

Having a Colostomy

*A Primer for The
Colostomy Patient*

Cheryl Van Horn, B.S., M.T., C.E.T.N.



THE CLEVELAND CLINIC FOUNDATION

9500 Euclid Avenue
Cleveland, Ohio 44195

Produced by the Department of Graphic Services / PWO 3323 5/99

notes or questions

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brochures

United Ostomy Association:

Sex and the Female Ostomate

Sex and the Male Ostomate

Sex, Courtship and the Single Ostomate

Ostomy Quarterly (magazine)

Ostomy Brochure

Colostomy, A Guide

Living With an Ostomy

Information for Gay Men, Lesbians, and their Caregivers

suggested reading

Jeter, K., **These Special Children**, Bull Publishing Co., Palo Alto, CA, 1980.

Mullen, B., VcGinn, K.A. **The Ostomy Book: Living Comfortably with Colostomies, Ileostomies, and Urostomies**, Bull Publishing Co., Palo Alto, CA 1980, Revised 1992.

Phillips, R.H., **Coping With An Ostomy**, Avery Publishing Group Inc., Wayne, N.J., 1983.

Schover, Leslie. **For the Female Who has Cancer and Her Partner**, American Cancer Society, 1988.

Schover, Leslie. **For the Male Who Has Cancer and His Partner**, American Cancer Society, 1988.

introduction

The word “colostomy” comes from two Greek words. Kolon is the original Greek word meaning “large intestine.” It became the English word for colon. **Stoma**, in Greek, means “mouth or opening.” Hence, a colostomy is defined as an opening in the colon. When a part of your large intestine is removed or it is disconnected, the new opening (colostomy) must be made in the colon where waste can leave your body.

Having a COLOSTOMY can save your life, but having one also means changes. This booklet will help answer your questions about these changes, how to live with them, and how to cope with some of the feelings you may have about them.

Of course, this booklet cannot answer all your questions so please ask questions of your own. Throughout the booklet, there are blank pages you can use to write down questions as you think of them and the answers when you hear them. Questions that other patients have asked are answered at the back of the booklet. Remember, there is no such thing as a silly question.

As you learn about your disease and colostomy surgery, it may help you to know that you are not alone. Each year thousands of people in the United States have this surgery—people of all ages (even newborn babies), and in all walks of life. Most are enjoying full, healthy, active lives years after their surgery.

In addition to your doctor and enterostomal therapy (ET) nurse, many other people are willing to help you with advice and emotional support. You can contact them through the United Ostomy Association (UOA), 19772 MacArthur Blvd. Suite 200, Irvine, CA 92612-2405 (949) 660-8624 or 1-800-826-0826. If you would like to talk to a UOA visitor while you are still in the hospital, your E.T. nurse can arrange this for you.

the digestive system

Knowing what your digestive system looks like and how it works will help you understand your surgery and how your digestive system will work afterward. The digestive system is a hollow tube that starts at the mouth, where you take food into the body, and ends at the anus, where waste passes out. In between are the esophagus, the stomach, the small intestine (small bowel), and the large intestine (large bowel, made up of the colon and rectum). Figure (1) shows what the digestive system looks like.

Digestion starts in the mouth, where you break up the food by chewing, and where chemicals in your saliva, called enzymes, start to break the food down into nutrients the body can use. When you swallow, the food mixture travels down the esophagus to the stomach. There the stomach's action and the strong digestive juices break down the food into a soupy mixture. This mixture then passes to the small intestine.

In the small intestine, the mixture becomes even more liquid. As this liquid travels through approximately 20 feet of small intestine almost all the nutrients and fluids your body can use are absorbed into the blood. The liquid "leftovers" are passed on to the colon (large intestine).

The colon, rectum and anus are the last sections of the digestive system. Although they are an important part of the system, they have little to do with digesting food or absorbing nutrients. You could think of the large intestine as the body's trash compactor.

As the "leftover" liquid flows through the colon it becomes solid waste (stool). The fluid is continuously absorbed while the colon rhythmically contracts and expands (peristalsis), propelling the stool up the ascending (or right colon), across the transverse colon, and down the descending (or left colon) to the curved sigmoid colon. The stool is stored in the sigmoid colon and rectum until it is time for you to have a bowel movement. The sphincter muscles in the anus allow you to control the exit of stool from the body.

If there are areas of disease or injury in your colon, rectum or anus, your large intestine must be diverted, or the diseased area removed. The surgeon will remove (resect) the troublesome area of the colon. This may or may not result in a colostomy. Since the colon is 5-6 feet long, a part of it can be removed without compromising good health

Crohn's Disease

Painful, complex inflammatory bowel disease affecting all or part of the intestine. Unlike ulcerative colitis, it affects all layers of the intestine, not just the lining.

Diverticulitis

Small outpouches in the bowel wall frequently found in people over 40 years of age. Usually not troublesome unless they become inflamed.

Giardia

A type of protozoa (one cell micro organism) that may inhabit the small intestine of man.

Giardiasis

An infection in the intestinal tract with symptoms of diarrhea, cramps, nausea, weight loss and vomiting caused by the giardia parasite.

Incontinence

Inability to control the passage of waste from the body.

Perineal Wound

The incision between the buttocks required when the anus and rectum are removed.

Peristalsis

A wave like motion that causes the digestive contents to move through the bowel.

Resect

To remove, or cut out.

Sphincter

A circular muscle that closes the anus.

glossary

Abdominoperineal Resection

The sigmoid colon, the rectum and anus are removed. A permanent colostomy is then formed bringing the colon to the abdomen.

Anastomosis

An end to end or side to side union. Joining together.

Anorectal Manometry

Measures the resting tone and contraction strength (squeeze) of the anal sphincter muscles. It also measures the length of the anal canal. This is done by inserting a catheter into the anal canal and taking pressure readings at intervals as the catheter is withdrawn.

Barium Enema

An x-ray study of the colon. A liquid substance containing barium is inserted through the anus or, in case of a person with a colostomy, through the stoma. It fills the large intestine and shows clearly on x-ray film.

Birth Defects

Babies may be born with a spinal defect (spina bifida) which could lead to problems of bowel and urinary control. Sometimes a child is born without an anus. Hirschsprung's disease is a congenital abnormality where there is an absence of special nerves in the colon that cause peristalsis. These abnormalities may lead to colostomy surgery. In most cases the colostomy is temporary.

Colon Cancer

The second most common malignant disease in the United States. If detected in its early stages, it is potentially the most curable of abdominal cancers.

Colonscopy

The colon can be visualized using the fiberoptic colonoscope. This is a lighted flexible tube several feet long that can be passed around loops and curves of the colon. Polyps can be removed with this instrument.

Colostomy Irrigation

An enema through the stoma. The water stretches the bowel causing it to expel the waste.

and nutrition. In fact one can live with no colon at all. This is because the important job of absorbing fluid, nutrients and vitamins is done by the small intestine.

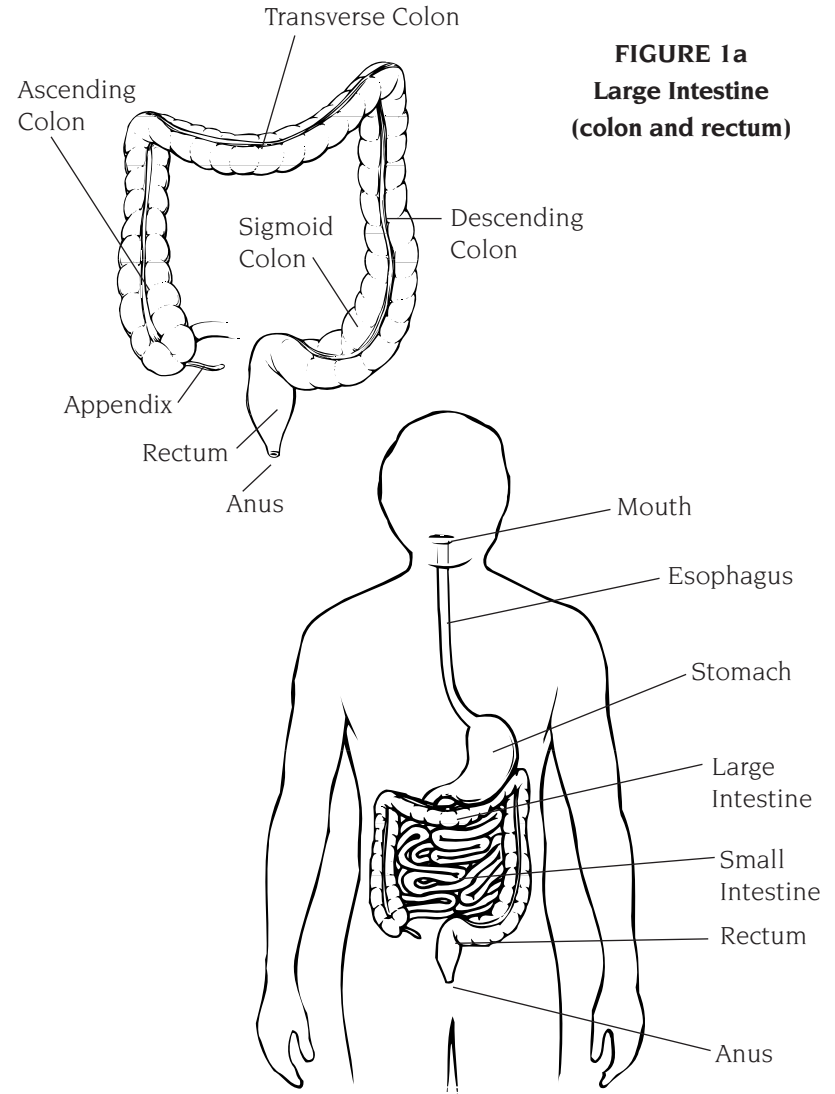


FIGURE 1
The Digestive System

who has colostomy surgery and why

People who need colostomy surgery have a disease, defect or injury in the large bowel (colon or rectum) serious enough that a part of the colon or rectum needs to be removed or disconnected.

Some common reasons for colostomy surgery are colon and rectal cancer, diverticulitis, Crohn's disease, birth defects and incontinence*. Less common reasons are injuries to the abdomen from motor vehicular accidents, industrial accidents, gun shot or stab wounds.

Some colostomies are permanent and some are temporary. A colostomy will be permanent if the anal sphincters must be removed or if they are not reliable. Anal sphincters will be removed if the disease (usually, but not always cancer) is invading or very close to anal tissue.

Incontinence will result when anal sphincters are not reliable. When this happens, a colostomy may solve the problem. A colostomy is much easier to manage than incontinence. When this type of surgery is needed, the bowel is diverted, a colostomy is made, but anal sphincters are not usually removed. The colostomy will be permanent if the anal sphincters cannot be surgically repaired. Anal sphincter function can be measured by a special test called anorectal manometry*.

In many cases, the area of disease or injury of the bowel does not involve the anal sphincter. When this happens, it may be possible for the surgeon to remove the affected area and immediately rejoin the remaining healthy bowel. This reconnection is called anastomosis*.

The surgeon may consider it necessary to allow this rejoined area (anastomosis) to heal for a period of time by diverting the passage of stool. A temporary colostomy is made upstream from the anastomosis allowing the bowel to heal satisfactorily. Some of the reasons for the temporary colostomy are infection, perforation or obstruction. In most cases of temporary colostomy, the continuity of the bowel can be re-established by closure of the colostomy in several months. This results in passing stool through the anus as before.

*See glossary for definition of terms.

25. My rectum and anus have been removed, but occasionally I have the urge to move my bowels as before. Why is this?

Although the surgery has removed the diseased rectum and anus, there are still nerve endings that may signal the urgency to have a bowel movement. Sometimes this urgency feeling is called the "phantom" rectum, similar to the "phantom" limb that amputees experience. These signals usually disappear in time. If they are distressing, try sitting on the commode for a few minutes. This usually relieves the feeling of urgency.

notes or questions

19. How much equipment should I take when I go on a trip?

Take twice the amount that you usually need for that period. Also, take a list of retailers in the community you are visiting. These lists are available from the manufacturers.

20. How often should I see a surgeon or ET nurse about my colostomy if I am not having any problems?

You will be advised about this in the course of your general follow-up. The colon remaining should be checked from time to time to assure that there is no recurrence of disease. Sometimes a check-up will help keep you informed on improvements in ostomy equipment and accessories.

21. Should I get a note from my doctor so I do not have to wear my seat belt in the car?

No. A seat belt can be adjusted to accommodate the stoma and the pouch. Your safety is more important than the minor inconvenience of a seat belt.

22. Will medications be as effective with a colostomy?

Persons with ascending or transverse colostomies should take medications in liquid or tablet form. Enteric coated pills may pass through unabsorbed. Persons with descending or sigmoid colostomies will not have this problem.

23. I see food remnants in the stool passing from my colostomy, like seeds and skins. Should I eliminate these things from my diet?

No. Food remnants are contained in stool normally. Just be certain that you are chewing your food properly.

24. I have a temporary loop colostomy and occasionally pass stool and mucus from the anus as well. Is this normal?

Yes. The bowel that is disconnected and "resting" will continue to secrete digestive fluids and mucus. As this builds up over time, the body will get the signal to pass it just as it did before the colostomy surgery. This is a normal function when the rectum is still present.

how a colostomy changes your body

When a part of your large intestine is removed or disconnected, the new opening in the colon may be an END or a LOOP COLOSTOMY.

To construct an END COLOSTOMY, the surgeon will bring healthy colon through an opening on the lower left side (usually) of your abdomen and stitch it to your skin. (See Figure 2.) This is called the **END COLOSTOMY STOMA**.

Not everyone will have a stoma like the end colostomy we have just described. The surgeon may decide to construct a **LOOP COLOSTOMY**. In this case, a loop of intestine is brought through the abdomen. It is cut only half way through, leaving the intestine otherwise intact, but with two openings. Once again, the surgeon stitches it to your skin. (See Figure 3.)

The **LOOP COLOSTOMY** is made for several reasons. Often it is used when the colostomy is intended to be temporary. Sometimes it is done to ensure a good blood supply to the stoma when the abdominal wall is thick. It is less complicated to close the loop colostomy when the time comes. Not all loop colostomies are temporary.

If a colostomy is necessary in the ascending colon, it will be on the right side and is called an **ascending colostomy**. When the colostomy is needed in the transverse colon it is called a **transverse colostomy** and will probably be in the area of the waistline. In the descending colon it is a **descending colostomy** and in the sigmoid colon, a **sigmoid colostomy**. The placement of the colostomy depends on the location of the disease, defect or injury to the bowel. (You will find the different colostomies discussed under "Types of Colostomies".)

A new colostomy will measure approximately 1-2 inches in diameter. It may protrude slightly, or it may be flat to your abdomen. This varies, depending on the location of the colostomy in the large intestine. Generally, a new transverse colostomy is larger than a descending or sigmoid colostomy. You can expect the new stoma to get smaller with time. In about six weeks to two months, it will shrink to its minimum size and will become softer.

The colostomy will be moist and beefy red, much like the inside of your mouth. Because the blood supply is near the surface, the stoma stays red and bleeds easily with touch or slight injury. This is not unusual or harmful.

cerned about odor, you can carry a pocket-sized room deodorizer spray. Flushing the toilet is usually adequate. Striking a match helps but NOT in a smoke free environment, i.e. airplane.

13. When I empty the pouch, it splashes. How do I prevent soiling myself?

Float a few sheets of toilet paper in the toilet before you empty the pouch. Another method is to flush the toilet while you are draining the pouch.

14. Can I get my supplies at the drug store?

Ostomy supplies are available in surgical supply houses. Very few drug stores carry these specialty items. Your ET nurse should give you information about local and mail order sources of supply when you are discharged from the hospital. Always compare costs from one supplier to another as prices vary.

15. I irrigate my sigmoid colostomy for regularity. What happens if I get the flu and have diarrhea?

Discontinue irrigations until the diarrhea has passed. Wear a secure pouching system during this time. Resume irrigations for regularity when dietary intake is normal.

16. I really don't like to irrigate my descending colostomy. What happens if I don't do it?

The bowel will move anyway. Be sure to always wear a secure pouching system.

17. What if the pouch leaks and I am away from home?

ALWAYS carry a spare set of supplies in case a leak occurs.

18. Why should I take ostomy supplies if I go to the hospital?

The hospital may not carry the exact type of supplies you need, or you may arrive when access to the ostomy supplies is limited. Always carry your own spare equipment.

7. Should I shower or bathe with the pouch on or off?

That is entirely up to you. There is no health reason why you cannot bathe with the pouch off. Remember stool may pass while you are washing. If that is distasteful to you, bathe or shower with the pouch on, or pick a time when your stoma is least likely to function.

8. What if water gets inside the stoma?

This will not happen. The wave-like motions of the bowel (peristalsis) move the bowel content in one direction - out of the body. Water would not be harmful, though, if it did get inside the stoma.

9. How often should I empty the pouch?

Empty the pouch when it is about one-third full. This way, the pouch will be less conspicuous under clothing. Emptying is easier to manage if the pouch is not too full and pouches last longer when they don't get so heavy. Emptying when it is time to urinate saves extra trips to the bathroom.

10. Should I rinse the pouch each time I empty it?

No. It is not necessary to rinse the pouch every time you empty it, but you may rinse as often as you wish. When the stool is thick or formed, it will be easier to empty if the pouch is flushed with warm sudsy water. Be sure to wipe the spout clean with each emptying, because residual stool on the outside of the pouch can be a source of offensive odor. Rinse the closure clamp from time to time as well.

11. Where should I change the pouch?

The pouch should be changed in the bathroom. This is a procedure for managing body waste, and the bathroom provides the proper environment for this.

12. What do I do about odor when I use a public restroom or the bathroom away from home?

Do not worry about it. That is what bathrooms are for. If you are

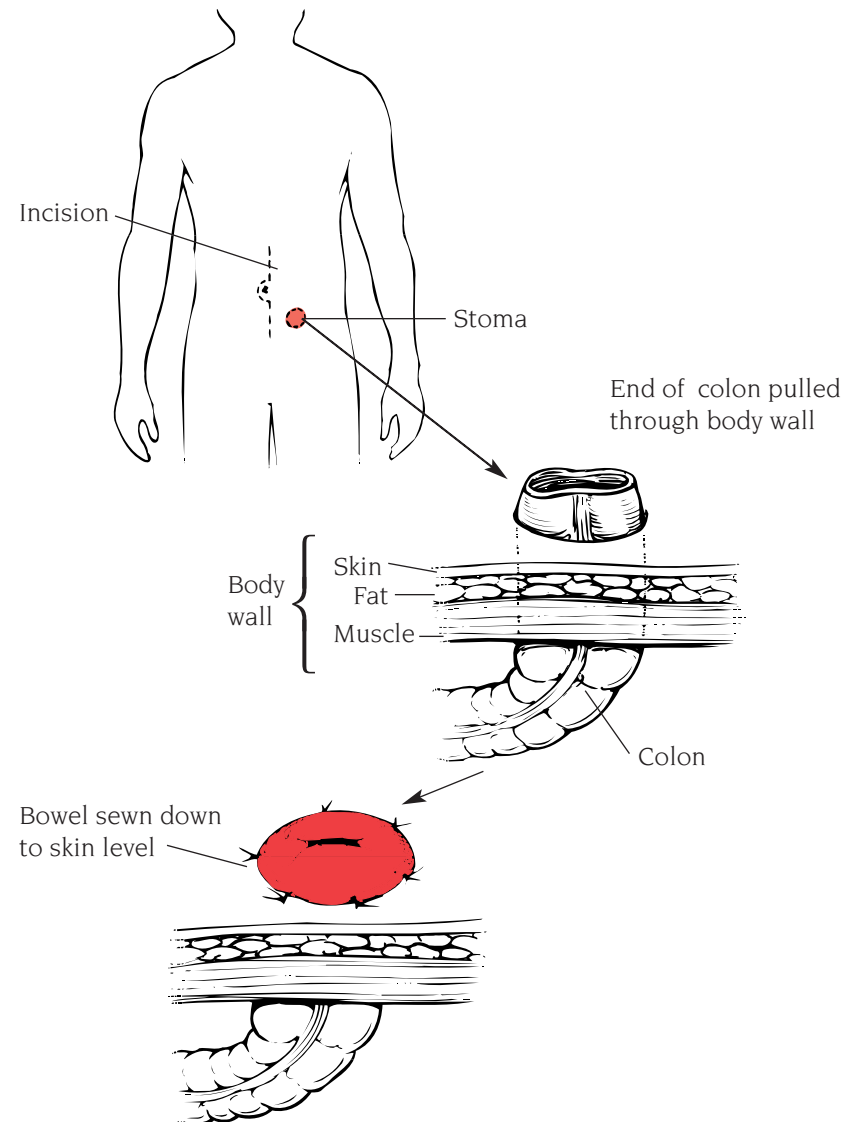


FIGURE 2
End Colostomy

questions & answers

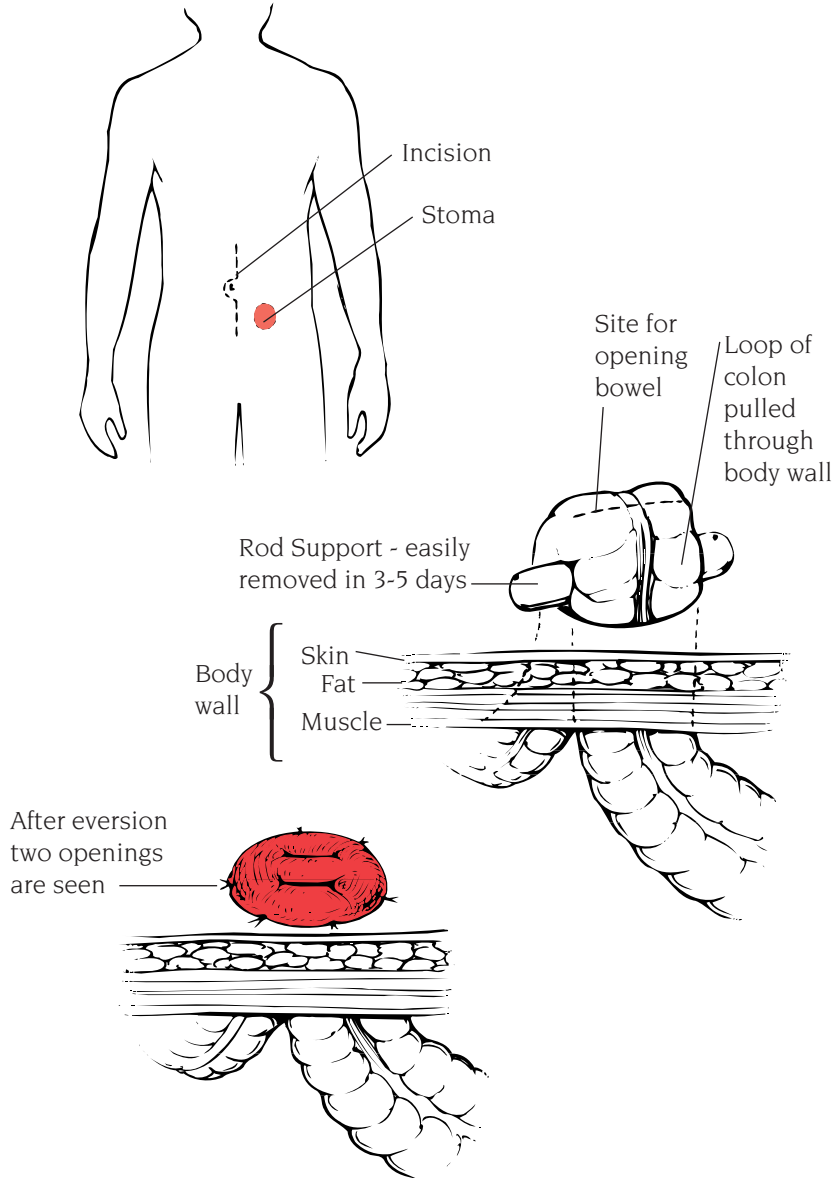


FIGURE 3
Loop Colostomy

1. Can I do the same things I used to do before my surgery?

Yes, and maybe a few more as your health improves. The few exceptions are heavy lifting (especially in the first three months after surgery) and contact sports that may result in a blow to the abdomen. If you have specific questions about this, ask your doctor.

2. Will the colostomy hurt when it is touched?

It will not hurt when it is touched. You will feel pressure, but not pain. For this reason the stoma must be protected from contact injury like blows or chronic rubbing. There are no nerve endings in the stoma which transmit sensation of pain.

3. Why is the stoma red?

It is red because this is the color of the inner lining of the digestive system. When the stoma is surgically constructed the bowel is folded back on itself to form a type of "cuff" exposing the lining.

4. Will the stoma always stay red?

Yes, it will always stay red because the lining of the intestine has a rich blood supply.

5. What color will the stool be?

The stool color will be brown. Occasionally food remnants can be identified. This is normal. Sometimes large quantities of highly colored foods such as licorice (black) or tomato sauce (red) change the color of the stool. Certain medications change the color of the stool. Iron pills, for example, cause the stool to be black. Check with your physician for specific information about medication and the effect on stool color.

6. The stool from my transverse colostomy is always loose. How do I know if I have diarrhea?

When you have diarrhea, the stool will become more liquid and the volume will increase. Many times there will be fever, cramping and nausea as well.

Colostomy irrigation may not be a successful method of regulation for persons with a history of irritable bowel or irregular bowel action. Irrigation may be cumbersome for persons with certain physical limitations, such as arthritis, visual impairment, paralysis, or palsy. Some persons find the procedure too time consuming or unpleasant. In these cases, using a reliable pouching system is an acceptable method of colostomy care.

Unlike your anus, the stoma has no sphincter muscle, so you cannot control the exit of waste. You will need to wear a pouch (ostomy collecting device) to collect the waste flow. (Methods of management are discussed later in this booklet.)

The E.T. nurse and the surgeon will make every effort to place and construct the stoma so you can see it easily, take care of it yourself, and so the pouch will fit well. Before you go to surgery, your doctor or ET nurse will find the best location for the stoma on your body. Because the shape of your abdomen changes as you move, they need to see you lying flat, sitting and standing. (See Figure 4.)

Pre-operative stoma siting is not always possible as in the case of emergency surgery or when a colostomy is unexpectedly found to be necessary during the operation.

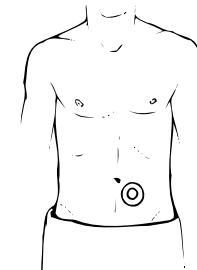
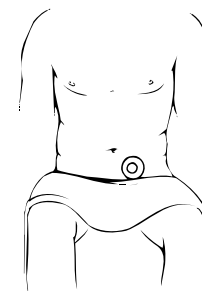


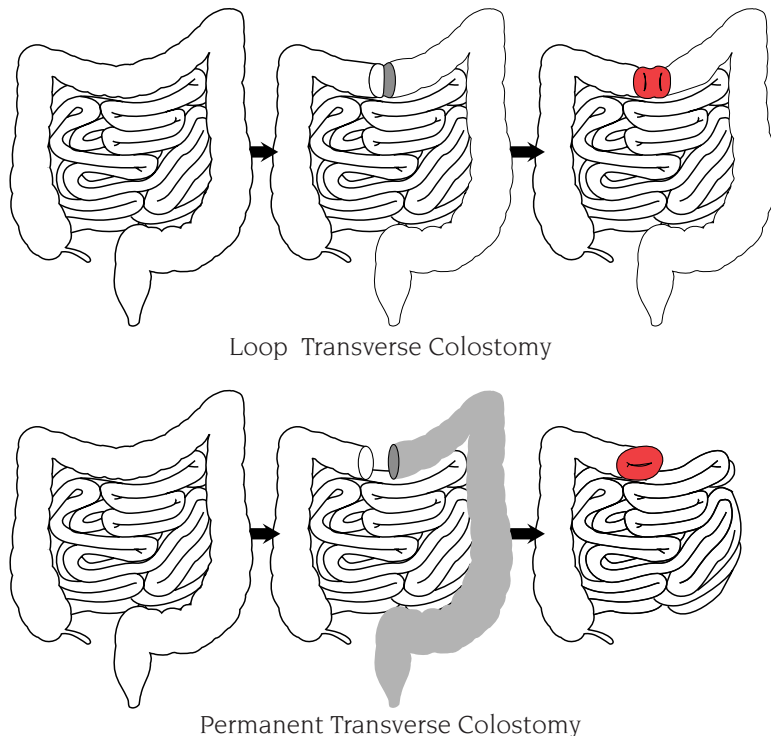
FIGURE 4
Stoma siting in lying, sitting and standing positions

types of colostomies

Ascending colostomy This rare type of colostomy is made in the ascending colon. Since it is the beginning of the large intestine, the consistency of the contents is still very liquid, contains harsh digestive enzymes and the frequency of the output is highly unpredictable. A properly fitted pouch needs to be worn at all times. Pouching methods are described later in this booklet.

Transverse Colostomy (See Figure 5.) This colostomy is made in the transverse colon. It may be in the right, middle, or left of the transverse colon depending on the location of the bowel disease or injury. Since the digestive contents have traveled 1/3 or 1/2 of the large intestine, the contents become thicker, like soft unformed stool. The harsh digestive enzymes are still present and are irritating to surrounding tissue. Because the frequency of the flow of stool is still highly unpredictable, a properly fitted pouch should be worn at all times. This type of colostomy may be temporary or permanent depending on the individual patient.

FIGURE 5 Transverse Colostomy



1. Fill the enema bag with 1000cc (one quart) of warm tap water.
2. Let the air out of the irrigation tubing by opening the clamp and letting water flow through the tubing. Close the clamp.
3. Hang the enema bag approximately shoulder high.
4. Sit on the toilet or on a chair in front of the toilet.
5. Remove the used colostomy pouch or stoma cover.
6. Center and secure the irrigation sleeve around the colostomy. Place the other end of the sleeve in the toilet.
7. Lubricate the cone tip of the enema bag with a water soluble lubricant.
8. Gently insert the cone tip into the stoma. Open the clamp and allow the water to slowly flow into the colon. The water should not leak around the cone, so hold it firmly in place. If cramping should occur, stop the flow of water and wait for the cramp to resolve. Relax. Deep breathe. Resume the flow of water when the cramp is gone.
9. When all the water has been instilled, withdraw the cone and wait for the return. After about 15 minutes, most of the fluid and stool will have passed. Rinse the irrigation sleeve with water/mild suds. Clamp the end and proceed with other morning activities.
10. After 45 minutes (usually) empty the contents of the irrigation sleeve into the toilet. Remove the sleeve. Gently cleanse the skin around the stoma. When the skin is dry, apply a security pouch or stoma cover.
11. Wash the irrigation sleeve and hang it to dry to reuse.

appendix

colostomy irrigation procedure for End Descending or Sigmoid Colostomy

PURPOSE: To establish a predictable time for bowel movements.

SUPPLIES NEEDED: Colostomy Irrigation Kit

PROCEDURE: Plan to irrigate when interruptions are not pending and you can relax during the procedure. Plan to irrigate about the same time each day or every other day.

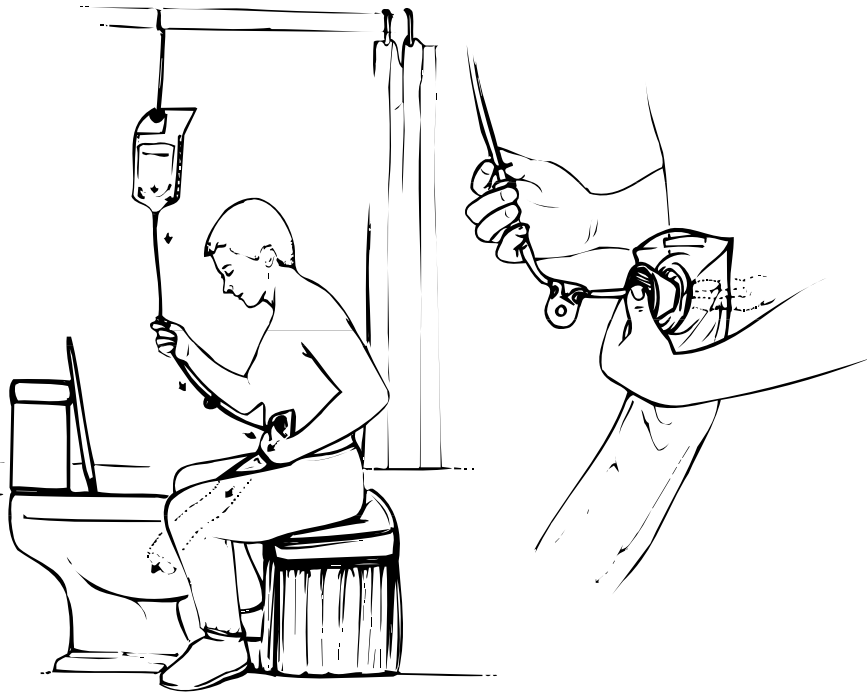


FIGURE 12
Colostomy Irrigation

Descending and Sigmoid Colostomy (See Figure 6, 7, & 8.) These types of colostomies are the most common. They are usually for cancer and may require the removal of the anal sphincters. The stool that passes from a sigmoid or descending colostomy is similar in form and consistency to normal bowel movement. The difference is that the anal sphincter is removed or disconnected, and the bowel control is gone. The enzymes have been absorbed, so the contents are not as irritating to the skin. A pouch will still be worn, but some persons with sigmoid or

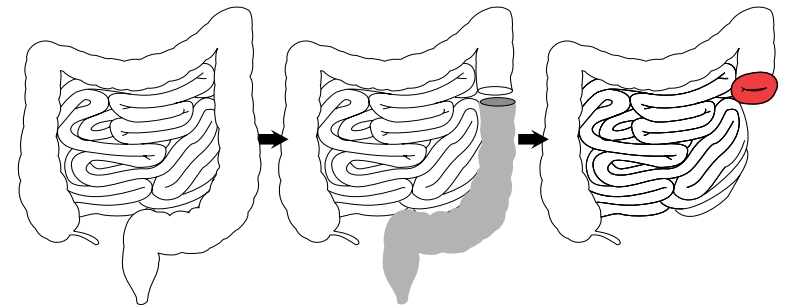


FIGURE 6 End Descending Colostomy

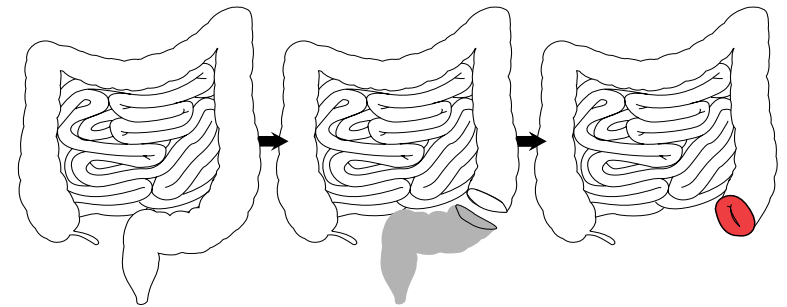


FIGURE 7 End Sigmoid Colostomy

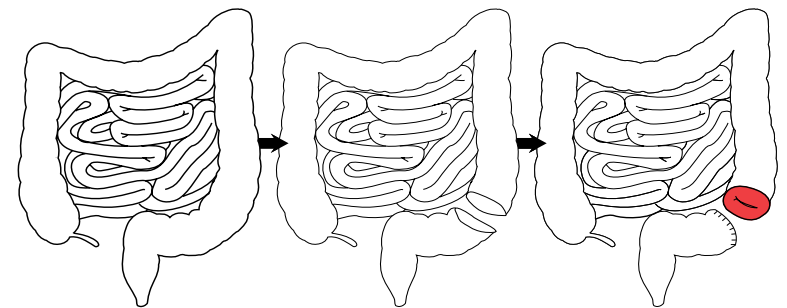


FIGURE 8 End Colostomy with Rectal Stump

descending colostomies can learn to regulate the passage of stool by colostomy irrigation. This is an enema through the stoma. Water is instilled, using a special cone tip or catheter. The water distends the bowel causing it to expel waste at a predictable time and place. This often insures no unpredictable passage of stool for 24-48 hours. Irrigation is elective and will be discussed in detail later in this booklet.

The object of colostomy surgery is to remove the diseased tissue, or repair an abnormality and to prevent the spread of disease. If the surgeon can safely remove the diseased tissue and preserve the function of the anal sphincters, it may be possible to rejoin the bowel. It may require having a temporary colostomy to facilitate healing of the rejoined area. When complete healing is determined, the temporary colostomy can be closed. (See Figure 9.)

ASK YOUR DOCTOR TO WRITE DOWN THE TYPE OF COLOSTOMY YOU WILL HAVE

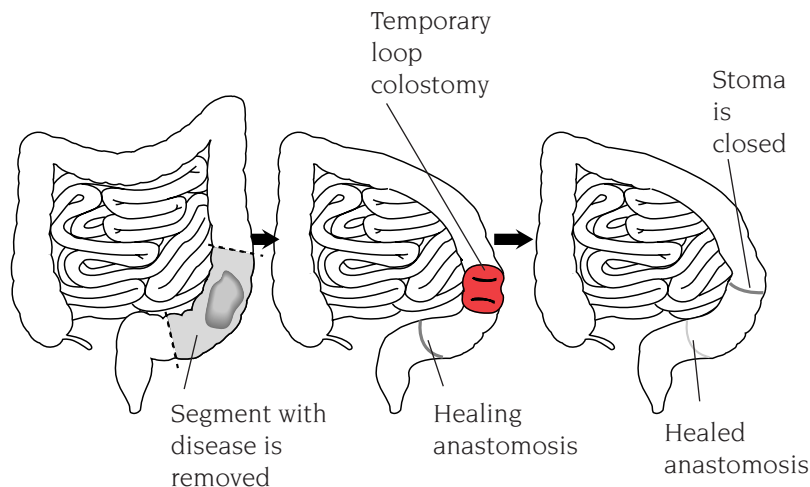


FIGURE 9

-
4. Keep a record of all your claims.
 5. Keep track of the amount NOT covered, since you may be able to deduct it from your income tax.
 6. If your claim is denied, ask why and resubmit it with a letter from your doctor if necessary.

The following are some things to consider when you file for reimbursement with these specific agencies:

medicare

If your Medicare card lists "hospital insurance only," you do not have coverage for your supplies. You can elect to pay a monthly premium for additional coverage, and your card will then read, "medical insurance coverage." In this case, Medicare covers a percentage of the ALLOWED cost of supplies after you pay the deductible. If you submit the Medicare claim yourself, attach your receipts or copies and a copy of your doctor's prescription to the form. Keep a set of receipts and the prescription as well as a copy of your claim.

medicaid

If you are approved for coverage, show your identification card and your current month's validation card to your supplier. If your income and assets are low and/or your medical expenses are high, you may be eligible. Some people who have medicare and no other insurance are eligible. Check with your county Department of Human Services.

veteran's administration

Veterans, depending on their eligibility and entitlement, may be able to obtain supplies from the pharmacy at the local VA medical center or outpatient clinic. Check with the local VA office.

reimbursement for supplies

Colostomy supplies can be costly, but almost everyone with a colostomy can be at least partly reimbursed by medical insurance, Medicare, Medicaid, the Veteran's Administration, the local Department of Human Services, or some social service agency.

Because colostomy supplies are considered prostheses, just like artificial limbs, teeth or eyeglasses, they will be deductible only to the extent they exceed 7.5% of your adjusted gross income. Be sure to keep careful, complete records of your medical expenses for a year so that you will know whether you can deduct them.

Filing for reimbursement and following up your claims can sometimes be difficult and frustrating. Fortunately, most surgical supply companies will file your claims and follow them up for you, saving you a lot of headaches.

Whether you file claims yourself or have a supplier do it for you:

1. Have your doctor write a prescription for your supplies and have it renewed every year. Most insurance companies, Medicare, and other agencies require this evidence of your need for the supplies. Suggested wording for the prescription is: This patient with a diagnosis of _____ had surgery for colostomy, requiring the use of the following prostheses _____.
2. Keep good records. Save all your statements and receipts so you will have good tax records or evidence to follow up claims.

If you purchase supplies and file claims yourself:

1. Check your policy or with the agency to find out whether you are covered for supplies. This may be under the category of "durable medical equipment."
2. Be sure to use the right claim form.
3. Get a receipt for every purchase. Save copies of the receipts and attach the originals to your claim form. (Medical insurance companies often require the originals, not copies.)

what to expect after surgery

Hospital stays after colostomy surgery average from one to two weeks. Abdominal surgery is stressful for the body, and it takes some time to recover, so do not make a judgment about the results right away. Although you can expect to feel better soon, the first few days after surgery will be uncomfortable, and pain medication will be available if you need it.

When you return to your hospital room, you will be wearing a pouch that was put on after surgery. Your digestive system will not be active for a few days. When it does start to function (usually indicated by passing gas into the pouch) you can begin to drink liquids. As you improve, you can gradually begin eating solid food.

On the first days after surgery, the ET nurse will change your pouch for you. As you recover, you will begin to participate actively in your colostomy care. You will start learning how to change the pouch by observing the ET nurse. Notice that she will have ready all the things she will need before she begins. You should do the same when you do it yourself. Among the items required are wipes or soapy wet cloths to clean the skin around the stoma, the pouch with its closure, the skin barrier (which fits against your skin around your stoma and attaches to the pouch), and deodorant. The next step will be to try changing the pouch yourself with the E.T. nurse standing by. The ET nurse will coach you through the process until you can confidently change the pouch on your own.

The ET nurse's support continues after you leave the hospital. You will see your ET nurse and your surgeon at four to six weeks, three to six months, and one year after you leave the hospital. When you come to the outpatient clinic, bring your colostomy supplies with you. Meanwhile, of course, your ET nurse is available by phone if you have a problem. **DO NOT HESITATE TO CALL!**

Your E.T. Nurse _____

Phone: _____

Alternate E.T. Nurse _____

Phone: _____

wearing a pouch

Wearing a pouch (ostomy collecting device) is one of the biggest changes you will face after surgery. It takes getting used to, but is not as difficult as you might imagine.

The basic piece of equipment is a pouch (made of odor-resistant plastic or vinyl) that collects the stool. The pouches attach to your body with adhesive skin barriers that are custom-fitted by your ET nurse and do not irritate your skin. A closure at the bottom of the pouch allows you to empty it without removing it from your body. (See Figures 10 & 11.)

You should find it reassuring that the pouch will not be conspicuous. It is small and stays flat, so you do not have to wear baggy clothes. The pouch for adults measures only about 6 inches by 8 to 10 inches. There are smaller varieties for children and infants. The pouch stays flat because you empty it when it becomes 1/3 full.

Opaque pouches and fabric pouch covers keep the waste from being visible when you are undressed. The use of a fabric pouch cover also makes wearing the pouch more comfortable by reducing heat build-up

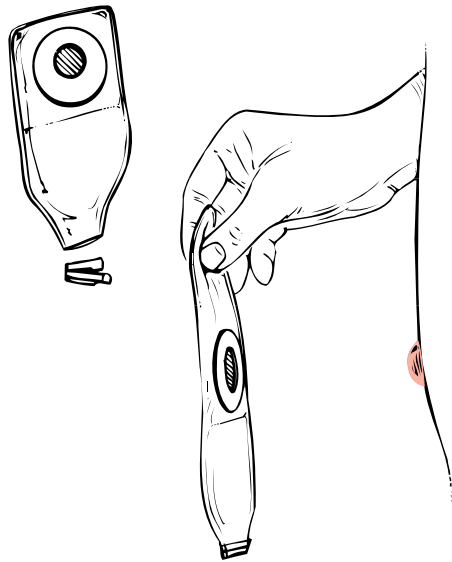


FIGURE 10
One piece pouch system

In a man, if the rectum and anus are removed, the nerves controlling erection may be affected. These are NOT the same nerves that control the sensation on the penis or the feeling of orgasm. For some men, erections recover with time. If not, a man should discuss the treatment options with his doctor. A few men may also experience dry orgasms - the feeling of climax without any seminal fluid. Dry orgasms feel just as good as normal ones to most men but will be a problem for fertility. A urologist may help with treatment for infertility.

A woman's sexual response is not medically impaired by this surgery, but some women may experience pain with intercourse. Using extra lubrication or changing positions can help. If that is not enough, she should consult her doctor. A woman's ability to conceive and bear children is rarely affected by having a colostomy.

Lovemaking itself does not have to change much. Empty the pouch beforehand. You and your partner may need to make some minor adjustments in positioning to avoid too much friction on your pouch, but contact during lovemaking cannot hurt your stoma.

If you have any questions or concerns about sex and intimacy, do not hesitate to seek advice from your ET nurse, a sex counselor, or a trusted friend in the UOA.

Ostomy Quarterly for a list of UOA chapters in the United States and Canada.

You also need to guard carefully against intestinal diseases, such as dysentery or “traveler’s diarrhea” and giardiasis when you travel or camp where the water may not be pure. If the water is not pure enough to drink, DO NOT use it for stoma care - for bathing with your pouch off, for cleaning the skin around your stoma, for colostomy irrigation, or for rinsing the pouch. Even pure-looking mountain streams in remote areas of the United States (in the East as well as the West) may have the Giardia parasite. Fortunately, there are water filters that remove it and most bacteria. These devices, which are available in most camping stores, are a good investment for traveler or campers who cannot carry bottled water.

intimacy

As you recover from your surgery and begin to resume or develop an intimate relationship, give yourself and your partner time. Try to resume or begin your sexual activity in a gradual, non-pressured way. After all, your partner needs to get used to and to overcome fear of hurting you and to the way your stoma and pouch look, just as you do.

Your attractiveness and sexual self-esteem are a part of you and cannot be “removed” in an operation. If you already have a warm, satisfying relationship, remember that it cannot easily be destroyed.

A single person with a colostomy should give a potential partner some time to come to value him or her enough as a person to overlook a physical imperfection. You do not have to tell a new friend about the colostomy on the first date, but do not let it become a long-term secret. Someone who genuinely cares for you will accept you as you are. Even if you are single, you have a right to discuss your sexual concerns with your health care team. Single patients often need the most support in this area.

From a medical standpoint, colostomy surgery does not impair the desire for sex or the nerves that control the orgasmic response. That means that touching in the genital area should feel normal and still lead to orgasm.

between the plastic pouch and your skin. Special undergarments are available for purchase as well.

Offensive odor does not have to be a worry either. The modern pouches are made of materials that confine odor to the inside of the pouch. The only time you should notice any odor is the time when you change or empty your pouch. Deodorants placed in the pouch, and attention to food intake can control these odors. (You will find these discussed in the Daily Living section of this booklet.)

The pouch should be changed about every three to seven days. After surgery, the ET nurse will teach you how to do this using the equipment that has been selected to fit your needs. Step-by-step instructions will be enclosed with your discharge folder. The ET nurse will also help you learn how to deal with other aspects of daily living, which are discussed in more detail in this booklet.

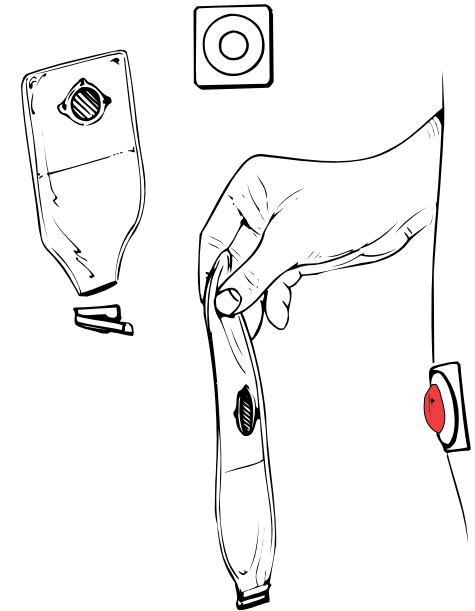


FIGURE 11
Two piece pouch system

colostomy irrigation

Persons who have had surgery for permanent sigmoid or descending colostomies are candidates to learn colostomy irrigation as a method of achieving predictable bowel movements. Those who have had a regular bowel habit before their illness are the best candidates for this procedure.

Colostomy irrigation is an enema administered through the colostomy. A special cone tip, or catheter* is gently inserted into the stoma. Approximately one quart of lukewarm tap water is slowly passed into the bowel. The water stretches the bowel, causing peristalsis (wave like motions) which expels the waste and water from the stoma into an extra long pouch (irrigation sleeve). See **Appendix** for detailed colostomy irrigation procedure.

This procedure has nothing to do with the health of the intestinal tract. It is done to establish a predictable time for the colostomy to function. If the technique works well and the person with a sigmoid or descending colostomy can count on regular evacuations, the need for a pouch is minimized. Often one can use a small security pouch or small pad. The body feels more like it did before. Irrigation equipment lasts a long time, so expense of colostomy supplies is reduced.

Irrigation does not work for all candidates. If the person does not remain stool free for at least 24 hours, irrigation is probably a waste of time. Some persons who are candidates dislike the procedure. In these cases, using the pouch as a method of management is best.

A more common procedure that may be requested by your physician is the colonoscopy. This is a sure way to observe the inside of the colon to be certain it is free of disease or to detect early abnormalities. The laxative bowel prep for this procedure requires the use of a secure pouching system. You will need to remain close to the bathroom to empty the pouch frequently.

The good news is that in some ways the barium enema or the colonoscopy are not as uncomfortable after a colostomy as they were before.

physical activity

You will be able to resume physical activity gradually after surgery. The only limits you may have to place on yourself are on very heavy lifting and contact sports, such as football, wrestling, or karate where you could receive a direct blow to your abdomen. Heavy lifting, especially in the first three months or so after surgery, could cause a hernia. But after you recover, you should have no problems lifting and holding lighter weights, like small children or bags of groceries. Talk to your doctor about how much you can lift and when.

Keeping your pouch on securely for sports is easy to do. For active sports involving running or jumping, a sport brief or close-fitting underpants will hold your pouch snugly against your body. For times when you will get wet, either from perspiring heavily from exercise, the sauna, or from being in a pool or jacuzzi, you can temporarily use waterproof tape to hold the edges of the pouch to your skin. Your ET nurse can show you how to do this.

travel

With a little planning, you can enjoy traveling as much as you like and where you like. Take plenty of supplies and medications along - double what you think you might need. Do not pack these supplies in luggage that you are going to check through baggage handlers. Carry them with you. If you cannot pack all the supplies you need for an extended trip, find out ahead of time where you can purchase them. You can get a list of

Stop using bismuth subgallate (for stool odor control) 48 hours before any x-ray procedures. The bismuth may cause a distortion of the film requiring the procedure to be repeated.

check-ups and follow-up visits to your physician

After you have had colostomy surgery, you will need to see your doctor in 1-2 months, 6 months and a year. Then proceed with annual checkups when you have been given a clean bill of health.

Take an extra pouch with you and any supplies you need for changing your equipment. When the doctor checks your stoma, it will be necessary to remove your appliance.

Barium enemas are not commonly used as a method of follow-up these days for post operative surveillance. However, if it is deemed necessary by your physician, barium can be instilled through the colostomy using a cone enema tip (like the one used for colostomy irrigation), or a soft Foley catheter(which has an inflatable balloon so that the barium will stay inside the colon).

The bowel preparation for barium enema studies consists of a harsh laxative. Be sure to have a secure pouching system in place before starting the bowel preparation. Some radiology departments may accept colostomy irrigation just before barium enema as a substitute for the laxative. Check with your physician and the radiology department about this.

An adhesive type disposable irrigating sleeve may be worn during the procedure to collect the excess barium that is passed as soon as the cone or catheter is removed. The sleeve will minimize the cleaning up process.

Soon after the procedure the person with a descending or sigmoid colostomy should irrigate to remove the residual barium that may harden quickly in the colon. If one does not irrigate, take a laxative approved by your physician. Drink abundant fluids and eat high fiber foods to prevent barium blockage.

the perineal wound

If the rectum and anus were removed (abdominoperineal resection), there will be an incision between the buttocks as well as the one on the abdomen. It may be completely stitched closed, or there may be a temporary drain placed in the wound. This depends on the extent of diseased tissue that was necessary to remove. If there is seepage from the wound, a dressing may be necessary during the healing phase.

Sometimes the wound care consists of simply showering the wound frequently for cleanliness. When there is drainage, sitz baths (soaking the wound in warm water) 20-30 minutes 2-3 times a day may be recommended for comfort and healing.

The healing time of the perineal wound varies from person to person. Again, it depends on how much diseased tissue needed to be removed. Most are healed within 2-3 months. Some continue minimal drainage for a year.

Immediately after surgery, sitting on a bed pillow or square of soft foam 3-5 inches thick provides comfort. Doughnut shaped rings are not recommended because they tend to pull the wound apart and may cause some swelling.

Besides the tenderness of the perineal wound, there may be feelings of urgency to have a bowel movement in the old way. This compares to the "phantom limb" sensation of amputees. This sensation can be relieved by changing position or by sitting on the toilet for a short while.

Any redness, excessive drainage, excessive pain or bulging in the perineal wound should be examined by your doctor.

adjusting to a colostomy

Living with a colostomy takes some psychological adjustment in addition to the physical adjustment in daily living. It is not unusual to feel depressed after the body is surgically changed. There is a kind of grief for the old habits of daily life and the parts of the body that are gone. Remember that the old YOU is not gone. You are the same person you were before surgery.

Give yourself time. It takes about three months to recover just physically from major surgery. If you feel blue or frustrated with your progress, it helps to talk to someone who understands what you are going through. Call your ET nurse or a member of the United Ostomy Association (UOA).

A good way to chase the blues is to set small goals for yourself - goals you know you can reach. Then you can feel like you are accomplishing something. Did the mail pile up while you were in the hospital? Try answering one letter today, then another or two tomorrow. You could begin to exercise by walking a short, easy distance and going a little farther each day. Putting in a little time every day on a craft or hobby helps give you a sense of achievement too, because you can see the progress you are making. If the blues do not go away - if you have crying spells and trouble sleeping, especially in the very early morning, and for more than a few weeks - seek professional help through your ET nurse or doctor.

Feeling in control is an important key to well-being. Bowel habits are one of the first things we, as children, learn to control, thereby increasing our sense of independence, dignity, and well-being. Naturally, it is disturbing to feel that you have lost that control. That is why it is so important to learn to change and empty the pouch yourself, or to do your own colostomy irrigations if you have a descending or sigmoid colostomy. The first few times may seem difficult, but it gets easier with practice. Knowing how puts you back in the driver's seat.

Feeling attractive is also important to a sense of well-being. It gives us confidence in social situations and sparks our intimate relationships. You may have negative feelings about the way your body looks with a colostomy. These feelings may undermine your positive feelings about your appearance and your self-confidence.

with a colostomy should have no problem taking prescribed and over the counter drugs, such as aspirin, antacids, Tylenol, etc.

However, time-released and time sustained tablets and capsules are not recommended for persons with ascending or transverse colostomies. Chewable, uncoated tablets and liquids are preferred because they will absorb more rapidly.

Remind your physician (and your dentist) that you have a colostomy (especially ascending or transverse) and he or she can prescribe your medications for maximum benefit to you.

Sometimes antibiotics may upset the bowel causing diarrhea. There could be a change in odor and color as well. Consuming buttermilk or yogurt helps the bowel movements return to normal.

Medications containing iron will cause the stool to be black. Some people report that iron causes loose stools and others have constipation.

Diuretics (water pills) can create a problem for persons with ascending or transverse colostomies because they cause the body to lose potassium in the urine. Bananas, oranges, and other foods high in potassium can be eaten to replace this loss.

The person who has a descending or sigmoid colostomy may experience constipation taking diuretics. Adequate fluid is important to prevent this.

Vitamins are often coated for slow release. Chewable or liquid forms are recommended unless they are for the descending or sigmoid colostomy patient.

Persons taking chemotherapy should discuss the possible side effects with their physician. Certain types of chemotherapy cause diarrhea, and others can be constipating.

Always check with your physician before using laxatives or stool softeners.

and not just thick liquid. Many times these episodes are accompanied with other symptoms such as nausea, vomiting, cramps and fever.

It will be necessary to empty the pouch more frequently and there may be an increase in offensive odor (depending on the cause). Protecting the peristomal skin is more challenging because the liquid stool contains higher concentrations of harsh digestive enzymes.

The causes of diarrhea are varied. Emotional upset may be the cause. Sometimes it is just a passing reaction to a food that the body is sensitive to. Other times it is due to the “flu”, food poisoning, an antibiotic (or other medication), or effect of radiation treatments.

Eating mashed, ripe bananas, tapioca, boiled white rice, baked potato without the skin, unsweetened applesauce and increasing water intake may help. Since diarrhea causes you to lose fluids and electrolytes (potassium and sodium), it is very important to prevent dehydration. Self medicating with over the counter drugs is not wise. Consult your physician if diarrhea is prolonged.

dehydration

Dehydration is characterized by excessive thirst, dry skin and dry mucous membrane. Urine will be dark in color. The urine volume will be decreased. Shortness of breath and fatigue may occur. Abdominal cramps sometimes occur.

The home remedy for dehydration is to take in plenty of liquid. Besides water, fluids containing sodium and potassium should be consumed. Broth, tea, tomato juice and milk are rich in sodium and potassium. Eating bananas, oranges, baked potatoes, broccoli and other vegetables that contain potassium and using extra salt (if you are not on a sodium restricted diet) on your food can help.

If dehydration is accompanied by vomiting and you cannot keep food and liquids down, consult your doctor.

One key to overcoming the negative feelings is to make some adjustments that help you continue to feel attractive. After surgery, you can gradually resume exercise to keep fit. Also, because the colostomy pouch is not bulky and does not show under clothes, you can continue to wear and build an attractive wardrobe. No one else, except your intimate partner, needs to know you have a stoma and wear a pouch unless you want to tell them.

daily living

This section of the booklet will outline some adjustments you need to make in daily living with a colostomy: how to practice good hygiene and skin care, how to manage your diet and medications, and how to prepare for physical activity and for travel. Once you learn these techniques, you will find that life with a colostomy is not very different from life without one.

hygiene and skin care

You can bathe or shower with your pouch on. As a matter of fact, you will be doing that most of the time, since you should remove your pouch only every three to seven days. It is also OK to bathe or shower with the pouch off. Be aware that your stoma may function while your pouch is off, so plan a bath or shower when the colostomy is least likely to be active. Many persons with colostomies report that first thing in the morning before eating or drinking is the best time. Each person soon learns a time that is best for their own lifestyle.

Keeping the skin around your stoma clean is an important part of colostomy care. The waste that comes through your colostomy may be irritating when it contacts your skin. If your skin does become irritated, a pouch will not stick as well, forcing you to change the pouch more often, causing more skin irritation and expense.

When you wash around the stoma, be gentle. Use a clean, soft cloth and a small amount of non-oily soap. Do not be concerned if you see a little blood. Some bleeding is normal because the stoma has such a rich blood supply. That explains why it is always red. Rinse and dry the skin well. Moisture, soap residue or bath oils can prevent the pouch from sticking. Use a hair dryer set on COOL or use an electric fan as gentle ways to dry your skin. A number of things can irritate skin, but you can avoid them. Here is how:

Some people with colostomies may be using a two-piece pouching system and reusing the pouch for economy or for special fitting considerations. It is important that if the pouch is to be reused, it should be properly cleaned. Rinsing with a cool to lukewarm mild suds or special detergents for perineal cleansing will reduce pouch odor. Be sure the pouch passes the “sniff” test before you use it again.

constipation

The person with a descending or sigmoid colostomy may experience constipation just as one would who did not have a colostomy. The reasons are similar. Lack of adequate fluid tops the list of causes. Other reasons for constipation are lack of adequate fiber, sedentary life style, some medications (especially pain medication), and certain types of chemotherapy.

The way to resolve most constipation problems is to increase fluid intake, increase intake of high fiber foods (whole grain breads and cereals, fruits and vegetables) and exercise.

Psyllium products are available over the counter. They provide a gentle way to add bulk to your diet. Consult your physician before using laxatives or stool softeners.

Colostomy irrigation may help relieve the constipation problem, but should not replace adequate fluid intake, a balanced diet, and exercise.

Persons with transverse or ascending colostomies are rarely troubled with problems of constipation.

diarrhea

The person with an ascending or transverse colostomy will probably pass stool that is thick liquid to soft unformed stool all the time. They may wonder how they can tell they have diarrhea. When it happens there will be a marked increase in volume and the output will be watery. It will be necessary to empty the pouch more frequently and there may

gas and odor

All foods may cause gas. Some foods, when consumed in large volumes, i.e., dried beans, onions, cabbage family, eggs, fish, asparagus, melons, beer, carbonated drinks and very fatty foods may cause more gas than others. Consume these foods in small amounts.

Swallowed air is another source of gas. Be sure to chew with your mouth closed (to avoid air swallowing) and avoid drinking through a straw.

You cannot prevent the colostomy from functioning by not eating. An empty bowel produces gas. Regular meals and unhurried meals are two ways prevent problems of excessive gas.

Many people with colostomies report highly offensive stool odor after eating certain foods such as eggs, garlic, onions and spices. There is no health reason to eliminate these foods. Simply be aware that they can produce a strong smelling stool that may be a social concern.

Some medications and vitamin supplements are responsible for a strong odor. If you suspect this is the case and the odor is bothersome, consult your physician. He or she may be able to change the prescription.

It is comforting to know that the modern colostomy pouches are made from high-quality odor-resistant materials. You may enjoy odor producing foods without fear of offending. Stool odor will be confined to the bathroom when you empty or change the pouch.

If you still feel the need to reduce the bathroom odor, there are deodorants available intended for use in colostomy pouches. Sometimes just rinsing the pouch with mild suds is helpful. Mouthwash can be used as a pouch deodorizer. Even vanilla has been reported as useful.

Over the counter medications taken by mouth to reduce stool odor are available in most drug stores. Bismuth subgallate, chlorophyll products and charcoal products are sold for this purpose. Foods that minimize odor include parsley, spearmint, yogurt and buttermilk.

Cause of irritation

Not cleaning well enough

Cleaning too roughly

Pulling out hair with pouch removal (you will see red dots around the follicles)

Leaking waste under the appliance

Chemical irritation or allergy

Tape tears

How to avoid it

Clean the skin carefully every time you change the pouch.

Wash gently.

Shave the hair around the stoma very carefully with an electric razor or clip with round ended scissors. (Do not use a razor blade.)

If this happens because your stoma has shrunk, see your ET nurse to have your equipment refitted. This may be necessary due to weight gain, weight loss or stoma changes. Do not try to fix a leak. Remove the pouch, clean your skin, and try again.

Follow the directions carefully for using solvents, pastes or cements. For example, you may need to let the alcohol in the paste evaporate before you put the pouch against your skin. If you have an allergy to a pouching material, you can be refitted with another non-irritating brand.

Gently push the skin away as you remove the pouch. If it is holding tenaciously, apply ostomy adhesive solvent to assist removal. Be sure to thoroughly rinse away the solvent before applying the fresh pouch.

Cause of irritation**How to avoid it**

Perspiration

Pouch covers are available to cover the pouch and to absorb perspiration. They act as underwear for the pouch, and prevent moisture build-up. Special undergarments are available that accommodate ostomy pouches. Consult the Ostomy Quarterly or ask your ET nurse.

Prevention is best, but if irritation develops, your ET nurse can advise you about what products to use and how to use them.

diet

Following any major abdominal surgery, there are temporary dietary restrictions. The first foods you will be given as you recover are clear liquids such as tea, jello and broths. Gradually you will advance to soft foods that are easy to chew.

If there is no medical reason for a special diet, for example, diabetes, heart disease, kidney disease or food allergy, the person with a colostomy can resume a completely normal diet in about six weeks after surgery. The length of the intestinal tract will be shorter so bowel movements may occur more frequently. It may take several weeks to establish the pattern that is normal for you.

As always, and especially while convalescing, your daily meals should include a sensible amount from the four food groups; dairy products, meats and other protein sources, fruits and vegetables, and bread and cereals. It is especially important to drink plenty of liquids. Chew all foods thoroughly.

Take care to maintain your normal weight because excessive weight gain (or loss) can effect the fit and wearing time of your pouch. If you

remain underweight after you resume a normal diet, you may need calorie and/or protein supplement. Be sure to consult your dietitian and doctor about it.

During the first six weeks after surgery, you need to eat soft foods. A dietitian will give you nutritional guidelines you can take home in your discharge folder. Here are some general guidelines for those first **six**

Include in your 6 week diet**Avoid the following for 6 weeks**

Cooked cereals without bran (like Cream of Wheat), white or part whole wheat bread, rice, cold cereals.

Coarse-grained bread or bread containing fruit, nuts and seeds. Cold cereals containing raw fruit, nuts and seeds.

Cooked, canned fruit (like applesauce, peaches and pears); fruit juices; soft fresh fruit without peels.

Fruit like coconut, dried fruit, fresh fruits (except bananas).

Vegetable soups, creamed soups with rice or potato, soft-cooked vegetables, and vegetable juices.

Vegetables like corn, bean sprouts, fresh celery, Chinese or stir-fry vegetables, cabbage family vegetables, sauerkraut.

Eggs, meat, poultry and fish.

Baked, steamed, broiled, stewed foods.

Milk and dairy products.

The key to resuming a normal diet after six weeks is to experiment. Add new foods one at a time. This way you can be sure which food bothers you. Just to be certain, try that offending food again after a week or so. It takes your digestive system a long time to fully recover. Eat regularly. Eat at a leisurely pace. Chew food well. Drink plenty of liquids. Remember, there is no health reason why you cannot enjoy the same foods you did in the past.