

# The Roadrunner



### Newsletter of the Ostomy Association of Albuquerque, NM

## **Next Meeting**

## Sunday, May 5, 2019 at 2 PM

Support Group Meeting, Aspen Room

The Executive Board Meeting is cancelled and

has been rescheduled to June 2, at 1 P.M.

## **Support Group Updates and Events**

## **Recent Events**

- February support group meeting was followed by speaker, Theresa Jaramillo, ۲ from Sandia Surgical, Inc. who explained partnering with ostomates for obtaining medical supplies locally. (Contact info on page seven.)
- March had a regular support group meeting.
- At April's meeting, Nurse Barbara showed some ConvaTec and Marlen products while we played a game of identifying ostomy system types!

## **Upcoming Events/ News**

- No speakers scheduled at this time for May, June, or July. Please pay attention ٠ to changes by email or regular mail as speakers can be added, etc. As usual, regular support group meetings will be held in those months. (Dates located in right side panel.)
- Members who would like to chair meetings are most welcome to do so. Please coordinate with Brian. If you have a topic you would like to present to the group, please coordinate that with Nurse Barbara.
- Thank you to all of you who attend regularly in support of others!! You are Super Heroes!! Maybe we should give you tight logo shirts and capes -- or not! You know who you are!
- It's already getting hot here in the desert and only expected to get hotter and hotter! Please remember to drink plenty of fluids. Pay attention to your symptoms of dehydration. Ileostomates need to include electrolytes. BE SAFE!

### Volume 53 Issue 2

**May 2019** 

#### **Upcoming Meetings:**

- May 5, 2019 (quarterly) no board meeting
- June 2, 2019 (Board meeting at 1 PM)
- July 7, 2019
- August 4, 2019 (quarterly)
- September 1, 2019

Meetings are at 2 PM in Aspen room at Kaseman Hospital unless otherwise stated.

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I had this vision of Uncle Sam pointing at me saying "I need you!" Only there was one difference, he had an Ostomy pouch sticking out of his stripped pants "Whoa Nellie, there he goes again!" Well Nellie and friend, I am afraid that is correct, I have written about this before. But the fact is that we need people to stay involved. Basically, we need people who have learned to live with their Ostomys successfully to attend meetings and assist those who are struggling or just need reassurance. We have been doing well with attendance and people coming, but we need more that than that. We need volunteers to fill roles in the organization, to help with tasks and eventually to take over for the current officers and committee chairs. We need volunteers for the Board so that fresh ideas are available. We got a lot of volunteers to do the premeeting phoning when we asked last month, and we appreciate that, but there is so much more that we could use a little help with. So, come on out and let us know you are ready to assist the group in whatever way you can. I believe you can only gain by doing this. You see what your potential is and realize this is only a slight detour. And you feel good about doing something for other people. If you feel that coming to a meeting is all you can do right now than we will understand. Keep coming and one of these days when you feel like you can do more, let us know. If anyone would like to talk about helping your Ostomy Association please talk to Brian Leen or Ben Palmer at the next meeting you attend or look at the officer's page in the Roadrunner where both of our names, email addresses and phone numbers are listed.



The Roadrunner



## **5 Things No One Tells You About Having an Ostomy**

from UOAA February 2019

Page 3

Having a surgery that results in an ostomy is a huge, lifechanging event. It can feel scary and there are so many 'unknowns'. Asking questions, and gathering as much information as possible before your surgery will help to prepare you for your new life and routine.

Based on others who have had surgery before you, we have put together a list of 'five things no one tells you before your ostomy'. These are 5 things many ostomates wish they had known before adapting to life as an ostomate. We hope this list helps to prepare you even more, and encourages you with moving forward into your new lifestyle and routine.

#### 1.) You are Not Alone

You may feel like your ostomy alienates you from your world, but you are not alone in this. There are many people who have had surgery before you and there is an extensive and supportive ostomy community available to you. Your adjustment process may take time, and if you are experiencing discouragement, talking about it with someone who understands can be helpful. There are also numerous ostomy blogs and websites dedicated to sharing stories and experiences, as well as tips on living with your ostomy and how to avoid common mishaps. Once you have settled into the routine that works best for you, consider adding to these resources or reaching out to someone you may know who is struggling with their new ostomy.

#### 2.) Your Quality of Life May Improve

Most ostomates are happy to find out that they are able to do everything they were already able to do before their surgery, and often, even more. There's a chance that your illness leading up to your surgery was debilitating and left you with little to no control over your own life. If this was the case, having an ostomy will be a profoundly new experience in which you have more control and less limits. You will be able to check items off of your bucket list that seemed impossible before.

There are Amazing Products Available to You
 In the first few months to a year after your ostomy, you

may take some time getting used to your appliance and how to change it out and clean the skin around your stoma. In addition to helpful information and tips online, you can also find an array of different products to help you manage your ostomy on a daily basis. It's amazing how far science and technology have come, and companies such as Coloplast, are continuing to develop new products with you in mind.

#### 4.) It Takes Time to Adjust - And That's Ok

While your ostomy should not hold you back from seeing and doing new things, it also is a big adjustment and there is no timetable on how and when you do this. Be patient with yourself and take the time you need to feel confident with caring for your new stoma. Use the information that is available to you, but do so without comparing your progress with that of others. Every body is different, so don't rush your recovery with unrealistic expectations and goals. Be kind to yourself.

#### 5.) Diet - Most of the Same Rules Still Apply

As far as diet and exercise, they are just as important after your ostomy as they were before. If you were a healthy person before your ostomy, continue to treat your body well with what you put in it and how you use it. Keep in mind that the foods that were good and healthy for your body before your operation are still good for you. Hydration is key. It is important to drink lots of liquids with an ostomy.

When you are in the hospital, chances are you will be given a list of what foods to avoid. Eating simple and bland soft foods directly after your surgery will be easier to digest, and will help your recovery. As you heal, it's okay to incorporate other foods into your regular diet, but it is recommended that you try them slowly and possibly even one at a time. Again, every body is different, and what affects someone else may not affect you in the same way. Keeping a journal or diary of how your body responds to different foods can be helpful.

For more information, visit www.coloplast.us





## **Tips for a Successful Recovery**

By Diana Gallagher, MS, RN, CWOCN, CFCN Facilitator for the NWA Ostomy Support Group

For many, ostomy surgery is lifesaving but their initial feelings on living life with an ostomy are negative. For individuals with years of unresolved incontinence or inflammatory bowel disease, however, life after surgery is frequently viewed as a positive improvement. For them, an ostomy is the promise of a return to a normal life.

As you prepare for surgery, the following are important tips to help you transition into your new life and embrace living with an ostomy.

(For more information visit www.ostomy.org or contact United Ostomy Associations of America at 1-800-826-0826.)

Select a surgeon with valuable experience in the type of surgery that you are facing. General surgeons as well as specialty surgeons can perform ostomy surgery. Specialty surgeons are those who have completed additional education, training, and fellowships within the specialty. These surgeons will be identified as Colorectal or Urology Surgeons. You can find a local physician through the websites for the American Society of Colorectal Surgeons or American Urological Association.

See an Ostomy Nurse. BEFORE surgery, your surgeon may refer you to a specialty nurse, like a Certified Wound Ostomy and Continence Nurse (CWOCN). If not, you will need to find a specialty nurse. This nurse will help ease your transition into living with an ostomy. Although education may be provided during your hospital stay it can be difficult to focus and remember because of anesthesia, surgical pain and stress. Your ostomy specialist will provide comprehensive education including practice pouch changes before surgery. In addition, he/she will identify and mark the best location for your ostomy. This is important because during surgery it is difficult for your surgeon to know where the waistband of your pants sits, where creases or irregularities exist and other special considerations to consider when selecting that optimal site. Attend a United Ostomy Associations of America (UOAA) affiliated support group (ASG) meeting in your community if possible. You may think that you do not need a support group or feel that you are the type of person who does not feel comfortable in a group setting. Put those feelings aside; listening in the beginning is a good start. Join your local group, even if you don't initially find someone your age with a similar story, there is a lot to learn. UOAA affiliated support groups are truly one of the BEST places to obtain the necessary education, helpful hints, support, and resources. Don't feel that you are alone.

**Determine which supplies will work best for you.** In the beginning, you will most likely receive sample products from a number of companies. It is helpful to keep the 2 piece products from each manufacturer separated; wafers from one company will not necessarily snap onto a pouch from another company. The sampling program will help you try a variety of products to learn which ones work best for you.

**Order your regular supplies.** Once you know what you like best, an order can be placed through a distributor. There are countless distributors to choose from and depending on insurance, your supplies can be delivered monthly or every three months. The first time that you order, it is logical to order a month's worth of supplies. As your expertise develops, you may fine-tune your list. Insurance normally pays 80% of supplies that are medically appropriate. If you have a secondary plan, the remaining 20% may be covered. Check for a list of the established limits for each product. Reorder supplies so that you are never without the supplies that you need.

**Select a place to keep your ostomy supplies organized.** Many people keep their basic supplies in a bathroom drawer, others buy a plastic organizer with several drawers





#### Tips for a Successful Recovery (continued)

#### (Continued from page 4)

that can be moved about. Excess supplies can be stored in a closet but regardless of where you choose to keep supplies, it is best to avoid temperature extremes and high levels of humidity.

**Be prepared.** In addition to the extra supplies that you keep on hand at home, always keep a small pouch with all the supplies necessary for a complete change with you. Like your other supplies, these should be kept away from temperature extremes and humidity. Hopefully, you will rarely need to make an unplanned change, but being prepared, makes most ostomates feel secure and confident. If you anticipate an occasional return to the hospital, keep a bag packed with your preferred supplies. The hospital may not have the brands that work best for you.

**Promptly consult your ostomy specialist for any problems.** This might be a decrease in normal wear time, a change in your stoma, or a problem with your peristomal skin. A good practice for all is to hydrate properly to avoid complications.

#### Recover from surgery and LIVE life to the full-

**est.** Having an ostomy does not change who you are or what you are able to do. After recovery, work to strengthen your abdominal muscles to help prevent hernia risk and enjoy all your old activities including swimming. Every October UOAA holds the Run for Resilience Ostomy 5k where people of all ages prove living with an ostomy does not need to be limiting.

Advocate for yourself. You will find that not everyone is knowledgeable about ostomies. Educate others when possible but always be willing to advocate for yourself and others. You can also help to advocate on the national level by supporting UOAA's advocacy program and taking part in events like Ostomy Awareness Day held on the first Saturday in October. UOAA works toward a society where people with ostomies and intestinal or urinary diversions are universally accepted and supported socially, economically, medically, and psychologically.

**Share your experience and tell your story.** Your story has the power to help others as they begin their journey. Connect with others in person or online and offer to help the next person who has this lifesaving surgery.

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#### **OAA Roadrunner Newsletter**

<u>Membership</u> is \$20.00 a year and includes the Roadrunner newsletter and monthly informative meetings. This money is used for promotional purposes and expenses of the OAA. Although chapter membership is encouraged, anyone with financial hardship, should see the Treasurer or President for help in this matter. No one is denied based on ability to pay.





## SOLUBLE VS. INSOLUBLE FIBER: WHAT'S THE DIFFERENCE?

From Vancouver Ostomy HighLife via Winnipeg Inside/Out If you have an ileostomy, should you eat fiber? How much? What kinds are the safest?

The intestine has a remarkable capacity to adapt. Matter/ digested food in the small intestine is quite watery, and after it moves into the large intestine, a good portion of the water is reabsorbed into the body. Most fiber is indigestible material from plants that acts like a sponge, soaking up water and increasing the bulk of the intestinal contents making matter move through the system more quickly. In a person with an intact colon, fiber is essential to preventing constipation and keeping a person "regular". This is the main function of fiber. A person without a large intestine (ileostomy) doesn't have a problem with constipation, and will have loose or watery stool. (Some ileostomates report that over time, their stool becomes less watery as the small bowel adapts and 'makes up' for the loss of the large intestine). This is especially possible if the last section of the small bowel (ileum) is still intact. However, consuming too much "insoluble" fiber may cause a blockage. Avoid or limit your intake of insoluble fiber such as bran, popcorn, seeds, nuts, skin/seeds/stringy membrane parts of the fruits and vegetables. However, another type of fiber (soluble) may be beneficial to the ileostomate. It may seem like a contradiction, but the function of soluble fiber is to make intestinal contents "thicker" and can actually help prevent diarrhea. This fiber is found in oatmeal, barley, dried beans, peas, Metamucil and in the pulp of fruits and vegetables. Most foods have a combination of both types of fiber, but the above examples show the differences. Adding pectin (Certo, used to make jam and jelly) to one's daily diet can help to minimize diarrhea. Add it to applesauce. How much of any of this stuff the individual ileostomate can safely eat is, unfortunately, often determined by trial and error (and sometimes, despite knowing better, having just o-n -e more taste of those nuts!) Pay attention to how much, and how fast, you are eating any kind of fiber. It might seem silly to measure one's intake of certain things by the bite, but it's best to be ultracautious as you resume eating after surgery. Add vegetables and fruits in very small amounts. Chew your chow carefully and thoroughly. Try not to learn your limits the hard way!

#### CHANGES IN YOUR SKIN AFTER CHEMO-THERAPY

Lauren Wolfe, RN, BSN, CWOCN, Island Ostomy News, Victoria Chapter via Ostomy Halifax Gazette and Winnipeg Inside/Out

Your Peristomal Skin and Chemotherapy changes the skin and this can cause problems when attaching your pouching system. Some of the skin reactions that you may experience include rashes e.g. fungal, folliculitis, or dry skin conditions. Chemotherapy can be harsh on the skin. Our skin is more prone to infections when receiving chemo. Applying a pouching system can create a warm moist environment which can become infected if the skin is compromised. It is not uncommon to develop a fungal infection; this often takes on the appearance of an allergy. Treatment for a fungal infection related to chemo can be challenging, it may require both an antifungal powder and a topical cortisone to reduce the inflammation. Topical creams are not an option for using below the flange. Thus, if you are concerned, please contact your ET nurse. Using an adhesive remover may be advisable to prevent skin stripping, which can create a break in the skin. If you have any concerns about the appearance of your peristomal skin, please contact your ET. Your Stoma and Chemotherapy Chemo and radiation can have some side effects that you should watch out for. Common concerns are nausea and vomiting or constipation or diarrhea. If you are experiencing diarrhea it may be necessary to take an antidiarrhea medication after talking to your family physician. If you are vomiting and struggling to keep fluids down, then seeking medical help is advised. Staying hydrated is extremely important and more so when on chemotherapy. Your stoma may increase in size; thus it is important to ensure that you resize your appliance regularly. · Your stoma may bleed a little more than usual. Although this is of course a little worrying, it really is no cause for concern. Be gentle when cleaning and wiping your stoma. If it starts to bleed, apply gentle pressure to the area. · Ulcers might appear on the stoma-these look very much like mouth ulcers. In the majority of cases these will disappear on their own.



## Support Group and Medical Resources

<ul> <li><u>New Mexico Ostomy Support Groups:</u></li> <li><u>Albuquerque: Ostomy Association of Albuquer-que meets monthly in Albuquerque, NM.</u> For current info call voicemail: (505) 830-2135 Email: <u>oa.albuquerque@gmail.com</u> Website: (coming soon!)</li> <li><u>Albuquerque: VA Ostomy Support Group</u> for military veterans. Meets at the VA Hospital, Al- buquerque, NM. For current info call ostomy nurse at VA Medical Center Hospital voicemail: (505) 265-1711, Ext. 5171 or 5232 or 4411</li> <li><u>Las Cruces: Ostomy Support Group of Southern</u> <u>NM</u>. Meets in Las Cruces, NM. For current info call ostomy nurse at Memorial Medical Center voicemail:</li> </ul>	<ul> <li>Ostomy Care in Albuquerque, NM</li> <li>Lovelace Medical Center Ostomy Nurses: (505) 727-8250</li> <li>Lovelace Medical Group—General Surgery — Ostomy Outpatient Clinic— Savanna Noel (505) 727-7096</li> <li>Presbyterian Main Hospital Ostomy Nurses: (505) 841-1251</li> <li>Presbyterian Outpatient Wound and Ostomy Care Clinic: (505) 823-8870</li> <li>University Medical Center Hospital Ostomy Nurses: (505) 272-9098</li> <li>Veteran's Administration Hospital Ostomy Nurses:</li> </ul>
(575) 640-5242 or (575) 521-5038 Manufacturer Resources:	(505) 265-1711 Ext: 5232 or 5171 or 4411 Local Supply Resources:
<ul> <li><u>Coloplast</u> Ostomy Supply Manufacturer: (855) 385-3991 Web: <u>www.coloplast.us</u></li> <li><u>ConvaTec</u> Ostomy Supply Manufacturer:</li> </ul>	HME: (Home Medical Equipment) 2 Locations:     -611 Osuna Rd. NE Albuquerque, NM     -10801 Golf Course Rd., NW Albuquerque, NM     Web: <u>www.hmespecialists.com</u>
<ul> <li><u>Coloplast</u> Ostomy Supply Manufacturer: (855) 385-3991 Web: <u>www.coloplast.us</u></li> <li><u>ConvaTec</u> Ostomy Supply Manufacturer: (800) 422-8811 Web: <u>www.convatec.com/ostomy</u></li> <li><u>Cymed</u> Ostomy Supply Manufacturer:</li> </ul>	<ul> <li><u>HME</u>: (Home Medical Equipment) 2 Locations:         <ul> <li>-611 Osuna Rd. NE Albuquerque, NM</li> <li>-10801 Golf Course Rd., NW Albuquerque, NM</li> <li>Web: <u>www.hmespecialists.com</u></li> <li>Cust. Svc. for both locations: (505) 888-6500</li> <li>Toll free: (866) 690-6500</li> </ul> </li> <li>Phillip's Pharmacy: carry some ConvaTec supplies</li> </ul>
<ul> <li><u>Coloplast</u> Ostomy Supply Manufacturer: (855) 385-3991 Web: <u>www.coloplast.us</u></li> <li><u>ConvaTec</u> Ostomy Supply Manufacturer: (800) 422-8811 Web: <u>www.convatec.com/ostomy</u></li> </ul>	<ul> <li><u>HME</u>: (Home Medical Equipment) 2 Locations:         <ul> <li>-611 Osuna Rd. NE Albuquerque, NM</li> <li>-10801 Golf Course Rd., NW Albuquerque, NM</li> <li>Web: <u>www.hmespecialists.com</u></li> <li>Cust. Svc. for both locations: (505) 888-6500</li> <li>Toll free: (866) 690-6500</li> </ul> </li> </ul>
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### Join Our Albuquerque Ostomy Support Group

#### OSTOMY ASSOCIATION OF ALBUQUERQUE MEMBER APPLICATION

The Ostomy Association of Albuquerque (OAA) is a member of the national American Ostomy Association. This allows us to have access to all the latest ostomy information available for our use. The OAA annual membership fee is \$20.00 and can be paid by check or cash. If being paid by check, make the check payable to Ostomy Assn. Of Albuquerque. Your payment can be mailed to OAA, PO Box 35598, Albuquerque, NM 87176-35598 or at any monthly meeting. If you are financilly unable to pay this fee, please call 505-275-2470 and leave a message with your name and telephone number and someone will contact you. Please complete the form below as best as you can and all information will be used for our records and be kept confidential.

	NAME:	DATE OF BIRTH:	
ł	STREET ADDRESS:		
	СІТҮ:	STATE:ZIP:	
	E-MAIL:		
OCCUPATION (If retired, enter former occupation):			
	HOBBIES:		
1	CHECK ALL THAT APPLY:		
[] Colostomy [ } lleostomy [ } Urinary Diversion [ ] Continent lleostomy [ ] Continent Urostomy [ ] Pull-Through			
	[ ] Parent with Child Procedure [ ] Spouse/Family Member [ ] Physican [ ] Nurse [ ] Other		
Year of Surgery; Reason for Surgery: [] Crohn's [] Ulcerative Colitus [] Cancer [] Birth Defects as a donation to support the ongoing work of the OAA			

#### Join United

Ostomy

Association

of America

Save the Date

The next UOAA National Conference will be held

August 6-10 2019 Philadelphia, PA



**UOAA's Mission** 

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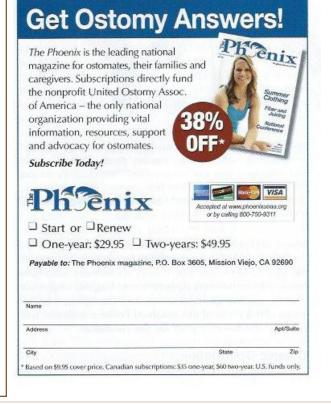
UOAA is an association of affiliated, nonprofit, support groups who are committed to the improvement of the quality of life of people who have, or will have, an intestinal or urinary diversion.

- 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.

Membership in UOAA is open to any nonprofit ostomy support group that meets UOAA's affiliation requirements. UOAA has an IRS Group 501(c)(3) charity status that its affiliated support groups can use.

1-800-826-0826

Website: <u>www.ostomy.org</u>







 President:
 Brian Leen

 505-856-0203
 Vice President:

 Vice President:
 Ben Palmer

 505-828-0936
 Image: Source President:

 Treasurer:
 Barbara Regan

 703-261-3920
 Secretary:

 Mark Walker
 Source President:

 505-242-2173
 Superiod President:

 Voicemail and Visitation Coordinator:
 Brian Leen, 505-856-0203

 Telephone Reminder:
 June Kulow <jckklk@hotmail.com>

people with ostomies and their care-

givers in the New Mexico region.

OAA publishes *The Roadrunner* 

update its members.

newsletter quarterly to inform and

<u>Membership</u> is \$20.00 a year and includes the Roadrunner newsletter

and monthly informative meetings.

This money is used for promotional

purposes and expenses of the OAA.

Although chapter membership is en-

ship, should see the Treasurer or

couraged, anyone with financial hard-

President for help in this matter. No

one is denied based on ability to pay.

Meetings are monthly at 2:00 PM in

the Aspen Conference Room at Pres-

byterian Kaseman Hospital. Meetings

are usually held on the first Sunday of

sional changes due to holidays, please

every month. Since there are occa-

#### **Ostomy Supply Closet:**

(donations & supplies)

Eunice Hoeft

Call ahead; 505-889-9705

Meeting Facilitator and Programs: Barbara D'Amore, BSN, CWOCN

damorebd@aol.com

Sunshine Committee: Bernice Newman: 505-298-2323 bernicenewman836@hotmail.com



### About Us

Ostomy Association of Albuquerque (OAA) is organized to support refer to *The Roadrunner* for information or call the association's voice-

mail.

**Executive Board Meetings** are held at 1 PM prior to the Quarterly meetings (Feb, May, Aug, and Nov.) in the Aspen Room. Everyone is welcome to attend and participate.

**Directions:** Address: Kaseman Hospital, 8300 Constitution Pl., NE; Albuquerque, NM. Kaseman Hospital is one block North of I-40 and Wyoming Blvd. Then it is about one block West of Wyoming on Constitution. Drive to West end of parking lot and enter the Emergency Room entrance. Take an immediate left, go through double doors and find Aspen room on the right side.

<u>Affiliation</u>: Ostomy Association of Albuquerque (OAA) functions as a chapter affiliate of the national organization supporting people with ostomies-- the United Ostomy Association of America (UOAA).

**The UOAA** holds biennial national conferences. They publish the wonderfully informative *Phoenix* magazine four times a year. There is a subscription cost for this publication. They have a great website with all kinds of information available for free. Much of it is available in any language on earth!

#### Contact Information:

United Ostomy Association of America

P.O. Box 525

Kennebunk, ME 04043-0525

1-800-826-0826

Web: www.ostomy.org

Find them on Facebook and Twitter.

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**Support Group Nurses:** 

Susan Mueller,

The Roadrunner

Postmaster: Contains Dated Material. Please do not delay.

> P.O. Box 35598 Albuquerque, NM 87176

### Ostomy Association of Albuquerque





## Helping each other to live well and do the things we love!

## How to Keep in Touch with Us

Contact us: For info please call voicemail 505-830-2135 or Email us at oa.albuquerque@gmail.com

<u>Unsubscribe or Change to Mailing Address or Email</u>: For any of these changes, please notify the sender by return Email. If your change concerns mailed copies, please call person in charge of mailing or send back cover page with your address and changes requested to return address. Thank You.

<u>Supplies:</u> If you have new and unused supplies you no longer need, please bring them to a support group meeting to be given to those who need them.

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