



BMT EDUCATION BINDER

**TEXAS TRANSPLANT PHYSICIANS GROUP
BLOOD AND MARROW TRANSPLANT
PROGRAM**

AT

**METHODIST HOSPITAL
7700 Floyd Curl Drive
San Antonio, Texas 78229**

**BMT Out-Patient Clinic – 210-575-3817
(After hours – 210-593-2406)**

BMT In-Patient Unit – 210-575-4890

**Please bring this binder to each out-patient or
in patient visit with the Bone Marrow
Transplant Program**

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Introduction

The staff at the Texas Transplant Physician Group and Methodist Hospital would like to welcome you to the transplant program. We understand that people can often feel overwhelmed and scared when they are told they need a transplant. Often fears and concerns can be lessened when you are informed about the process you will be going through. We would like to give you this book to help you understand the transplant process.

This book is designed to provide you with information that will help you during the transplant process, and it is organized so that you can easily find the information that you are seeking. Please bring this book with you whenever you come to the hospital or the clinic. It can help you organize your medication list, your appointments, and gives you a place to list your questions for the transplant team. Remember that your transplant team is always here to answer your questions and help guide you through the transplant process.

Welcome to the Stem Cell Transplant Clinic at Methodist Hospital. We know that this time in your life is most likely very stressful. We have compiled a list of clinic procedures and other suggestions that have helped past patients feel less stressed and more in control. We hope that by following these suggestions you will have a successful transplant experience.

1. Please be prepared to have a caregiver present **24 hours a day** for at least 2 weeks (possibly longer) following your transplant. Patients can become very ill, very quickly and having a caregiver present ensures your safety.
2. Please make sure your caregiver brings all your medications to the hospital **prior** to your discharge. This ensures that you will have what you need and that you know how to take your medications.
3. Please do not alter the dose of **ANY** of your medications without first discussing this with clinic staff. This can be very dangerous.
4. When you are discharged from the hospital, there will be a period of time that you will be seen daily in the clinic. Our expectation is that you arrive for your clinic appointments on time.
5. You may need to spend several hours in the clinic a day after your transplant. During this time you will receive treatments such as IV fluids or undergo further tests.
6. We do realize that there are unexpected circumstances that may delay your arrival and we ask that you call ahead as soon as you know you will be late and let the clinic know about the delay.
7. If you are late you will be moved to later in the schedule and will see the doctor after other scheduled appointments are completed. It is very important that you be on time so you don't delay the patients coming after you and your time with the doctor is protected.
8. If you need to cancel an appointment, we ask for minimum 24 hour notice unless the event is due to an emergency. Your cooperation with the schedule will be appreciated by the doctors, nurses, and your fellow patients.
9. Please do not hesitate to call or come to the clinic if you have questions. **There are no stupid questions in bone marrow transplant!**

Remember, you and your family are not alone during this stressful time. Stem cell transplant is a team sport and the staff and doctors are here to support you with your needs.

FINANCIAL INFORMATION YOU NEED TO KNOW ABOUT YOUR CLINIC VISIT AT METHODIST HOSPITAL

- You are scheduled to receive services at a clinic at Methodist Hospital.

Please refer to your insurance benefits manual for an understanding of your out-of-pocket expenses related to hospital outpatient services. These clinics are hospital outpatient clinics.

- The physician examining you is an independent contractor and not part of Methodist Hospital. The physician will submit a separate bill to your insurance company.

Your insurance company will receive two bills – one from the hospital and one from the doctor.

- During your clinic visit, the doctor might order lab work and/or x-rays. If so, the physicians who interpret the results, called pathologists and radiologists, will also bill for their services.

Their claims will be separate from the hospital and transplant physician's bills.

- You are responsible for any applicable hospital or doctor co-pays according to your insurance plan. The hospital and the physician co-pay will be billed to you after your visit.

We understand that insurance claims can be difficult to understand. We provide this information in hopes of making the process easier to understand. Please contact your insurance company if you have any questions regarding your coverage and benefits.

Thank you for choosing the Methodist transplant team. We look forward to seeing you in our clinic soon.

**Methodist Hospital Billing Questions can be directed to:
(210) 575-4076**

**Texas Transplant Physician Group Questions and payments can be directed to:
(210) 575-6755**

Payments to Texas Transplant Physician Group can also be made at the hospital clinic via phone.

QUICK REFERENCE

If any of the following symptoms occur, please call 210-575-3817 (normal business hours) or 210-593-2406 (after hours):

- Any time you think something is not right
- If you are unable to take your medication
- Fever of 100.4 or above
- Several days of fever between 99-101.5 (when not being seen daily in the clinic)
- Vomiting , loose bowel movements longer than one day, or constipation lasting longer than 2 days
- Shortness of breath or any difficulty breathing
- Cough lasting longer than 1 day
- Mouth sores, sore throat, or trouble swallowing that stop you from taking medicines or drinking fluids
- Pain when urinating or having a bowel movement or blood in urine or stool
- You or a family member are exposed to chicken pox, measles, tuberculosis, herpes, or any other serious infection
- Change in mental status (confusion or trouble thinking clearly)
- Any signs or symptoms of infection such as
 1. Fever over 101.5
 2. Shaking, chills
 3. Tenderness or redness at central venous catheter site
 4. Excessive fatigue or tiredness
 5. Blisters on lips, mouth sores, sore throat
 6. Burning or painful urination
 7. Skin sores
 8. Rash
 9. Itching
 10. Coughing up phlegm
 11. Sinus Pain
 12. Ear ache
- If you need assistance with any forms, (i.e. FMLA, disability, etc) please allow 5 business days for your coordinator to complete.

Helpful Numbers

Transplant Clinic	210-575-3817
Transplant Inpatient Unit	210-575-4890
Transplant Physicians	210-575-3817
Nurse Manager	210-575-4896
BMT Coordinators	210-575-3817
Appointment Scheduling	210-575-3817
Financial Advisor	210-575-7363
Social Worker	210-575-6670 / 210-575-5160

Please remember that you are responsible to be at all your appointments in a timely manner. Late arrival may result in a longer wait before you will be seen. If you are unexpectedly delayed, please call the clinic immediately.

HELPFUL HINTS FROM ONE PATIENT TO ANOTHER.....

ORGANIZATION

Use your Binder!!

1. In the binder, keep a sheet of drugs to check off after taking them, because chemo brain makes it is easy to forget.
2. It can also be used for lab sheets which help keep track of blood/platelet levels.
3. Ask for doctors and nurses business cards so you know who you talked to.
4. Keep track of gas mileage sheets with signatures for Leukemia Lymphoma Society or other grants
5. Save receipts: food, co-pays, lodging, RX, gas, insurance premiums, etc.

MINDSET

Thinking of the long hospital stay as something other than that got me through my twenty days. My mindset was that the room was a rehab center suite to recover stress and I had people waiting on me, bringing my food, etc.

Booklet Dodie Osteen's *Healed of Cancer* from Lakewood Church, Houston TX
http://joelosteen.lakewood.cc/site/PageServer?pagename=JOM_homepage Or Amazon.com.

ROUTINE

1. Eating at the same time every day.
2. Getting up and taking a shower every day at the same time
3. Trying to sleep at the same time every night
4. Changing from day clothing to pajamas

EXERCISE

You can lose up to 4% of your strength just by lying in bed per day.

1. Making the bed was an aerobic exercise
2. Getting my own towels in the morning
3. Walking around the BMT unit
4. The general exercise sheet received in the BMT binder

FOOD

Foods that worked for me when I had throat and mouth sores

1. Hospital food- cold ham sandwich
2. Fluffy scrambled eggs with lots of cheese
3. Hard boiled eggs
4. McDonald's plain fish fillets for lunch – other meats were stringy and this went straight down
5. Ice cream – this numbed my tongue but I did taste the ice cream
6. Frozen pancakes with only butter on them
7. Only bottled water
8. Macaroni and lots of extra cheese
9. Chocolate boost (drinking with a straw made it go down faster and with less taste).
10. Banana bread (Whole foods has this if you don't want to make it homemade)
11. Watermelon was the best – like a sponge that cleared everything off after I finished eating. This helped me to get all the pills I would need to take down.

GVHD SKIN RASH

1. Use the creams your transplant MD has prescribed – they really help!
2. Baby powder for armpits instead of deodorant
3. Stay out of the sun – it worsens the rash.

SUPPORT

Friends/Family/Co-Workers/Significant Other

Just talking on the phone or emailing was a big help

CLEANLINESS

Keeping my room clean felt better

Caregivers used gloves and the disinfectant cleaner and wiped down my door, handles, phone, tv/nurse call remote, IV pump handle, light fixtures, drug scanner, and computer daily.

KEEPING BUSY

Positive Attitude is Everything

Hang man games	Magazines	TV	Radio
Books	Sudoku	Cross Stitch	CD/Tape
Word Find	Knitting	Crocheting	DVD/Computer

10 Tips for Family Caregivers

- Choose to **take charge** of your life, and don't let your loved one's illness or disability always take center stage.
- Remember to **be good to yourself**. Love, honor and value yourself. You're doing a very hard job and you deserve some quality time, just for you.
- **Watch out** for signs of depression and don't delay getting professional help when you need it.
- When people offer to help, **accept the offer** and suggest specific things that they can do.
- **Educate yourself** about your loved one's condition. Information is empowering.
- There's a difference between caring and doing. **Be open to technologies and ideas** that promote your loved one's independence.
- **Trust your instincts**. Most of the time they'll lead you in the right direction.
- **Grieve for your losses**, and then allow yourself to dream new dreams.
- **Stand up for your rights** as a caregiver and a citizen.
- **Seek support** from other caregivers. There is great strength in knowing you are not alone.

Reprinted from their website with permission of the National Family Caregivers Association, Kensington, MD, the nation's only organization for all family caregivers. 1 800-896-3650: www.nfcares.org

Pre-Transplant

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Pre-Transplant

Collecting Bone Marrow Stem Cells

Bone Marrow Stem cells are the “mother” cells that make all the blood cells. With enough stem cells, the bone marrow can be re-made. When patients receive high dose chemotherapy and/or radiation, the bone marrow is affected so much that it will not grow back unless it is “rescued” by new stem cells. Sometimes a patient may have a diagnosis that does not affect his/her marrow. In that case, stem cells can be collected from the patient for later use after high dose chemotherapy. This is called an autologous stem cell collection. When a patient has diagnosis that affects his/her bone marrow, the stem cell collection will come from another person. This person would be a donor of allogeneic stem cells. There are different ways to collect stem cells.

- **Growth Factor Mobilization**

Stem cell production is stimulated using growth factors. Growth factors are given by injection every day for 4-5 days. Sibling donors can be collected or “mobilized” this way.

- **Chemotherapy Mobilization**

Sometimes chemotherapy, such as cytoxan, is used. The patient will be given one dose of cytoxan followed by approximately 9 days of growth factor. The use of chemotherapy may help reduce disease as well as assist in the stem collection for heavily treated patients.

- **Use of other Medications**

A combination of different chemotherapy drugs can be used –such as an “ICE” regimen that the patient’s primary oncologist gives as a part of the patient’s regular therapy – along with growth factors can lead to stem cell collection. Usually, the patient will be given more than 9 days of growth factor before stem cells can be collected.

A new drug called AMD may soon be available. It is given, along with growth factors, as an injection in the evening before collection is planned.

The growth factor or chemotherapy mobilization process will then continue as follows:

The stem cell count in the blood will be checked with a blood test. When the stem cell count is high enough, the process to collect the stem cells will begin. This process is called apheresis. Apheresis is a procedure where the patient’s blood is separated through a machine that is similar to a dialysis machine. The stem cells are collected and the rest of the blood is returned to the patient. An apheresis collection takes about 4-5 hours. Most patients need about 2 to 3 daily collections to get enough stem cells. This is an outpatient procedure.

A central venous catheter (CVC), which is an intravenous tube placed into a large vein, is needed to allow the collection of stem cells. Most patients will have the CVC placed at the hospital a few days before apheresis is to start. The CVC is placed surgically (usually in an outpatient setting). You will be given medication through your vein to make sure you are comfortable.

The side effects of apheresis include numbness and tingling around the mouth or fingertips, a metallic taste in the mouth, and feeling cold. These side effects are temporary. You may also have a temporary decrease in the blood clotting cells called platelets. Blood counts are checked every day during apheresis.

You will be more comfortable if you wear loose comfortable clothing during apheresis. You may bring reading material, crafts, or other items to pass the time while you are receiving apheresis. There is a TV in the apheresis room. You may have visitors with you during apheresis.

Bone Marrow Harvesting

Another way to collect stem cells is bone marrow harvesting. This a procedure performed in the day surgery area of the hospital by your Bone Marrow transplant physician. This procedure is performed under general anesthesia and lasts about 45 minutes. Stem cells are usually removed from the back of the hips by inserting needles into the bone marrow cavity. After the procedure the patient is observed for several hours and may then go home. Some patients may experience soreness in the hips for up to one to two weeks, but you can resume activity/work the next day.

Your transplant doctor will decide which mobilization process would be best for you.

Radiation Therapy

As a part of your treatment you may receive radiation therapy, which is the use of high energy x-rays directed at your cancer cells. Radiation therapy is used to kill cancer cells and prepare your body to receive the transplant. You will receive radiation treatments one or two times a day for one to four days as prescribed by your doctor.

Before beginning the radiation treatment a radiation oncologist will review your medical records and perform a physical examination. The radiation therapy team will schedule a planning session or simulation where x-rays and measurements will be taken and your treatment will be fully explained. Special ink will be used to mark your skin to outline the treatment areas. Don't wash over or draw over these lines. At this time you may also be measured for special shields to protect certain areas of the body if needed. The planning visit can take up to 2 hours. Each treatment visit will last 60-90 minutes. The length of time you will actually be receiving treatment is 20-30 minutes on each side of the body. The additional time is needed to prepare you for treatment. You will change into a hospital gown. The radiation therapist will put you on a table and dim the lights. Laser lights in the room are used to line up your markings exactly the same before every treatment. You will need to remain still during your treatment but you do not have to hold your breath. The radiation therapist will leave the room during the treatment but will be able to see and hear you at all times. The radiation treatment will not cause your body to become radioactive. You may kiss and hug loved ones and be in contact with people.

Side effects of radiation include dry mouth, diarrhea, fatigue, nausea, loss of appetite, and red, tanned or tender skin. You may experience all, some or none of the side effects. You may require extra rest during radiation therapy due to fatigue. Ask for help when you need it. To

help minimize any discomfort you will be given an anti-nausea medication prior to each treatment. Please let your nurse or doctor know if you feel nauseated.

It is important to drink plenty of fluids each day. Drink 6-8 glasses of fluids daily. If you develop diarrhea, try a clear liquid diet (broth, jello, tea) and frequent small meals. Avoid milk and milk products if they upset your stomach. Limit your intake of foods that may cause gas or are high in fiber, such as beans, broccoli, cabbage, and bran cereals. Notify your nurse or doctor if you have diarrhea lasting longer than one day.

The Hospital Stay

Not all people receive treatment in the hospital. Your doctor will let you know if you can expect to be in the hospital during your treatment.

We encourage you to bring familiar items from home because we believe maintaining your normal routine is important. You may bring posters, photographs, or pictures to brighten your room. Please do not place nails or tacks in the walls- tape is available.

You may bring a washable blanket and pillows. No feather pillows are allowed. Please wash these items in hot water before bringing them into the hospital. Other items you may wish to bring include:

- Radio/tape player
- Video tapes or games. There is a TV in each room.
- Handwork (avoid projects that require sharp needles)
- Art projects
- New coloring books and crayons, puzzles, models
- Clean books and magazines, cards and games, stationary

Hospital gowns are provided but you may feel more comfortable in your own clothes or nightwear. Avoid bringing irreplaceable clothing as it may become soiled. You must have someone to wash your clothes while you are in the hospital. Clothing that opens in the front and can be lifted in the back is best. Other items you may wish to bring include:

- Bathrobe, sweat suits, cotton underwear, socks, washable slippers, scarves, turbans, and caps
- Lotions, creams, and makeup should be new and unopened. Used products may contain germs. Try to select products that do not have heavy perfumes, dyes, or lanolin as you may be more sensitive after treatment
- Glasses (you will not be allowed to wear contacts, so bring your glasses)
- Food from home that is well cooked and stored at proper temperatures

Limited items:

- No fresh or dried flowers or plants are allowed because they carry germs
- Finger nail file, nail clippers, or scissors are not allowed
- No razors (you may not shave using a razor, but electric shavers are allowed)
- No Tampons

Mail

Mail can be sent to:

Patient Name
Methodist Hospital
Bone Marrow Transplant Unit
Room ____
7700 Floyd Curl
San Antonio, TX 78229

Visitors

Visiting is encouraged. Visiting hours are not limited. One adult may sleep in your room. All visitors must be screened to make sure they are not sick before visiting a patient. Sick people will not be allowed to visit unless there are special circumstances. All visitors must WASH HANDS before entering the room. Children 12 and under are not allowed on the Bone Marrow Unit unless by special permission of the transplant physician.

Daily Hospital Routine

Each morning between 4:00 and 6:00 a.m. the nurses will take blood samples and measure your weight. This is done early so the test results are available when the doctor comes to see the patient in the morning.

Several times each day the nurse will listen to your heart and lungs, check your abdomen, and look into your mouth. This is done to check for side effects of the treatment. You will see the doctor every day between 8:00 a.m. – 11:00 a.m. This is the time the doctor is available to answer your questions. If your family has questions, this is the time they may talk to your doctor. A nurse practitioner may also see you in the morning. Other information about the hospital stay include:

- You will need to shower each day to decrease the risk of infection
- A collection bowl will be placed in the toilet to collect all urine and bowel movements. The nurse will also measure vomit. Please do not flush any of the above until it has been measured by the nurse
- Mouth care must be done at least 5 times a day to decrease infections (you may use a soft toothbrush, but do not floss)
- Do not take any medications not given to you by the nurses
- You will not be able to participate in any sexual activity, other than closed mouth kissing, hugging, and gentle masturbation. Do not put any objects, including fingers in the rectum or vagina.

What Will Happen During Chemotherapy?

- Fluids will be given through your vein to protect your body from some of the effects of chemotherapy. Fluids may make you urinate more often.
- You will receive anti-nausea medication. This medication may make you feel sleepy but works very well to prevent nausea and vomiting.
- There will be pumps in your room to deliver the chemotherapy and other medications
- Anyone who handles your body fluids, such as urine, will need to wear gloves. Visitors should not use the bathroom in your room.
- Chemotherapy affects the white blood cells that fight infection, the red blood cells that carry oxygen, and the platelets that help blood clot. When you have low blood counts, you will be asked to follow special precautions.

Hair Loss

Hair loss (alopecia) is a common side effect of chemotherapy, but not all drugs cause hair loss. Your doctor can tell you if hair loss might occur with the drug or drugs you are taking. When hair loss does occur, the hair may become thinner or fall out entirely. Hair loss can occur on all parts of the body, including the head, face, arms and legs, underarms and pubic area. The hair begins to grow back after the treatment is over. Sometimes, hair may grow back a different color or texture.

Hair loss does not always happen right away. It may begin several weeks after the first treatment. Many people say their head became sensitive before losing hair. Hair may fall out gradually or in clumps. Any hair that is still growing may become dull and dry.

How can I care for my scalp and hair during chemotherapy?

- Use a mild shampoo.
- Use a soft hair brush.
- Use low heat when drying your hair.
- Have your hair cut short. A shorter style will make your hair look thicker and fuller. It also will make hair loss easier to manage if it occurs.
- Use sun screen, sun block, hat or scarf to protect your scalp from the sun if you lose hair on your head.
- Avoid brush rollers to set your hair.
- Avoid dyeing, perming or relaxing your hair.

Some people who lose all or most of their hair, choose to wear turbans, scarves, caps, wigs or hair pieces. Others leave their head uncovered. Still others switch back and forth, depending on whether they are in public or at home with friends and family members. There are no “right” or “wrong” choices; do whatever feels comfortable for you.

If you choose to cover your head:

- Get your wig or hairpiece before you lose a lot of hair. That way, you can match your current hair style and color. You may be able to buy a wig or hairpiece at a specialty shop just for cancer patients. Someone may even come to your home to help you. You also can buy a wig or hair piece through a catalog or by phone.
- You may also consider borrowing a wig or hairpiece, rather than buying one. Check with the nurse or social work department at your hospital about resources for free wigs in your community.
- Take your wig to your hairdresser or the shop where it was purchased for styling and cutting to frame your face.
- Some health insurance policies cover the cost of a hairpiece needed because of cancer treatment. It is also a tax-deductible expense. Be sure to check your policy and ask your doctor for a “prescription”.

Losing hair from your head, face or body can be hard to accept. Feeling angry or depressed is common and perfectly all right. At the same time, keep in mind that it is a temporary side effect. Talking about your feelings can help. If possible, share your thoughts with someone who has had a similar experience.

Prevention of bleeding

Chemotherapy can make the cells in your blood, which prevent bleeding, decrease. These cells are called platelets. You will need to follow special rules to decrease the risk of bleeding.

- Use a soft toothbrush
- Ask for help to walk if you are dizzy or weak to prevent falls
- Do not use suppositories, enemas or tampons
- Avoid sexual activity, other than closed mouth kissing, hugging, or gentle masturbation. Do not put objects or fingers in the vagina or rectum

Tell the doctor or nurse if you have any of these symptoms:

- Unexpected bruising
- Small, red spots under the skin
- Reddish or pinkish urine
- Black or bloody bowel movements
- Bleeding from your gums or nose
- Vaginal bleeding
- Headaches or changes in vision

Staying Well

- Avoid anyone who is sick
- Wash your hands often during the day and always before and after eating, as well as before and after going to the bathroom
- Ask all your visitors, nurses and doctors if they have washed their hands
- Clean your mouth at least 5 times a day
- Take your temperature at least twice a day and any time you feel warm or cold or are having chills
- Shower daily
- Drink fluids throughout the day
- Eat nutritious foods
- Walk often
- Sit up in the chair as much as possible
- Exercise
- Wear a mask outside of your home, the clinic, or the transplant unit

What to Expect During the Transplant

The transplant takes less than one hour and is done in your hospital room or as an outpatient in the clinic. Staff members from the stem cell laboratory will bring the cells to your room. If frozen, the cells will be thawed. The stem cells will come in a bag and dripped in or will be injected slowly through the central venous catheter. Medications are available if needed to help with any side effects.

Some stem cells are frozen and preserved in a chemical called DMSO. You will receive medication before the transplant to prevent any reaction to the preservative used for storage. The DMSO has a distinct odor and taste. Some patients compare it to oysters or garlic. Hard candy, such as peppermints or butterscotch, can help cover the taste. The odor of the DMSO may last a few days as it is released from your body. You may experience the following symptoms during a transplant:

- Chills
- Cough
- Shortness of breath
- Abdominal cramps
- Nausea and vomiting
- Pink or red urine
- Flushing/Redness to face

Not all patients experience these symptoms, but if you do, know that they do go away shortly upon completion of the stem cell infusion.

CLINICAL RESEARCH TRIAL PARTICIPATION

The Texas Transplant Physician's Group (TTPG) actively participates in clinical research trails (studies) and functions as a research center.

Clinical research studies are an important choice for doctors and patients. Research studies are conducted by doctors to improve diagnosis, treatment, prevention, increase survival, and improve quality of life.

All clinical research studies undergo an ethical approval process by the Methodist Healthcare System Institutional Review Board.

The Doctors of TIMS feel that providing research opportunities to all patients provides cutting edge treatment and the potential to improve overall outcome.

All patients are screened continually for potential opportunities to take part in a research study. If you are identified as a potential candidate for a research study, your doctor will speak to you about taking part in a specific research study. Your doctor will discuss the details of the study with you.

If you volunteer to take part in a research study, you will be asked to sign a study informed consent. The signed informed consent document allows your doctor to obtain data by intervention or interaction with you, or allows the doctor to obtain identifiable private information for study purposes.

Taking part in a research study allows you to actively participate in your health care. You always have the right to stop taking part in the research at any time for any reason.

Transplant

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Transplant

Bone Marrow Support

The Bone Marrow Transplant process can involve not only physical discomfort, but psychological and emotional discomfort as well. We often hear patients and families state that the emotional and psychological stress can be more difficult to handle than the physical discomfort. Feelings of isolation, being dependent on a caregiver, dealing with setbacks in treatment, feelings of helplessness and loss of control, and waiting for the marrow to engraft can all be very taxing for patients and families. We here at Texas Transplant Institute and Methodist Hospital are dedicated to serving the needs of the whole person and the whole family. Please feel free to ask for any of these services and a visit from us at any time during the transplant process. Below are some services that are available to BMT patients and families:

- Counseling Services and Caregiver Support Time
- Book Library
- Books on Tape
- Motivational/Relaxation Tapes
- Games/Puzzles/ and more...

Please stop by or call the BMT Social Worker @ 575-6670

BMT Caregiver Support Group

For: BMT Caregivers

When: Tuesdays
2:00 – 3:00 pm

Where: 10-Central Oncology Clinic Waiting Room

Contact: The BMT Social Worker @ 575-6670

Oncology Support Groups at Methodist Hospital

Family Support Group

For: Anyone whose life has been touched by their loved one's cancer

When: Thursdays from 2:00- 3:00 pm

Where: 8 South Family Waiting Room

Contact: Oncology Support @ 575-4558

Prayer/Healing Service

For: Everyone is welcome

When: Tuesdays from 6:00- 7:00 pm

Where: 8 South Family Waiting Room

Contact: Oncology Chaplain @ 575-6788

LOCAL SUPPORT GROUPS

Disclaimer: This information has been compiled by a social worker of the Methodist Health Care System from various unsolicited sources. Methodist does not endorse or recommend any of the groups listed. Determination of the professional ability of the agencies named, as well as the services provided, is the responsibility of those seeking services.

Name	Date	Time	Location	Contact
iConnect Support Group Young Adult Cancer Survivors (21-40 yrs)	4th Thursday	6:30-8 PM	La Madeline 722 NW Loop 410	210-377-1775 or 210-575-6950
National Ovarian Cancer Coalition	2nd Wednesday	6:30 PM	La Madeline 722 NW Loop 410	Diedre Steele 210-497-5259
Alamo Ovarian Cancer Alliance	1st Wednesday	12:30-1:30 PM	Varies	Linda Tarver 210-824-3496
L.I.F.E. After Breast Cancer (Cancer Therapy and Research)	8 week educational group 4 times a year (January, April, July, October)	Varies	1st floor of the Grossman Building Library (CTRC)	210-450-5574
Breast Friends Forever (Cancer Therapy and Research)	1st and 3rd Tuesday	10:30-11:30 AM	5th floor of breast clinic (CTRC)	210-450-5570
S.O.S. Survivors Offering Support for patients and families	1st Tuesday	7:00 PM	Northeast Methodist Board Room	210-575-0355
Alamo Breast Cancer Foundation-Keep Abreast	1st Monday	Varies	Varies	210-989-9410
American Cancer Society-Coping with Breast Cancer for USAA employees	Last Thursday	11:30-12:30 PM	USAA	USAA Brigett Jourdan 210-498-1385
American Cancer Society-Look Good, Feel Better	Varies	Varies	By Appointment	By appt. 210-614-4211
American Cancer Society-Reach to Recovery for Breast Cancer Survivors	Varies	Varies	Varies	210-614-4211

Ovarian Cancer Support Group	Varies	Varies	Brooke Army Medical Center	210-916-4457
Woman to Woman Warriors-Breast cancer/lymphedema support group	3rd Thursday	5:30 PM	Woman Health Boutique	Jessie Phillips 210-615-6606
The Centex Carcinoid Fighters Group	Bi-monthly; alternate between Austin and San Antonio	Varies	Varies	Jude Filler 512-472-7224
SACCS San Antonio Carcinoid Cancer Support Group	4th Saturday of Odd months	Varies	Friends Meetinghouse	Catherine Jett 201-341-3219
Us Too Prostate Cancer Support Group	1st Monday	5:30-6:30 PM	Ecumenical Center for Religion and Health	210-344-5201
Ostomy Association of South Texas	Last Monday	7:30-8:30 PM	American Cancer Society	210-614-4211
The Leukemia and Lymphoma Society Myeloma Support Group	2nd Wednesday	6-7:30 PM	Warm Springs Rehabilitation Hospital	210-377-1775
San Antonio Blood Cancer Support Group (MDS,Leukemia, Myeloma, Lymphoma)	3 rd Wednesday Monthly Dinner Served	6:30-8 PM	John Hornbeak Bldg 4450 Medical Drive 78229 COLORADO Rm	210-377-1775 x111
San Antonio Lost Chord Club	3rd Sunday	2:00 PM	American Cancer Society	210-614-4211
American Cancer Society	1st Tuesday	6:30-7:30 PM	Northeast Baptist Hospital	210-297-7005
American Cancer Society-I Can Cope	Varies	Varies	Baptist Cancer Center	Stacy Kemp 210-595-0258; ACS-210-614-4211
American Cancer Society- Society Dialogue Program	2nd and 4th Monday	4:30-5:30 PM	Multiple Locations	210-614-4212

"Your Grey Does Matter" San Antonio Brain Tumor Support Group	2 nd Tuesday	10am-11:30am	CTRC 7979 Wurzbach Grossman Bldg Library	Teresa Zdansky 210-386-5608
Caregiver Support Group for caregivers of cancer patients	Thursdays	2-3 PM	Methodist Hospital 8th floor-South Meditation Room	Nikki Yuill LCSW 210-575-4558 or Jenna Carrera 210-575-6950
Prayer/Healing Support Group for cancer patients and loved ones	Tuesdays	6-7:00 PM	Methodist Hospital 8th floor-South Meditation Room	Rick Ricker 210-575-6788
The Harbor GYN cancer Support Group	2nd Tuesday	7-8 PM	Northwest Church of Christ Counseling Center	Phyllis Goodson 210-688-9434
Harvest Fellowship Cancer Support Group	3rd Monday	9-11 AM	Harvest Fellowship Community Church	951-687-6902
Patient and Family Support Group-Bilingual	1st and last Thursday	11-12:30 PM	University Health Center-Downtown, 527 N. Leona, 1st Floor	Carmen Budreau 210-358-3620
Cancer Support Group (patients and families)	1st and 3rd Tuesday	3-4 PM	Northeast Baptist Hospital, 8811 Village Dr., Executive Dining Room	Pastoral Care 210-297-2750 (call first)
Cancer Care Centers General Cancer Support Group	Tuesdays	1130-1230pm	4411 Medical Drive Ste. 100	210-595-5300
Take Time Out to Live (Patients and Families)	Wednesdays	6:30 PM	Audie L. Murphy VA Hospital Floor 5B, Room B-502	Pauline Amstead 210-617-5300 ext. 14338
Healing Support Group (Families)	Wednesdays	11-12 PM	Audie L. Murphy VA Hospital 7th Floor, Room E715	Susan Krantz 210-617-5300 ext. 65116

Breast Cancer Support-Hospice New Braunfels	Call for information	Call for information	613 N. Walnut New Braunfels, TX 78130	Jane Wyatt or Elaine Craig 830-625-0369
Texas Prostate Brachytherapy Services Prostate Seed Implant Discussion Group	Call for information	Call for information	Call for information	Phyllis Kincaid 210-949-7526
Boerne General Cancer Support Group- Non Denominational	2 nd and 4 th Monday's	7-830 pm	St.Marks Presb. Church-Narthex	Joan Godsey Larry Warren
Sarcoma Support Group	2 nd Tuesday monthly	7-8pm	CTRC 7979 Wurzbach Grossman Bldg Library	210-450-5570
Caregiver Support- Leeza's Place	Varies	Varies	WellMed 14100 Nacogdoches Rd.	Rita Avendano 210-599-4614
<u>WELLNESS CENTERS</u>	Complimentary Therapies such as: Tai Chi, Massage, Counseling,	and Support Groups.		
Pink MD Wellness Center www.pinkmd.com	Call for Info	Mon-Fri 8:30am-5:30p	19016 Stone Oak Pkwy. 78258	210-674-6563
SLEW Wellness Center (Support Lending for Emotional Wellbeing) Slewellness.org	Call for Info Free support for disadvantaged women	Call for Info	12521 Nacogdoches Rd 78217	210-654-7900
CTRC Wellness Center www.ctrc.net	Call for Info		7979 Wurzbach Ste. G111 78229	210-450-5570
Inspiritas at the START Center Thestartcenter.com	Call for Info		4383 Medical Dr. 1 st floor 78229	210-593-2639

Relaxation Exercises

How to Reduce Stress, Anxiety and Pain

What are some of the ways I can relieve stress?

For some people, anxiety and pain can be relieved without using medicine. Often, people can relieve their pain and anxiety with the use of relaxation, imagery and distraction. You may need the help of health professionals to learn to do these for yourself. Friends or family members can help with some of them. The techniques are also useful along with medicines.

How does relaxation work?

Relaxation relieves pain/stress or keeps it from getting worse by reducing tension in the muscles. It can help you fall asleep, give you more energy, make you less tired, reduce your anxiety and make other pain/stress relief methods work better. Some people, for instance, find that taking a pain medicine or using a cold or hot pack works faster and better when they relax at the same time.

Are there any basic guidelines for using relaxation techniques?

- Understand that your ability to relax may vary from time to time and that relaxation cannot be forced.
- Remember that it may take up to 2 weeks of practice to feel the first results of relaxation.
- Try several relaxation methods until you find one that works for you.
- Stick with the same method so that it becomes easy and routine for you. Use it regularly for at least 5 to 10 minutes twice a day.
- Check for tension throughout the day by noticing tightness in each part of the body from head to foot. Relax any tense muscles. You may use a quick technique such as inhale/tense, exhale/relax, described below.
- If you have any lung problems, check with your doctor before using a relaxation technique that requires deep breathing.

Is there any special position I should be in when I am doing relaxation exercises?

Relaxation may be done sitting up or lying down. Choose a quiet place whenever possible. Close your eyes. Do not cross your arms or legs because that may cut off circulation and cause numbness or tingling. If you are lying down, be sure you are comfortable. Put a small pillow under your neck and under your knees or use a low stool to support your lower legs.

How do I do relaxation?

There are many methods. Here are some for you to try.

- **Visual concentration and rhythmic massage:**

Open your eyes and stare at an object, or close your eyes and think of a peaceful, calm scene. With the palm of your hand, massage near the area of pain in a circular, firm manner. Avoid red, raw, swollen, or tender areas. You may wish to ask a family member or friend to do this for you.

- **Inhale/tense, exhale/relax:**

Breathe in (inhale) deeply. At the same time, tense your muscles. For example, you can squeeze your eyes shut, frown, clench your teeth, make a fist, stiffen your arms and legs, or draw up your arms and legs as tightly as you can. Hold your breath and keep your muscles tense for a second or two. Let go! Breathe out (exhale) and let your body go limp.

- **Slow, rhythmic breathing:**

1. Stare at an object or close your eyes and concentrate on your breathing or on a peaceful scene.
2. Take a slow, deep breath and as you breathe in, tense your muscles (such as your arms).
3. As you breathe out, relax your muscles and feel the tension draining.
4. Now remain relaxed and begin breathing slowly and comfortably, concentrating on your breathing, taking about 9 to 12 breaths a minute. Do not breathe too deeply.
5. To maintain a slow, even rhythm as you breathe out, you can say silently to yourself, "In, one, two out, one two". It may be helpful at first if someone counts out loud for you. If you ever feel out of breath, take a deep breath and then continue the slow breathing exercise. Each time you breathe out, feel yourself relaxing and going limp. If some muscles are not relaxed, such as your shoulders, tense them as you breathe in and relax them as you breathe out. You need to do this only once or twice for each specific group.
6. Continue slow, rhythmic breathing for a few seconds up to 10 minutes, depending on your need.
7. To end your slow rhythmic breathing, count silently and slowly from one to three. Open your eyes. Say silently to yourself: "I feel alert and relaxed". Begin moving about slowly.

- **Other methods you can add to slow rhythmic breathing:**
 - a) Imagery
 - b) Listen to slow, familiar music through an earphone or headset.
 - c) Progressive relaxation of body parts: Once you are breathing slowly and comfortably, you may relax different body parts, starting with your feet and working up to your head. Think of words such as limp, heavy, light, warm or floating. Each time you breathe out, you can focus on a particular area of the body and feel it relaxing. Try to imagine that the tension is draining from that area. For example, as you breathe out, feel your feet and ankles relaxing. The next time you breathe out, feel your calves and knees relaxing, and so on up your body.

- **Relaxation tapes:**

Ask your doctor or nurse to recommend commercially available relaxation tapes. These tape recordings provide step-by-step instructions in relaxation techniques.

Will I have any problems with using relaxation techniques?

Some people who have used relaxation for pain/stress relief have reported the following problems and solutions to them:

- Relaxation may be difficult to use with severe pain. If you have this problem, use a quick and easy relaxation method such as visual concentration with rhythmic massage or breathe in/tense, breathe out/relax.
- You may have a feeling of “suffocation”. If so, take a deep breath.
- Sometimes breathing too deeply for a while can cause shortness of breath. If this is your problem, take shallow breaths and/or breathe more slowly.
- You may fall asleep. If you do not wish to fall asleep, sit in a hard chair while doing the relaxation exercise or set a timer or alarm.
- You might get feelings of depression or withdrawal. Sometimes being relaxed makes you aware of problems you have been worrying about subconsciously. If this happens, talk to someone who can help you sort out your feelings.

If you have trouble using these methods, ask your doctor or nurse to refer you to therapist who is experienced in relaxation techniques. Do not continue any relaxation technique that increases your pain, makes you feel uneasy or causes any unpleasant effects.

What is Biofeedback?

With the help of special machines, people can learn to control certain body functions such as heart rate, blood pressure, and muscle tension. Biofeedback is sometimes used to help people learn to relax. Cancer patients can use

biofeedback techniques to reduce anxiety and help them cope with their pain. Biofeedback usually is used with other pain-relief methods.

What is imagery and how does it work?

Imagery is using your imagination to create mental pictures or solutions. The way imagery relieves pain is not completely understood. Imagery can be thought of as deliberate daydream that uses all of your senses – sight, touch, hearing, smell, and taste. Some people believe that imagery is a form of self-hypnosis. Certain images may reduce your pain and stress both during imagery and for hours afterward. If you must stay in bed or can't go out of the house, you may find that imagery helps reduce the closed-in feeling. You can imagine and revisit favorite spots in your mind. Imagery can help you relax, relieve boredom, decrease anxiety and help you sleep.

How do I use the technique of imagery?

Usually, imagery for pain/stress relief is done with the eyes closed. A relaxation technique may be used first. The image can be something, such as a ball of healing energy or a picture drawn in your mind of yourself as a person without pain (for example, imagine that you are cutting wires that transmit pain signals from each part of your body to your brain). Here is an exercise with the first image – the ball of energy. It is a variation of the technique credited to Dr. David Bresler at the Pain Control Unit, University of California, Los Angeles (UCLA).

- a) Close your eyes. Breathe slowly and feel yourself relax.
- b) Concentrate on your breathing. Breathe slowly and comfortably from your abdomen.
- c) As you breathe in, say silently and slowly to yourself: “In, one, two”. As you breathe out, say “out, one, two”. Breathe in this slow rhythm for a few minutes.
- d) Imagine a ball of healing energy forming in your lungs or on your chest. It may be like a white light. It can be vague. It does not have to be vivid. Imagine this ball forming, taking shape.
- e) When you are ready, imagine that the air you breathe in blows this healing ball of energy to the area of your pain. Once there, that ball heals and relaxes you.
- f) When you breathe out, imagine the air blows the ball away from your body. As it goes, the ball takes your pain with it (Do not blow as you breathe out, breathe out naturally).
- g) Repeat the last two steps each time you breathe in and out.
- h) You may imagine that the ball gets bigger and bigger as it takes more and more discomfort away from your body.
- i) To end the imagery, count slowly to three, breathe in deeply, open your eyes, and say silently to yourself: “I feel alert and relaxed”. Begin moving about slowly.

Are there any problems with using imagery?

The problems are similar to the ones that may occur with relaxation techniques.

What is distraction, and how does it work?

Distraction means turning your attention to something other than the pain/stress. Many people use this method without realizing it when they watch television or listen to the radio to “take their minds off” the pain. Distraction may work better than medicine if pain is sudden and intense or if it is brief, lasting only 5 to 45 minutes. Distraction is useful when you are waiting for pain medicine to start working. If pain is mild, you may be able to distract yourself for hours. Some people think that a person who can be distracted from pain does not have severe pain. This is not necessarily true. Distraction can be a powerful way of temporarily relieving even the most intense pain.

Resources

General Cancer

American Cancer Society

877-227-1618, San Antonio – 210-614-4211

www.cancer.org. Provides publications on treatment and patient care, support groups. Local offices also provide one free wig.

American Institute for Cancer Research (AICR)

800-843-8114 (nutrition hotline) or www.aicr.org. Focuses on the link between diet and cancer. Provides free educational publications.

Cancer Care, Inc.

2275 Seventh Ave., 22nd Floor, New York, NY 10001, (212) 302-2400 or (800) 813-4673, or www.cancercare.org. Offers information, counseling and support groups, financial assistance for non-medical expenses and referrals to local services such as housekeeping, nursing care and health aides.

Cancer Hope Network

800-552-4366 (toll free) 1-800-552-4366 (talk to support volunteer) or info@cancerhopenetwork.org

Leukemia and Lymphoma Society

www.lls.org 210-377-1775 or 800-955-4LSA

National Cancer Institute (NCI)

NCI Public Inquiries Office Building, 31, Room 10A03, 31 Center Dr., MSC 2580, (301) 435-3848 or (800) 422-6237, www.cancer.gov. Provides information and referrals to local resources.

National Coalition for Cancer Survivorship

1010 Wayne Ave., Suite 770, Silver Spring, MD 20910-5600 (877) 622-7937 or (888) 650-9127, or www.canceradvocacy.org. A network of independent organizations and individuals working in the area of cancer survivorship and support.

Employment/Financial Resources

Americans with Disabilities Act (ADA) information line
800-514-0301 www.ada.gov

Job Accommodations Network
www.askjan.org 800-526-7234

Equal Employment Opportunities Commission
800-669-4000 www.eeoc.gov

Social Security Administration
800-772-1213 or www.ssa.gov

Needy Meds
www.needymeds.org. Information about patient assistance programs through the pharmaceutical companies. Provides information about assistance with the cost of healthcare.

Patient Advocate Foundation
800-532-5274 or www.patientadvocate.org. Non-profit organization that works to help patients resolve insurance, job retention, and debt problems that result from health problems.

Co-Pay Relief Program <http://www.copays.org>

Partnership for Prescription Assistance <https://www.pparx.org/Intro.php> \

Grants and Patient Resources

Lymphoma & Leukemia Society
Patient aid program assists with \$150/year. Their Co-Pay Assistance Program also provides up to \$10,000 a year for specific diagnoses. www.lls.org . 800-955-4572

National Foundation for Transplants (NFT)
www.transplants.org/Donations.php. 800-955-4572. Assists patients with a grant up to \$3000 to organize fundraisers and/or search for a donor. They assist in maintaining accounts for tax deductible contributions to be made on a patient's behalf.

National Transplant Assistance Fund and Catastrophic Injury Program
<http://www.transplantfund.org>. Provides fundraising assistance for transplant.

NMDP Search Assistance Fund

Assists patients with grants up to \$10,000 for the search of an unrelated donor in the event that the patient has no insurance or does not have search coverage on their medical plan. The Transplant Coordinators help with the application process for this program. www.marlow.org 1-800-627-7692

NMDP Post BMT Grant

888-999-6743 (ext 7262) or www.marlow.org/PATIENT/financialassistance.html. This is a grant for patients that obtained a donor from the NMDP registry. The grant can be up to \$1500.00 to go toward transplant-related expenses. The Transplant Social Worker will assist with the application process for this program.

No Insurance

www.hrsa.gov/. Click on “Obtaining Free Care”

Blue Cross Blue Shield Texas Risk Pool

www.txhealthpool.org or 1-888-398-3927. The Texas Health Insurance Risk Pool provides health insurance to Texans who are unable to obtain adequate health coverage due to their medical condition or who are considered Federally Eligible Individuals as defined by the Health Insurance Portability and Accountability Act (HIPAA) of 1996.

Foundation For Health Coverage Education www.coverageforall.org

800-234-1317 provides information about free and low cost coverage options

Communicating for Agriculture and the Self Employed

www.selfemployedcountry.org/usa 800-432-3276. Publishes a state-by-state analysis of comprehensive health insurance programs for high-risk individuals (e.g., people with cancer) including plan summaries and monthly premium information.

www.covertheuninsuredweek.org. Primarily related to uninsured children.

Appeals to Insurance

www.patientsarepowerful.org. Gives sources to help you follow through with an appeal.

www.medicarerights.org or 1-888-466-9050 (for Medicare HMO appeals) or 202-589-1316. Gives information about appealing a Medicare denial.

Health-Related Resources

American Medical Association

www.ama-assn.org. Includes stories about medical issues and news and lets you search for doctors by name or medical specialty.

American Board of Medical Specialties

866-275-2267 or www.abms.org. Lets you determine whether a doctor is board certified and search for board-certified physicians.

Healthfinder

www.healthfinder.gov. Developed by the U.S. Dept of Health and Human Services and it allows users to search for information about different health topics and drugs, and provides a directory of doctors, dentists and hospitals; it also provides links to health organizations and other resources.

Medline Plus

www.nlm.nih.gov/medlineplus Sponsored by the U.S. National Library of Medicine (NIH) and includes current health news, drug information, a medical encyclopedia, and resources for finding doctors, dentists and hospitals.

Ask NOAH (New York Online Access to Health): Pharmacy/Drugs and Medications

www.noah-health.org/en/pharmacy/index.html. Includes links to dozens of pharmacy-and medication-related Web pages. Also includes an index of health topics and resources. Caters to the Spanish-speaking community.

Center for Drug Evaluation and Research (CDER)

www.fda.gov/drugs/default.htm . Includes information about prescription and over-the-counter drugs, drug safety, and links to major drug-information pages. 888-463-6332 or 301-796-3400

Division of Over-the-Counter Drug Products

www.fda.gov/cder/Offices/OTC/default.htm. Information about over-the-counter drugs and their safe use.

www.drugs.com. Includes a database with drug information drawn from 3 leading medical-information suppliers; provides a free drug-information service for both prescription and OTC drugs.

Hand washing/Infection Control

www.cdc.gov/ncidod/op. Practical and useful tips on preventing infectious diseases. Gives detailed information about why it's important to wash your hands and proper technique.

www.medterms.com. Gives plain translations of terms your doctor uses.

U.S. FDA's Center for Food Safety and Applied Nutrition

www.fda.gov/Food/default.htm . Includes information about supplements

Medical Studies

www.clinicaltrials.gov. Gives an up-to-date database of ongoing and upcoming medical studies looking for volunteers.

www.centerwatch.com (or phone 617-856-5900). Thomson Centerwatch Clinical Trials Listing Service. Lists more than 41,000 studies.

www.nccam.nih.gov/clinicaltrials Includes studies about alternative medicines 1-888-644-6226

Agency for Healthcare Research and Quality

www.ahrq.gov/consumer. Aimed primarily at healthcare professionals, but has some health information for consumers as well. 301-427-1104

Cochrane Collaboration

www.cochrane.org. Not-for-profit organization that maintains a searchable database of key clinical studies for hundreds of conditions.

Young Adults

Planet Cancer – people with cancer ages 18-35

www.planetcancer.org. Planet Cancer is a community of young adults with cancer (You know, that age between “pediatric” and “geriatric”, where no one knows whether to give you a lollipop or have a serious talk about your fiber intake.). It’s a place to share insights, explore our fears, laugh, or even give the finger to cancer with others who just plain get it. We don’t deny the dark side of illness and death here, but we also firmly believe that laughter and light can turn up in the strangest places.

I[2]y

Imtooyoungforthis.org or stupidcancer.com/

Provides education, support, information exclusively for young adults (ages 15-40) going through cancer treatment.

Ulman Cancer Fund for Young Adults

www.ulmanfund.org. headquarters- 410-964-0202 Provides support programs, education and resources free of charge to benefit young adults, their families and friends, who are affected by cancer, and to promote awareness and prevention of cancer. Networks survivors, parents, and loved ones with another peer for support.

SAMM Fund

Financial assistance programs for young adults with cancer (17-35yo).

866-439-9365. www.thesamfund.org

Scholarships/Education for Cancer Survivors and family (primarily under the age of 40): www.cameronsiers.org/life-grants.php

American Society for Reproductive Medicine www.asrm.org

Provides information and referral to local sperm banks across the country (205) 978-5000. M-F 8-5pm C.S.T.

Fertile Hope www.fertilehope.org

888-994-HOPE. Non-profit organization dedicated to helping cancer patients faced with infertility.

University of Texas Health Science Center – UT Medicine Fertility Dept.
8300 Floyd Curl Dr.
MARC Building, 5th Floor
San Antonio, TX 78229
210-450-9500. Ask for Fertility/Sperm Banking
For sperm banking prior to chemotherapy.

Education/Support

BMT Support Online

586-575-9910 or www.bmtsupport.org. Provides interactive chat area, and 2 online support groups – one for patients and survivors, the other for caregivers. Both groups meet weekly at scheduled times.

BMT-Talk (Internet Mailing List)

www.acor.org. Online peer support for patients, survivors and caregivers.

Cancer Source

www.cancersourcemd.com. Information on managing fatigue, resources and an opportunity to ask questions, talk, listen and share ideas and concerns through mailing lists, message boards, support groups or live chat events.

Cancer Symptoms

www.cancersymptoms.org. This site is designed for patients and caregivers to provide information on learning about managing each of six common cancer treatments symptoms, including fatigue and pain.

CarePages

www.carepages.com. This is a free web site that patients can create to stay in touch with friends and family during their illness. Also has a discussion board for patients/friends/family to ask for help or advice.

CaringBridge

651-452-7940 or www.caringbridge.org. A website where patients can easily create their own web page free of charge. News about a patient's progress can be posted to the web page periodically so that family members and friends can know what's happening. Those who visit the patient's website can also leave messages of encouragement and hope in the "guest book".

National Family Caregivers Association (NFCA)
800-896-3650 or www.nfcacares.org. Publishes quarterly newsletter “Take Care!” which has self-help action-oriented information from the perspective of family caregivers of the chronically ill and disabled. This program can also link you to other caregivers for support.

ONCO CHAT

www.oncochat.org. Online peer support for cancer survivors, families and friends. A chance to chat and share with people whose lives have been touched by cancer.

The Wellness Community

www.cancersupportohio.org . 614-747-2820. Education and support for persons experiencing cancer, and their families.

Disease Specific Resources

Aplastic Anemia / MDS

Chronic Disease Fund – Good days

www.gooddaysfromcdf.org. 877-968-7233. Helps with the cost of medications for patients with MDS.

Aplastic Anemia & MDS International Foundation

800-747-2820 or www.aamds.org. Free educational materials, emotional support, links to other patients and their families.

Leukemia and Lymphoma Society

800-955-4572 www.lls.org

Co-pay Assistance for MDS.

Patient Access Network

866-316-7263, www.patientaccessnetwork.org

Assistance with deductibles, co-pays, coinsurance, out-of-pocket costs for patients with MDS and aplastic anemia.

Lymphomas & Leukemias

Cure for Lymphoma Foundation

212-213-9595. Publications and support to patients/families.

Leukemia & Lymphoma Society
800-955-4LSA or www.lls.org. Publications, support groups, financial aid.
CO-pay assistance for CLL, Hodgkins, NHL

Leukemia Texas
www.leukemiatexas.org 214-265-7393. Provides up to \$1000 per year of financial assistance for necessary treatment expenses not covered by insurance or other third parties.

NORD – Hodgkin Lymphoma Co-pay Assistance Program
800-999-6673 or www.rarediseases.org. Program for the uninsured or underinsured to help with medication costs. It administers assistance programs for certain pharmaceutical and biotechnology companies.

Healthwell Foundation
Healthwellfoundation.org. 800-675-8416. Provides financial assistance for medication co-pays, insurance premiums, deductibles, and coinsurance costs for patients with NHL or CML or Hodgkins.

Lymphoma Research Foundation www.lymphoma.org. 800-500-9976. Provides information, education and some financial assistance.

Patient Access Network
866-316-7263 www.patientaccessnetwork.org
Provides assistance with deductibles, co-pays, coinsurance, out-of-pocket costs for patients with NHL.

Patient Services Inc.
800-366-7741 www.uneedpsi.org
Provides assistance with co-pays, coinsurance, deductibles for patients with CML.

Multiple Myeloma

International Myeloma Foundation
800-452-2873 or www.myeloma.org. Publishes newsletters and brochures about Multiple Myeloma. Sponsors groups and patient conferences.

Chronic Disease Fund – Good Days
www.gooddaysfromcdf.org. 877-968-7233. Provides assistance for medication costs for patients with multiple myeloma.

Patient Access Network

866-316-7263 www.patientaccessnetwork.org

Provides assistance with deductibles, co-pays, coinsurance and out-of-pocket costs for patients with multiple myeloma.

Leukemia and Lymphoma Society

800-955-4572 www.lls.org

Co-pay Assistance Fund for multiple myeloma

Bone Marrow Transplant

BMT InfoNet

888-597-7674 or www.bmtinfonet.org. Not-for-profit organization that provides publications and support services to BMT patients at all stages.

Also can give attorney referrals for insurance problems.

National Bone Marrow Transplant Link (nbmtLink)

800-link-bmt (800-546-5268) or www.nbmtlink.org. Serves as a clearinghouse for BMT patients/families. Provides resource information and peer support.

National Marrow Donor Program (NMDP) – Be the Match

888-999-6743 or www.marrows.org . 1-800-627-7692 This not-for-profit organization facilitates marrow, stem cell and cord transplants for patients who do not have a matched related donor available. The Office of Patient Advocacy is the arm of the NMDP that serves the public through advocacy, education and outreach.

Bone Marrow Foundation

www.bonemarrow.org 1-800-365-1336. Provides financial support and free information/education for transplant patients and their families.

DECISIONS



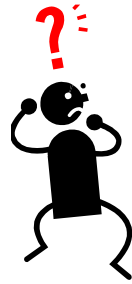
(Advance Directives)

Over the course of any medical illness, many decisions need to be made. They usually deal with whether or not to start or continue treatment of an illness. Who makes those decisions?

YOU DO!

Most of the time, you are in control of what happens to you in the hospital. In order to make wise choices about your treatment you must:

- **Understand your illness.** You must be kept up to date about your medical condition, treatments and chances for recovery.
- **Know your prognosis.** Prognosis means what the illness will do to your health over the next days, weeks and months.
- **Understand the treatment** being offered to you and how it will affect your prognosis.



If you are sick, physically or mentally, and cannot make your own decisions and choices, who will make them for you? Anyone can plan for this possibility in advance, in two ways.

MEDICAL POWER OF ATTORNEY

1. First, you should name an “agent” in a simple document called a Medical Power of Attorney. The “agent” is, a person of your choice who will make ALL of your medical decisions for you should you become unable to make them for yourself. These decisions are made together with your doctor(s). Everyone, even healthy people should name someone they know and trust to be their medical power of attorney, just in case. It is important that your agent know what you would want to do in a variety of different medical situations. Would you want surgery, chemotherapy, a feeding tube, various other kinds of treatments or nothing at all?



DIRECTIVE TO PHYSICIANS

2. Second, you can complete a paper called a Directive to Physicians. This paper tells your doctor that if you have a terminal illness or an irreversible illness and you are unable to make decisions for yourself, that you do or do not want life-sustaining treatment, in certain situations.
 - Terminal Illness – one where you would likely die soon, even if treatment continues.
 - Irreversible Illness – a permanent illness that requires life-sustaining treatment and renders you unable to make decisions. In this paper you should be very specific and state your wishes about things like:
 - CPR – restoring stopped breathing and heartbeat
 - IV Therapy – Providing food, water or artificial nutrition through a tube in your vein.
 - Feeding Tubes – providing artificial nutrition through a tube inserted through the stomach, nose or throat
 - Dialysis – cleaning the blood when the kidneys aren't working



Many people find that thinking about these things is frightening and depressing. Still, there are many good reasons for everyone to complete these papers while they are able to do it.

1. It helps your family by freeing them of the responsibility and stress – of having to make difficult decisions for you.
2. It helps your health care providers by giving them directions for the kind of care you want.

We encourage you to think about your health care decisions and then talk to your physician and your family about how you feel. Make sure your doctor and family have copies of your advanced directives.



DIRECTIVE TO PHYSICIANS AND FAMILY OR SURROGATES

INSTRUCTIONS FOR COMPLETING THIS DOCUMENT:

This is an important legal document known as an advance directive. It is designed to help you communicate your wishes about medical treatment at some time in the future when you are unable to make your wishes known because of illness or injury. These wishes usually are based on personal values. In particular, you may want to consider what burdens or hardships of treatment you would be willing to accept for a particular amount of benefit obtained if you were seriously ill.

You are encouraged to discuss your values and wishes with your family or chosen spokesperson, as well as your physician. Your physician, other health care provider, or medical institution may provide you with various resources to assist you in completing your advance directive. Brief definitions are listed below and may aid you in your discussions and advance planning. Initial the treatment choices that best reflect your personal preferences. Provide a copy of your directive to your physician, usual hospital, and family or spokesperson. Consider a periodic review of this document. By periodic review, you can best assure that the directive reflects your preferences.

In addition to this advance directive, Texas law provides for two other types of directives that can be important during a serious illness. These are the Medical Power of Attorney and the Out-of-Hospital-Do-Not-Resuscitate Order. You may wish to discuss these with your physician, family, hospital representative or other advisers. You also may wish to complete a directive relative to the donation of organs and tissues.

DIRECTIVE

I, _____ (INSERT YOUR NAME), RECOGNIZE THAT THE BEST HEALTH CARE IS BASED UPON A PARTNERSHIP OF TRUST AND COMMUNICATION WITH MY PHYSICIAN. MY PHYSICIAN AND I WILL MAKE HEALTH CARE DECISIONS TOGETHER AS LONG AS I AM OF SOUND MIND AND ABLE TO MAKE MY WISHES KNOWN. IF THERE COMES A TIME THAT I AM UNABLE TO MAKE MEDICAL DECISIONS ABOUT MYSELF BECAUSE OF ILLNESS OR INJURY, I DIRECT THAT THE FOLLOWING TREATMENT PREFERENCES BE HONORED:

If, in the judgment of my physician, I am suffering with a terminal condition from which I am expected to die within six months, even with the available life-sustaining treatment provided in accordance with prevailing standards of medical care:

___ I request that all treatments other than those needed to keep me comfortable be discontinued or withheld, and my physician allow me to die as gently as possible; OR

___ I request that I be kept alive in this terminal condition using available life-sustaining treatment. (THIS SELECTION DOES NOT APPLY TO HOSPICE CARE.)

If, in the judgment of my physician, I am suffering with an irreversible condition so that I cannot care for myself or make decisions for myself and am expected to die without life-sustaining treatment provided in accordance with prevailing standards of care:

___ I request that all treatments other than those needed to keep me comfortable be discontinued or withheld, and my physician allow me to die as gently as possible; OR

___ I request that I be kept alive in this irreversible condition using available life-sustaining treatment. (THIS SELECTION DOES NOT APPLY TO HOSPICE CARE.)

Additional requests: (After discussion with your physician, you may wish to consider listing particular treatments in this space that you do or do not want in specific circumstances, such as artificial nutrition and fluids, intravenous antibiotics, etc. Be sure to state whether you do or do not want the particular treatment.)

AFTER SIGNING THIS DIRECTIVE, IF MY REPRESENTATIVE OR I ELECT HOSPICE CARE, I UNDERSTAND AND AGREE THAT ONLY THOSE TREATMENTS NEEDED TO KEEP ME COMFORTABLE WOULD BE PROVIDED AND I WOULD NOT BE GIVEN AVAILABLE LIFE-SUSTAINING TREATMENTS.

IF I DO NOT HAVE A MEDICAL POWER OF ATTORNEY, AND I AM UNABLE TO MAKE MY WISHES KNOWN, I DESIGNATE THE FOLLOWING PERSON(S) TO MAKE TREATMENT DECISIONS WITH MY PHYSICIAN COMPATIBLE WITH MY PERSONAL VALUES:

1. _____
2. _____

(If a Medical Power of Attorney has been executed, then an agent already has been named and you should not list additional names in this document).

If the above persons are not available, or if I have not designated a spokesperson, I understand that a spokesperson will be chosen for me following standards specified in the laws of Texas. If, in the judgment of my physician, my death is imminent within minutes to hours, even with the use of all available medical treatment provided within the prevailing standard of care, I acknowledge that all treatments may be withheld or removed except those needed to maintain my comfort. I understand that under Texas law this directive has no effect if I have been diagnosed as pregnant. This directive will remain in effect until I revoke it. No other person may do so.

Signed _____ Date _____

City, County, State of Residence _____

Two competent adult witnesses must sign below, acknowledging the signature of the declarant. The witness designated as Witness 1 may not be a person designated to make a treatment decision for the patient and may not be related to the patient by blood or marriage. This witness may not be entitled to any part of the estate and may not have a claim against the estate of the patient. This witness may not be the attending physician or an employee of the attending physician. If this witness is an employee of a health care facility in which the patient is being cared for, this witness may not be involved in providing direct patient care to the patient. This witness may not be an officer, director, partner or business office employee of a health care facility in which the patient is being care for or of any parent organization of the health care facility.

Witness 1 _____ Witness 2 _____

DEFINITIONS:

- **“Artificial nutrition and hydration”** means the provision of nutrients or fluids by a tube inserted in a vein, under the skin in the subcutaneous tissues, or in the stomach (gastrointestinal tract).
- **“Irreversible condition”** means a condition, injury or illness:
 - (1) that may be treated, but is never cured or eliminated
 - (2) that leaves a person unable to care for or make decisions for himself/herself; and
 - (3) that, without life-sustaining treatment provided in accordance with the prevailing standard of medical care, is fatal.

Explanation: Many serious illnesses such as cancer, failure of major organs (kidney, heart, liver or lung), and serious brain disease, such as Alzheimer’s dementia, may be considered irreversible early on. There is no cure, but the patient may be kept alive for prolonged periods of time if the patient receives life-sustaining treatments. Late in the course of the same illness, the disease may be considered terminal when, even with treatment, the patient is expected to die. You may wish to consider which burdens of treatment you would be willing to accept in an effort to achieve a particular outcome. This is a very personal decision that you may wish to discuss with your physician, family, or other important people in your life.

- **“Life-sustaining treatment”** means treatment that, based on reasonable medical judgment, sustains the life of a patient and without which the patient will die. The term includes both life-sustaining medications and artificial life support, such as mechanical breathing machines, kidney dialysis treatment, and artificial nutrition and hydration. The term does not include the administration of pain management medication, the performance of a medical procedure necessary to provide comfort care, or any other medical care provided to alleviate a patient’s pain.
- **“Terminal condition”** means an incurable condition caused by injury, disease or illness that according to reasonable judgment will produce death within six months, even with the available life-sustaining treatment provided in accordance with the prevailing standard of medical care.

Explanation: Many serious illnesses may be considered irreversible early in the course of the illness, but they may not be considered terminal until the disease is fairly advanced. In thinking about terminal illness and its treatment, you again may wish to consider the relative benefits and burdens of treatment and discuss your wishes with your physician, family or other important persons in your life.

INFORMATION CONCERNING THE MEDICAL POWER OF ATTORNEY

THIS IS AN IMPORTANT LEGAL DOCUMENT. BEFORE SIGNING THIS DOCUMENT, YOU SHOULD KNOW THESE IMPORTANT FACTS:

Except to the extent you state otherwise, this document gives the person you name as your agent the authority to make any and all health care decisions for you in accordance with your wishes, including your religious and moral beliefs, when you are no longer capable of making them yourself. Because “health care” means any treatment, service or procedure to maintain, diagnose or treat your physical or mental condition, your agent has the power to make a broad range of health care decisions for you. Your agent may consent, refuse to consent or withdraw consent to medical treatment and may make decisions about withdrawing or withholding life-sustaining treatment. Your agent may not consent to voluntary inpatient mental health services, convulsive treatment, psychosurgery or abortion. A physician must comply with your agent’s instructions or allow you to be transferred to another physician.

Your agent’s authority begins when your doctor certifies that you lack competence to make health care decisions.

Your agent is obligated to follow your instructions when making decisions on your behalf. Unless you state otherwise, your agent has the same authority to make decisions about your health care as you would have.

It is important that you discuss this document with your physician or other health care provider before you sign it to make sure that you understand that nature and range of decisions that may be made on your behalf. If you do not have a physician, you should talk with someone who is knowledgeable about these issues and can answer your questions. You do not need a lawyer’s assistance to complete this document, but if there is anything in this document that you do not understand, you should ask a lawyer to explain it to you.

The person you appoint as agent should be someone you know and trust. The person must be 18 years of age or older or a person under 18 years of age who has had the disabilities of minority removed. If you appoint your health or residential care provider (e.g., your physician or an employee of a home health agency, hospital, nursing home or residential care home, other than a relative), that person has to choose between acting as your agent or as your health or residential care provider; the law does not permit a person to do both at the same time.

You should inform the person you appoint that you want the person to be your health care agent. You should discuss this document with your agent and your physician, and give each a signed copy. You should indicate on the document itself the people and institutions who have signed copies. Your agent is not liable for health care decisions made in good faith on your behalf.

Even after you have signed this document, you have the right to make health care decisions for yourself as long as you are able to do so, and treatment cannot be given to you or stopped over your objection. You have the right to revoke the authority granted to your agent by informing your agent or your health or residential care provider orally or in writing or by your execution of a subsequent Medical Power of Attorney. Unless you state otherwise, your appointment of a spouse dissolves on divorce.

This document may not be changed or modified. If you want to make changes in the document, you must make an entirely new one.

You may wish to designate an alternate agent in the event that your agent is unwilling, unable or ineligible to act as your agent. Any alternate agent you designate has the same authority to make health care decisions for you.

THIS POWER OF ATTORNEY IS NOT VALID UNLESS IT IS SIGNED IN THE PRESENCE OF TWO COMPETENT ADULT WITNESSES. THE FOLLOWING MAY NOT ACT AS ONE OF THE WITNESSES:

- (1) THE PERSON YOU HAVE DESIGNATED AS YOUR AGENT;
- (2) A PERSON RELATED TO YOU BY BLOOD OR MARRIAGE;
- (3) A PERSON ENTITLED TO ANY PART OF YOUR ESTATE AFTER YOUR DEATH UNDER A WILL OR CODICIL EXECUTED BY YOU OR BY OPERATION OF LAW;
- (4) YOUR ATTENDING PHYSICIAN;
- (5) AN EMPLOYEE OF YOUR ATTENDING PHYSICIAN;
- (6) AN EMPLOYEE OF A HEALTH CARE FACILITY IN WHICH YOU ARE A PATIENT IF THE EMPLOYEE IS PROVIDING DIRECT PATIENT CARE TO YOU OR IS AN OFFICER, DIRECTOR, PARTNER OR BUSINESS OFFICE EMPLOYEE OF THE HEALTH CARE FACILITY OR OF ANY PARENT ORGANIZATION OF THE HEALTH CARE FACILITY; OR
- (7) A PERSON, WHO, AT THE TIME THIS POWER OF ATTORNEY IS EXECUTED, HAS A CLAIM AGAINST ANY PART OF YOUR ESTATE AFTER YOUR DEATH.

MEDICAL POWER OF ATTORNEY

DESIGNATION OF HEALTH CARE AGENT

I, _____ (INSERT YOUR NAME) APPOINT:

NAME: _____

ADDRESS: _____

_____ PHONE: _____

AS MY AGENT TO MAKE ANY AND ALL HEALTH CARE DECISIONS FOR ME, EXCEPT TO THE EXTENT I STATE OTHERWISE IN THIS DOCUMENT. THIS MEDICAL POWER OF ATTORNEY TAKES EFFECT IF I BECOME UNABLE TO MAKE MY OWN HEALTH CARE DECISIONS AND THIS FACT IS CERTIFIED IN WRITING BY MY PHYSICIAN.

LIMITATIONS ON THE DECISION-MAKING AUTHORITY OF MY AGENT ARE AS FOLLOWS:

DESIGNATION OF ALTERNATE AGENT

(YOU ARE NOT REQUIRED TO DESIGNATE AN ALTERNATE AGENT, BUT YOU MAY DO SO. AN ALTERNATE AGENT MAY MAKE THE SAME HEALTH CARE DECISIONS AS THE DESIGNATED AGENT IF THE DESIGNATED AGENT IS UNABLE OR UNWILLING TO ACT AS YOUR AGENT. IF THE AGENT DESIGNATED IS YOUR SPOUSE, THE DESIGNATION AUTOMATICALLY IS REVOKED BY LAW IF YOUR MARRIAGE IS DISSOLVED.)

IF THE PERSON DESIGNATED AS MY AGENT IS UNABLE OR UNWILLING TO MAKE HEALTH CARE DECISIONS FOR ME, I DESIGNATE THE FOLLOWING PERSONS TO SERVE AS MY AGENT TO MAKE HEALTH CARE DECISIONS FOR ME AS AUTHORIZED BY THIS DOCUMENT, WHO SERVE IN THE FOLLOWING ORDER:

A. FIRST ALTERNATE AGENT

NAME: _____

ADDRESS: _____

_____ PHONE: _____

B. SECOND ALTERNATE AGENT

NAME: _____

ADDRESS: _____

_____ PHONE: _____

THE ORIGINAL OF THIS DOCUMENT IS KEPT AT:

THE FOLLOWING INDIVIDUALS OR INSTITUTIONS HAVE SIGNED COPIES:

NAME: _____

ADDRESS: _____

NAME: _____

ADDRESS: _____

DURATION

I UNDERSTAND THAT THIS POWER OF ATTORNEY EXISTS INDEFINITELY FROM THE DATE I EXECUTE THIS DOCUMENT UNLESS I ESTABLISH A SHORTER TIME OR REVOKE THE POWER OF ATTORNEY. IF I AM UNABLE TO MAKE HEALTH CARE DECISIONS FOR MYSELF WHEN HIS POWER OF ATTORNEY EXPIRES, THE AUTHORITY I HAVE GRANTED MY AGENT CONTINUES TO EXIST UNTIL THE TIME I BECOME ABLE TO MAKE HEALTH CARE DECISIONS FOR MYSELF.

(IF APPLICABLE) THIS POWER OF ATTORNEY ENDS ON THE FOLLOWING DATE: _____

PRIOR DESIGNATION REVOKED

I REVOKE ANY PRIOR MEDICAL POWER OF ATTORNEY.

ACKNOWLEDGMENT OF DISCLOSURE STATEMENT

I HAVE BEEN PROVIDED WITH A DISCLOSURE STATEMENT EXPLAINING THE EFFECT OF THIS DOCUMENT. I HAVE READ AND UNDERSTAND THAT INFORMATION CONTAINED IN THE DISCLOSURE STATEMENT. (YOU MUST DATE AND SIGN THIS POWER OF ATTORNEY.)

I SIGN MY NAME TO THIS MEDICAL POWER OF ATTORNEY ON _____ DAY OF

_____ (MONTH) _____ (YEAR) AT

(CITY AND STATE)

(SIGNATURE)

(PRINT NAME)

STATEMENT OF FIRST WITNESS

I AM NOT THE PERSON AS AGENT BY THIS DOCUMENT. I AM NOT RELATED TO THE PRINCIPAL BY BLOOD OR MARRIAGE. I WOULD NOT BE ENTITLED TO ANY PORTION OF THE PRINCIPAL'S ESTATE ON THE PRINCIPAL'S DEATH. I AM NOT THE ATTENDING PHYSICIAN OF THE PRINCIPAL OR AN EMPLOYEE OF THE ATTENDING PHYSICIAN. I HAVE NOT CLAIM AGAINST ANY PORTION OF THE PRINCIPAL'S ESTATE OF THE PRINCIPAL'S DEATH. FURTHERMORE, IF I AM AND EMPLOYEE OF A HEALTH CARE FACILITY IN WHICH THE PRINCIPAL IS A PATIENT, I AM NOT INVOLVED IN PROVIDING DIRECT PATIENT CARE TO THE PRINCIPAL AND AM NOT AN OFFICER, DIRECTOR, PARTNER OR BUSINESS OFFICE EMPLOYEE OF THE HEALTH CARE FACILITY OR OF ANY PARENT ORGANIZATION OF THE HEALTH CARE FACILITY.

SIGNATURE: _____

PRINT NAME: _____ DATE: _____

ADDRESS: _____

SIGNATURE OF SECOND WITNESS

SIGNATURE: _____

PRINT NAME: _____ DATE: _____

ADDRESS: _____

A LETTER FROM THE CHAPLAIN

Dear BMT Patients, Loved Ones and Friends,

Welcome to the transplant program! I am the chaplain assigned to the Transplant Unit at Methodist Hospital. As part of the BMT Team, the Chaplain along with our social worker and psychologist, are here to provide you with the best of care both during and after your transplant. In addition, we have Catholic priests available here most of the time if you desire sacramental ministry. We also have practitioners of other faiths on-call should the need arise. We always have a chaplain available in the hospital every day, all day and night.

As a member of the BMT Team, I will be calling on you to assess your spiritual needs and provide pastoral care. If you do not desire this, please know that I am not pushy and will refrain from contact at your request. Some people do not want to see me because their faith is “different”, and they assume that I cannot help them or will expect them to change somehow. I and our other chaplains are not here to change you. Rather, we are here to help you strengthen and deepen your present spiritual resources. We affirm the validity you have found in whatever your faith may be, because we believe this can be a doorway to finding new purpose for living in spite of your disease and its treatments.

Our main chapel is located on the first floor in the central tower, just off the main lobby across from the validation desk. For Catholics, we offer masses Monday through Friday at noon, and on Sunday at 3:30 pm. We have a service of scripture and prayer at 1:00 pm and a Spanish language service at 6:00 pm on Sunday. The chapel is open all the time for private prayer and meditation.

Here at Methodist, we are concerned about the whole person, body and spirit. The chaplains’ goal is to help patients and loved ones strengthen and renew their spirituality in order to cope with the many emotional difficulties of cancer and cancer treatment.

You don’t have to be reminded of all the changes which a cancer diagnosis can bring. Yet, this can be an opportunity for discovering what is really most important in your life, and setting new priorities for yourself. It will be my pleasure to assist you with this during your stay here at Methodist and as your return for clinic visits. To reach the main Chaplain office, please call (210) 575-4030. My office number on the 8th floor is (210)575-6788.

Wishing the Best for You,

R.C. “Rick” Ricker, chaplain

Pet Safety Tips during Treatment

Discuss the type of pets you have with your doctor. It is safe to have contact with your pets, though people who have received transplants are more likely than most people to get diseases from animals. However, simple tips can be followed to reduce your risk of getting sick after contact with animals. **Keep Clean!**

Avoid direct contact with animal feces or stool. If you do come into contact with animal feces, wash your hands thoroughly with running water and soap.

Caring for your pet:

If your pet is ill, seek veterinary care as soon as possible. Any cat or dog that has diarrhea should be checked by a veterinarian for infection with *Cryptosporidium*, *Giardia*, *Salmonella* and *Campylobacter*. Notify your Transplant Physician of your pet's infection and let them know what the vet tells you.

Caring for Birds:

Avoid going into the room where your bird lives. Do not handle your bird. Do not clean bird cages. Bird cage linings should be cleaned daily. Do not handle items contaminated with bird droppings.

Caring for Fish:

Do not clean fish tanks. Do not put your hands in the water of the fish tank.

Caring for Cats:

If you have a cat, have another person clean out litter on a regular basis. Do not place litter boxes in kitchens, dining rooms, or other areas where food is prepared and eaten. Keep your cat indoors. Avoid handling stray cats. Pet cats do not need to be tested for toxoplasmosis.



Feeding your pet:

Just like people, pets can get disease from eating contaminated food. By protecting your pet from food borne diseases, you can protect your own health as well. Pets should be fed only high-quality commercial pet foods. If eggs, poultry, or meat products are given to your pet as supplements, they should be well-cooked. Any dairy products given to your pets should be pasteurized. Additionally, pets should be prevented from drinking toilet bowl water and from having access to garbage. Do not let your pet scavenge for food, hunt, or eat other animals' feces.

Getting a new pet:

When getting a new pet, avoid animals that are ill, stray, or young (less than 6 months old). These animals are more likely to carry diseases that can make you ill.

Animals to avoid

The following animals are considered high-risk:

- Reptiles, including lizards, snakes and turtles
- Baby chicks and ducklings
- Exotic pets, including monkeys. Note: All persons should avoid direct contact with wild animals. Do not adopt wild animals as pets or bring them into your home.
- Rodents, such as hamsters, ferrets, guinea pigs and gerbils.

If you accidentally come into contact with these animals and their environment (their food or cage, for example), wash your hands thoroughly with running water and soap.

Avoid visiting farms, ranches, and petting zoos.

These pet safety guidelines for bone marrow transplant patients were developed from the following CDC resource: Guidelines for preventing opportunistic infections among hematopoietic stem cell transplant recipients. *Morbidity and Mortality Weekly Report*, October 20, 2000; 49 (RR10): 1-128

FOOD

Changed Sense of Taste or Smell

Your sense of taste or smell may change during your illness or treatment. Foods, especially meat or other high-protein foods, can begin to have a bitter or metallic taste. Many foods will have less taste. Chemotherapy, radiation therapy or the cancer itself may cause these problems. For most people, changes in taste and smell go away when their treatment is finished.

There is no foolproof way to prevent changes to your sense of taste or smell, because each person is affected differently by illness and treatments. However, the tips below should help if you have this problem. (If you also have a sore mouth, sore gums or a sore throat, talk to your doctor, nurse or registered dietician. They can suggest ways to help you without hurting the sore areas.)

- Choose and prepare foods that look and smell good to you.
- If red meat, such as beef, tastes or smells strange, try chicken, turkey, eggs, dairy products or mild-tasting fish instead.
- Help the flavor of meat, chicken or fish by marinating it in sweet fruit juices, sweet wine, Italian dressing or sweet-and-sour sauce.
- Try using small amounts of flavorful seasonings, such as basil, oregano or rosemary.
- Try tart foods, such as oranges, or dill pickles that may have more taste. A tart lemon custard might taste good and will also provide needed protein and calories. (If you have a sore mouth or throat, tart or citrus foods might cause pain or discomfort.)
- If smells bother you, try serving foods at room temperature, turning on a kitchen fan, covering foods when cooking and cooking outdoors in good weather.
- Try using bacon, ham or onion to add flavor to vegetables.
- Visit your dentist to rule out dental problems that may affect the taste or smell of food.
- Ask your dentist or doctor about special mouthwashes and good mouth care.

Food Safety

How to shop safely for perishable food:

When shopping for raw and cooked perishable foods, be sure the food is being stored at a safe temperature in the store. Don't select perishable food from a non-refrigerated aisle display. Never choose packages which are torn or leaking. To guard against cross-contamination, put raw meat and poultry into a plastic bag, so meat juices won't drip on other foods, such as lettuce and fruit that will be eaten raw. **Put refrigerated or frozen items in the shopping cart last, and take food home immediately.**

Deli Foods:

When ordering food from the deli department, be sure the clerk washes his/her hands between handling raw and cooked items, or puts on new plastic gloves. Don't buy cooked ready-to-eat items which are touching raw items or are displayed in the same case. Although the risk associated with foods from deli counters is relatively low, persons at risk may choose to avoid these foods or thoroughly reheat luncheon meats and hot dogs before eating.

Shelf-Stable Foods

Don't purchase cans that are dented, leaking or bulging; food in cracked glass jars; or food in torn packaging. Tamper-resistant safety seals should be intact. Safety buttons on metal lids should be down and should not move or make a clicking noise when pushed. Although product dating is not required by Federal regulations, observe any "use-by" dates found on products. Do not use if beyond expiration date! Follow carefully the handling and preparation instructions on product labels to ensure top quality and safety.

Food Storage at Home

Immediately refrigerate or freeze perishable foods after transporting them home. Use a refrigerator thermometer to be sure the refrigerator is cooling to 40° F or below; the freezer should be at 0° F.

Refrigerator:

Make sure thawing juices from meat and poultry do not drip on other foods. Leave eggs in their carton for storage and don't place them in the door of the refrigerator. Keep the refrigerator clean. Store ground meat, poultry, and fish up to 1 or 2 days; other red meats, 3 to 5 days. After cooking, use food within 3 to 4 days, or freeze for longer storage.

Freezer:

Food stored constantly at 0° F will always be safe. Only the quality suffers with lengthy storage. It is of no concern if a product date expires while the product is frozen. Freezing keeps food safe by preventing the growth of microorganisms that cause both food spoilage and food borne illness. Once thawed, however, these microbes can again become active, so handle thawed items as any perishable food.

Pantry:

Store canned foods and other shelf stable products in a cool, dry place. Never put them above the stove, under the sink, in a damp garage or basement or any place exposed to high or low temperature extremes. Store high acid foods such as tomatoes and other fruit up to 18 months; low acid foods such as meat and vegetables, 2 to 5 years.

Food handling at home:

Food borne illness can be caused by improper food handling or preparation in the home. Wash utensils, can openers, cutting boards, and countertops in hot, soapy water before and after coming in contact with raw meat, poultry or fish. Wash kitchen towels and cloths often in hot water in a washing machine. Wash hands with soap and warm water before and after handling food, after using the bathroom, after changing diapers, or handling pets.

Cutting boards:

Research shows that nonporous surfaces, such as plastic, marble, tempered glass and pyroceramic are easier to clean than wood. Wood surfaces are considered porous. Regardless of the type of cutting board you prefer, wood or a nonporous surface, consider using one for fresh produce and a separate one for raw meat, poultry, and seafood. This will prevent bacteria on a cutting board that is used for raw meat, poultry, or seafood from cross-contaminating a food that requires no further cooking. Cutting boards need to be maintained and monitored for cleanliness. They should be washed with hot soapy water or placed in the dishwasher. Solid hardwood cutting boards are dishwasher safe; however, wood laminates should not be washed in the dishwasher. After thoroughly washing your cutting board, you can sanitize it with a solution of 1 tablespoon of unscented, liquid chlorine bleach in 1 gallon of water. Once cutting boards of any type become excessively worn or develop hard-to-clean grooves, they should be discarded.

Cooking food safely

Do not eat raw or undercooked meat, poultry, fish or eggs. **Use a food thermometer to be sure foods have reached a safe minimum internal temperature.** Cook foods to the following safe minimum internal temperatures as measured with a food thermometer:

- Beef, veal and lamb steaks, roasts, and chops may be cooked to 145° F
- All cuts pork to 160° F
- Ground beef, veal and lamb to 160° F
- Egg dishes, casseroles to 160° F
- Leftovers to 165° F
- Stuffed poultry is not recommended. Cook stuffing separately to 165° F
- All poultry should reach a safe minimum internal temperature of 165° F

When reheating foods in the microwave, cover and rotate or stir foods once or twice during cooking and check the food in several spots with a food thermometer.

Safe handling of leftovers:

Bacteria begin to multiply rapidly in the “danger zone” between 40° F (recommended refrigerator temperature) and 140° F. Therefore, bacteria on food left out at room temperature will become unsafe in a matter of hours. Refrigerate leftovers at 40° F or below or freeze (0°) as soon as possible. **Never leave perishable food out of refrigeration longer than 2 hours, 1 hour in air temperature above 90° F.** Divide

leftovers into shallow containers. This encourages rapid, even cooling. Cover with airtight lids or enclose in plastic wraps or aluminum foil. Use leftovers within 3 to 4 days.

Safe reheating of leftovers

Even though foods may have been safely cooked, bacteria from the air or people's hands can contaminate the leftovers. Always reheat leftovers thoroughly in conventional or microwave oven or on the stove top. When reheating foods in the microwave, cover and rotate or stir foods once or twice during cooking. Always test reheated leftovers in several places with a food thermometer to be sure they reach 165° throughout. The food should be steaming hot.

This information is taken from <http://www.fsis.usda.gov>

Eating Out

Avoid going to restaurants during peak times, when there are large crowds. Select a restaurant with a reputation for cleanliness. In fast food restaurants ask that your food be prepared fresh. Use single packet condiments. Avoid salad bars, delicatessens, buffets, sidewalk vendors, yogurt and ice cream from soft serve machines.

Are there any restrictions on my diet after I leave the hospital?

Observe safe food handling techniques:

- Wash all fruits and vegetables
- Thaw meat in microwave or refrigerator and use right away
- All meat should be cooked until well done
- No raw seafood, raw eggs or raw meat
- Cook eggs until whites are completely hard and yolks are thickened
- Do not leave perishable food out for more than one hour
- Check expiration dates on all foods
- Discard any questionable foods
- Keep hot foods hot and cold foods cold
- Avoid well water

Mouth Care

Your mouth and throat may become tender or painful and actually may develop sores as a side effect of the treatment. This may take several days to develop. Your ability to eat, drink, and speak may temporarily be affected. Infection can also occur as a result of mouth sores. Brush the teeth and gums with a soft toothbrush at least 4 times a day. If you develop sores in your mouth, tell your doctor or nurse. You may need medicine to treat the sores. Mouth sores can be uncomfortable. Tell your doctor or nurse so that medication can be provided to make you more comfortable. If the sores are painful or keep you from eating, you can try these ideas.

Sore Mouth or Throat

Certain foods will irritate an already tender mouth and make chewing and swallowing difficult. By carefully choosing the foods you eat and by taking good care of your mouth, teeth, and gums, you can usually make eating easier. Here are some suggestions that may help: Try soft foods that are easy to chew and swallow, such as:

- Milkshakes
- Bananas, applesauce and other soft fruits
- Peach, pear, and apricot nectars
- Watermelon
- Cottage cheese, yogurt
- Mashed potatoes, noodles
- Macaroni and cheese
- Custards, puddings and gelatin
- Scrambled eggs
- Oatmeal or other cooked cereals
- Pureed or mashed vegetables, such as peas and carrots
- Pureed meats
- Avoid foods or liquids that can irritate your mouth. These include:
 - a) Oranges, grapefruits, lemons or other citrus fruit or juice
 - b) Tomato sauces or juice
 - c) Spicy or salty foods
 - d) Raw vegetables, granola, toast crackers, or other rough, coarse or dry foods
 - e) Commercial mouthwashes that contain alcohol
- Cook foods until they are soft and tender
- Cut foods into small pieces
- Use a blender or food processor to puree your food
- Mix food with butter, margarine, thin gravy, or sauce to make it easier to swallow
- Use a straw to drink liquids
- Use a smaller-than-usual spoon, such as a baby spoon
- Try foods cold or at room temperature. Hot foods can irritate a tender mouth and throat
- Try drinking warm bouillon or salty broth; it can soothe throat pain
- Try sucking on ice chips
- If swallowing is hard, tilting your head back or moving it forward may help.

- Rinse your mouth often with water to remove food and bacteria and to promote healing

Ask your doctor about anesthetic lozenges and sprays that can numb your mouth and throat long enough for you to eat meals

How can I cope with mouth dryness?

- Have a sip of water every few minutes to help you swallow and talk more easily. Consider carrying a water bottle with you so you always have some handy
- Try very sweet or tart foods and beverages, such as lemonade; these foods may help your mouth make more saliva. (Do not try this if you also have a tender mouth or sore throat and the sweet or tart foods make it worse.)
- Suck on hard candy or popsicles or chew gum. These can help make more saliva.
- Eat soft and pureed foods, which may be easier to swallow.
- Keep your lips moist with lip salves.
- Moisten food with sauces, gravies, and salad dressings to make it easier to swallow
- If your dry mouth problem is severe, ask your doctor or dentist about products that coat, protect, and moisten your mouth and throat. These are sometimes called “artificial saliva”.

Diarrhea

When chemotherapy affects the cells lining the intestine, it can cause diarrhea (watery or loose stools). Infection can also cause diarrhea. If you have diarrhea that continues for more than 24hrs, or if you have pain and cramping along with diarrhea, call your doctor. In severe cases, the doctor may prescribe a medicine to control the diarrhea. Do not take any over-the-counter medicines for diarrhea without asking your doctor.

How can I help control diarrhea?

- Drink plenty of fluids. This will help replace those you have lost through diarrhea. Mild, clear liquids, such as water, clear broth, sports drinks such as Gatorade or ginger ale, are best. If these drinks make you more thirsty or nauseous, try diluting them with water. Drink slowly and make sure drinks are at room temperature. Let carbonated drinks lose their fizz before you drink them.
- Eat small amounts of food throughout the day instead of three large meals
- Unless your doctor has told you otherwise, eat potassium-rich foods. Diarrhea can cause you to lose this important mineral. Bananas, oranges, potatoes and peach and apricot nectars are good sources of potassium.
- Ask your doctor if you should try a clear liquid diet to give your bowels time to rest. A clear liquid diet does not provide all the nutrients you need, so do not follow one for more than 3 to 5 days.
- Eat low-fiber foods. Low-fiber foods include white bread, white rice or noodles, creamed cereals, ripe bananas, canned or cooked fruits without skins, cottage cheese, yogurt with seeds, eggs mashed or baked potatoes without skin, pureed vegetables, chicken or turkey without the skin and fish.
- Avoid high-fiber foods, which can lead to diarrhea and cramping. High-fiber foods include whole grain breads and cereals, raw vegetables, bean, nuts, seeds, popcorn and fresh and dried fruit.
- Avoid hot or very cold liquids, which can make diarrhea worse.
- Avoid coffee, tea with caffeine, alcohol and sweets. Stay away from fried, greasy or highly spiced foods, too. They are irritating and can cause diarrhea and cramping.
- Avoid milk and milk products, including ice cream, if they make your diarrhea worse.

Constipation:

Some anticancer medicines, pain medicines and other medicines can cause constipation. It can also occur if you are less active or if your diet lacks enough fluid or fiber. If you have not had a bowel movement for more than a day or two, call your doctor, who may suggest taking a laxative or stool softener. Do not take these measures without checking with your doctor, especially if your white blood cell count or platelets are low.

What can I do about constipation?

- Drink plenty of fluids to help loosen the bowels. If you do not have mouth sore, try warm and hot fluids, including water, which work especially well.
- Check with your doctor to see if you can increase the fiber in your diet (there are certain kinds of cancer and certain side effects you may have which a high-fiber diets is not recommended). High fiber foods include bran, whole-wheat breads and cereals, raw or cooked vegetables, fresh and dried fruit, nuts and popcorn.
- Get some exercise every day. Go for a walk or you may want to try a more structured exercise program. Talk to your doctor about the amount and type of exercise that is right for you.

BMT Exercise Packet

Packet Includes:

Exercise Recorder Sheets
Level 1 Exercise Program
Level 2 Exercise Program

BMT Exercise Record Sheet – Level 1

Please mark on the calendar each day you work on your exercises.

Exercise	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Quad Sets							
Heel Slides							
Supine Knee Bent							
Hip Abduction							
Bridging							
Knee Extension- Sitting							
Hip Flexion- Standing							
Shoulder Flexion- Standing							
Walking							

BMT Exercise Record Sheet – Level 2

Please mark on the calendar each day you work on your exercises.

Exercise	Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
Knee Flexion- Standing							
Knee Step Up/Down-Lateral							
Knee Step Ups							
Seated Pushups							
Shoulder Abduction w/elastic							
Shoulder Rolls							
Knee Wall Slide							
Sit to Stand							
Shoulder External Rotation w/elastic							
Walking							

Personal Program For: UE/LE Program BMT – Level 1



AROM Gait Walking

- Walk at a comfortable pace, at least 10-15 minutes 3 times a day, or 20-25 minutes 2 times a day or all at once for 30-45 minutes a day.

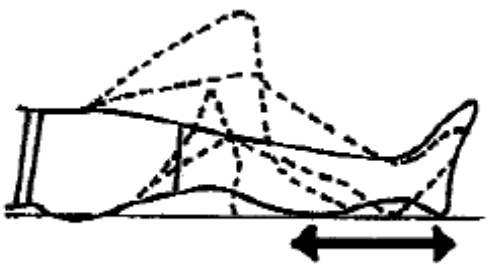
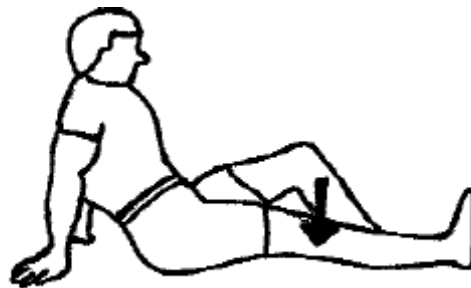
Knee Ext Sit (Quad Sets)

- Sit with leg extended.
- Tighten quad muscles on front of leg, Trying to push back of knee downward.

Special Instructions:
Do not hold breath.

Perform 1 set of 10 repetitions, once a day.

Hold exercise for 5 seconds,
Rest 10 seconds between sets.



AROM Hip/Knee Fix (Heel Slides)

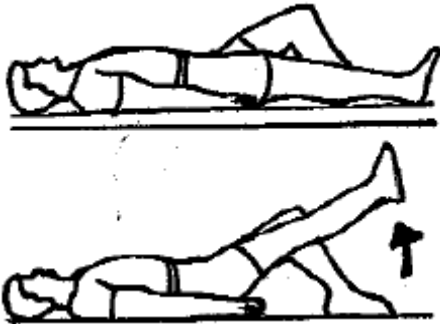
- Lie on back with legs straight.
- Slide heel up to buttocks.
- Return to start position
- Repeat with other leg.

Perform 3 sets of 20 repetitions,
once a day.

Perform 1 repetition every 4 seconds,
Rest 1 minute between sets.

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These exercises are to be used only under the direction of a licensed, qualified professional.
Methodist Outpatient Rehabilitation Clinic

Personal Program For: UE/LE Program BMT – Level 1



AROM Hip Fix (SLR) Supine Knee Bent

- Lie on back with uninvolved knee bent.
- Raise straight leg to thigh level on bent leg.
- Return to starting position.

Perform 1 set of 20 repetitions, once a day.

Perform 1 repetition every 4 seconds,
Rest 1 minute between sets.

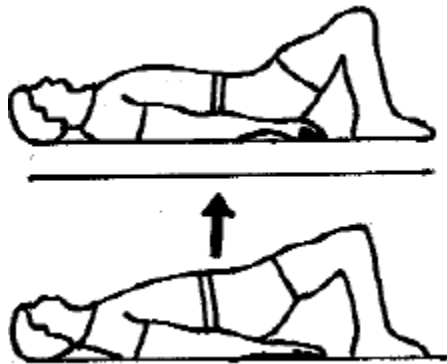
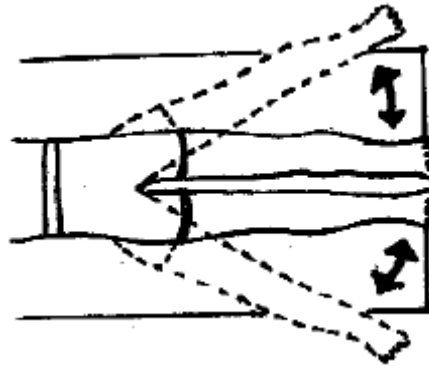
AROM Hip ABD Bil Supine

- Lie on back on firm surface, legs together.
- Move both legs out to side, keeping knees straight.
- Return to start position.

Special Instructions:
Use pillowcases to reduce friction.

Perform 3 sets of 20 repetitions, once a day.

Perform 1 repetition every 4 seconds,
Rest 1 minute between sets.



AROM Lumbar Bridging Bil

- Lie on back with knees bent.
- Lift buttocks off floor.
- Return to start position.

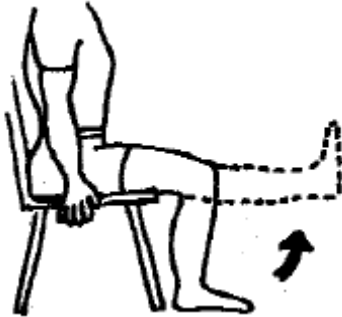
Special Instructions:
Maintain neutral spine.

Perform 3 sets of 20 repetitions, once a day

Perform 1 repetition every 4 seconds,
Rest 1 minute between sets.

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Personal Program For:
UE/LE Program BMT – Level 1



AROM Knee Ext (LAQ) Sit

- Sit with involved leg bent to 90 degrees.
- Straighten leg at knee.
- Return to start position.

Perform 1 set of 20 repetitions, once a day.

Perform 1 repetition every 4 seconds,
Rest 1 minute between sets.

AROM Hip Fix Alt Sit

- Sit in chair with feet on floor.
- Alternately lift left and right knee up and lower slowly,

Perform 3 sets of 20 repetitions, once a day.

Perform 1 repetition every 4 seconds,
Rest 1 minute between sets.

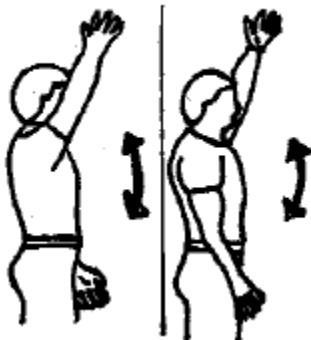


AROM Shld Fix Alt Bil Stand

- Begin with arms at side, palms facing in, sitting or standing.
- Raise left arm upward in front, overhead, as shown.
- Raise right arm as you lower the left arm
- Continue.

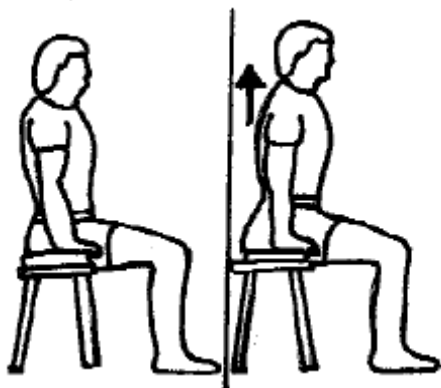
Perform 3 sets of 20 repetitions, once a day

Perform 1 repetition every 4 seconds,
Rest 1 minute between sets.



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Personal Program For: Upper Extremity BMT – Level 2



AROM Shld Depress Bil (Seated Pushup)

- Sit on firm surface, with arms at side.
- Push downward with both hands, raising buttocks off the chair or seat.
- Return to start position.

Special Instructions:

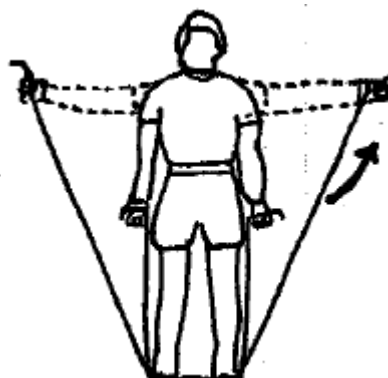
Keep elbows straight.
sometimes helps to place a book on each side of your body, and place your hands on them.

Perform 1 sets of 20 repetitions, once a day

Perform 1 repetition every 4 seconds,
Rest 1 minute between sets.

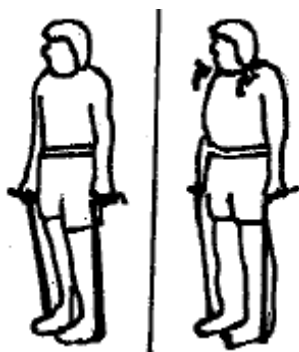
Resist Shld ABD Bil (Vert Emphasis) w/ Elastic

- Stand on elastic.
- Hold elastic in both hands.
- Begin with arms at sides.
- Position palms forward.
- Keep elbows straight and lift arms to shoulder level.
- Lower and Repeat



Perform 1 set of 10 repetitions, once a day.

Perform 1 repetition every 4 seconds,
Use elastic
Rest 1 minute between sets.



Resist Shld Elev/Retract Bil w/Elastic (Shld Rolls)

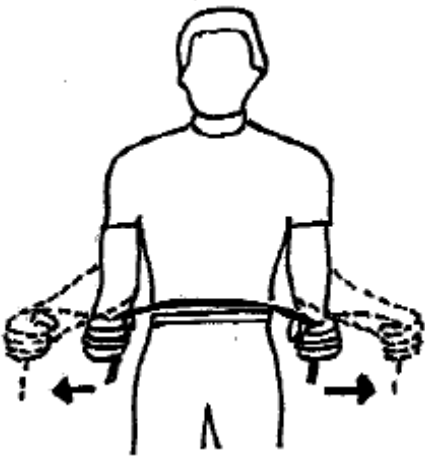
- Stand, arms at side.
- Stand on elastic as shown, holding elastic in hands.
- Raise shoulders upward towards ears, and roll backwards.
- Return to start position.

Perform 1 set of 10 repetitions, once a day

Perform 1 repetition every 4 seconds,
Use elastic,
Rest 1minute between sets.

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Personal Program For:
Upper Extremity BMT – Level 2



Resist Shld ER Bil w/Elastic

- Arms at side, elbows bent.
- Grasp elastic, as shown.
- Move hands outward, keeping arms at side.
- Return to starting position.

Perform 1 sets of 10 repetitions, once a day

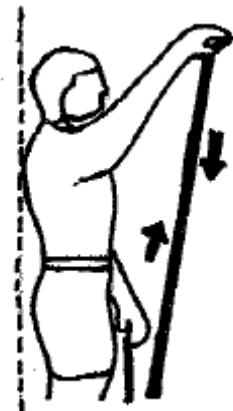
Perform 1 repetition every 4 seconds,
Use elastic,
Rest 1 minute between sets.

Resist Shld Fix Alt Bil w/ Elastic

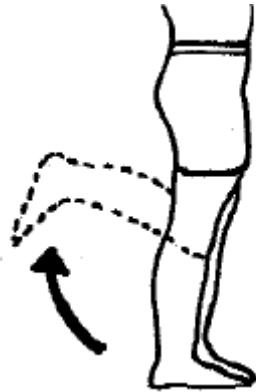
- Secure elastic at floor level or stand on elastic.
- Start with both arms at side, holding elastic.
- Keep elbow straight, raise one arm in front and over head and lower.
- As arm is lowered raise other arm in front and over head.

Perform 1 set of 10 repetitions, once a day.

Perform 1 repetition every 4 seconds,
Use elastic
Rest 1 minute between sets.



Personal Program For:
Lower Extremity BMT – Level 2



AROM Knee Fix Uni Standing

- Stand, bend involved leg toward hip through full range.
- Return to starting position.
- Do not bend legs at hips.

Perform 1 sets of 20 repetitions, once a day

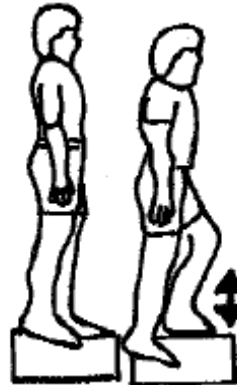
Perform 1 repetition every 4 seconds,
Rest 1 minute between sets.

AROM Knee Step Up/Down Lateral Partial

- Place involved leg on edge of step.
- Step up, lifting uninvolved leg off floor.
- Lower uninvolved foot toward floor but not floor.
- Step up again and continue.

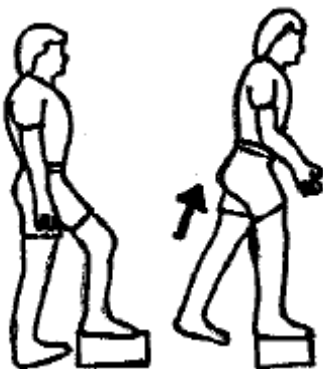
Perform 1 set of 20 repetitions, once a day.

Perform 1 repetition every 4 seconds,
Rest 1 minute between sets.



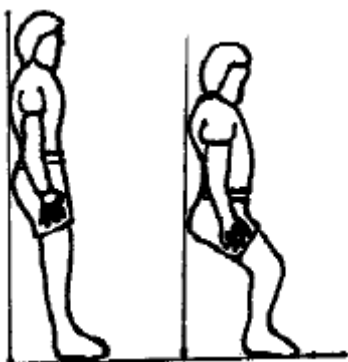
AROM Knee Step Ups

- Stand with involved leg up on step.
- Shift weight over knee.
- Step up slowly.
- Step back down leading with involved leg.
- Repeat



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Personal Program For: Lower Extremity BMT – Level 2



AROM Knee Wall Slide Bil Partial

- Lean on wall, feet approximately 12 inches from wall , shoulder distance apart.
- Bend knees to 45 degrees.
- Hold 5 seconds.
- Return to starting position

Perform 1 sets of 20 repetitions, once a day

Perform 1 repetition every 4 seconds,
Rest 1 minute between sets.

AROM Vestib Sit to Stand Head Neutral

- Begin in sitting position.
- Keep head facing forward.
- Slowly stand.
- Sit and repeat.

Special Instructions:

Begin slowly at first, then speed up as possible.
When this activity can be done quickly without
Dizziness, slow down and close eyes.
Gradually speed up again.

Perform 1 set of 20 repetitions, once a day.

Perform 1 repetition every 4 seconds,
Rest 1 minute between sets.



AROM Gait Walking

- Walk at a comfortable pace, at least 10-15 3 times a day, or 20-25 minutes 2 times a day, or all at once for 30-45 minutes a day.

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Signature: _____

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Methodist Outpatient Rehabilitation Clinic

Post Transplant

- Outpatient Care
- Preventing Infection
- Sexual Activity
- Fatigue
- Nausea/Vomiting
- Pain
- Medication Order

Post-Transplant

Outpatient Care

Initially, you will be seen daily in the outpatient clinic during your treatment and recovery. You will see the doctor or nurse practitioner daily. When you arrive at the clinic, the nurse will perform a physical examination, measure your weight, and draw blood samples. **Please bring all your medications to the clinic each day.** The nurse will review your medication schedule with you. Tell the nurse when you are having problems taking any medications. Do not take any medication not prescribed by the bone marrow transplant doctor. Ask your doctor about over the counter medication, vitamins, herbal products and topicals. You will need to take some doses of medication while you are in the clinic. **Do not take Prograf before your clinic visit.** Wait until after your blood is drawn.

The length of time required for the daily clinic visit is determined by your medical condition. Clinic visits may last from 1-8 hrs depending upon the treatment needed. Adult visitors are welcome in the clinic. At times the clinic may become crowded. Visitors may be asked to wait in the waiting room if needed. **No children under 12 are allowed in the clinic.**

Please do not arrive early for your appointment unless you are ill and need immediate attention. Patients are seen based on their appointment time. Coming early may result in longer wait for service. Arriving late may cause you to miss being seen by the doctor. However, if you will be unavoidably early or late please call the clinic so that alternate arrangements can be made.

You may not drive until approved by your doctor. Please have someone escort you to and from the clinic each day. We will validate parking tickets in the clinic. A refrigerator is available if you wish to bring food or snacks. It is difficult to regulate the room temperature so please dress warmly and in layers. Do not wear strong smelling perfumes or bring strong smelling foods into the clinic, out of consideration for others who may not be feeling well. Wash hands upon entering and leaving the waiting room and clinic.

Wear a mask when you come into and exit the hospital. If you are running a fever, have a cough, sores or any rashes or blisters on your skin, let the staff know when you check in so precautions can be taken to prevent the spread of possible infections.

Please bring your binder to each appointment and write down any questions or concerns that you want to discuss with a nurse or your doctor. It is important that you tell the nurse or doctor about any problems that you are having, even if they are usual for you.

Always stop at the appointment desk to confirm your next visit before you leave the clinic.

Preventing Infection

Chemotherapy will make the infection fighting cells in your body decrease. The doctor will monitor a type of white blood cell called a neutrophil. You are at risk of developing an infection, when your neutrophil count is less than 500.

Most infections come from bacteria normally found on your skin and in your mouth, intestines and genital tract. Sometimes the cause of an infection may not be known. Even if you take extra care, you still may get an infection. But there are some things you can do. These restrictions are also known as “neutropenic precautions”.

How can I help prevent infections?

- Wash your hands often during the day. Be sure to wash them before you eat, after you use the bathroom and after touching animals.
- Clean your rectal area gently but thoroughly after each bowel movement. Ask your doctor or nurse for advice if the area becomes irritated or if you have hemorrhoids.
- Stay away from people who have illness you can catch, such as a cold, the flu, measles or chicken pox.
- Try to avoid crowds.
- Do not cut or tear the cuticles of your nails. No pedicures or manicures.
- Be careful not to cut or nick yourself when using scissors, needles or knives.
- Maintain good mouth care.
- Do not squeeze or scratch pimples.
- Take a warm (not hot) bath, shower or sponge bath every day. Pat your skin dry using a light touch. Do not rub too hard.
- Use lotion or oil to soften and heal your skin if it becomes dry and cracked.
- Clean cuts and scrapes right away and daily until healed with warm water, soap and an antiseptic.
- Avoid contact with animal litter boxes and waste, bird cages and fish tanks.
- Avoid standing water, for example bird baths, flower vases or humidifiers.
- Do not get any immunizations, such as flu or pneumonia shots, without checking with your doctor first.
- Do not eat raw fish, seafood, meat or eggs.
- Use an electric shaver instead of a razor to prevent breaks or cuts in your skin.

Sexual Activity, Dysfunction and Infertility

Now that you have gone through the bone marrow transplant process, you probably want to resume a normal lifestyle. This includes wanting to be sexually active with your partner again. Remember, it may take some time after a transplant before you are emotionally and physically ready to resume sex.



Fatigue can remain a long-term problem for many people and can cause a decrease in the desire for sex. Intimacy, such as dry kissing, holding hands, hugging, caressing and cuddling can be done throughout most of the transplant process. The key to resuming sexual activity is communication between you and your partner. Open discussions about your feelings and your level of tiredness can lead to satisfaction for both of you. Members of the transplant team can let you know if your counts are adequate for sexual activity.

Body image can affect desire and attractiveness. Many physical changes (examples can include: being without hair, nausea and vomiting, diarrhea and a catheter in your chest) can leave a transplant recipient feeling unattractive. This is an opportunity for you to find some positive aspects about yourself. The American Cancer Society recommends this exercise. Look at yourself in the mirror fully clothed as if on a date and say some positive things about yourself. Continue this exercise until you are comfortable with how you see yourself; then start the exercise in the nude. Again, find something positive about yourself. Ask your partner to tell you what they see positive in you and remember those things.

Sexual Activity

Sexual intercourse should not be started until your platelet count is greater than 50,000 and your neutrophil count is greater than 2,000. Water-based soluble lubricants can soothe dryness during intercourse and will also prevent injury or infection. Sexual positions that used to be pleasurable may no longer be comfortable. Talk to your partner and find something that works well for both of you. You will be given a booklet “Sexuality and Cancer” by the American Cancer Society on your second visit; information in this booklet can be helpful. Please let us know if you want another booklet.

To reduce your chances of infection, genitalia should be washed and you should urinate after intercourse. Never have sex with anyone who has open wounds, herpes outbreak or sores to their genitalia. Wet kissing should not be done if there are some sores to one’s mouth.

If you are sexually active with more than one partner, you should use condoms to prevent getting a sexually transmitted disease. A female condom or vaginal dam is not as

effective as male latex condoms. Some spermicidal gels can cause skin irritation and should be used with caution. If you or your partner is suspected of having a sexually transmitted disease (STD), condoms may not be a sufficient barrier and medical attention will be necessary. It is best not to have sexual activity during treatment for STDs.

Oral sex is permissible as long as there is no biting, gentleness is used and there are no oral or genital lesions, nor any mucositis. If you have more than one partner, oral sex can be made safer if wearing a condom or vaginal dam. Masturbation is acceptable; be sure to check your genitalia for bruising or petechiae. Promptly let your physician know if there is bruising, petechiae, sores, pain, drainage or an infection to your genitalia.

Avoid penetration into the vaginal or rectum with sexual aid devices such as vibrators or dildos. Anal sex should be avoided because of infection risk and bleeding. Please consult your physician if you wish to resume anal sex.

Sexual Dysfunction

Sexual dysfunction can affect both men and women after transplant. This period can last a few weeks or as long as several months. Some cases of sexual dysfunction may also require some psychological counseling, especially if dysfunction was a problem prior to cancer treatment. Having open discussions with your partner and your healthcare provider is the first step to resolving sexual dysfunction.

Chemotherapy and/or radiation can alter functioning of sex organs. A woman's vagina can become dry, causing pain and irritation during intercourse. This can be solved by using a water-soluble lubricant (such as K-Y jelly). Lubricants that are colored or scented should be avoided to prevent irritation. Persistent vaginal dryness requires a full gynecological exam. Let your physician or nurse practitioner know if there are changes to your vagina (dryness, pain, possible menstrual changes, discharge) so that a gynecological referral can be made for you.

Women can experience irregular periods, or not have any at all, after a stem cell transplant. If your period lasts more than 7 days, notify your doctor or nurse practitioner. It is not recommended to use tampons for your menstrual period until told it is okay. Cancer treatments can interfere with an erection by damaging nerves, blood vessels or hormonal balance. Performance anxiety can interfere with a man's erection and in some cases, counseling, medical or surgical treatments may be necessary to restore or maintain erections. Problems caused by anxiety can include: loss of sexual desire, trouble reaching orgasm, premature ejaculation, and erection problems without medical reason. If you are experiencing pain with your ejaculation or are concerned about erectile dysfunction, talk to your primary care physician.

Infertility

If you are of child bearing age during cancer treatment, infertility can be a problem for many men and women, especially after a bone marrow transplant. You may have been told you may not get pregnant or father children, after a transplant. It is still unclear if

people are able to have children after a transplant, therefore, some form of birth control should be used once intercourse has started until you are ready to start a family.

Men have the option of sperm banking before treatment starts, but women are not always able to store eggs prior to treatment due to time constraints. If you want to start a family after a stem cell transplant, a referral to an infertility specialist should strongly be considered. There are also support groups such as Fertile Hope and the Lance Armstrong Foundation to offer advice and direction. Be advised that most insurance companies do not cover costs of fertility preservation.

Online Resources

American Cancer Society www.cancer.org

American Association of Sex Educators, Counselors and Therapists (AASECT)
www.aasect.org

Fertile Hope www.fertilehope.org

Lance Armstrong Foundation www.laf.org

Fatigue

Fatigue, feeling tired and lacking energy, is the most common symptom reported by cancer patients. The exact cause is not always known. It can be due to your disease, chemotherapy, radiation, low blood counts, lack of sleep, pain, stress, poor appetite, along with many other factors. Fatigue from cancer feels different from fatigue of everyday life. Fatigue caused by chemotherapy can appear suddenly. Patients with cancer have described it as a total lack of energy and have used words such as worn out, drained, and wiped out to describe their fatigue, and rest does not always relieve it. Not everyone feels the same kind of fatigue. You may not feel tired, while someone else does, or your fatigue may not last as long as someone else's does. Fatigue after a transplant can last from months to one year.

How can I cope with fatigue?

- Plan your day so that you have time to rest
- Take short naps or breaks, rather than one long rest period
- Save your energy for the most important things
- Try easier or shorter versions of activities you enjoy
- Take short walks or do light exercise if possible
- Talk to your health care provider about ways to save your energy

Nausea and Vomiting

Many patients fear that they will have nausea and vomiting while receiving chemotherapy. But new drugs have made these side effects far less common and when they do occur, much less severe. These powerful antiemetics, or anti-nausea drugs, can decrease nausea and vomiting in most patients. Different drugs work for different people, and you may need more than one drug to get relief. Do not give up. Continue to work with your doctor and nurse to find the drug or drugs that work best for you. Also, be sure to tell your doctor or nurse if you are very nauseated or have vomited for more than a day or if your vomiting is so bad that you cannot keep liquids down.

What can I do if I have nausea and vomiting?

- Drink liquids at least an hour before or after mealtime, instead of with your meals. Drink frequently and drink small amounts.
- Eat and drink slowly.
- Eat small meals throughout the day, instead of one, two, or three large meals.
- Eat foods cold or at room temperature so you won't be bothered by strong smells.
- Chew your food well for easier digestion
- If nausea is a problem in the morning, try eating dry foods like cereal, toast, or crackers before getting up. (Do not try this if you have mouth or throat sores or are troubled by a lack of saliva.)
- Drink cool, clear, unsweetened fruit juices, such as apple or grape juice or light-colored sodas such as ginger ale that have lost their fizz and do not have caffeine.

- Suck on mints, or tart candies. Do not use tart candies if you have mouth or throat sores.
- Prepare and freeze meals in advance for days when you do not feel like cooking.
- Wear loose-fitting clothes.
- Breathe deeply and slowly when you feel nauseated.
- Distract yourself by chatting with friends or family members, listening to music or watching a movie or TV show.
- Use relaxation techniques.
- Try to avoid odors that bother you, such as cooking smells, smoke or perfume.
- Avoid sweet, fried or fatty foods.
- Rest but do not lie flat for at least 2 hours after you finish a meal.
- Avoid eating for at least a few hours before treatment if nausea usually occurs during chemotherapy.

Whatever the cause, nausea can keep you from getting enough food and needed nutrients. Here are some ideas that can help:

- Ask your doctor about antiemetics that might help you control nausea and vomiting.
- Try foods that are easy on your stomach, such as:
 - Toast, crackers and pretzels
 - Yogurt
 - Sherbet
 - Angel food cake
 - Cream of wheat, rice or oatmeal
 - Boiled potatoes, rice or noodles
 - Skinned chicken that is baked or broiled, not fried
 - Canned peaches or other soft, bland fruits and vegetables
 - Clear liquids
 - Ice chips
 - Carbonated drinks
- Avoid foods that:
 - Are fatty, greasy or fried
 - Are very sweet, such as candy, cookies or cake
 - Are spicy or hot
 - Having strong odors
- Eat small amounts, often and slowly. Eat before you get hungry, because hunger can make feelings of nausea stronger.
- If nausea makes certain foods unappealing, then eat more of the foods you find easier to handle.
- Avoid eating in a room that's stuffy, too warm or has cooking odors that might disagree with you.
- Slowly drink or sip liquids throughout the day. A straw may help. Have foods and drinks at room temperature or cooler; hot foods may add to nausea.
- Don't force yourself to eat favorite foods when you feel nauseated. This may cause a permanent dislike for those foods.

Pain

Not everyone with cancer or who receives chemotherapy experiences pain from the disease or its treatment. But if you do, it can be relieved. The first step to take is to talk with your doctor, nurse and pharmacist about your pain. They need to know as many details about your pain as possible. You may want to describe your pain to your family and friends. They can help you talk to your caregivers about your pain, especially if you are too tired or in too much pain to talk to them yourself.

You need to tell your doctor, nurse and pharmacist and family or friends:

- Where you feel pain.
- What it feels like – sharp, dull, throbbing, steady.
- How strong the pain feels.
- How long it lasts.
- What eases the pain, what makes the pain worse.
- What medicines you are taking for the pain and how much relief you get from them.

Using a pain scale is helpful in describing how much pain you are feeling. Try to assign a number from 0 to 10 to your pain level. If you have no pain, use a 0. As the numbers get higher, they stand for pain that is getting worse. A 10 means the pain is as bad as it can be. You may wish to use your own pain scale using numbers from 0 to 5 or even 0 to 100. Be sure to let others know what pain scale you are using and use the same scale each time, for example, “my pain is 7 on a scale of 0 to 10”.

The goal for pain control is to prevent pain that can be prevented and treat the pain that can't. To do this:

- If you have persistent or chronic pain, take your pain medicine on a regular schedule (by the clock)
- Do not skip doses of your scheduled pain medicine. If you wait to take pain medicine until you feel pain, it is harder to control.
- Try using relaxation exercises at the same time you take medicine for the pain. This may help to lessen tension, reduce anxiety and manage pain.
- Some people with chronic or persistent pain that is usually controlled by medicine can have breakthrough pain. This occurs when moderate to severe pain “breaks through” or is felt for a short time. If you experience this pain, use a short-acting medicine ordered by your doctor. Don't wait for the pain to get worse. If you do, it may be harder to control.

Managing Medications

You will receive many types of medication during your treatment. Medications may be scheduled or as needed. Take your scheduled medications about the same time every day. As needed medication, may be prescribed to help control symptoms, such as, pain, diarrhea or nausea.

If it is hard to take a large number of medications at one time, ask the nurses how to alter the medication schedule.

Problems swallowing medication

Some medication may also be crushed or given in a liquid form if swallowing is a problem. Ask your nurse, doctor or pharmacist.

Missed doses

If you miss a dose of your scheduled medication, calculate the time between the missed dose and the next dose. If less than half of the time between doses has passed, you may take the missed dose and continue on your regular time schedule.

If more than half of the time between doses has passed, skip the missed dose and take the next dose at the regular time.

Vomiting

If vomiting occurs within 15 minutes of taking a medicine dose, look to see if the medicine is in the vomit. If you can see the medicine in the vomit, you may repeat the dose. Do not repeat the dose if the medicine is in a liquid form.

Pain Medication

Pain medication works best when taken before pain is severe. If you are in pain, take your pain medication around the clock. Pain medication might make you drowsy, but this will improve with time. If the medication is not controlling your pain, let the doctor know. Your body heals better if you are not in pain.

Nausea Medication

If you are feeling sick to your stomach, take the anti-nausea medication around the clock. If food worsens the nausea, take the medication 30-60 minutes before meals.

Medication Refills

Please request a refill 2 days before your medication runs out to allow enough time for processing. Please allow 5-7 days (minimum) for mail order refills.

Glossary of Common Medications

Trade Name	Generic Name	Function	Comments
Afrin	Oxymetalozone	Relieve nasal congestion	Do not use more than 3 days
Ambien	Zolpidem	Sleep aid	Take only as needed
Anzemet	Dolasetron	Prevent/treat nausea and vomiting	
Ativan	Lorazepam	Prevent/treat nausea and vomiting	May cause drowsiness
Benadryl	Diphenhydramine	Itching	Take only as needed
Catapres-TTS patch	Clonidine	Control blood pressure	Rotate patch sites weekly. Use protective cover over patch.
Cipro	Ciproflaxcin	Prevent/treat bacterial infection	Do not take with anti-acids
Compazine	Prochlorperazine	Prevent/treat nausea and vomiting	Take only as needed
Cytovene	Ganciclovir	Prevent/treat CMV infections	
Diflucan	Fluconazole	Treat/prevent fungal infections	May take with food
Dilaudid	Hydromorphone	For pain	
Duragesic	Fentanyl	For pain	Rotate patch sites
Fibercon	Polycarbophil	For diarrhea	Take with a glass of water
Immodium	Loperamide	Treat diarrhea	Take as needed
K-Dur	Potassium Chloride	Potassium replacement	Take with food. Do not chew or crush.
Leucovorin	-----	Prevent side effects of Methotrexate	
Levaquin	Levofloxacin	Treat/prevent bacterial infections	Do not take with anti-acids
Lexapro	Escitalopram	Anti-depressant	Do not stop taking medication suddenly
Lortab	Hydrocodone, acetaminophen	Pain	
Medrol	Methylprednisolone	Prevent/treat graft versus host disease	
Neupogen	Filgramtim	Increase white blood cells	Injection
Pen-Vee-K	Penicillin V & potassium	Prevent/treat bacterial infections	Take on an empty stomach
Pepcid	Famotidine	Treat/prevent ulcers	

Peridex	Chlorhexidine gluconate	Antibacterial mouthwash	
Trade Name	Generic Name	Function	Comments
Phenergan	Promethazine	Prevent/treat nausea	
Pink magic	Viscous lidocaine/Mylanta/benadryl	For mouth/throat pain	
Prednisone	-----	Anti-inflammatory	Take with food
Prograf	Tacrolimus, FK507	Prevent graft versus host disease	Do not take before clinic visits. Take with food
Provera	Medroxyprogesterone	Prevent menstrual periods	Take with food
Rifampin	-----	Prevent/treat bacterial infections	Take on empty stomach. Urine may turn orange.
Roxanol	Morphine	For pain	
Sandimmune	Cyclosporine	Prevent graft versus host disease	Do not take before clinic visits
Septra/bactrim	Cotrimoxazole	To prevent PCP infection	
Slo-mag	Magnesium Chloride	Replace magnesium	Take with meals
Solu-medrol	Methylprednisolone	Prevent/treat graft versus host disease	Take with food
Vancomycin	-----	Treat infections	
Valcyte	Valgancyclovir	Treat CMV infections	
Xanax	Alprazolam	Treat/prevent anxiety	May cause drowsiness
Zovirax	Acyclovir	Prevent/treat viral infections	May take with food

Patients undergoing chemotherapy and/or a bone marrow transplant are advised to avoid any medications containing aspirin or aspirin-like ingredients. These products may adversely affect the platelets and therefore, should be avoided.

Aspirin

(ASA; Acetyl Salicylic Acid)

Alka Seltzer Pain, Relief and Antacid
Alka Seltzer Plus Cold Medicine
Anacin Analgesic
Anacin Maximum-Strength Analgesic
Arthritis Bayer Timed-Release Aspirin
Arthritis Pain Formula Arthritis-Strength
Bufferin Ascriptin
Ascriptin A/D
Aspergum
Aspirin, any brand
Bayer Aspirin
Bayer Children's Chewable Aspirin
Buferin
Congespirin Chewable Cold Tablets
Coricidin D
Coricidin
Ecotrin
Ecotrin Maximum Strength
Excedrin
Extra-Strength Bufferin
4-Way Cold Tablets
Midol
Panalgesic
St. Joseph's Cold Tablets for Children
Sine-Off Sinus Medicine
Triaminicin
Vanquish

Bismuth Sub Salicylate

Pepto Bismol Liquid and Tablets

Magnesium Salicylate

Doan's Pills

Salicylamide

Os-CAL-Gesic Tablets

Topical Medications

(external use)

Methyl Salicylate

Analgesic Balm
Arthrocare Lotion
Ben Gay
Deep Down Pain Relief
Icy Hot
Mentholatum Deep Heat
Sinex Decongestant Spray

Salicylamide

Compound W
Freezone
Mediplast
Whitfields Ointment

Note: Do not take Motrin, Advil, Ibuprofen or any other over-the-counter medication not prescribed by your doctor.