


# Chronic Graft versus Host Disease:

## *Self-Management Options to Improve Symptoms, Function, and Well-Being*

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# Purpose

This presentation will explore options to manage symptoms and maintain and improve health and well-being while living with chronic GvHD

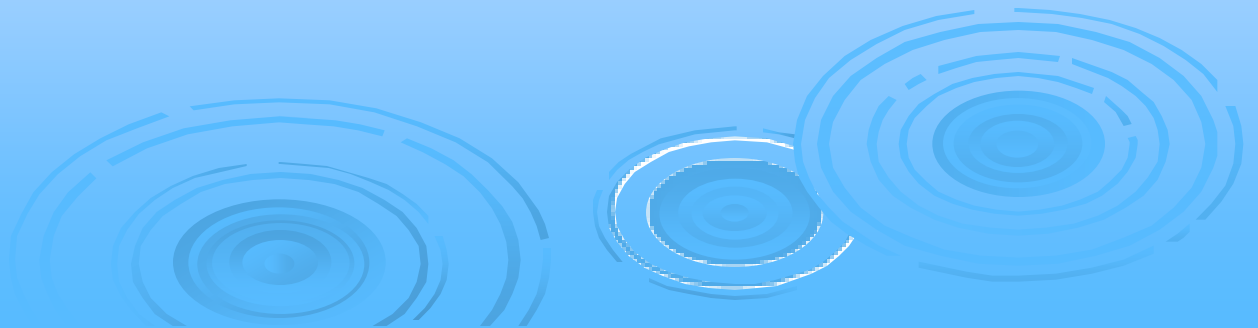


Additional resources that may be helpful :

- ***Survivorship Guide For Bone Marrow/ Stem Cell Transplant:Coping with Late Effects***
  - ([www.nbmtlink.org/resources\\_support/spg/index.htm](http://www.nbmtlink.org/resources_support/spg/index.htm))
- ***Resource Guide for Stem Cell Transplant***
  - ([www.nbmtlink.org/resources\\_support/rg/index.htm](http://www.nbmtlink.org/resources_support/rg/index.htm))
- ***Long-Term Survival Guidelines for Recommended Post Transplant Care***
  - ([www.marlow.org/PHYSICIAN/Medical\\_Education/Quick\\_Reference/index.html](http://www.marlow.org/PHYSICIAN/Medical_Education/Quick_Reference/index.html))

# Overview of Topics

- Options for Managing Common GVHD-Related Symptoms
  - Skin
  - Mouth
  - Eyes
  - Lungs
  - Vulvovaginal
  - Muscle pain/cramping , joint pain, and joint restrictions
- Peripheral Neuropathy
- Sleep Disturbances
- Fatigue
- Sexuality & Intimacy
- Stress Management
- Exercise
- Nutrition

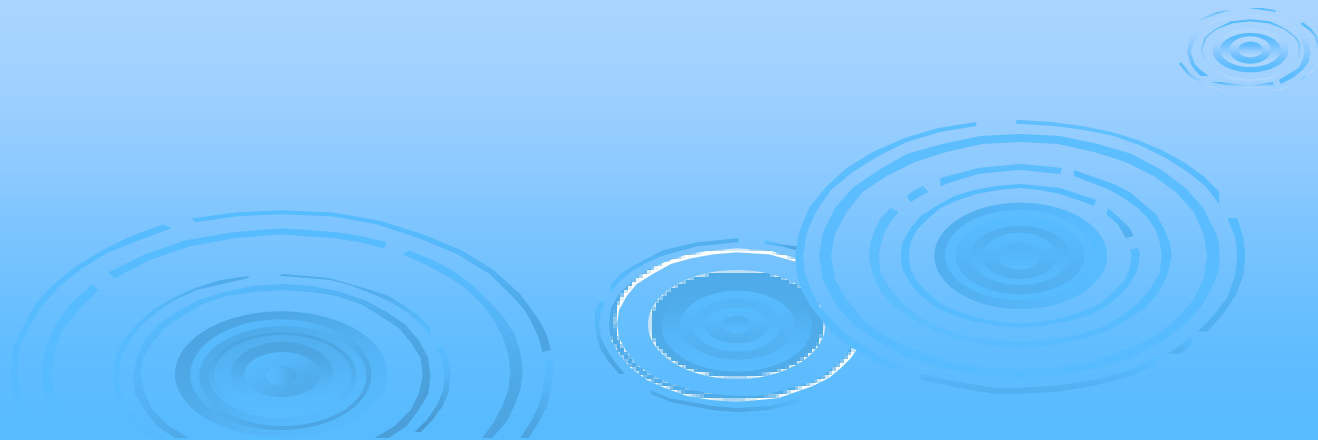


# Skin and Soft Tissues

- **Immunosuppressive therapy**
- **Clinical trials of new therapies such as imatinib mesylate**
- **Extracorporeal photopheresis (ECP)**
- **PUVA**
- **Topical immunosuppressants (topical steroids, tacrolimus ointment)**
- **Emollients/lubricants**
- **Avoid overheating (GVHD destroys sweat glands)**
- **Sun exposure can cause GVHD to flare**

# Oral GVHD

- **Topical immunosuppressive mouth rinses and ointments**
- **Saliva substitutes for dry mouth**
- **Oral PUVA**
- **Routine dental prophylaxis (cleaning) and fluoride applications/mouth rinses**



# Ocular (Eye)GVHD


- Annual ophthalmologic evaluation
- Preservative-free artificial tears
- Topical immunosuppressive agents (steroid eye drops and ointments, cyclosporine eye drops)
- Temporary and permanent lacrimal duct occlusion
- Scleral lenses
- Autologous serum eye drops



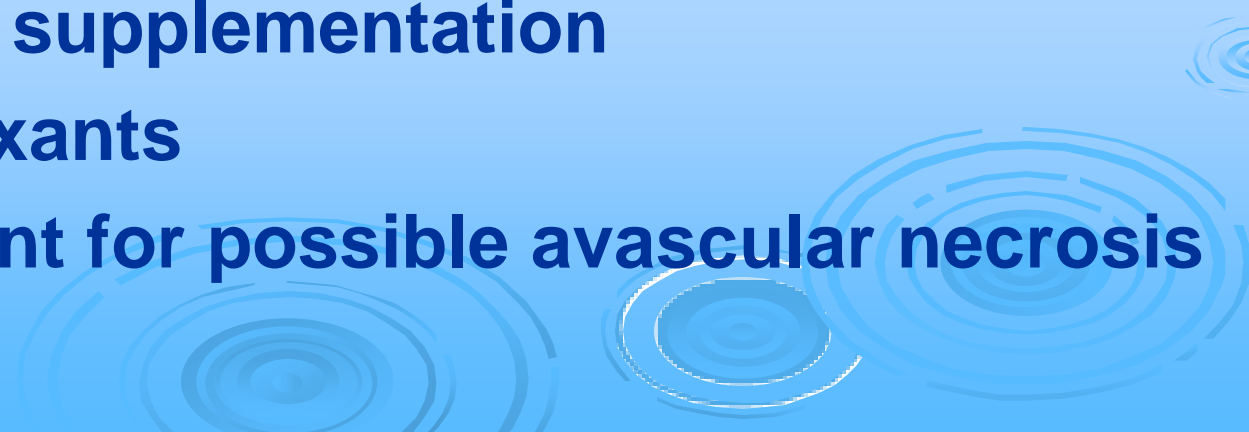
# Lung GVHD

- Pulmonary function studies at regular intervals
- Prevent infections: preventative antimicrobials/antibiotics, vaccination, annual flu shot,
- Report immediately symptoms such as shortness of breath with activity, wheezing, cough, and difficulty breathing
- Do not smoke
- Clinical trial
- Consider inhaled steroids, inhaled medications that relax the muscles in the lungs (beta-agonists), montelukast, Azithromycin

# Vulvovaginal GVHD

- Annual gynecologic examination
  - Topical steroids, cyclosporine, or tacrolimus ointment.
  - Consider risk/benefit ratio for low dose vaginal estrogen (eg. Estring)
  - Lubrication during sexual intercourse
  - Vaginal dilators to reduce synechiae/webbing/narrowing
  - Sexual counselling
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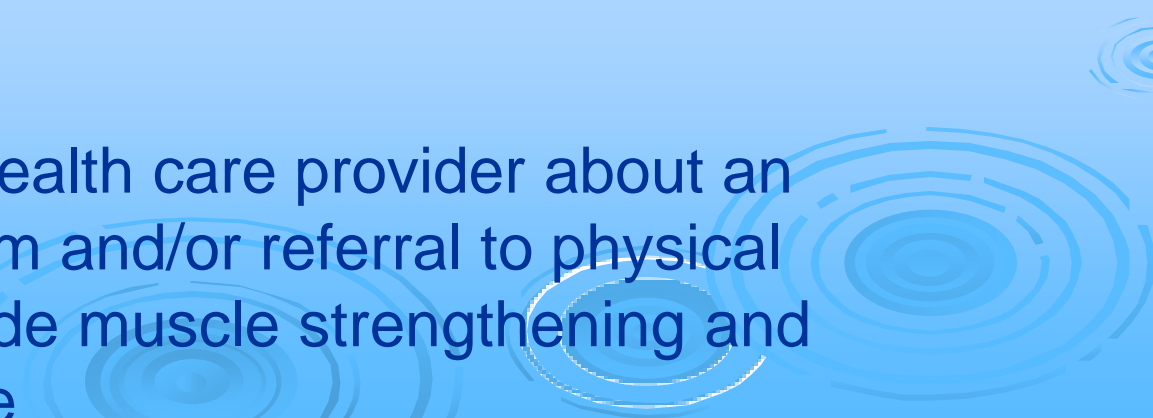
# **Muscle Pain/Cramping, Joint Pain/Restrictions**

- **Immunosuppressive treatment**
  - **Clinical trial**
  - **Physical therapy for stretching and strengthening**
  - **Application of heat**
  - **Acupuncture**
  - **Magnesium supplementation**
  - **Muscle relaxants**
  - **Evaluate joint for possible avascular necrosis**
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# Peripheral Neuropathy

- **Caused by inflammation, injury, or deterioration of the peripheral nerve fibers**
- **Results in numbness, tingling, aching, pins and needles, burning, shooting pains, cramping, weakness, clumsiness**
- **May occur as a side effect of cancer treatment**
  
- **Other common causes include:**
  - *Certain immunosuppressive medications*
  - *Diabetes mellitus*
  - *Nutritional imbalances, especially deficiencies of vitamins B12 or B6*
  - *Alcohol abuse*
  - *HIV/AIDS*
  - *Lead poisoning*
  - *Hypothyroidism*
  - *Auto-immune disorders*
  - *Hereditary peripheral neuropathies (such as Charcot-Marie Toothe disease)*
  - *Medications including anti-tuberculosis medications such as isoniazid or ethambutol; antibiotics such as gentamycin or ciprofloxacin; phenytoin used to control seizures*
  - *Atherosclerosis/ ischemic disease (blood vessel and/or heart disease)*

# Things to Consider

- Ask your health care provider if you might benefit from a comprehensive neurologic examination and neurologic screening studies
  - If you have a painful peripheral neuropathy (eg. shooting pains, pins and needles, aching) talk with your team about strategies for managing the pain of peripheral neuropathy:
    - medications such as neurontin, tricyclic antidepressants,
    - transcutaneous electrical nerve stimulation (TENS)
    - massage
    - Acupuncture
  - Talk with your health care provider about an exercise program and/or referral to physical therapy to provide muscle strengthening and improve balance
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# Peripheral Neuropathy Resources

- **Cancer Symptoms**

- ([www.cancersymptoms.org/peripheralneuropathy/overview.shtml](http://www.cancersymptoms.org/peripheralneuropathy/overview.shtml))

- **MayoClinic**

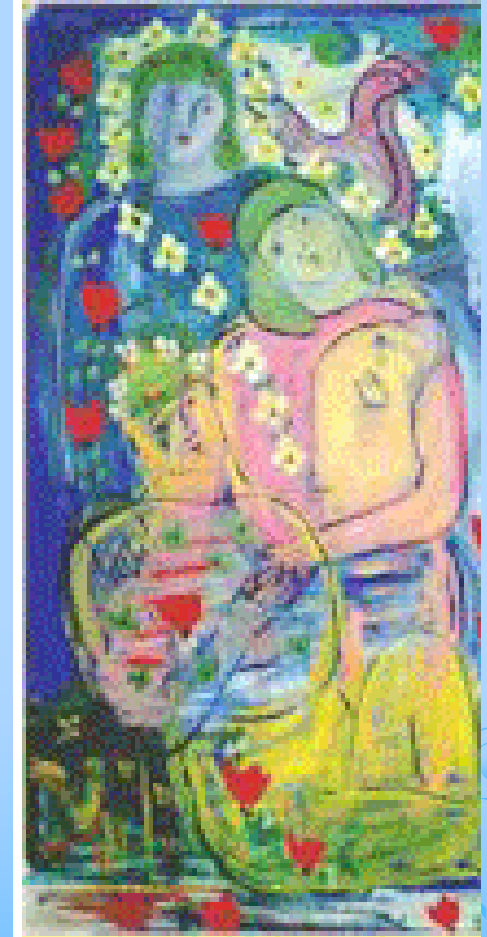
- ([www.mayoclinic.com/health/peripheral-neuropathy](http://www.mayoclinic.com/health/peripheral-neuropathy))

- **Oncolink**

- ([www.oncolink.com/coping/article.cfm?c=5&s=70&ss=52&id=577](http://www.oncolink.com/coping/article.cfm?c=5&s=70&ss=52&id=577))

# Fatigue

- Fatigue can be a frustrating reminder of all that you have been through and what you are coping with now
- Fatigue can last for months to years and is physically and emotionally draining for the patients and their families
- Individuals recovering from transplant often find that fatigue is particularly difficult to manage, and often describe it as a 'tiredness' unlike any other
- General weakness may be accompanied by limb heaviness, decreased ability to concentrate, sleeplessness, and/or irritability

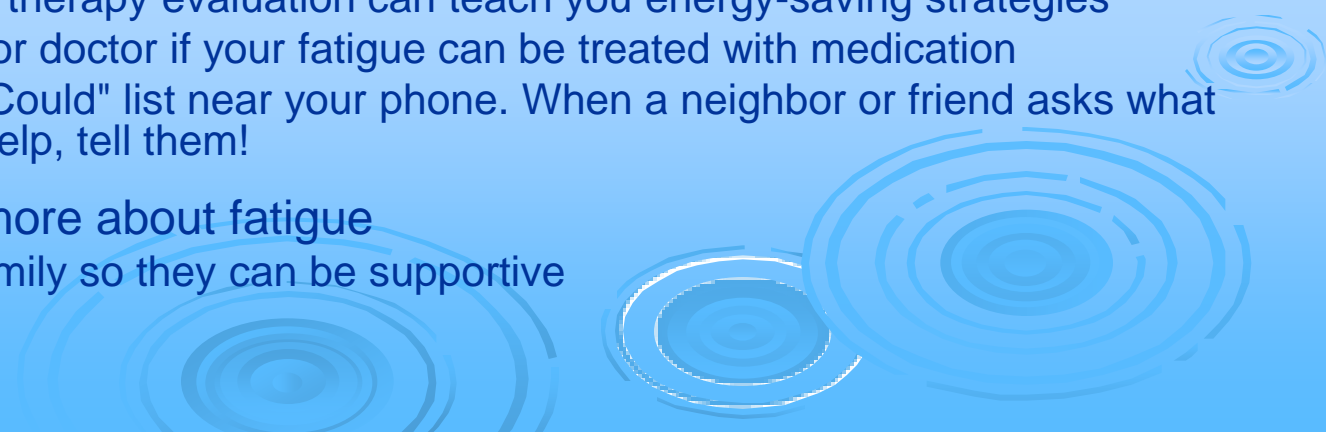


# Things to Consider

- If you are experiencing this type of extreme tiredness, begin by speaking to your nurse or doctor about it. A low blood count, sleep disturbances, stress, depression, poor nutrition, infection, or medication side effects can all contribute to this exhaustion
- A few simple tests will help your health provider eliminate some immediately treatable causes for fatigue. These tests include the following:
  - Blood count to check for anemia or infection
  - Thyroid function tests
  - Physical examination

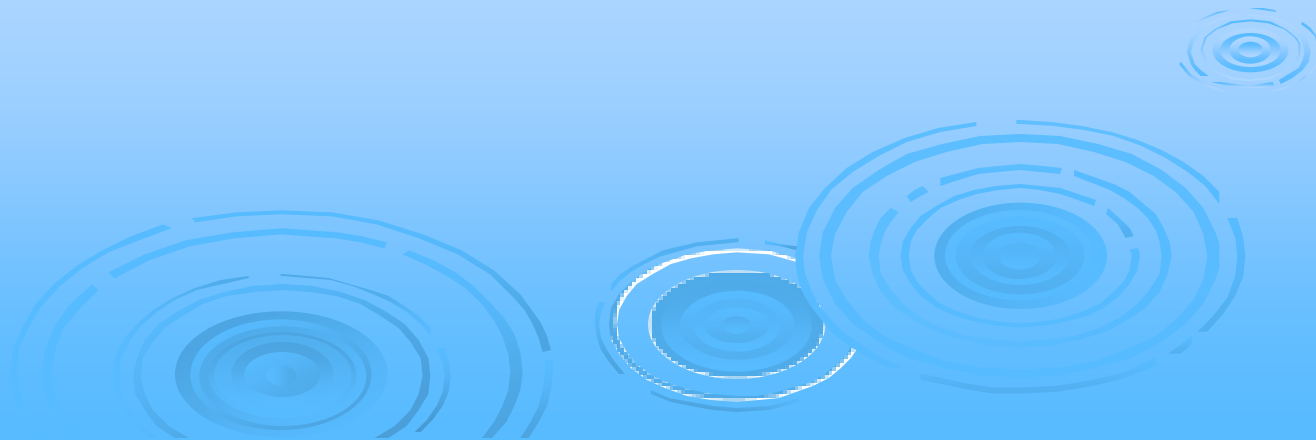


# Strategies for Managing Fatigue

- **Energy** – Develop your own "energy conservation" program
    - Pace yourself through the day, saving necessary activities for the time of day you tend to have more energy
    - Keep a journal to learn your energy patterns
  - **Appetite** – Eat healthful, appetite-stimulating foods
  - **Exercise** – A moderate amount of exercise may help improve your energy level
    - Find a friend to walk with. He or she can encourage you to get out when you're tempted to stay in
  - **Sleep** – Go to bed at a regular time each day and follow a regular routine
  - **Resources** – Your healthcare team, friends, and family are there to help you!
    - An exercise or physical therapy program can also help with strengthening muscles
    - An occupational therapy evaluation can teach you energy-saving strategies
    - Ask your nurse or doctor if your fatigue can be treated with medication
    - Keep a "Wish I Could" list near your phone. When a neighbor or friend asks what they can do to help, tell them!
  - **Education** – Learn more about fatigue
    - Educate your family so they can be supportive
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# Fatigue Resources

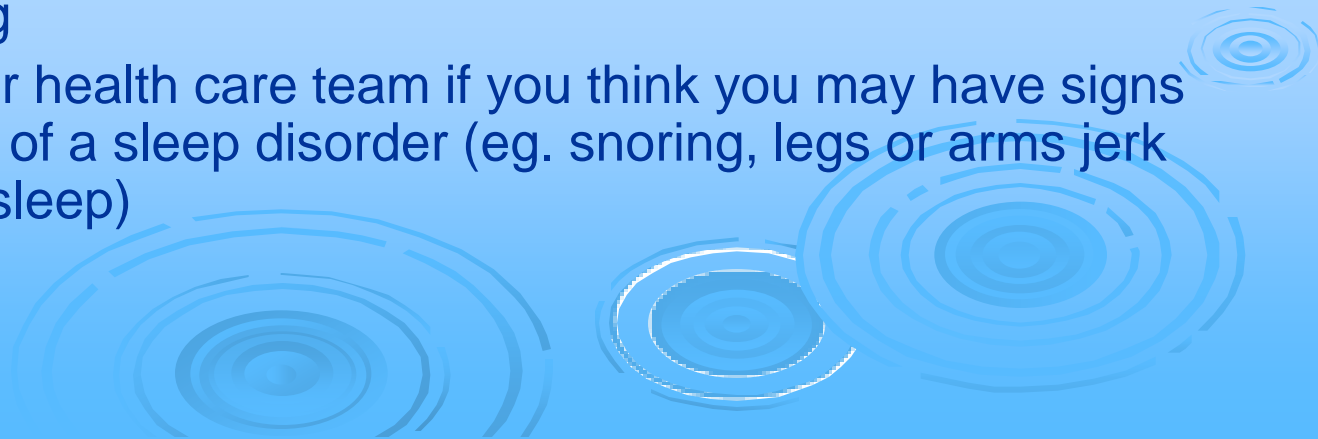
- **The Oncology Nursing Society**
  - ([www.cancersymptoms.org/fatigue](http://www.cancersymptoms.org/fatigue))
- **The Leukemia and Lymphoma Society**
  - ([www.leukemia-lymphoma.org/all\\_mat\\_toc.adp?item\\_id=9635&cat\\_id=1214](http://www.leukemia-lymphoma.org/all_mat_toc.adp?item_id=9635&cat_id=1214))
- **Livestrong: Resource for Cancer Survivors**
  - ([www.livestrong.org/atf/cf/%7BFB6FFD43-0E4C-4414-8B37-0D001EFBDC49%7D/Fatigue.pdf](http://www.livestrong.org/atf/cf/%7BFB6FFD43-0E4C-4414-8B37-0D001EFBDC49%7D/Fatigue.pdf))



# Sleep Disturbances

Many people have difficulties sleeping, and adding the stress to body and mind of undergoing a transplant and experiencing chronic GvHD typically doesn't make the problem better

- Sleep problems include difficulty falling asleep, staying asleep, waking up too early in the morning, or feeling too sleepy during the day
- Lack of adequate sleep or sleep that is not sufficiently 'deep' can leave you feeling fatigued, irritable, and with difficulties concentrating
- Talk with your health care team if you think you may have signs or symptoms of a sleep disorder (eg. snoring, legs or arms jerk often during sleep)



# Things to Consider

- Restrict the amount of time spent in bed as close as possible to the actual sleep time
- Go to bed only when sleepy, not just fatigued but sleepy
- If unable to sleep (e.g. within 20 min), get out of bed and go to another room and return to bed only when sleep is imminent
- Avoid daytime napping
- Use the bed and bedroom for sleep (and sex) only; no eating, TV watching, radio listening, planning or problem solving in bed
- Maintain a regular sleep schedule, particularly a strict arising time every morning regardless of the amount of sleep the night before



# Sleep Disturbance Resources

- **National Institutes of Health; National Heart Lung and Blood Institute**
  - ([www.nhlbi.nih.gov/sleep](http://www.nhlbi.nih.gov/sleep))
- **American Psychological Association**
  - ([www.psychologymatters.org/insomnia.html](http://www.psychologymatters.org/insomnia.html))
- **National Sleep Foundation**
  - ([www.centers.sleepfoundation.org/insomnia](http://www.centers.sleepfoundation.org/insomnia))
- **Talk About Sleep**
  - ([www.talkaboutsleap.com/sleep-disorders/archives/cancer\\_english.htm](http://www.talkaboutsleap.com/sleep-disorders/archives/cancer_english.htm))



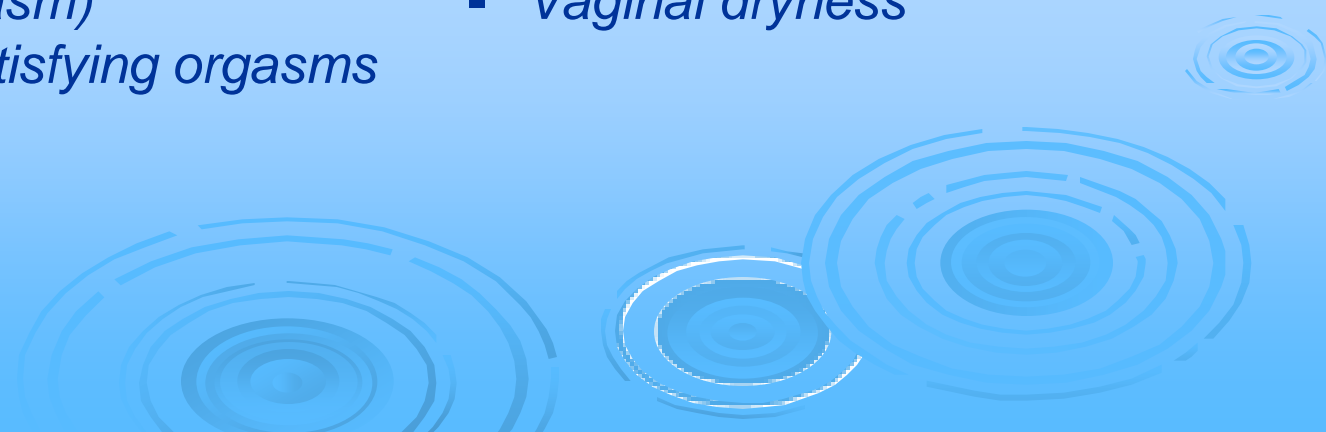
# Sexuality and Intimacy

- Sex might be the last thing on your mind as you manage the challenges after a stem cell transplant
- As time goes on, many people want to get back to a "normal" life as much as they can – which includes resuming sexual intimacy with their partners
- The sexual side effects of prior treatment and GvHD can make resuming sexual activity more difficult
- It may take time for you to regain your sexual function after cancer treatment
- Know that if you had a positive and satisfying sex life before cancer, you will likely resume that after your treatment



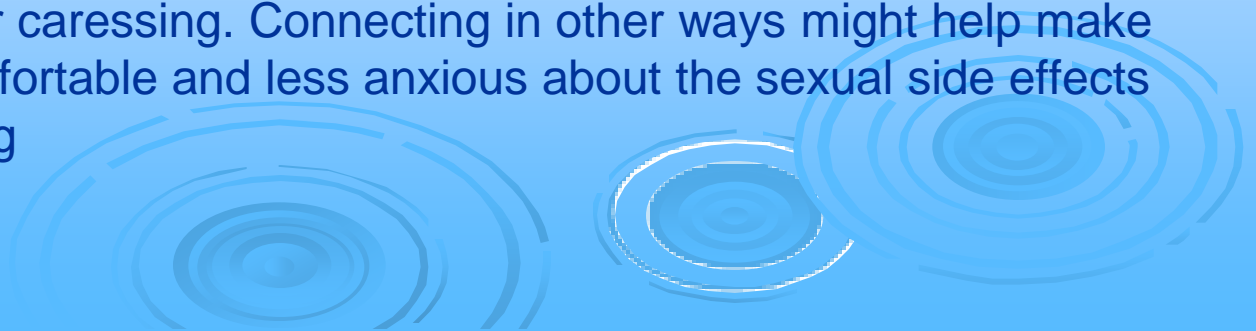
# Things to Consider

The treatment you received and the extent of your chronic GvHD will influence whether you experience any sexual side effects

- The most commonly reported side effects among men include:
    - *Inability to achieve or maintain an erection (erectile dysfunction)*
    - *Difficulty climaxing*
    - *Orgasm without discharge of semen (dry orgasm)*
    - *Weaker, less satisfying orgasms*
    - *Loss of libido*
    - *Pain during sex*
  - The most commonly reported side effects among women include:
    - *Difficulty reaching climax*
    - *Loss of desire for sex*
    - *Pain during penetration*
    - *Reduced size of the vagina*
    - *Vaginal dryness*
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# Resources for Sexuality & Intimacy

- **Talk with your health care team.** Though talking about sex can be awkward, you'll never find a solution if you don't let someone know what you're experiencing. Write down your questions if it makes you feel more comfortable. Also know that your team may be embarrassed or hesitant to talk about sex. Ask to be referred to a specialist or seek support from other members of your health care team, such as nurses and counselors
- **Talk with your partner.** Let your partner know what you're experiencing and how he or she can help you cope. For instance, you might find that using a lubricant eases your vaginal dryness or changing positions helps you avoid genital pain during sex. Together you can think of solutions to ease you back into a fulfilling sex life
- **Explore other ways of being intimate.** Intercourse isn't your only option for closeness with your partner. Consider spending more time together talking, cuddling or caressing. Connecting in other ways might help make you feel more comfortable and less anxious about the sexual side effects you're experiencing



# Resources for Sexuality & Intimacy

- **National Cancer Institute**
  - ([www.nci.nih.gov/cancertopics/pdq/supportivecare/sexuality/Patient](http://www.nci.nih.gov/cancertopics/pdq/supportivecare/sexuality/Patient))
- **Cancer Backup**
  - ([www.cancerbackup.org.uk/resourcessupport/relationshipscommunication/sexuality](http://www.cancerbackup.org.uk/resourcessupport/relationshipscommunication/sexuality))
- **American Cancer Society**
  - ([www.cancer.org/docroot/MIT/mit\\_7.asp?sitearea=MIT](http://www.cancer.org/docroot/MIT/mit_7.asp?sitearea=MIT))
- **Cancer Supportive Care Programs**
  - ([www.cancersupportivecare.com/sexuality.html](http://www.cancersupportivecare.com/sexuality.html))



# Stress Reduction



- Chronic GvHD affects patients and their caregivers on a daily basis
- The chronic nature of the disease adds stress to lives of patients, caregivers and support systems
- Being able to identify ways to reduce and manage stress may help you and your caregiver

# Questions to ask Yourself?

- How do I manage stress?
- How does my caregiver, support person or spouse manage their stress?
- What can I do to limit stress?
- Do I build “down time” into my schedule?
- Do I have a system for organizing medical information, appointments etc. so that it is easily accessible?



# Ways to Reduce Stress

- Make time in your schedule for “down time”
- Develop an exercise regimen
- Have a hobby or something you enjoy doing that helps you to relax
- Explore yoga, tai chi and therapeutic massage
- Address depression with your medical team



# Resources for Stress Management

- Work with your medical team to set up a communication system which is effective
- Support groups - e.g. face-to-face, telephone, web-based, blogs
- The Wellness Community – support groups, Yoga, Tai Chi and educational presentations
- Local community center or gyms for classes
- Counseling for children at school



# Resources for Stress Management

- **National Bone Marrow Transplant Link**
  - ([www.nbmtlink.org](http://www.nbmtlink.org))
- **Bone Marrow Transplant Info. Net**
  - ([www.bmtinfonet.org](http://www.bmtinfonet.org))
- **National Marrow Donor Program**
  - ([www.marrows.org](http://www.marrows.org))
- **Lance Armstrong Foundation**
  - ([www.livestrong.org](http://www.livestrong.org))
- **Planet Cancer**
  - ([www.planetcancer.org](http://www.planetcancer.org))
- **The Cancer Support Community (also known as the Wellness Community)** ([www.cancersupportcommunity.org](http://www.cancersupportcommunity.org))



# Exercise

- Exercise can decrease stress, lessen fatigue and slow or stop muscle loss
- Exercise can increase range of motion and mobility



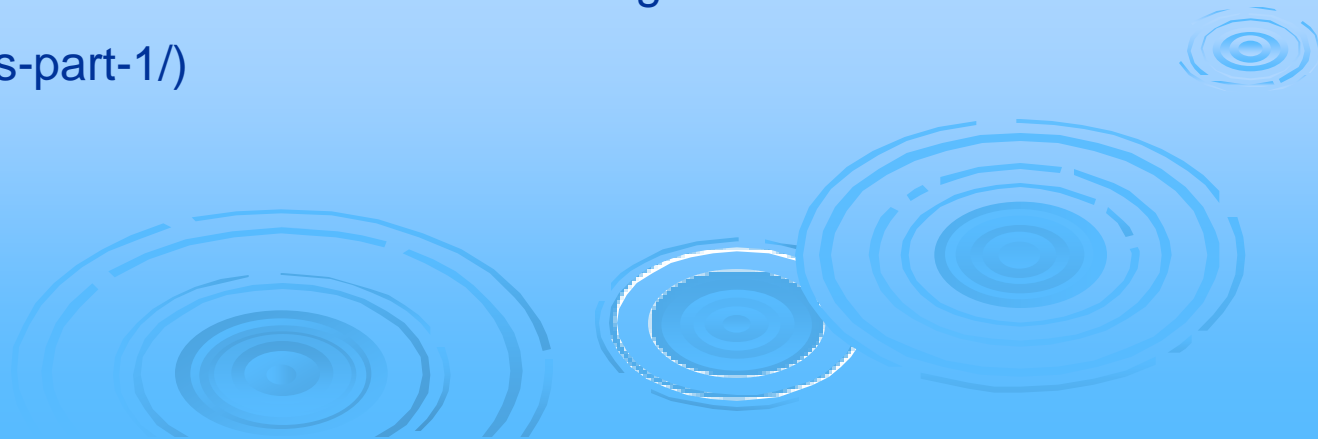
# Things to Consider

- Talk with an occupational or physical therapist at your medical center to design a regimen best suited for you
- Keep hydrated all times!
- Many community centers/recreation centers have a variety of options
- Do something you enjoy!
- Add variety to your regimens
- Look into options of physical therapy vs. local gym vs. home
- Classes at local hospitals that have rehabilitation programs
- DVD, video, or web-based exercise programs



# Exercise Resources

- **National Cancer Institute**
  - ([www.cancer.gov/cancertopics/energybalance](http://www.cancer.gov/cancertopics/energybalance))
- **American Cancer Society**
  - ([www.cancer.org/docroot/MIT/MIT\\_2\\_1x\\_ExerciseToStayActive.asp](http://www.cancer.org/docroot/MIT/MIT_2_1x_ExerciseToStayActive.asp))
- **Cancer Supportive Care Programs**
  - ([www.cancersupportivecare.com/exercises.html](http://www.cancersupportivecare.com/exercises.html))
- **Gilbert Guide**
  - ([www.gilbertguide.com/2008/04/25/exercise-guidelines-for-seniors-and-cancer-patients-part-1/](http://www.gilbertguide.com/2008/04/25/exercise-guidelines-for-seniors-and-cancer-patients-part-1/))



# Nutrition



- Chronic GvHD increases calorie needs by up to 30%
- Very important to eat well-balanced meals and snacks
- Keep protein intake up to repair muscle and body tissue



# Nutrition Considerations

- Eat a well-balanced diet
- Optimize protein intake (ex. beans, red meat, nuts, peanut butter)
- Keep well hydrated
- Check with your clinical team regarding multivitamin supplement without iron



# Nutrition Considerations

- Be aware of diet restrictions with certain medications
- Request to see a dietician
- Do not take any nutritional supplements (vitamins, herbal supplements etc.) without obtaining approval from your healthcare team
- If you have diabetes from prednisone therapy, it is most beneficial to see a diabetic educator for thorough teaching



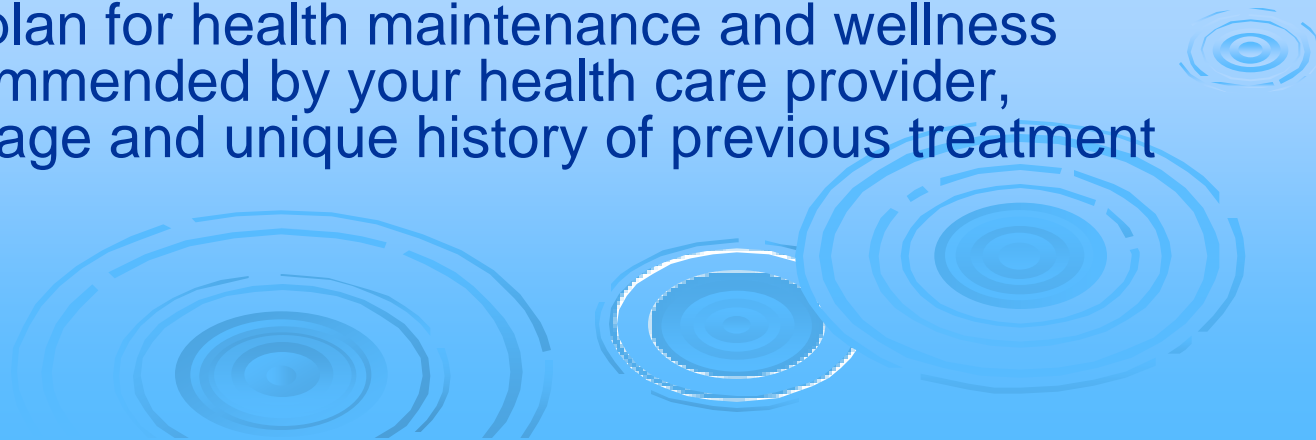
# Nutrition Resources

- **National Cancer Institute**
  - ([www.cancer.gov/cancertopics/eatinghint](http://www.cancer.gov/cancertopics/eatinghint))
- **American Institute for Cancer Research**
  - ([www.aicr.org/site/PageServer?pagename=pub\\_nutrition\\_cs](http://www.aicr.org/site/PageServer?pagename=pub_nutrition_cs))
- **American Dietetic Association**
  - ([www.eatright.org](http://www.eatright.org))
- **American Cancer Society**
  - ([www.cancer.org/docroot/MBC/MBC\\_6.asp?sitearea=ETO](http://www.cancer.org/docroot/MBC/MBC_6.asp?sitearea=ETO))



# Health Maintenance

- Continued self maintenance and screening/early detection activities are important
- The transplant itself, together with the natural aging process can put you at higher risk for certain health problems, but these can be prevented and/or treated
- General health issues (mammogram, hypertension, PSA level) can be put on the 'back burner' when you are dealing with the early complications of transplant and chronic GvHD
- Individualized plan for health maintenance and wellness should be recommended by your health care provider, based on your age and unique history of previous treatment



# Questions to Ask Yourself

- When did you last have a dental visit for cleaning, evaluation and fluoride treatment?
- Are you regularly having a pulmonary function study to evaluate your lungs?
- Do you consistently apply sun screen or wear protective clothing?
- Do you check your skin monthly head to toe for pigmented lesions (brown, tan, black freckles/moles) that might be changing in size, shape or other characteristics (such as bleeding or erosions)?
- If you are a woman, have you had a recent Pap smear and mammogram? If you are a man, have you had your PSA checked?
- If you are over 50 or have a family history of colon cancer or previous history of polyps, have you had a colonoscopy?
- When was your thyroid function last checked (particularly important if you received total body irradiation as part of your treatment)?
- Do you see ophthalmology on a regular basis for a Schirmer's test and eye exam?
- Have you had regular screening for osteoporosis? If you are osteopenic (have a lower bone mineral density) do you have a prevention plan (medications to build up bone strength, calcium supplements, vitamin D, weight bearing exercise) to limit progression to osteoporosis?

# Health Maintenance Resources

- **Mayo Clinic**
  - ([www.mayoclinic.com/health/cancer-survivor/CA00073](http://www.mayoclinic.com/health/cancer-survivor/CA00073))
- **Cancer Survivors Online**
  - ([www.cancersurvivors.org](http://www.cancersurvivors.org))
- **National Cancer Institute**
  - (<http://dccps.nci.nih.gov/ocs/resources.html>)
- **National Marrow Donor Program**
  - ([www.marrow.org/PHYSICIAN/Patient\\_Care\\_Post\\_Tx/index.html](http://www.marrow.org/PHYSICIAN/Patient_Care_Post_Tx/index.html))

