Living a Full Life With an Ostomy

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Ostomy 101

- Ostomy: Surgically created opening to expel waste
- Stoma: part of intestine brought out of abdomen
- Pouch/ Flange: appliance used to contain waste and protect skin
Stoma Stats

- No one really knows how many ostomates are in the US or World Wide
- Estimates range from 450,000-800,000
- Colostomy = ileostomy= urostomy
- Average age = 68.3

Ostomy Statistics: The $64,000 Question. Turnbull, G. Ostomy Wound Management 2003
Why?

- Cancer: rectal, colon, bladder, cervical and other cancers of pelvic region
- Inflammatory Bowel Disease
- Issues @ birth: Hirschsprung’s, Spina Bifida, Imperforate anus, NEC, and other genetic disorders
- Neurological/ Neurogenic issues: MS, SCI
- Perforation/ Trauma: accident, gun shot
- Diverticulitis
Common Concerns

- Leaks
- Odor
- Alienation
- Noise
- Body Image
- Clothing
- Sleeping

- Dating
- Sex
- Sports
- Travel
- Leisure Activities
- Feeling Dirty
Leaks

- Most common fear
- Reason people stay home
- Empty when 1/3 full
- Pouch to match the person and lifestyle
- Fear decreases over time
- Never leave home without supplies
Is that a pouch I smell?

- Shouldn’t be!
- Fecal pouches are odor proof, urine are odor resistant
- Could mean infection
- Watch what you eat
- Lots of Products Available
- Who doesn’t smell when they use the bathroom

Don’t forget the Orange Grove!
Clothing

- No need to buy a new wardrobe
- May need to modify
- Belt line and clothing preference should be thought about when stoma site marking
Clothing
Disclosure

Tell the World

Keep your mouth shut, not a soul needs to know!!!!!
Dating
Sex

- Yes you Can, once cleared by Surgeon
- No Stoma is not for sex
- Partner Won’t hurt stoma
- May need to try different positions
- UOA Free Guide “Intimacy, Sexuality, and an Ostomy”, can download off UOAA website
Sex

- Empty Pouch
- Ensure it's well secured & not going to fall off
- Intimacy Pouch
- Cumber buns
- Split Crouch undies
- Scarves
- Birthday suit > pouch and all
Swimming

- #1 question
- Make sure its secured
- May want waterproof tape
- Have fun
- Yes you can scuba dive
Swimming
Have Bag, Will Travel

- No need to put away the suitcase
- Always bring plenty of extra supplies
- Keep supplies in more than one bag
- If traveling abroad, may want to contact the International Ostomy Association
- Airlines allow ostomy scissors in carry-on that are less than 4 inches in with supplies

Barbara Kupfer et al. Chandler House 2000
Sports

- Wait 6 weeks
- May need protective equipment
- May need a specific system
- Empty pouch
Sports
Bottom Line

- There is Nothing you CANNOT do, even if your poo (or pee) comes out of your belly and not your bottom
- OK: everything but take a laxative if you have an Ileostomy
Helpful Links

- CCFA: http://www.ccfa.org
- UOAA: http://www.uoaa.org
- American Cancer: http://www.cancer.org
- International Ostomy Association (IOA): http://www.ostomyinternational.org