NWA Ostomy Support Group - A UOAA Affiliate February 2021

Stronger Together

Northwest Arkansas Ostomy Support Group's Newsletter

LOVE IS IN THE AIR

INTIMACY/SEXUALITY WITH AN OSTOMY

Having an ostomy is a major life change. No one has an ostomy unless they have had a health problem. The ostomy can be a part of the solution to address that problem. For individuals who have suffered with Ulcerative Colitis, an ileostomy is a cure. For those with cancer, the ostomy is an important part of fighting the cancer. A diversion can remove pain, improve symptoms and allow individuals the opportunity and strength to truly fight the disease. There are countless reasons why an ostomy is needed and the common factor in each situation is that it is NEEDED and can actually improve an individual's quality of life.

Another commonality is that we are all human and humans are all sexual beings. Intimacy is important for everyone. We all crave touch and caring and sexuality in one form or another. Having an ostomy does not change that. Age does not change that and a health crisis does not either. Intimacy is a component of humanity. Sexuality is only a small part of intimacy that offers a number of health benefits.

Orgasm releases a flood of oxytocin, a hormone that improves your mood. Sex also has benefits for heart health, reduces stress and depression, improves self esteem and promotes more restful sleep. Talking openly with your partner is important.. You need to discuss what you find enjoyable and be open to trying something new. A change in position, flirty night garments, a binder, lubrication, and a change in routines may be helpful as you adjust to having sex with an ostomy.

Adults have always made preparations in anticipation of romantic evening. Personal hygiene, colognes, clothing to set the mood, a nice meal, lighting, etc are fairly standard. An ostomy may add a few items to your preparations but the result will be worth it. Your health care provider will not recommend sexual activity for 4-8 weeks following surgery. When you are ready will depend on the surgery you have had and any underlying disease. You need to find time that you are well rested and emotionally and physically ready.

In the beginning this is all new territory. Things will not be the same as they were before surgery and may not be perfect. It is important to continue to talk with your partner, be honest and continue looking for ways to please each other.

If there is an ongoing problem, please seek guidance from a member of your medical team, primary physician, surgeon, or CWOCN.

For more details on intimacy and sexuality, please download the guide from the UOAA at UOAA.org. It is an excellent document that every ostomy patient should have.

Making Sense Out of Insurance

There is perhaps nothing more confusing than insurance. Just looking at a bill from the hospital or a provider is enough to confuse anyone- even medical professionals. Depending on your personal situation, you will have different options for insurance coverage. Insurance plans are grouped into either private plans or government sponsored programs.

If you are employed, your insurance may be an important benefit that comes with your job. Depending on your employer, your insurance may be covered at a reduced cost to you. Employers are required to pay at least 50% of the premium. Most employers offer choices for coverage A higher monthly cost to you may be tied to lower deductible or expanded coverage and benefits. Insurance at an additional cost may be available for your family.

If you have private insurance as opposed to Medicare or Medicaid, it is important to review your policy **before** it is needed. You should know what the required deductible is. The deductible is the amount that must be paid before your insurance will begin paying its portion. The size of a deductible can vary widely from hundreds of dollars to thousands with some plans. It is also important to know what services are covered and your responsibility for those services. Some plans will have a set copayment that you may owe directly to a provider. That amount may be higher when for specialists as opposed to primary providers. Finally, you need to know what your coinsurance is . This is the amount you owe after your deductible has been paid and your insurance has paid its part. On average, a single policy will normally pay 80% with the remaining 20% being your responsibility. This amount may be covered by a secondary insurance policy or paid directly by the policy holder. Based on insurance, the amount that any service costs may vary. It is often negotiated on your behalf by your insurance carrier. The direct cost of any procedure may also vary between facilities and providers. "Shopping around" for the best rates and the best fit for you is not appropriate but critically important. You should consider what the maximum out of pocket is since after that is met, the plan would pay 100% of all appropriate fees. You should also

review the Network that is available. Some providers will be in- network while others might be out of Network coverage. This is especially critical if you want to continue with established providers and preferred hospitals. You also need to anticipate need if you might need care in a tertiary care settings like MD. Anderson, The Mayo Clinic or other major providers. Some may be in the plan's network and others not. If you go to a facility or provider that is out of network, you will have a much higher responsibility.

If you do not have private insurance, you may be eligible for government sponsored insurance, known as entitlement programs. Medicare is based on national coverage based on age or disability while Medicaid is state sponsored and tied to low income for eligibility. In spite of legislation assuring coverage for all, there are still some who are uninsured and others with policies that only provide coverage under the most catastrophic circumstances.

When you turn 65, you will be eligible for Medicare. You can sign up for Medicare 3 months before the month your 65th birthday falls in or the 3 months following that month. Medicare is also available for individuals under the age of 65 with a disability that prevents them from working. If you have a disability getting placed on Medicare is not automatic. It often takes applying and being denied multiple times before being granted Medicare. It is only available 24 months after the disability occurred except in certain critical health conditions like ALS or renal failure. Occasionally, an attorney is involved to help streamline the process. Individuals who chose to continue working after they turn 65 will need to decide if it is financially advantageous to keep their employer sponsored insurance, opt into Medicare or have a combination of both. Start a conversation with your HR department well in advance of needing to make this decision.of your 65th birthday. There are times companies have certain requirements regarding your Medicare enrollment. Waiting may result in missed opportunities and benefits. You can enroll in Medicare at a later date but penalties will be imposed.

Insurance has its own language that it is important to understand. Most insurance is based on Medicare. PART A covers hospitalization, inpatient skilled nursing care, home health with supplies and hospice care. For Medicare patients, part A

has no premium cost but only addresses these services. To expand that coverage, individuals can opt in for additional coverage. If you have part A you can buy part B for a monthly premium; part B is a fee for service insurance that covers physician fees, outpatient services/ hospitalization, home health, equipment, ambulance transportation, some drugs, and prosthetic /orthotic devices.

Another option for Medicare eligible individuals is Part C. These policies are called Medicare Advantage (MA) or Medicare Advantage Prescription Drug (MAPD) plans. They are designed as Health Maintenance Organizations (HMOs) or Preferred Provider Organizations (PPOs), essentially, this means they are network-based plans. People who have Part A and Part B and live in the plans service area can purchase Part C for a monthly premium. Some plans cover prescription dugs, additional hospital benefits, and sometimes ancillary benefits like fitness programs and limited dental coverage.

Medicare Part D policies are available to cover outpatient prescription drugs to Medicare beneficiaries. Drug costs can be very high. A drug plan is encouraged for most. It will have tiers with generic and common drugs being available at a very moderate cost while more expensive drugs are available but with higher tiers the cost goes up. If a medication is not covered an exception may be requested by the prescribing provider if it is medically necessary. Otherwise, the individual must pay the retail value of the medication.

Unlike Medicare that is a national program, Medicaid is a state governed. Benefits vary widely from one state to another. It is available for low income individuals and families. It covers basic inpatient and outpatient services including home health. Medicaid may also cover services not covered by Medcare such as eyeglasses, hearing aids and prescription drugs. The cost for Medicaid is minimal and payments for services goes directly to the provider. For ostomy patients needing supplies, Medicaid can be a blessing but in some states can severely limit the supplies that an individual can obtain. The limitation may be a monetary constraint or restrictions on what products can be obtained. Although Arkansas has set an appropriate monetary limit for ostomy supplies, it has placed unreasonable restrictions on which items will be covered. In the coming months, we hope to

change those restrictions through education and if necessary political action. Stay tuned for how you can help. Our taxes support Medicare and Medicaid so it is to all of our benefits to have the most appropriate and cost effective programs.

After you have received any services, you should review the Explanation of Benefits, or EOB that is sent to you. This statement will show the latest services you have received, the total amount of money billed by the provider (clinician or facility), the amount your health insurance allows and covers and the amount you will be responsible for paying. It is important to review these statements for accuracy.

It is important to honestly evaluate the services that you anticipate needing in the coming year. In addition to the standard policies for health coverage, you may want to support additional programs like ground or air ambulance transportation. If you have any plans for travel in the post-Covid world, travel insurance may offer peace of mind and important coverage.

Medicare Allowables

All insurance bases the majority of what supplies are allowed monthly based on standardized guidelines from Medicare. Similar supplies (regardless of brand) are identified by a HCPCS code. Some insurance companies are not willing to pay for certain products. In that case, talk with your CWOCN and research your most cost effective alternative.

A4362	Ostomy Faceplate (2 piece barrier)	20/month
A4424	1 piece with Drainable Pouch & filter	20/month
A5061	1 piece with drainable pouch	20/month
A4425	Drainable Pouch for use with barrier	20/month
A4416	Closed 1 piece pouch -flat & filter	60/month

A4417	Closed 1 piece convex pouch & filter	60/month
A4419	Closed end Pouch for 2 piece & filter	60/month
A5054	Closed Pouch for 2 piece no filter	60/month
A5056	Drainable 1 piece/ext wear/filter	40/month
A5057	Drainable 1 piece/ext wear/filter/convex	40/month
A5073	Urinary pouch for barrier	20/month
A5071	1 piece urinary pouch	20/month
A4432	Urinary pouch for 2 piece & faucet	20/month
A4428	Urinary pouch & ext wear barrier& tap	as needed
A5102	Bedside drainage bottle most varieties	2/6 months
A4367	Ostomy Belt (1")	1/month
A4369	Ostomy Skin Barrier spray or brush	2 oz/month
A4371	Ostomy Powder	10oz/6months
A4402	Ostomy Lubricant	4oz/month
A4405	Barrier Paste non pectin base	4 oz/month
A4406	Barrier Paste pectin base	4 oz/month
A4422	Ostomy absorbent material	no fee schedule
A4455	Adhesive remover or solvent	2 oz/month
A4456	Remover wipes	50/month

Education Corner - Prolapsed Stomas

Last month we focused our attention on peristomal hernias which are a very common complication. Another complication that is less common but all too often seen in conjunction with a peristomal hernia is a prolapsed stoma.

A prolapsed stoma occurs when a stoma telescopes out on itself resulting in a stoma that is much longer than normal. The increased length may be an inch or several inches. If the stoma becomes swollen, it can appear much larger as well making pouching difficult.

A prolapsed stoma can happen for a number of reasons:

- **The abdominal muscles are weak and fail to support the stoma adequately**
- **Straining, which can happen with lifting or even forceful coughing or sneezing. Any increased pressure within the abdomen that forces a segment of bowel in the case of a hernia or stoma in the case of a prolapse to push outward can cause these complications.**
- **Significant weight gain or obesity increases the chance of complications**
- **Pregnancy**
- **Surgical technique with poorly sited stomas or openings that are too large or a stoma brought up through an abdominal incision.**

Prolapsed stomas are seen more commonly with colostomies than ileostomies and are more common with loop ostomies. Once a stoma has prolapsed, it is likely to prolapse again. When managing a prolapse at home, there are several simple tricks. The first is to lie down and relax. That alone may be enough to solve the problem. Lying down helps reduce the pressure in the abdomen allowing the stoma to recede back into position and return to normal size and length. This is called a spontaneous reduction. If simply lying down is not enough to reduce the stoma to its normal size, you have a number of other options for managing this condition at home.

These include the following:

- **While lying on your back, massage around the stoma. It is important that you do this by feel rather than raising your head to look at the stoma. Raising your head is like doing a mini sit up and will further increase the abdominal pressure.**
- **If the stoma is swollen, you can apply a cold compress wrapped in a soft towel. Do not leave any cold pack in contact with the skin or stomas for more than 30 minutes.**
- **Manipulation of the stoma is something you can try at home. By feeling and again not looking with your head elevated, remove the pouch and insert a**

finger into the opening of the stoma and gently lift it up as you apply gentle downward pressure. This can guide the stoma back into normal position

- If none of these strategies work, then it is time for Mary Poppins to come to the rescue. Simple white table sugar will effectively draw fluid from the swollen stoma allowing the size to reduce so that it can move back into a normal position. To do this, you will need to be lying on your back. There are two methods to make this this easier. The first method requires that you put on a new pouch. Be sure to use generous caulking. If the prolapse is very large, this could be a problem since the pouch that you use normally may not be large enough. For prolapses that can be repouched, you can then fill the pouch with simple white table sugar. You have to pour in enough sugar to completely cover the stoma. You will need to hold the end of the pouch up so that the sugar continually sits on top of the stoma. As soon as the prolapse is reduced, you will have to remove the "treatment" pouch and apply a new pouch cut to fit the opening and protect the peristomal skin. I recommend cutting at least 1/4 inch larger than normal and protect the exposed skin with caulking since it is likely that the prolapse may reoccur. A pouch that is not cut large enough to accommodate a prolapsed stoma can cause the stoma to be strangulated by a pouch opening that is now too small. It is important to work with your CWOCN to determine a good pouching choice to accommodate a stoma that is prone to change size while protecting the peristomal skin.

- The second method is the one I prefer. It is similar but does not require a new pouch until the prolapse has resolved and works regardless of how large a prolapse may be. Once you remove the existing pouch, clean and dry the skin. Expect more mucus from the mucosal tissue that the stoma is made from when there is a prolapse. Cut the bottom out of a large Styrofoam cup and place it over the stoma. Use waterproof tape or adhesive (Dermapro silicone tape, Hytape, or protective barrier arcs) to seal the cup to the abdomen Once the cup is in place, add enough table sugar to completely cover the stoma and lie quietly and patiently wait. A normal reduction can take 30 minutes or longer and as the sugar melts, you may have to add more sugar. Once the prolapse has resolved, hold the cup against the skin while you remove the tape. Top the cup to go over the stoma and slide the cup of sugary syrup and stool to the side of the abdomen and then directly into a trash bag. Clean the skin with water or ostomy wipes or jump into the shower. Repouch as recommended above with an extra 1/4 inch opening and more caulking to protect the skin and cushion the stoma.

Holding the prolapse in place is an ongoing concern. NuHope Hernia Support Belts have an option for a prolapse strap but you could try light compression like a Comfort Wrap or other binder such as a maternity band or even a 6 inch waist. Even with compression, a prolapse is likely to reoccur.

COVID 19 is still a force changing all of our lives. Stay safe, stay smart, stay in, socially distance, wear your mask, wash your hands, AND get your immunization as soon as you are able. It is the ticket for our lives to return to normal.

RESOURCES

NWA Ostomy Support Group on Facebook

NWA Ostomy Support Group on the web -nwaostomy.weebly.com

Hope Cancer Resources 479-361-5031

United Ostomy Association of America -UOAA.org. **Go online or call to request

Wound Ostomy Continence Nurses Society-WOCN.org ** find a nurse feature allows you to find a specialty nurse anywhere in the world

Wound Ostomy Continence Nursing Certification Board -WOCNCB.org **allows individuals to find a certified nurse and identify their scope of practice and how to contact them

World Council of Enterostomal Therapists -WCETN.org ** International Organization for nurses practicing in Wound Ostomy and/or continence nursing

Educational websites through manufacturers and distributors

In-person outpatient consultation with Diana Gallagher and/or Taylor Garcia by requesting a referral to Highlands Oncology Group- Surgical Department

Jennifer Juergens is available for inpatients at NW MEDICAL CENTER

***Be careful about "Dr. Google" information that is not sponsored by a reputable organization is not always accurate.**

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