FROM US TO YOU

LIVING WITH AN OSTOMY, THE EXPERIENCE

A program of the United Ostomy Associations of America, Inc.

“SEIZE THE OPPORTUNITY...”
Presenter’s Guide

Scheduling Presentations and Increasing Program Awareness

- Local businesses, organizations and groups should be contacted to bring about awareness of this informative opportunity
- Some of the suggested groups and organizations are
  - Medical facilities in your surrounding area
    - Hospitals
      - Staff-education department
      - Nursing administration
        - Surgery department
        - Post-operative care unit
    - WOCN and ET nurses
    - Home health agencies
    - Long-term care facilities
    - Clinics
    - Schools or colleges with nursing programs
- Contact area newspapers
  - Ask if the run free or discounted ads to help promote programs for non-profit organizations
  - Contact a reporter and see if they would do a story on the project with a local angle

Logistics and Planning

- Ensure that the organization knows the presentation is on non-medical information
  - Confirm that they know the presentation is life as an ostomate, actual experience-based knowledge and that you are not a medical professional
- Establish a mutually-acceptable date and time for the presentation
- Decide what modules will be presented
- Ask the organization for an expected number of attendants
- Print or copy the appropriate modules
  - Provide one copy for each person attending the session
- Obtain supporting documentation and materials from manufacturers or the UOAA
- Take your own ‘travel bag’ as each facility has different prosthetics
- We are to promote all manufacturers and not be a biased source of information
  - Try to have actual prosthetics on hand for the attendant to see
- Ensure that you have information and fliers for your support group
- Be prepared to give the national UOAA phone number when asked, 800-826-0826
- Take a copy of the Phoenix magazine and subscription cards
  - Encourage them to subscribe for updated information for their patients
  - Take sample copies of The Phoenix Patient Resource magazines available from UOAA
- Request room set-up
  - Podium, tables, microphone, etc.
  - The presenter can put the presentation on their laptop, which would require a projector and screen
- Re-confirm with the organizational contact three days before the presentation
- Allot enough time before the presentation to find the proper location and prepare the room
- Allow time after the presentation for a question and answer session
- Have all participants sign-in on a provided sheet
- Ask if parking is available at no charge and if it is not, what the charge is and can the fee be waived or validated.
- There is no fee that needs to be paid by the hosting organization
  - Some organizations may ask about giving a donation to the presenter
  - Donations are always accepted and can be made to the presenter’s support group or the UOAA
Mission

- The United Ostomy Associations of America are an association of affiliated, non-profit support groups who are committed to the improvement of the quality of life of people who have, or will have, an intestinal or urinary diversion.
- It is dedicated to the provision of information, advocacy and service to, and for, its affiliated support groups, their members and the intestinal/urinary diversion community at large.
- It is organized to grow and develop while remaining independent and financially viable.

Purpose

The United Ostomy Associations of America is dedicated to serving the members of the intestinal and urinary diversion community. It is through the commitment to improve the quality of life for ostomates that the “Life as an Ostomate, by an Ostomate” project was conceived. The UOAA found that there is a great opportunity to help home health providers, long-term care facility workers and general staff nurses better understand the unique needs of an ostomy patient.

Caring for ostomates goes beyond the immediate post-operative recovery period. The issues that need to be addressed are psychological, psychosocial and nutritional. New ostomates also need information on stoma management, product awareness, dealing with insurance and general life management of life with a stoma. A healthy awareness of the broad spectrum of issues for ostomy patients will help healthcare professionals be more prepared to deal with the overall well-being of a patient.
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MODULE 1

Pre-surgery and Hospitalization

by Kaytie Torango & LeeAnn Barcus
Module 1: Pre-Surgery and Hospitalization

What is an Ostomy?

- The work “ostomy” is derived from a Greek work that means “mouth”
- An ostomy is a surgically created opening from a body organ to the outside for the excretion of body wastes
- Ostomies are further named for the organ involved
- The most common types of ostomies are:
  - Ileostomy
    - Fecal diversion using small intestine
    - Total removal or bypass of large intestine
    - May be permanent or temporary
    - Stoma is usually placed on right side of the abdomen
    - Smaller stoma than colostomy
    - Loose to watery output
  - Colostomy
    - Fecal diversion using colon
    - Small bowel intact
    - May be permanent or temporary
    - The stoma is often on the left side of the abdomen
    - Stoma is often larger in diameter than ileostomy
    - Fecal output typically soft to solid stool
  - Urostomy
    - Surgical procedure to divert the passage of urine
    - Removal or bypass of bladder
    - May be permanent or temporary, but is most often permanent
    - An ileal conduit uses a piece of the small intestine to create a stoma
    - Stoma is usually placed on the right side of the abdomen
    - Output is urine; may have mucous present

The Informed Patient

- There are many misconceptions regarding ostomy surgery
  - (Instructors note: Share a personal story or experience to illustrate this point)
- Basic ostomy information is essential for patients and their caregivers
- Not all patients will have time before their ostomy surgery to read and gather information
- It is crucial for the healthcare providers following the surgery to be especially sensitive to this issue
- Patients should be encouraged to educate themselves and gain as much insight as they can
  - Decreases feelings of “I am alone”
  - Helps to reduce anxiety and stress
  - Provides information on activities of daily living
- Encourage the patient to meet with a person who has an ostomy
The UOAA offers a visitation program
- Encourage patients to seek support and guidance. The following list of organizations offer additional information and resources for patients and caregivers:
  - United Ostomy Associations of America - www.ostomy.org
  - United Ostomy Associations of America Magazine - www.phoenixuoaa.org
  - Nurses specializing in ostomy care - www.wocn.org
  - American Cancer Society - www.cancer.org
  - Crohn’s and Colitis Foundation of America - www.ccfa.org
  - Bladder Cancer Advocacy Network - www.bcan.org
  - Pull Thru Network - www.pullthrunetwork.org
  - Bladder Extrophy - www.abc.org
- Before the surgery is performed, ask the patient if they would like to see an ostomy pouch so they can touch, feel, and handle the products
  - Hands-on experience with pouching system can help:
    - Begin the learning process and bring about questions
    - Give the patient experience with placing them on their body
    - Lessen fears
  - Individual needs vary

Body Image
- Offer the patient an opportunity to express concerns and feelings by asking open-ended questions. Feelings and concerns vary, but may include:
  - What will I look like?
  - Will I still be lovable?
  - Can I go back to my pre-surgery activities?
  - Anger, depression, feelings of loss
- Suggestions on ways to cope:
  - Encourage the patient to voice their concerns and discuss them with their loved ones
  - Involve caregivers and partners in as much pre-surgery preparation as possible
  - Be patient - adjustment takes time

Marking the Stoma Site (Hospital nurses only)
- Proper marking of the stoma site is very important.
- If a wound, ostomy, continence nurse (WOCN) is not available, ask the surgeon to mark the site prior to surgery.
- The health care provider marking the site should observe the patient’s abdomen in standing, sitting, and lying positions to assure proper placement.
  - Proper marking helps to ensure optimal management of the pouch.
  - After the stoma site has been marked, the patient should be encouraged to put on clothes, walk around, and move with the pouch/prosthetic in place.
MODULE 2
Ostomy Products and Manufacturers

by LeeAnn Barcus
Module 2: Ostomy Products

- General information
  - Correct term: pouch/prosthetics; prosthetics should be used when dealing with insurance/Medicare
  - Pouch/prosthetics are usually made of an odor-barrier plastic materials
  - Most products are designed to be disposable, but some are reusable
  - In most cases, the cost of pouch/prosthetics are covered by insurance
  - One size does not fit all - there are many manufacturers with many different choices

- Types of pouch/prosthetics
  - One or two-piece pouching systems
    - Opaque or transparent
    - Variety of available sizes
      - Mini or pediatric
      - Standard/long
      - High volume
    - Integrated filter option (for ileostomy and colostomy only)
  - Drainable
    - Clamp
    - Integrated closure
    - Valve opening (urostomy and high output ileostomy pouches/prosthetics)
  - Closed
  - Barriers
    - Flat or convex
    - Pre-cut or cut-to-fit
    - Oval

- Accessories
  - Skin Barrier/Paste strips – to increase convexity or fill in uneven surfaces around stoma
    - Come in a variety of shapes and sizes
  - Skin Barrier powders
    - For wet or irritated skin
  - Belts for pouch and hernia support
  - Irrigation cones and sleeves (for colostomy only)
  - Stoma caps
  - Pouch covers
  - Undergarments
  - Pouch liners
  - Filters

- Deodorizers
  - Sprays
  - Drops
  - Oral tablets
Ostomy Product Manufacturers

- There are a number of companies, listed below, that manufacture ostomy products
  - Many companies have an ostomy nurse on staff to assist customers
  - Many companies provide free samples of their products
  - Many major manufacturers will provide educational material at no cost
  - Manufacturer’s websites:
    - Coloplast – www.coloplast.com  (800) 533-0464
    - ConvaTec – www.convatec.com  (800) 422-8811
    - Cymed, Inc. – www.cymed-ostomy.com  (800) 582-0707
    - Genairex, Inc. – www.genairex.com  (877) 726-4400
    - Hollister, Inc. – www.hollister.com  (888) 740-8999
    - Nu-Hope Laboratories – www.nu-hope.com  (800) 899-5017
    - Perma-Type Company – www.perma-type.com  (800) 243-4234
    - Torbot Group – www.torbot.com  (800) 545-4254
    - ** Instructor’s note: Consider providing a handout of this list

Reimbursement

- All insurance companies and plans vary
- Patients should speak with their employer or insurance company to obtain their policy of durable medical equipment reimbursement
- Most insurance companies follow the Medicare guidelines for the reimbursement or allowed supply per month
- Supplies must be ordered through an approved Durable Medical Equipment (DME) company
  - Many supply companies accept Medicare assignment and will help with the billing to the insurance company or Medicare
  - Some supply companies accept Medicaid assignment. Patients can contact their state Medicaid office to find out where and how to get supplies

Changing the Pouching System

- During hospitalization the pouch/prosthetics are generally changed more often so the nurse can assess the stoma, the incision, and provide teaching
- Gather all supplies and place at the bedside
  - Measuring guide, new pouching system, scissors, water and any other items that might be used for the pouch change.
  - Explain carefully to the patient what will be done
  - Provide privacy
- Carefully remove the pouch/prosthetic
  - Dispose of the pouch/prosthetic according to your facility protocol (usually in contaminated waste bins)
- Assess the stoma for color and general appearance
- Wash the skin around the stoma using warm water
- Dry the skin
  - Assess the skin around the stoma
  - If denuded skin is noted consider using a light dusting of a skin barrier powder
  - Do not use any ointments or creams on the skin that will interfere with adhesion
  - Notify the ostomy nurse if a rash or skin irritation is present
- Measure the stoma with a measuring guide
  - The stoma is expected to change size in the weeks following surgery
  - Slide the measuring tool over the stoma, close to the stoma base, and determine the size of the stoma with no skin showing around the stoma
  - Trace the size of the stoma onto the back of the skin barrier and cut along the line
- Apply the pouching system
  - Remove the release paper from the adhesive side of the skin barrier and place around the stoma
  - Press to the skin to ensure a good seal
  - If using a two-piece system, snap the pouch on the flange
  - Close the bottom of the pouch.
- Patient education:
  - Involve patient in all pouch changes
  - As patient’s condition permits ask them to help in the steps of the pouch change
  - Start by instructing the patient on how to empty the pouch and encourage them to help the staff in emptying the pouch throughout the day. This will insure them of acquiring the skill of emptying the pouch prior to discharge.
  - Minimum expectation before discharge should be that the patient can empty their pouch and give verbal understanding of how a pouch/prosthetic is changed
  - A home care nurse referral should be considered for further instruction and support if indicated.
- Provide written instructions for the patient and contact information before they are discharged

After Discharge

- The wear-time for pouch/prosthetics depends on the individual
  - Average wear time is 4 days
  - Pouching/prosthetic use and needs and preferences will change over time
  - The size of the stoma may change
  - Body contours may change as healing takes place, making a change in product necessary
  - The patient will gradually form an opinion about what works best for their needs
  - Ostomy nurse consultation is helpful for learning about the best options for each patient’s needs
- The routine and time of day for changing a pouch/prosthetic is very individualized
  - For ileostomy, the best time is usually first thing in the morning, because there’s less discharge from the stoma at that time
• For urostomy, the best time is first thing in the morning, before any liquids are consumed
• Because colostomy output is often more predictable, the patient may wait until after a bowel movement
  ■ Supply storage should be in a cool, dark place away from heat sources
  ■ Keeping ample supply on hand is very important
  ■ Disposal of ostomy supplies - empty pouch before disposal and discard in a plastic bag (zip lock is helpful)

**When to Seek Help from an Ostomy Nurse**

■ If there’s inconsistent wear time
■ When the skin around stoma is irritated
■ For help choosing a different pouching system and determining the available options
■ If the patient has physical or emotional difficulties related to the stoma
■ If the patient has questions related to reimbursement
MODULE 3

Activities of Daily Living

by LeeAnn Barcus
Module 3: Activities of Daily Living

Showering
- Showers and baths are fine with a stoma!
  - May shower or bathe with the pouching system in place, or with the entire system removed
  - Water should be in a gentle stream
  - Soaps containing cream or glycerin should be avoided, and the area should be rinsed well
  - Ostomy shower covers are an accessory available to persons with an ostomy
  - The shower may be a good time and place to change the pouching system

Exercise
- Persons with an ostomy can do most of the activities that they did prior to surgery
- Patients should check with their physician for lifting restrictions before engaging in any activity
  - Since some patients will be healthier after surgery than they were before, the physical activity level for those individuals may be higher than the pre-surgery level
- Person with an ileostomy needs to be especially aware of hydration and heat
  - Dehydration can set in quickly and without much warning; especially in those with ileostomies.
  - Extremely hot temperatures can either increase or decrease the amount of output
  - *Advise that recovering surgery patients must check with physician prior to resuming or changing activity levels, lifting, and/or adding any exercise program to their regimen

Work
- Most patients can return to work after the appropriate surgical healing time prescribed by the physician.
- There is no need for an employer or co-workers to know of an employee’s ostomy, but the employee can share the information if they feel it is appropriate.
- It is a good idea to keep an pouching supplies with them for emergencies
- The United Ostomy Associate of America offers advocacy support for anyone who encounters issues with an employer or manager.
  - www.ostomy.org

Travel
- Persons with an ostomy can travel just as they did before surgery
- Extra supplies are a must while traveling
  - A good rule of thumb is to pack three times as many supplies as will be needed on the trip
- Pack supplies in different places throughout the luggage, in case something would be damaged
- Remaining well hydrated while traveling is important for ostomy patients

Air Travel
- It is a good idea to pack supplies and pouch/prosthetics in a carry-on as well as in checked luggage
- Hints for air travel
  - Supplies and pouch/prosthetics should be packed in a clear, plastic pouch/prosthetic for easy observation of the contents
  - A letter from the patient’s physician stating that they have had ostomy surgery may lessen delays at security
  - It is best to empty the pouch prior to entering the security area
  - Persons with an ostomy should be prepared to explain what an ostomy is to security workers if the pouch/prosthetic is detected during a pat-down
    - A private room should be requested if security requires an examination of the pouch/prosthetic

Driving
- Persons with an ostomy may resume driving once released to do so by their physician
- Seat belts can, and should, be worn at all times while riding in a vehicle
- A small pillow or a folded towel can be placed between the seatbelt and the stoma for protection, if needed
- Seat belt clamps can be used to keep the seatbelt at a comfortable position

Sleeping
- Urostomy patients often hook their pouch to an overnight drainage container
- Pouches should not be allowed to get overfilled (more than ½ full); thus, may need to emptied once during the night
- Filter pouches are good for preventing gas build-ups while sleeping (for colostomy patients)
- Persons with an ostomy should watch food and beverage intake prior to going to bed
  - Less input equals less output; generally avoid large snacks or meals 2 hours prior
- An anti-gas medication, such as Gas X, can help minimize gas
- Any sleep position that’s comfortable is acceptable
- Use of a waterproof mattress protector may help allay concerns about a nighttime pouch leak

*Other pouch/prosthetics management tips or personal information about living with an ostomy can be added by the presenter at this time.*
Module 4

Clothing, Outings and Social Functions

by LeeAnn Barcus
Module 4: Clothing

Immediately after surgery

- Wear what’s comfortable (as any other surgical patient)
- After initial surgical healing time, persons with an ostomy can wear the same clothing as they did before surgery
  - Some patients may need to make minor adjustments for their personal comfort or to accommodate stoma location:
  - If belts are problematic, try suspenders (for example)
- Suits
  - May need slightly larger waistline than before surgery
  - T-shirts can help to smooth the appearance of the pouch
  - Slightly smaller undergarments can help hold pouch in place
- Dresses
  - Control top pantyhose can help with pouch security
  - Smaller, or closed end pouches for evening apparel can be worn
  - Midline girdles can be worn to minimize pouch bulging as it fills

Sports and Recreational Activities

- Swimming
  - Women may find that tankinis work best
    - These suits are easier to manage for emptying purposes
    - They also still provide the coverage a woman may want over their mid-section
    - If a woman prefers a one-piece suit style, they should look for a suit with draping or a print to conceal the outline of the pouch
  - After swimming, the pouch and area around it should be dried thoroughly
  - Some persons with an ostomy choose to “picture frame” the pouch with waterproof tape
    - This helps to give an increased sense of security
    - It helps to maintain an optimal seal
    - Adds security and offers time for the patient to get potential leaks taken care of
  - Fears often associated with swimming are:
    - Leakage
      - A secure skin barrier should not leak
      - Do not swim within the first few hours of a new flange placement; the flange needs time to adhere well to the skin before it is introduced to chlorine and water.
      - Ostomies do not present a containment issue in public pools unless the seal is compromised
    - Someone will see the ostomy
- Individuals who ask about the ostomy should be given a brief explanation
- Emptying the pouch often will minimize any bulge and decrease visibility
  - Inability to go down water slides or dive
  - One-piece suits will help to maintain better pouch safety for these activities

**Sports**
- A physician’s release or advisement should be obtained before resuming strenuous activity or sport after surgery
  - Most can resume all of their usual activities
- A protective stoma guard may be needed for aggressive sports
- Adequate hydration must be maintained when participating in sports
- Some sports drinks that are pre-mixed can increase fecal output due to the sugar content in them
  - Pre-made sports drinks can be diluted to help with this problem
  - These drinks can also be purchased in powder form
Module 5
Intimacy and Sexuality

by Kaytie Torango & LeeAnn Barcus
Module 5: Intimacy and Sexuality

Physical Changes Caused by Ostomy Surgery

- Surgery, chemotherapy and radiation in the pelvis may affect sexual functioning and should be discussed with patients prior to and after surgery
  - There may be no effect, or it will vary depending on the type and reason for surgery
  - Sexual activity may resume after healing is complete
- Encourage patients to express any concerns
- Encourage women of childbearing age to discuss birth control and pregnancy issues with physician

Emotional Effects of Ostomy Surgery

- New patients may be concerned about their attractiveness/desirability
- Like physical healing, emotional healing varies with each person
  - First attempts at intimacy may be awkward (inform patients of this and ensure them that it may get easier with time)
- There may be fears of leakage during intercourse
  - Always empty pouch/prosthetics beforehand
- Patients may have a desire to cover the pouch/prosthetic during intimacy to conceal the pouch
  - Some examples include: using an opaque pouch, pouch cover, mini-pouch, boxers, tank top, etc (speaker can add a personal story here)

Seeking Professional Help

- Unresolved emotional or physical issues related to sexuality
- Inability for partner to discuss the issue
MODULE 6

Dietary

by LeeAnn Barcus
Module 6: Diet

Speaker should provide a Handout, such as the UOAA food chart

Food Tolerance

- Most patients can resume their usual diet without restrictions once the physician has released them to do so
- Just as food tolerance varies between individuals, it varies just as much between persons with an ostomy
- Food tolerance can change with little notice
- New foods should be introduced slowly and in moderation
- Sometimes keeping a food diary can help figure out if a problem is food related
- Absorption can be an issue with those who have short bowel (though short bowel does not occur in all who have had ostomy surgery, it is a fact for some who have had multiple bowel resections due to Crohns)
  - Small intestine, for ileostomy, will increase absorptive function over time
  - Depending on the portion of intestine removed, absorption of some vitamins and minerals may be compromised, especially Vitamin B-12 (person with terminal ileum resected should be informed of their need to monitor for issues related to B-12 Deficiency)

Concerns

- Gas
  - Gas is a significant concern for persons with a colostomy or ileostomy
  - Refer to UOAA Food Chart for suggestions
- Ileostomy Food Blockages
  - Food blockages may occur with an ileostomy or when the opening in the muscle has tightened
  - Warning signs of a blockage
    - No output
    - Pain
    - Nausea
    - Vomiting
    - Abdominal distention
    - Sudden change in consistency
      - No stool; fluid only
  - Causes of blockage are individualized
    - One persons with an ostomy may be able to tolerate something that another cannot
    - If a person is prone to blockage, foods that can cause an obstruction may include:
      - Celery
      - Citrus Pulp
- Coconut
- Corn
- Fruit Skins
- Mushrooms
- Nuts
- Popcorn
- Chinese vegetables

• Techniques to alleviate a blockage are
  - Take a warm shower
  - Massage the abdomen
  - Remove the pouching system if stoma is swollen
  - Do knee-to-chest repetitions
  - Drink hot tea and eat soda crackers
  - Go to nearest emergency room if pain and blockage persist

■ Output
  • Dealing with, and understanding, the output can also be an area of concern for persons with an ostomy
  • Output is individualized and depends on:
    - The length of intestine remaining
    - Foods that are consumed
    - Amount of fluids taken in
    - The outdoor temperature
      - Certain stressors can affect output
  • Watery output from colostomy or ileostomy
    - Thickening foods can help alleviate the issue
    - persons with an ostomy can try the following foods
      - Bananas
      - Applesauce
      - Pasta
      - Rice
      - Breads
      - Puddings
      - Potatoes
      - Marshmallows
      - Peanut butter
    - Determining the cause
      - High sugar intake
      - Heat stress or a change in weather
      - Consumption of caffeine
    - Decreasing fluid intake during meals and drinking after the meal may help
  • Thick output
    - Increase water and overall fluid intake
  • Constipation (most common with colostomy)
    - This can be caused by a number of factors
• Diet
• Medication
• Inactivity
• Person with an ileostomy should not take laxatives without the direction of a physician

• General ways to help prevent constipation with a colostomy:
  - Increase exercise and overall activity
  - Increase fiber intake
  - Increase consumption of raw fruits and vegetables
  - Increase fluid intake
  - Drink warm liquids to help motility

• Diarrhea
  - Consult a physician
  - Maintain proper hydration
    • Avoid high sugar content fruit juices at this time (these will actually increase output for some)
    • Try increasing foods that help thicken stool (see list of foods)
    • Electrolyte containing drinks may be recommended by healthcare provider
  - Determining the cause
    • Can be caused by a number of factors, depending on the individual
    • Foods that may be problematic for some people include:
      - Beans
      - Beef
      - Chocolate
      - Peas
      - Prunes
      - Raw fruits
      - Spicy foods
      - Spinach

• Odor
  - Contemporary pouches are made with special plastic films that prevent odor from coming through the pouch wall.
  - Colostomy and ileostomy:
    • Certain foods can intensify odor, such as:
      • Asparagus, raw vegetables, fish, beans, egg, garlic, some spices, fish oil, strong cheeses, and garlic
    • Foods that may help to decrease odor:
      • Yogurt, buttermilk, peppermint oil, parsley
    • These are helpful suggestions, but the experiences of each persons with an ostomy are different
      • Some are more prone to odor
      • Depends on stoma placement along the intestinal tract

• Urinary ostomies
There are only a few foods that cause odor in urine
- Asparagus
- Yeasty breads
- Beer

Infection or bacteria can increase urine odor and mucous with a urostomy

▪ **Medications**

Pharmacist should be notified that the person has an ostomy (as medication absorption may be altered with certain types of ostomy; and may affect the type of medications that are appropriately prescribed for the person). Timed-release and sustained release medications (even OTC) may not be appropriate with an ileostomy.

- Some medications can cause increased odor
  - Antibiotics
  - Some vitamin supplements
  - Some herbal supplements
- Deodorants for the pouch are available and may help
  - Internal deodorizers
    - These are tablets taken by an persons with an ostomy to calm odors within the body
  - Pouch deodorizers
    - These are deodorizers that are placed directly in the pouch
    - Most manufacturers have a variety of deodorizers to offer
    - Do not use aspirin as a pouch deodorant (can cause bleeding of the stoma)

**Vegetarian Diets**

- Vegetarians should be able to follow their pre-surgery diet
  - Raw fruits and vegetables should be introduced slowly and in moderation
    - Special caution should be paid by a person with an ileostomy
  - Adequate protein intake is also especially important for vegetarian persons with an ostomy
  - Gas and odor may be more of a concern with this diet

**Color change**

- The color of ileostomy fluid can change with certain foods and beverages
  - Mainly a concern of those with an ileostomy. Be sure to inform patients so they don’t think red output is necessarily blood
    - Medications
      - Iron tablets will cause output to become very dark, almost black
    - Food
      - Some foods that can make output look red are
- Beets
- Red food dye
- Strawberries
- Tomato sauce
- Red beverages

- When should the healthcare provider be notified?
  - If the color change of stool is unrelated to a food or beverage
  - If urine from urostomy is foul, extremely strong in odor, or makes a sudden change in color

If mucous output from urostomy stoma increases significantly and is accompanied by pain or decreased urine output
Module 7: Support Organizations

The United Ostomy Associations of America, Inc.

- The United Ostomy Associations of America (UOAA) is an alliance of affiliated non-profit support groups who are committed to improving the quality of life for people who have, or will have, an intestinal or urinary diversion.
- The UOAA is dedicated to providing information, advocating and serving its affiliated support groups, their members and the intestinal and urinary diversion community at large.

Functions of Local UOAA Affiliated Support Groups

- To provide periodic educational, and mutual support through meeting formats
- To conduct in-service sessions to help educate the local nursing community
- Implement an ostomy patient visiting program
  - The UOAA has a mandatory patient visiting training program that covers the following topics
    - Understanding and following HIPPA regulations
    - How to help a patient without offering medical advice
    - How to handle patient visits either by phone or in person
    - How to utilize the advocacy program
    - Support that is available for the persons with an ostomy and the caregiver
  - Visitors are given assignments based on the following criteria
    - Type of ostomy
    - Gender
    - Age
    - Location
  - Pre-surgical visits can be helpful, when possible
    - These visits help a potential persons with an ostomy see how their quality of life will be better after surgery
    - Persons with an ostomy can answer non-medical questions of the prospective persons with an ostomy and their caregiver
  - Post-surgical visits can also be very helpful
    - The ostomy visitor can help by staying in contact, either by phone or a visit to the hospital
    - They are there to reassure the persons with an ostomy and caregiver that this is a most difficult time and things will be improving
    - They are there to be a comforter and an understanding companion
  - Helping a new persons with an ostomy once they are home from the hospital is critical
    - Visitors can provide information about the UOAA and local meetings
    - They can also help the new persons with an ostomy access the UOAA website and subscribe to Phoenix magazine
    - Visitors can accompany the new persons with an ostomy to their first UOAA meeting to meet others who are fully participating in life
Virtual meetings have been organized throughout the United States to provide support for the following ostomy communities:

- Children
- Teens and young adults
- Adults 30 years and older
- Persons with continent diversions
- Same-sex, bisexual and transgender communities

To locate a local affiliated support group or to contact a virtual support group, visit the UOAA’s website at [www.ostomy.org](http://www.ostomy.org).
Conclusion

These Modules were devised to aide in the care of patients who have undergone bowel or bladder diversion surgeries. The information provided in these modules is an accumulation of personal experience, shared information, and issues faced by those who have undergone diversion surgeries. It is not intended to be medically based, but within the realm of the experience nature.

Our desire, with these modules, is to provide some insight to better care for the ostomy patient and provide some much needed information to patients.

We thank you for the opportunity to share these informational modules with you and your nursing staff.