. Having a two piece system allows greater flexibility when servicing.

2. The collection pouches can be closed at the bottom, or have a drain to permit cleaning and extended use. Both the one piece and two piece systems are available with a closed (disposable) or drainable bottom to the pouch.
   a. The pouches with a closed bottom on the bag are disposable when full of fecal matter.
   b. The pouches with a drain at the bottom of the bag can be cleaned and reused more than one time.

3. The plastic film used to compose the bag has a highly polished surface to permit removal of the accumulated waste collected in the pouch. It is advisable to use a deodorant and lubricant to control maintenance.

4. Many of the bag designs have what is called a comfort layer on the outside of the film. This creates a buffer layer for the wearer between their skin as well as their clothing.

5. There are as many designs - ranging from opaque materials to “see through” to facilitate the varying needs of the user. Frequently, a hospital will use see-through bags for a new user to allow adjustment to the colostomy. Having see-through bags will allow visual inspection during this adjustment period, and permit the user to get acclimated to the function of the colostomy.

6. There are different types of closures available on drainable bags. All Perform a similar function - which is to seal off the bottom opening. Some manufacturers use clips to seal, while others use variations of “hook and loop” type closures (“Velcro” type fasteners). I personally prefer the “hook and loop” because it is less bulky and easy to use.
7. Another product to be aware of is called a Stoma Cap. It is a small pouch generally around 3 inches in diameter and can be used for limited periods of time. This product most often is used during athletic activities such as swimming, tennis, golf or any active sport. The Stoma Cap permits a low profile for the user wearing athletic apparel.

Note: There are many other products on the market that are generally variations of those noted in this compendium. New products are introduced frequently and use of the Internet can help identify them.

Attachment to the Body

The wafer or flange is the means by which the collection system is attached to the body. There is an adhesive that is hypoallergenic on the wafer designed to form a solid bond that will not leak fluids or odor. Preparation and properly affixing the wafer will assure successful use. Please note that there are different adhesives to match the chemical make-up of different people.

The steps required to properly apply the wafer are as follows:

1. There are a number of products available to condition the skin to better accept the collection system. I personally found them unnecessary.
2. The first step is to clean your hands before coming in contact with the Stoma area.
3. If there is body hair present, it must be shaved to permit good adhesion to the system.
4. Once shaved, I use a product called Williams Lectric Shave (available at most pharmacies, department stores or supermarkets) to remove any adhesive residue left and clean the area to accept the wafer. Dry the area well.
5. The wafer should be warmed to body temperature to achieve maximum adherence. This can also be accomplished if you are using a two-piece system by placing the wafer under your arm (arm pit) while you prepare the area for its acceptance. This will warm to body temperature. If you are using a one-piece product, heat it with a hair dryer.
6. Remove the backing from the adhesive side and carefully affix the wafer to the abdomen - insuring a good seal around the Stoma.

Note: The wafer can be cut to the Stoma size - or they can be ordered from the supplier pre-cut to your Stoma size. Ordering them pre-sized saves time and they are cut with no rough edges.

The above applies to both one-piece and two-piece systems, and the steps should be carefully followed to achieve a good serviceable bond.
Life Experience

I personally was in the hospital for five days following surgery owing to my wife Virginia, who came to the hospital daily and made me walk and do the things necessary to regain mobility. Thanks to her my recovery was accelerated, and I was released in five days to return home.

I came home with a box of clear bags supplied by a knowledgeable Ostomy nurse named Carol Burton. Carol had spent time with me before undergoing the operation, and came to my room to provide me supplies and make sure I had the dexterity to use them. Arriving home to deal with all this was a real life experience.

The pouches supplied were clear, two piece and drainable. My first experience cleaning the pouch involved using a plastic bottle to provide a supply of water. I would stand in front of the commode, raise the pouch and pour water into it. I would then sit backwards on the commode and carefully lower the pouch drain opening into the commode, and then release the end - allowing the contents to drop into the toilet bowl. It took 3 or 4 “fill and drop” procedures to get the pouch reasonably clean. Yes there were many mishaps that were not pleasant to deal with.

I concluded there had to be a better way of cleaning this system. I went on the Internet to see if I could find a more suitable product. I went to the local medical supply store and met a very helpful lady by the name of Peggy Quigley, who patiently showed me all she had available. I bought several hundred dollars worth of supplies to try. The store had scheduled a demonstration by one of the manufacturer’s reps and Peg invited me to attend.

I went to the demonstration and ordered the company’s latest innovations to try (I still have most of them – unused). When I next went back to buy more supplies, I told Peg: if I could not find a suitable product, I would design and make my own. I joined the local Ostomy Support Group and began attending meetings. In the meantime, I went to the local hardware stores to find materials to fabricate pouch design modifications that would make my life more normal.

I took the best product I could find that had some good characteristics I liked, and modified it in my garage. With the help of my son Blaine, we fabricated several different designs - which I would later test. Interestingly, as crude as the originals were, they worked and made my life so much easier. Constant work and refinement led to serviceable products. I later allowed others to try the product with heart-warming success. Alice Fatch, whom I met at a support group meeting where I presented my invention, was the first person allowed to use it. It made her life much easier and me very happy just for helping.
Ostomy E-Z Clean System

The system I devised is called Schena Ostomy E-Z Clean. Its’ function is to clean the pouch without all the cumbersome and time-consuming steps. My design incorporates a manifold in the upper portion of the pouch above the Stoma. There is an inlet at the top of the pouch to permit hook-up to a pressurized water source. A tethered plug closes the top and also allows for relief of any accumulated gas pressure. I devised a simple water supply that is attached to the water inlet of the commode.

To use this system, one sits forward or backward on the commode and drops the pouch drain into the toilet bowel. The inlet is then opened and the water feed system is attached. Turn the water valve on, depress the thumb trigger and in 30 seconds to a minute or 2 the pouch is totally cleaned. The body waste drops into the toilet bowel and is then flushed away. Flushing the pouch until the exiting water runs clear assures a clean Stoma. The user then wipes the excess water from the drain end, closes it and replaces the inlet cap – done.

I use the system 10 or 12 times a day because I don’t like having any waste in my pouch. Everyone is different and each Stoma has output depending on the individual and their eating habits. The objective of this system is to permit fast, efficient hygienic cleaning of the pouch. Since it also cleans the exposed body skin, it prevents the skin from becoming irritated.

I have applied for a patent on my system and formed a company (Schena Ostomy Technologies, Inc.) to refine, produce and make the product available to all who may need it. The newest product design has two chambers in the bag to permit a low profile and more efficient cleaning. The upper plenum is where the water is introduced via the inlet that will service Colostomy or Iliostomy patients. Water inlets join the upper chamber and lower pouch creating a water sheet that washes down the pouch into the toilet bowel - carrying accumulated waste. It is fast, efficient and hygienic.

Portability is also an issue that has been addressed by having a water source that can be hooked up to any sink spout to permit travel without access to facilities. A portable fixture will be available for evenings out where a public facility must be used. Being a Colostomate, the pouches we produce will be user friendly and possess characteristics that only a user would know to incorporate into the design.

This product was designed to help a person with a Colostomy / Iliostomy achieve a surprising level of normality. It has certainly helped me adjust to living my life without compromising the activities that made life worth living. Helping people with a Colostomy / Iliostomy regain their self-respect and lead a normal life has become my mission in life.
Helpful Tips

1. Carefully wash your hands before servicing your Ostomy to avoid creating any transmittal of germs.

2. Prepare the materials you will use before hand to avoid potential problems while servicing your Ostomy.

3. Sitting backwards on the toilet facing the water closet allows you to use the top of the water closet as a work surface to hold supplies you will be using.

4. If you use a two piece system, place the wafer under your arm pit to warm it to body temperature (while you prepare the Stoma area to accept the system). This will provide better adhesion to your abdomen. You can also use a hair dryer to warm the wafer to body temperature.

5. Williams Lectric Shave (available at most pharmacies, super markets or department stores), works well to remove adhesive residue. Drying the area well after use provides a clean dry surface for attachment of the wafer. Medicated powder dusted on irritated skin and coated with a barrier film can help rashes that develop.

6. A small quantity of no-stick cooking spray directed into the pouch will provide a slippery surface that will make cleaning easier. This can be done when changing pouches, and may be used anytime thereafter.

Note: Tincture of Benzoin (available at most pharmacies) is helpful to aid in preparing the skin to accept the flange (if you have difficulty achieving a good seal).

7. If you want to deodorize the pouch, mix a small quantity of mouthwash with water and put some in your pouch before attaching.

8. If you use a two-piece system, sleep with one pouch and change to a second pouch for daytime wear. Doing so will prolong wear time due to the nighttime abuse created by restless sleep.

9. When the interior finish of the pouch begins to lose its shine, the pouch should be changed to allow efficient cleaning. Continued exposure to acidic body waste eats away at the finish. A general rule is to change the system every 3 to 5 days or at least weekly.

10. Follow the product manufacturers instructions for best results since they know their product characteristics and limitations better than anyone.

As with any advice provided, use good judgment in applying the above to your personal application. If something works for you, don’t change it unless you feel doing so will improve your application use and quality of life.
Appendix A

Schena Ostomy E-Z Clean Pouch System

You will not believe how it will change your life!

Portable Water Feed Sink Hook-Up

Fixed System Hanger
Commode Hook-Up
Ostomy Nurse Assistance

The companies available from your local Ostomy Support Group have the availability of Ostomy nurses that can speak to you by phone and help with any problems you are experiencing. In addition, most support groups have OCN nurses as members of their group that can help you solve most problems.

Your local Ostomy Association can refer you to area Ostomy nurses who make house calls to help solve problems.

If you have problems locating your local association, call Schena Ostomy Technologies and someone will help you to locate the association in your area.

NOTE: Do not wait until the area surrounding your Ostomy is inflamed with a rash to call for assistance. Call early for a solution to your problem. In most cases it is a matter of finding the right product and applying the wafer properly.
Products of Schena Ostomy Technologies, Inc.
For more information and product details, go to the company web site www.ostomyezclean.com and click on “Product Catalogue” on the Home Page. Certain products like “Trial Kits” are available direct from the manufacturer using PayPal and shipment is Priority Mail.