The Austi-Mate Journal

Ostomy Association of Austin Monthly Publication
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This Bi-monthly newsletter is available online at www.austinostomy.org

Have you paid your dues?

The Ostomy Association of Austin is a volunteer based Non-Profit Health Support group dedicated to providing mutual aid and education, information and advocacy for persons and their families who have had or will have ostomy surgery. It is our vision to educate, empower and inspire through information and mutual support in all phases of life.

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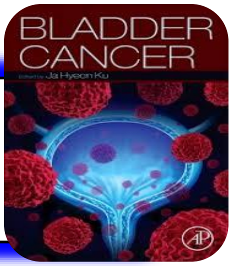
We hope you had a nice summer, made some new memories, and stayed healthy! We're looking forward to meeting **in person on Thursday, September 8th**. We moved this meeting to the second Thursday due to Labor Day weekend. We will simultaneously incorporate our virtual meeting as well. More information on page 5.

Texas Ostomy Services at Digestive Health is a new clinic for Ostomates and is now open in Austin. Read more about it on page 4.



Newly Diagnosed Bladder Cancer

Article from the Bladder Cancer Advocacy Network (BCAN) website

You've just learned that you or a loved one has bladder cancer. After being newly diagnosed, it's natural for you to be upset, depressed, panicked and overwhelmed. Know you are not alone and that there are people out there to help you.

There are several resources available to you as you begin your cancer journey:

- Learn more about bladder cancer. Frequently Asked Questions
- Download or order a copy of our new patient handbook "Bladder Cancer Basics for the Newly Diagnosed" by clicking here.

To help you become the best advocate for your own health, we have put together this list, compiled by individuals who are living with bladder cancer. We hope you find it useful.

When you are newly diagnosed:

1. Don't panic. When we first hear the C word, we all think the worst is going to happen. Many times, a diagnosis of cancer does not bring the worst-case scenario.
2. Have a good cry, kick something, yell and then get on with fighting your illness. If you get depressed, see a therapist or talk to your health care provider. There's a lot they can do to help you.
3. Be patient with the ones who love you. Remember, this is hard on them also. Cancer affects the whole family.
4. Accept help from your family and friends who offer. Ask them for support, help and understanding.

To begin the fight:

1. Bladder cancer is a treatable disease. Learn as much about your diagnosis as you can. Look on the internet, search medical libraries, request BCAN's patient handbook. Read the literature yourself. If you find that researching it upsets you, let someone close to you do it and bring you the relevant information.
2. Many urologists don't know enough about bladder cancer. If you want the best treatment, find a highly-regarded urologist who specializes in bladder cancer. If you can, seek help in a major cancer center where they treat many cases of this disease. Choose a urologist you trust and with whom you feel comfortable. Find a doctor who will talk to you.
3. Get 2nd, 3rd and 4th opinions if you are so inclined. Doctors can and do vary significantly on the treatments they recommend.
4. Remember, bladder cancer is not just bladder cancer; it is a disease that can effect the entire urinary system including your kidneys. That's why it is important to move forward with a correct diagnosis and course of treatment as soon as possible to prevent the spread to other parts of your urinary tract.
5. Understand your options. Talk them over with your significant other, family members, or close friends and make decisions that are agreeable to both of you.

When you visit a doctor:

1. Write down your questions BEFORE your appointment and allow space to write down the answers. Or, take a tape recorder with you.
2. Ask a lot of questions.

3. Have a family member or friend accompany you just to hear what is being said. Four ears are generally better than two.
4. Get copies of every report and test result, keep them and learn exactly what they mean.
5. 5. Suggested questions to ask your doctor:

   - What kind of bladder cancer do I have?
   - What is the stage of the disease? Has the cancer spread?
   - What is the grade of the tumor?
   - What are my treatment choices? Which do you recommend for me? Why?
   - What are the expected benefits of each kind of treatment?
   - What are the risks and possible side effects of each treatment?
   - What is the treatment likely to cost? Is this treatment covered by my insurance plan?
   - How will treatment affect my normal activities?

As you travel down this road:

1. Investigate clinical trials if appropriate for your cancer.
2. Do what you can to improve your health and strengthen your immune system.
3. Be diligent. Don’t put off a doctor’s appointment or test, even if your check-ups are clear. If you are scheduled every three months — be there. Same holds true for every six months or every year.
4. Reach out to other cancer survivors. Your experience will help others.
5. How to get a second opinion:

- Before starting your treatment plan, or having surgery, you may want to get a second opinion about the diagnosis, stage, and treatment. Some insurance companies require a second opinion; others may cover it if the patient requests this.
- Gathering medical records and arranging to see another doctor may take a little time. In most cases, a brief delay in treatment will not affect the outcome. To find a doctor for a second opinion, you can ask your own doctor for a referral. You should also consider contacting the Urology Department at a Comprehensive Cancer Center.
- In general, physicians at the cancer centers see a higher volume of bladder cancer patients and have considerable experience dealing with the disease.

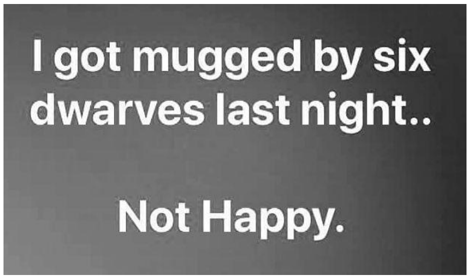
And finally, some words from those who are in this fight:

“Encourage your medical team to work with you as an individual, not as an illness. (There is not a “one size fits all’ treatment for any disease.) Believe in yourself. Be your own best friend. Be kind to yourself as you would a friend in need. Know the disease is not who you are.” Karen, diagnosed in 2003

The adult version of "head, shoulders, knees and toes" is "wallet, glasses, keys and phone."

A truck loaded with Vicks vapor rub overturned on the highway.

Amazingly, there was no congestion for eight hours.



I got mugged by six dwarves last night..

Not Happy.

Texas Ostomy Services at Digestive Health
New Clinic Now Open

Texas Ostomy Services at Digestive Health opened the first clinic of its kind for the Austin community on August 1. The clinic is located downtown at 1601 Trinity St. in the UT Health Transformation Building.

Texas Ostomy Services is offering comprehensive ostomy services from marking and education prior to planned surgeries, post-op care and education, troubleshooting for fit and peristomal problems, and supply management. Ostomy care is provided by Kara Jackson, BSN, RN, CWON who has been practicing wound and ostomy care for the past 7 years (the last 5 in Austin). Kara is excited to helping to provide care and support to the ostomate community in Austin and is acutely aware of the need for such a resource. Dr. Ivatury, who oversees the clinic and is a passionate advocate for ostomates. Since his arrival in Austin about a year ago, the clinic has been a high priority for him to get off the ground.

Any ostomate or person planning to have surgery where an ostomy will be created can be seen in the clinic. A referral from any provider is needed to make an appointment. The team at Texas Ostomy Services is excited to get to know the ostomy community better and provide support in any way they can.

Our team is also engaged in research projects aimed at improving support for people with ostomies. You can find out more about the current research project, **The Speaking Stoma Project** below

The Speaking Stoma Project

Do you have an ileostomy, colostomy, or urostomy? Have you had it for at least a year? Do you want to help develop a health communication guide for people with ostomies? We would love to hear from you!

You are invited to participate in a new research study – the Speaking Stoma Project. We want to learn about the important social interactions that people with ostomies encounter and strategies in communication for these situations.

This study is being conducted by Srinivas (Joga) Ivatury, MD and some other colleagues from Dell Medical School and the Center for Health Communication at The University of Texas at Austin

This study has been reviewed by The UT Austin Institutional Review Board

If you agree to take part in this study, you will be asked to participate in a focus group or individual interview via Zoom. The focus group or interview will take approximately one hour. You are welcome to use a pseudonym on your Zoom screen and blank out your screen. We will audio record the focus groups and capture the chat, but we will not identify you in the transcripts of the recordings, the chat, or in any reports of the data. The group will be asked about the various social situations and different means to deal with these as a person with an ostomy.

We will provide a $25 gift card as a token of our appreciation.

Please click on the link below or use this QR code to join the Speaking Stoma Project:

https://texascommunication.qualtrics.com/jfe/form/SV_eR4j559nxP4KqeG

To Be or Not to Be ...
Open About Your Ostomy …That Is The Question?

Friends of Ostomates Worldwide-USA Spring 2021 Newsletter
Ostomy Pearls Rachel Hendee, PA-C, MMS, MPH

Every person with an ostomy has their own unique story and journey. Someone may have been suffering from Inflammatory Bowel Disease for many years before finally agreeing to surgery and an ostomy. Someone else may have been blindsided with a new rectal cancer diagnosis and find themselves with an ostomy just a few short weeks later. Others may have lived their entire lives with an ostomy due to trauma or congenital anomaly, and therefore, know no other way of life. No matter the reason for the needing it, every person has a different path to acceptance of their ostomy. Some are immediately open about their ostomy and are happy to discuss their new situation with friends, family or even new acquaintances. Others remain incredibly private and choose only to reveal knowledge of their ostomy to a minimal few. And I think the majority of ostomates fall somewhere on the spectrum between these two extremes. A person's place on this spectrum can also change over time (in both directions), depending on both positive and negative experiences someone might have.

The important thing to remember is that as an ostomate - it's **YOUR CHOICE**. There is no right or wrong way to live with an ostomy. It can also be comforting to know if a patient is facing an upcoming ostomy surgery or as a new ostomate that there are many things one can do to conceal and hide their ostomy should they choose to do so.

Here is a list of tips:

- High waisted clothing - Luckily high waisted pants, shorts and swimsuits are currently in fashion, making it easy to find articles of clothing to conceal your ostomy without having to purchase specific items made for ostomates.

- Clothing that is patterned or loose fitting will help to make a full ostomy bag less noticeable until you are able to empty it. Also, keeping with you a light jacket, sweater or scarf that can be worn or placed around your waist can be useful.

- Control top underwear or belly band. You don't want anything that is extremely tight that will occlude stoma output but a snug fit will help to conceal any bulges as the bag may fill up.

- Empty your pouch often. If you empty often output will not accumulate in bag and will be less noticeable.

- Use an ostomy appliance with a filter. A filter will help to prevent gas build up in the bag even when you have no output. Because the filter uses carbon, gas is able to be released but no odor.

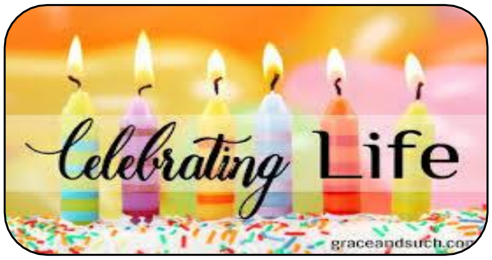
- Avoiding foods with increased gas production can help to prevent the ballooning that can happen as well. Over the-counter anti-gas medication can also help to prevent/treat increased gas. However, please discuss with your medical provider before trying this.

- Remember - you are likely more self-conscious of your ostomy than anyone else around you. Even if you may think it is very noticeable, chances are it is not!

No matter how open you choose to be about your ostomy, remember that it is your choice. But also remember all that you have been through with the journey that led you to your ostomy. Your stoma is like a scar or wound, proof of a hard battle you have fought and won.

Borders:

All Ostomy types
Colostomy-related
Ileostomy-related
Urostomy related



Yearly Anniversaries:

September & October 2021

Dorothy Ruhl, 28; Dwight Vance, 26
Eddie Padilla, 9; Mary Meshbane, 14

Problem-Solving Clinic is Open

The Ostomy Problem Solving Clinic is open on the first Thursday of the month at the Gethsemane Lutheran Church from 1-4 pm

- Text or call Karen Hollis, RN, CWON, at **512-785-7448**
- Text/leave your name, number, type of ostomy and problem.
- Karen will contact you

First Thursday of the month.

Meetings will be combined:
In-Person & Virtual

September 8
(First Thursday is Labor Day weekend)
October 6
November 3
December 1

Join Zoom Meeting (click on live link)
Meeting ID: 886 3266 6521
Passcode: Welcome!

*Download the Zoom App prior to joining the link

Tom's family receives the horrible news.

Are you in need of donated supplies? We have **plenty** available!
Please contact Carol Laubach, (512-339-6388) and indicate what type of ostomy you have, brand preference, size, and whether it's a one or two piece. This will help to get you the best fitting supplies possible.

We are a health support group, a non-profit, tax-exempt 501(c)(3), organization of volunteers whose purpose is to provide mutual aid and education to persons who have ostomies and their families. Membership fees and donations are tax deductible.

The information contained within our newsletters is for informational purposes only and may not be applicable to everyone. **Please do not follow any medical advice in our Newsletter without first checking with your physician or Wound Ostomy Continence Nurse**.

OAA Membership Application

Name____
Ostomy Type_________________________ Surgery Date__________________
Address____
City_________________________State_____Zip_______Phone_____________
Year of Birth__________________ Email__________________________________
Spouse/Relative/Partner/Friend Name____________________________________

I do _____I do not_____ give permission for my name to be included in our newsletter or membership directory. ____

Signature Date

Annual Dues:

$25________ Ostomate
$15 ________ Spouse/Relative/Partner/Friend/Other
$25 ________ Professional

Mail Application to:
Ostomy Association of Austin
P.O. Box 143383
Austin, TX 78714

Newsletter Preference: Check one

________ Printed version via US mail
________ Email notification/download to your computer via website www.austinostomy.org

Membership benefits include:

- Monthly support & informational meetings
- Social events
- The Austi-Mate Bi-Monthly Newsletters

The Phoenix magazine is the official publication of the United Ostomy Associations of America. The Phoenix magazine is published quarterly - Annual subscriptions are $19.95.
https://phoenixuoaa.org/
Toll-free 800-750-9311.