



A Message of Hope

By Joanne Heitzman

TOTAL PELVIC EXENTERATION*

October 2010

*I am a five year survivor of Leiomyosarcoma.
I wrote this brochure to help anyone who will undergo
this radical surgery to save their life.
I am blessed to have a loving and supportive husband
who has stood strongly beside me during my entire
journey. My two daughters and their families have
encouraged me and have given me renewed strength
and purpose to fight against LMS. I am a
grandmother of five and live in Towaco, New Jersey.*

A total pelvic exenteration has a long and scary sound. However, it is a life-altering surgery which can also be a life saving surgery and needs to be thoroughly investigated and confronted. I was forced to make this difficult decision and have never regretted it. A total pelvic exenteration is a surgical procedure in which the pelvic organs are removed (including the reproductive organs, bladder and/or rectum). I know I did the right thing to save my life and have continued on to make a life for myself and meet the many challenges along the way. I did not know anyone to speak with beforehand so kind of went with the flow. What I have decided to share with you are my own personal experiences and observations with what has worked for me along this journey. It is my hope to make your life just a little bit easier and provide you with the confidence and assurance that you can survive and do well with this type of surgery. There is always hope and certainly never give up!

When I was first diagnosed with Leiomyosarcoma, a very rare form of cancer, where only four in a million patients are affected and where there is a very poor survival rate, I had to really look into the deepest recesses of my heart and set my mind that I would do well with this surgery. By picturing myself doing well and thinking positively I helped myself along the way.

there is always hope

Some patients even find it helpful to keep a journal and enjoy looking back at the recorded successes along the way. It can be a difficult journey with many bumps along the way but somehow writing about them seems to lessen some of the anxiety.

I had 7 ½ weeks of pelvic radiation therapy before the major surgery. I purchased a personal peroneal spray bottle to cleanse the affected area and prevent urine from hitting the areas that may be burned. Larger size underpants with elastic waist to prevent chafing and rubbing also helped.

Understand that you will be tired and try to rest as much as possible and inform others that you are fatigued and need rest. Ask your physician specifically about side effects so you know what to expect, when and in the future.

My dermatologist recommended purchasing a large jar of Aquaphor, a great skin moisturizer, to help keep my skin well hydrated and prevent any breakdown and avoid bed sores. I rubbed it into my backside, hips and heels everyday for about three weeks before surgery. In fact the nurses remarked what great shape my skin was in since I did not have those horrible bedsores. I saved the times for lying on my back when my husband and family came to visit. The rest of the time I rotated side to side so no one area received pressure all the time. I supported my back with pillows to keep from rolling over.

and certainly never give up!

One of the first things I did was to take a class on “How to Prepare for Surgery” by Peggy Huddleston and learn relaxation techniques. I always thought I knew how to relax but it was rather like falling into bed so exhausted that you conked out, not necessarily relaxed at all. This was one of the best things I ever did and helped me learn how to actually relax my body and get rid of some of the stress. I must admit I was somewhat suspicious that it may all be “hokus pokus” but at least it gave me a measure of control that I was doing something rather than just anxiously awaiting surgery.

Preparing for surgery can be a very emotional time and you will need all the help you can receive. No one can completely understand the emotions unless they have had to endure this procedure. By practicing the relaxation techniques, you will feel calmer before surgery, have less pain and recover faster. Ask someone to say the healing statements for surgery from Peggy Huddleston’s book, such as a member of the OR team, family members or anyone you choose. I asked everyone to say them!

These relaxation techniques provided great relief and helped me through the toughest of times. It allowed me to use a lot less pain medication and when I was released from the hospital following a ten-hour hour surgery and three-week stay, an occasional Tylenol was all I needed for pain. Blood pressure readings and cholesterol levels dropped considerably so I no longer needed medications.

I began to imagine...

Make sure to ask your surgeon just what will be accomplished at the time of surgery, the approximate recovery time and what your limitations will be both in the hospital and when you return home. Find out how soon you can stand up after surgery and walk. Walking is the best way to alleviate the gas that builds up. You should know how much you can move around in bed and how much to lift your legs to chest to exercise. Be prepared to jot down some notes. Always ask your doctor about any unusual feelings, sometimes it is normal and patients worry unnecessarily. Get your Operative Report so that you will be able to understand the changes made to your body.

In preparing for surgery and gradually accepting the fact that my body would no longer eliminate body wastes the same way, I began to imagine how I would manage and picture myself handling this "new life". It is a good idea to make some room in a dresser, closet shelf, or purchase plastic drawers on wheels so you can store your new medical supplies so they will be easily accessible and convenient for daily use. The hospital will send you home with adequate supplies but then you are on your own to order your supplies and decide what works best for you.

Before leaving the hospital be sure to get a prescription for sterilized water to irrigate your bladder if you have a neobladder or urinary diversion. Mine was called an Indiana Pouch and was made from part of my colon.

... this "new life"

The irrigation prevents mucous build up and is a medical necessity but is only dispensed with a prescription. You will also need a 60cc syringe to perform the irrigation. Both need prescriptions from your doctor.

Be sure to get a list of foods to avoid that cause constipation and diarrhea and consult with the dietician as to what you will be able to eat.

Find out ahead of time before you leave the hospital just what foods you will be able to eat and digest once home so they will be readily available and start out with small servings. Avoid immediate visitors as you will be tired and need to rest.

Your family will also have to adapt to a new set of circumstances and it is important to have relaxed time to talk with the caretakers and go over your needs and concerns. After such major surgery some patients may even find it scary being home alone.

I learned that it is perfectly normal to feel the urge to eliminate stool and urine like you did before and even found myself walking into the bathroom to sit down! It is a weird feeling but normal and your body has a wonderful way of adapting. There will also be times that you literally feel like your “rear end is falling out”, especially when you are on your feet awhile. Getting off your feet really helps a lot.

Coming home from the hospital: The big day!



Once you are home and feeling better, explore the possibility of participating in an ongoing support group for you and family. Many hospitals have them now. Contact the Sarcoma Foundation of America to register the type of sarcoma surgery you had, treatments, etc. Debbie Winstead runs the Sarcoma Patient Registry 8:00 am - 5:00 pm EST1-866-501-6780

While in the hospital it is easy to get up out of bed with the assistance of aides and hand rails on the bed, but how to manage at home is another question. I began exercising my upper body to try and keep my arms strong. My husband and daughter rigged up a “draw sheet” (regular flat sheet folded in eighths, placed it across the bed under the buttocks area and tucked in on both sides. This way I could grab on the sheet and slowly pull myself up to sitting position by myself. Oh, to be independent again...a waterproof mattress cover is also a good idea at this time.

Not being able to sit awhile after surgery makes it difficult to read in bed, so perhaps listening to music or watching movies will help you. I also found that the little Reader’s Digest Magazine was just the right size to read in bed. It is important to nap in order to heal and a wedge pillow for under the tummy is a great asset, soft and cuddly which helps a lot. A large body pillow or king size pillow for from rolling over. Purchase a room deodorizer and hand sanitizers along with plenty of paper towels and baby wipes which come in handy.

Oh, to be independent again...

Once home I quickly changed from a frilly nightgown gal to being a real pajama girl for convenience sake which was so much more suited for my new appliances and easier to handle. A simple plastic or wooden clip clothespin was chosen to pin my clothes up and out of the way while taking care of business.

I needed to take medicine in the middle of the night with food, so we purchased small snack size cups of applesauce, jello and pudding that did not need refrigeration. I could gobble it down and go right back to sleep which helped a lot.

When I was finally able to sit at the kitchen table for meals, we purchased a donut or ring pillow that helped a lot with the pressure of sitting. Pillows were a lot of help as I had a small wedge pillow that I would place under me when I was on my side. Several of those squishy pillows that Bed, Bath & Beyond and Target sell were helpful for putting between me and my seat belt. This protected the new stomas should we have to stop the car suddenly or be rear ended in an accident. Those pillows were also helpful between your knees while lying on your side in bed.

During my recovery I constantly pictured myself being well and tried to surround myself with positive thinking people. Those who insisted on telling me how many they knew who died of cancer or had complications with their ostomies, etc. and were negative just did not get return calls.

During my recovery I

When I arrived home I ordered my MedicAlert Bracelet so that if I were ever unable to communicate or in an accident, emergency responders would realize that I have a neobladder that needs to be catheterized and a colostomy to be taken care of as well along with the list of medications I take and the names of my physicians to contact.

MedicAlert:1-800-432-5378
.....www.medicalert.org

Many varieties of bracelets and necklaces are available.

Consider subscribing to the Phoenix Magazine, which is the official magazine for the United Ostomy Association of America. It offers many beneficial tips and publishes true stories as well. You will soon realize that you are not alone on this journey and many others have succeeded and lived well with ostomies for many years.

In addition, I joined an ostomy support group at a local hospital (most hospitals have some type of support group) which has been very helpful as well. It was at a meeting that I met the most wonderful WOCN RN nurse who offered to become inverted and as I was not a candidate for a surgical revision so what to do? The RN knew all about making molds for custom appliances and this way the custom wafer would perfectly fit my retracted stoma and prevent leakage. Yes, there was an answer for my problem, I just had to be patient, keep on searching and never give up hope.

constantly pictured myself being well...

I did not know that there was a company that would customize a pouch specifically for the patient's needs, but there is one, Nu-Hope Labs in Pacoima, CA.

.....1-800-899-5017

I can certainly testify that I have not had any leakage problems since I began using the custom fit appliances.

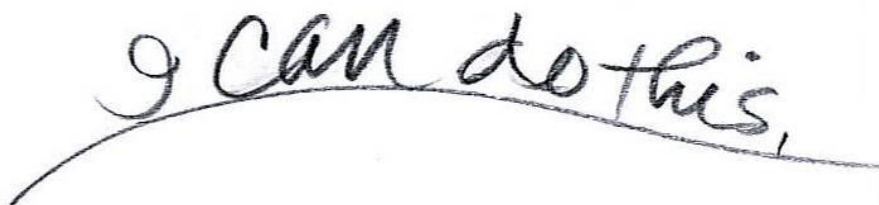
Do realize that there will be those times when you become frustrated, confused and anxious and it happens to all of us. Stop what you are doing, take a deep breath and say to yourself "I CAN do this, others have and I can too!" The power of positive thinking is extremely valuable. Try to remember that how you may think about the problem is more important than the problem itself, so always think positively.

If you are diagnosed with Leiomyosarcoma, ask your physician to arrange to have a tissue sample sent to the LMS Tissue Bank at Stanford University where they are doing ongoing research for LMS.

Eileen Mason is the secretary for Dr. Matt van de Rijn
Stanford Hospital, Department of Pathology L235
300 Pasteur Drive, Stanford, CA 94305-5324

.....1-650-498-6458

Your hospital should send the paraffin block, a copy of the pathology report and an H & E slide (diagnostic glass slide).



I CAN do this.

Join the National Leiomyosarcoma Foundation and complete their Patient Medical History Questionnaire to be used by researchers.

.....1-888-449-6805

.....www.nlmsf.org

On a personal note, there is one thing that I have learned during this whole process and that is the power of Hope. Hope is possible just about wherever you are on this journey of life and everyone has different hopes. Hope is not foolish or unrealistic but can be a cherished gift from your bout with cancer. It may help alter your own very unique path in life and no one can shatter that hope. By promising yourself to stay strong so that nothing can disturb your peace of mind and look at the bright side of life, you create a haven for happiness and realize nothing good comes out of being negative. Surround yourself with loving and supportive family and friends, think about the best, work for the best and most of all, never give up. Cancer is so limiting but it cannot cripple love, shatter your hopes or ever silence your courage and most of all conquer your spirit!

others have and I can too!

Useful telephone numbers:

American Cancer Society..... 1-800-ACS-2345
Bloch Cancer Foundation..... 1-800-433-0464
Director: Roseann Wickman.....blochcancer@gmail.com
LeioMyoSarcoma Foundation..... 1-888-449-6805

Apparel:

Options: Ostomy Support Barrier, Inc..... 1-800-736-6555
92 Hayden Street, Sayre PA 18840
Makes female/male built in support barrier underpants with
pockets.www.options-ostomy.com

Intimate Moments & Apparel 1-201-825-9486
Jeanne Russo

Yentel's Secrets - fabric covers for Ostomy pouch
..... www.yentlssecrets.com
Jean Polnerow & Jeanette Katt..... 1-800-749-3685

Major manufacturers of ostomy supplies:

Coloplast, Inc..... 1-888-726-7872
ConvaTec..... 1-800-422-8811
Cymed Ostomy Co..... 1-800-582-0707
EHOB (formerly VPI)..... 1-800-899-5553
Genairex, Inc. 1-727-539-1365
Hollister, Inc. 1-800-323-4060
Marlen Manufacturing & Development 1-216-292-7060
Nu-Hope Labs..... 1-800-899-5017
(the only one I know of that makes custom pouches)
OSTO EZ Vent 1-888-562-8802
Vents for pouches for gas releasewww.KemOnline.com
Sto-med Gard – makes shower guard to keep pouch dry
PO Box 722005 M, San Diego CA 92172

Deodorizers & Pills for Odor:

Just a Drop to go.....www.justadrop.ca
PreLam1-914-421-1234
Ostofresh1-888-427-6380
(samples provided)www.ostofresh.com
Put liquid deodorant in pouch to help control odor.
Triad Medical
125 W. Jackson Ave. Suite 203
PO Box 142
Knoxville TN 37901
Parthenon Co1-800-453-8898
Makes Devrom pills to take orally for odor as well as
Davko external pills for the pouch.

Waterproof Tape:

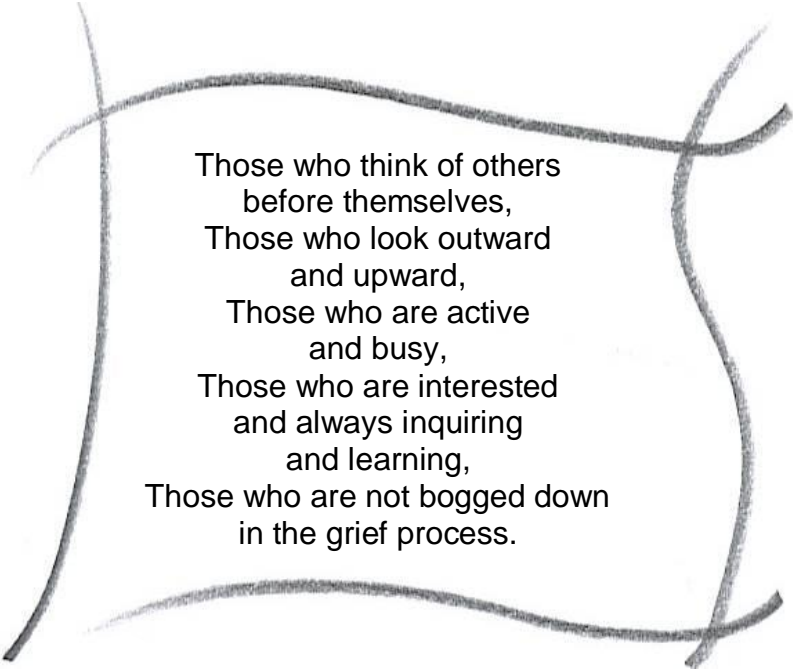
Nu-Hope Labs.....1-800-899-5017
Waterproof adhesive tape strips
Used to picture frame pouch to prevent water leaking while
bathing or swimming. Helpful to prevent colostomy leaking
into urostomy and during infection drainage.
HY-Tape International(Pink tape).....1-800-248-0101
PO Box 540
Patterson NY 12563-0540
Waterproof, latex free and non-allergenic adhesive tape
available in varying widths

Miscellaneous:

Austin Medical AMPatch stoma covers1-866-217-3857
.....chris@ampatch.com

From the Philadelphia Ostomy Association:

These are a few types of people who fare better after ostomy surgery:



Those who think of others
before themselves,
Those who look outward
and upward,
Those who are active
and busy,
Those who are interested
and always inquiring
and learning,
Those who are not bogged down
in the grief process.

Learn
through the ostomy association chapter

Lean
on each other

Laugh
through troubles with a positive outlook

Lead
others through your time, by volunteering

In my moment of despair and total frustration after trying every conceivable appliance I could find I wrote about my experience:

*I always knew problems could come about
but didn't realize I couldn't go out
To feel tied down and trapped in my own home
thank goodness for the telephone!
Kept on trying new things to hang on in there
something must work out, but when or where
Many times it was a frightful scare
and it felt no one seemed to care
Oh, I must cheer up and be strong
and learn which works right or wrong
Otherwise I will retract inside and fail
might just as well be in jail
So I continue to pray and pray along
till I learn what does belong
I pray for something that does fit
and keeps the leakage down a bit
Till I learn what is best for me
and will allow me to be
The same old person who can cope
and never give up hope.....
Others have been through this before.*

There is always hope...

*No matter what happens along the way,
I feel the need to choose life
You cannot give in to grief and despair
You may hit rock bottom
But you always have a choice
And to choose life means
A commitment not merely to survive
But to live and live with hope
There is always hope*



HOPE AND HOPELESSNESS

ARE BOTH CHOICES

WHY NOT

CHOOSE HOPE?

Joanne Heitzman
approved the final version of this booklet,
“A Message of Hope”
on Wednesday, October 27, 2010.
Joanne lost her battle to Leiomyosarcoma
on October 31, 2010.

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*The information above are the opinions and offered as suggestions of the author and not intended to be considered medical advice or in any manner directives. The author encourages all readers to verify the information and/or appropriateness of these suggestions with their own medical treatment professional.

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