Post-surgery guidelines for patients undergoing sigmoid colon resection, colon pouch reconstruction and ilestomy, followed by its reversal after three months of recovery.

Guidelines are based on the experiences of patient Mirta Mihovilovic. Original surgery required complete resection of rectum and a large portion of the sigmoid colon (~35cm in total)

What to expect following ileostomy. Dos and Don'ts

1) Starting 24h h after surgery and up to 10 days there after, you may develop skin itching/ rash. The severity will depend on the patient ability to tolerate narcotics that are given during surgery and thereafter. Narcotics in general are capable of stimulating skin cells and cause skin and systemic (whole body) "allergies" (the scientific term for this condition is *mast cell degranulation*). This adverse reaction (varying in intensity from patient to patient) also can increase the likelihood of headaches. It is important to note that patients can be dehydrated relatively easily due to the *ileostomy* (see below), but dehydration is not responsible for itching or skin rash; the culprit is the overload of narcotics that the detoxifying systems of the patient are not able to clear up.

   Different patients have different abilities to clear up the drugs. Accordingly, symptoms can vary from a mild itch to an overall skin rash in more severe cases. Consult with your PCP or dermatologist and, if not allergic to Calamine lotion and Diphenhydramine HCl (the active ingredient in Benadryl), use Calamine for the affected skin and take the minimal doses of Diphenhydramine HCl (infant doses are best if patient reaction is severe, because at this point your body may have problems clearing up any drug and drug-related compounds).

2) During your recovery period at the hospital (5 to 7 days on average) you will be hydrated through an IV line with saline fluids and will be given medications that promote water retention. Lack of a functional large intestine, and the consequent excretion of fecal matter through the small intestine (*ileum)* does not allow for water absorption which normally occurs in the large intestine (*colon)*. At the time of discharge from the hospital you will be disconnected from the saline IV; to avoid dehydration, you will need to keep taking medication; you could be put on a narcotic-like drug in combination with atropine, a smooth muscle (gut) relaxant. If you feel energy-depleted by the narcotic-like drug, other options are available. (Ask your care provider, before leaving the hospital, how to proceed if the medication you are taking causes adverse effects when used for an extended period of time). In addition to your medication, liquid ingestion, along with the consumption of foods that help retain water become crucial.

   It is then imperative that patients drink plenty of nutritious fluids (fruit juices, milk, soy milk, soups); but to promote water retention these should be taken along with a snack or foodstuff that will promote water absorption (breads, rice-based snack, noodle-based snacks, in general any food that is able to soak up a water). AVOID salty liquids, as they may

promote more dehydration (water moves towards places of high salt concentration, so if the liquid that goes into your small intestine is high in salts, it may even take away water from the intestinal cavity). If dehydration starts occurring, you will know, because you will start feeling depleted of energy: AVOID all kinds of salty snacks, go for your basic bread and water; AVOID salty liquids.

You will also be instructed to avoid fresh fruits and vegetables; the fibers they contain could clog your *stoma*. Please be sure to observe these instructions. If you chew thoroughly, however, you most certainly can have apples and carrots and can suck on juicy fruits like oranges and grapefruit. Grated apples and carrots worked fine with me, as did peeled fresh tomatoes. On the other hand, I could not tolerate raw lettuce; stewed fruits and cooked veggies were all OK. Do not be shy, if for some reason you end up with fibrous foodstuff in your mouth, just take it out of your mouth and dispose of it.

3) Duke has an excellent nursing staff; they will teach you all you need to know about caring from your *stoma*.

4) If during the period that you have to take care of the *stoma* you see bleeding coming from the edge of it, DO NOT PANIC! It happens and usually stops on its own. Nonetheless call either the osteomy nurse or the emergency number given to you at the time of discharge. You need to document all occurrences to get the best treatment possible. You might want to keep a diary.

5) Lower pelvic (and for women also vaginal) edema is a possible surgical side effect. NOTE: Mine went away starting at week 4 **after ileostomy reversal** and resolved by week 8.

6) For women: You may experience mild vaginal bleeding due to the release of a stitch that is used to move the uterus out of the surgical field during your operation. I bled for a few days (during week 6-7 post surgery).

What to expect after reconnection: Dos and Don’ts

1) The allergy-type reaction described in 1) above occurs at skin level, but a similar reaction, characterized by tenderness to the touch in your abdomen and “gut” over-reactivity may also occur at the intestinal level. Narcotic-related “allergies” can now be more intense: your large intestine has literally become “dormant” due to inactivity; therefore receiving food suddenly over-stimulates it. Thus, you will feel successive and sudden urges to evacuate (the technical term for this over-reactivity of the “gut” is *gastro-colic reflex*). The *gastro-colic reflex* is usually worst in patients who have lost a larger portion of intestines). Over-reactivity will not be permanent, but will take weeks to subside and become manageable: it may

take more than five weeks to be back to a normal state with just one or two bowel movements per day. Initial evacuations are, at one given time, small in size and liquid in nature; because these evacuations are so numerous (day and night), they may result in inflammation of the anal sphincter and hemorrhoids, should these be present. Keeping the area clean is the number one issue. After each evacuation, wash with water (a squeeze bottle works fine) and gently pat the area dry.

a) To control itching and inflammation of the area use Tucks cream containing hydrocortisone (anti-itching product).
b) To reduce hemorrhoidal swelling, use Phenyleprine, glycerin and shark liver oil (the compounds present in preparation H, available in generic brands).
c) Use Zinc Oxide Cream (diaper rash cream), if you notice any breaks in the skin associated with the hemorrhoids and adjacent areas.

If bowel evacuation urges are too frequent (personally, the first week after surgery, in part due to a severe systemic “allergic” reaction at skin and “gut” level, I endured up to 40 such urges in a 24 hour cycle. I used to actually evacuate every 5 urges. Sometimes the urge was so intense it was not possible to hold).

IMPORTANT: Consult with your PCP or Dermatologist as soon as you notice you have a post-surgery skin itch/rash. Be specific: tell them that you have received narcotics and the kind of surgery you underwent; make sure Calamine and Diphenhydramine HCl are OK for you and then start using CALAMINE and infant doses of Diphenhydramine HCl as soon as possible. Your recovery will proceed faster, you will avoid “allergy-related migraine type headaches” and you will feel ON YOUR WAY TO RECOVERY.

2) Diet is of extreme importance to control the *gastro-colic reflex*, to avoid dehydration (less likely now that the patient once again has a functional large intestine) and to repopulate your colon with appropriate *intestinal flora* (bacteria).

Once your physician gives the OK to ingest soups, you are also ready to take your 3-omega fatty acid, your multivitamins and a supplement which contains GOOD bacteria (Lactobacillus acidophilus and Bifidobacterium lactis); even if you lack appetite try to eat; at least take your dietary supplements. **(IMPORTANT: Consult your PCP or GI doctor, if you have additional health related issues).** A reliable source of GOOD bacteria, used by Integrative Medicine practitioners is *Ultra Flora Plus* from Metagenics. Products from Metagenics, although are not FDA certified, have been proven worth its value (Disclaimer: I DO NOT HAVE ANY TIES WITH THE COMPANY, EXCEPT THAT I BUY A FEW OF THEIR PRODUCTS through the Internet). If you tolerate yogurt you should have it, but be cautious. You may experience some bloating; this is OK, but AVOID excessive bloating. Note that Lactobacillus and Bifidobacterium will not stay in your “gut”; they will rather help your gut to be recolonized by the appropriate bacteria.

Your care provider will first give the OK for a liquid diet, by day 2 you will probably be also eating crackers and by day 3 or 4, eggs. If not allergic to the following food items, also introduce bread, potatoes and rice as soon as possible;

they will help you retain water and somewhat de-activate the *gastro-colic reflex.* **About fresh fruits and veggies:** My experience would suggest that during the first week you should avoid raw fruits and veggies and drink only small amounts of pasteurized juices. Introduce bananas by week 2. Bananas are good as the first fresh fruit to try; they help retain water and control the *gastro-colic reflex*. Later on introduce one fruit or veggie at the time, but eat only a small portion. See how your body reacts and adjust ingestion accordingly. For example, at present, eight weeks after reconnection, I must limit myself to six prunes a day, if not I accentuate my *gastro-colic reflex*. Any new food item should be introduced gradually, eating a small portion at one time. Avoid swallowing highly fibrous food stuff by chewing thoroughly and then simply spitting left over fiber into a napkin.

Inform your PCP and/or GI physician when you will have your reconnection and be in contact with these professionals. If, after a few days post-reconnection, urges to evacuate are frequent and/or if the anal area gets inflamed, they can coach you and, if necessary, prescribe medicines to control the *gastro-colic reflex* and ongoing inflammatory processes associated with your surgery. Sometimes they may medicate just for a day or two to ameliorate your "gut over-reactivity". Use your judgment and don't ever over-medicate. One thing you have to AVOID is to make your intestine unresponsive to the foods that you ingest. **Remember that you are aiming for one or two well-controlled bowel movements per day.**

This surgery as a procedure is a blessing, but its post-operative period can be tough. It will depend on many factors including how well you can detoxify from the drugs that are given to you in the hospital.

Additional Note from Mirta Mihovilovic to all personnel involved in the care of patients undergoing a *non-permanent ileostomy*

I hope that these notes, based on my personal experience, will help create a brochure to give to patients undergoing non-permanent ileostomies. Please feel free to contact me if you have questions and comments. I am listed in the Duke University phone directory and my home contacts are given below.

Be well.

Mirta Mihovilovic, Ph.D.
Chapel Hill, NC 27517

Phone (919) 968-1237
E-mail mihov001@bellsouth.net