

# Living Well During and After Transplant

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# Conflict of Interest Disclosure

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- No financial interest
- No discussion of off-label medication use
- Presentation is for educational purpose
- Presentation may be shared

# Presentation Overview

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- Living Well – what does it mean?
- Complications/side effects of transplant
- Management of side effects and stress
- Tips on how to live well after transplant

# Living well with transplant

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What is living well?

*Taking care of the mental, physical and spiritual aspects of life.*

*What are things that you (as a patient) can do to improve your life?*



# Living well with transplant – Spiritual matters

- *Why is this happening to me?*
- *What is the meaning of my struggles?*
- *How do I find joy and purpose in life?*



## Prayer for Serenity

God, grant me the serenity  
to accept the things I cannot change,  
the courage to change the things I can,  
and the wisdom to know the difference.

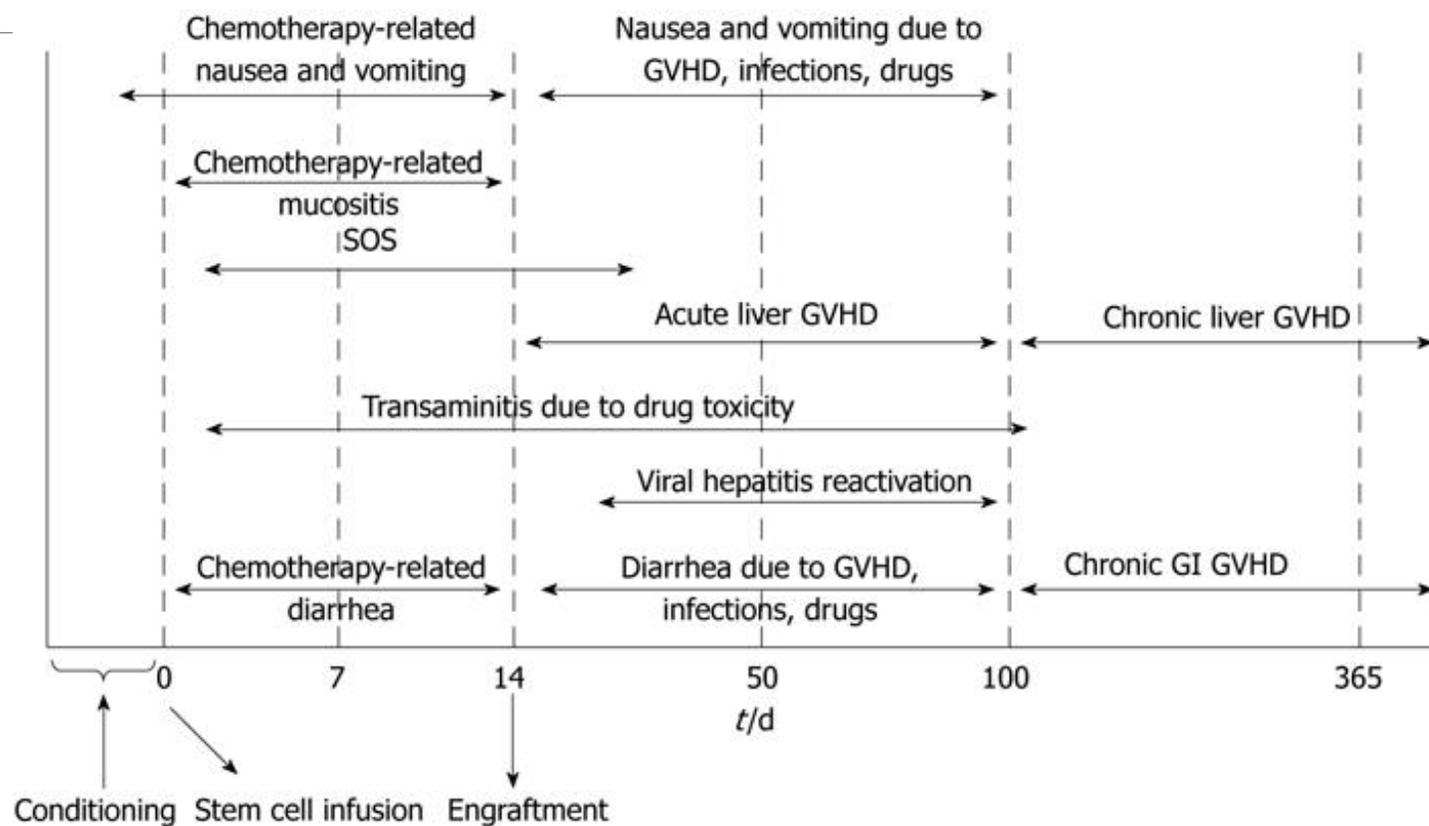
- Reinhold Niebuhr

# Complications of Donor Stem Cell Transplantation - Physical

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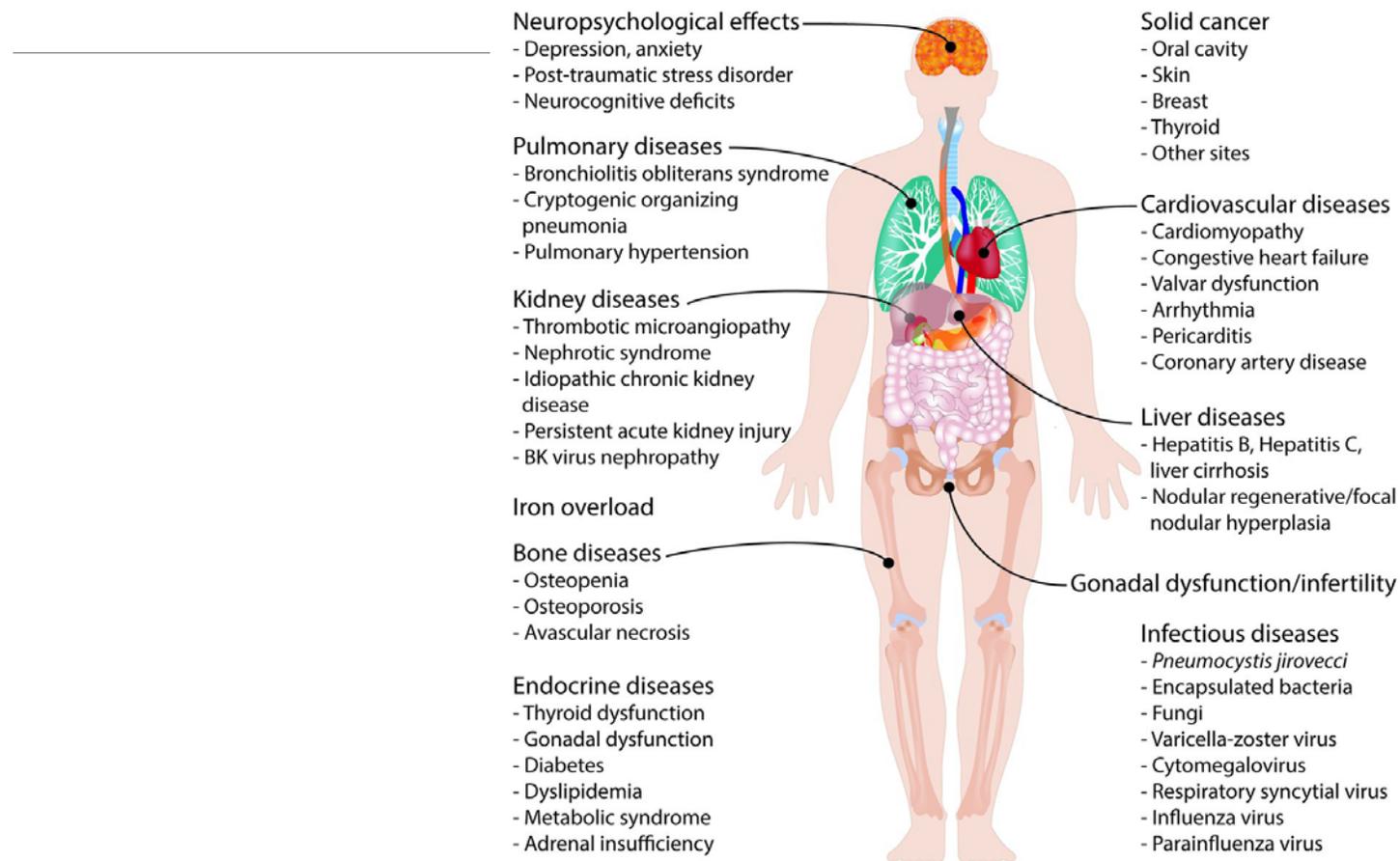
1. Toxicities related to the conditioning regimen and/or anti-rejection/immunosuppression medications
  - Mucositis/Gastrointestinal toxicities
  - Organ injuries
  - Hematologic side effects
2. Infections
3. Graft-versus-host disease (GVHD)

# Donor Stem Cell Transplantation – Acute GI Complications



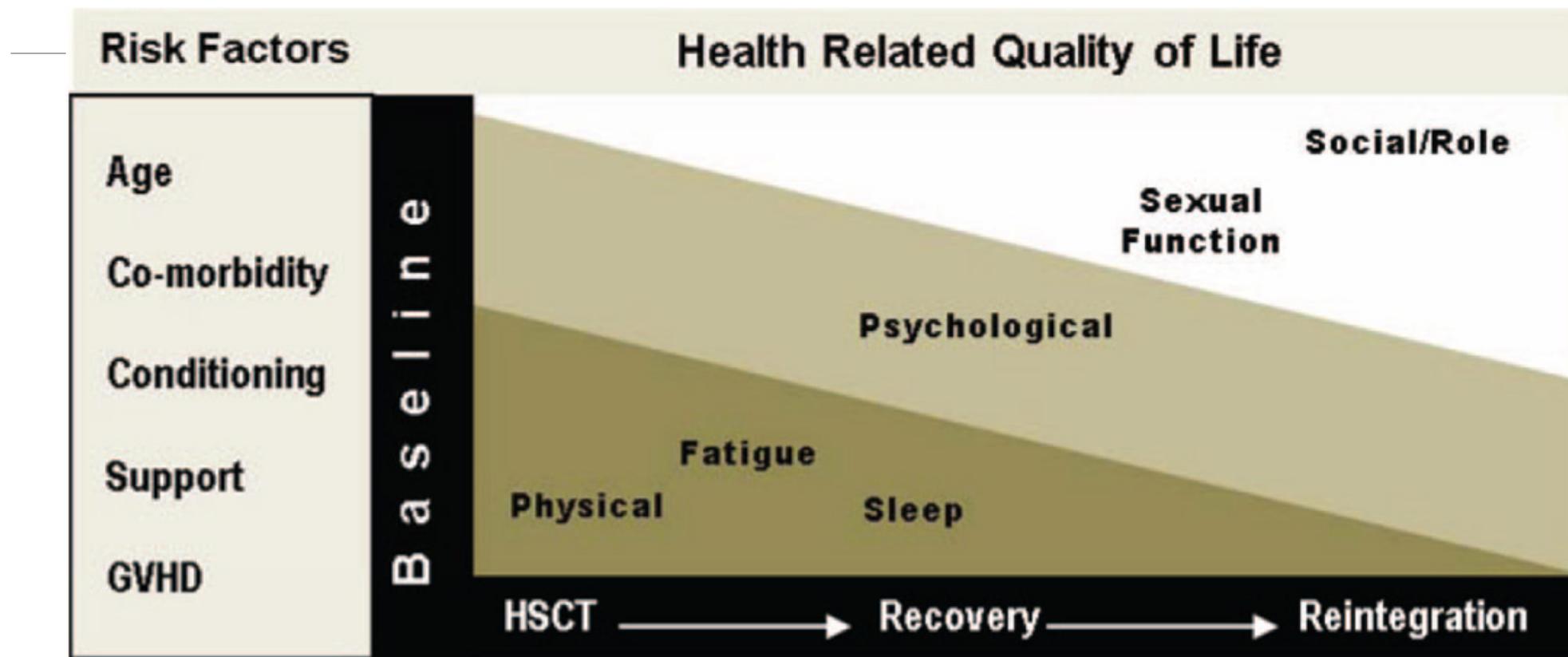
Tuncer, HH et al. 2012 World J. Gastroenterol.

# Long-term Complications of Donor Stem Cell Transplantation



Inamoto and Lee. 2017 Haematologica

# Quality of Life Following Donor Stem Cell Transplantation



Beavens M. 2010 ASH Hematology Education

# Complications of transplant - GVHD

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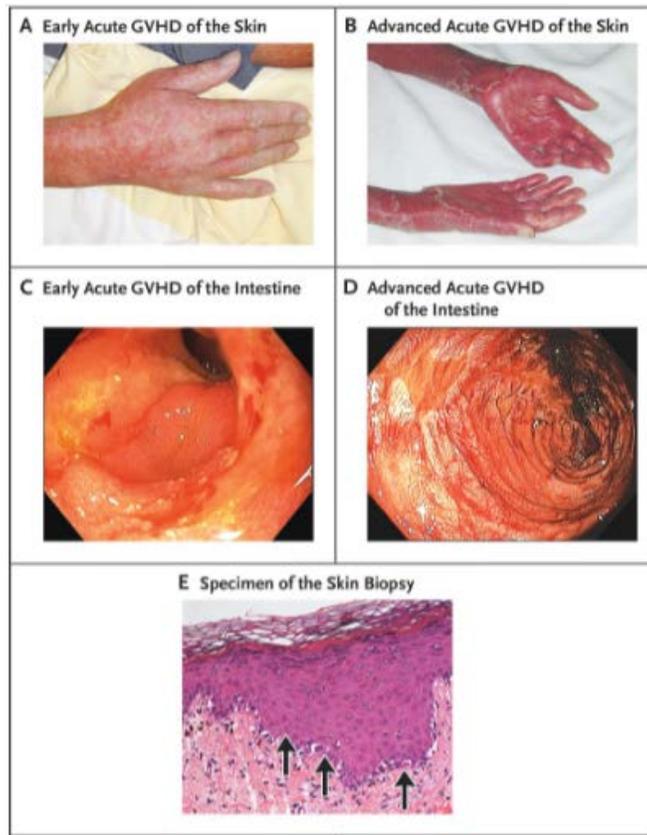
- Graft-versus-host disease (GVHD) is a potentially serious complication of allogeneic stem cell transplantation. Allogeneic stem cell transplantation is a procedure in which a person receives stem cells from a donor
- Some of the donor cells may recognize the patient's healthy cells as "non-self," and unleash an attack on the patient's healthy tissues and organs. When the donor cells ("the graft") attack the cells of the patient ("the host"), the condition is called "graft-versus-host disease" or GVHD. This "attack" may impair an organ's function or may cause it to fail altogether

# Complications of transplant - GVHD

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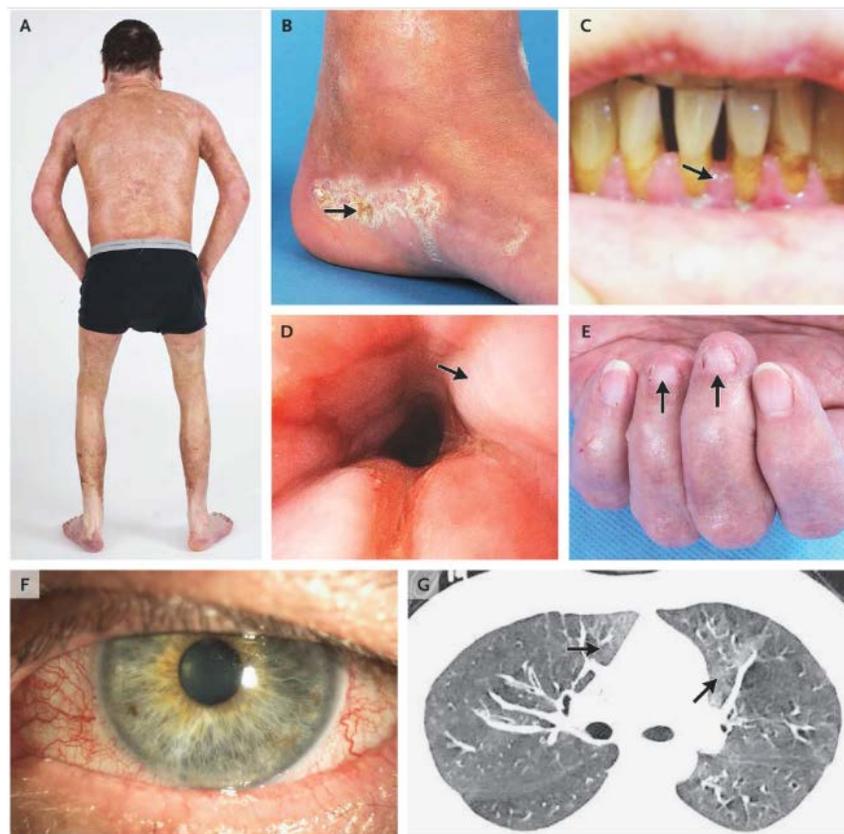
- There are two main categories of GVHD: acute GVHD and chronic GVHD.
  - Each type of GVHD affects different organs and tissues and has different signs and symptoms.
    - Patients may get one type or both types of acute and chronic GVHD, one following the other (sequentially) or both at the same time (concurrently).
    - Some patients may not develop GVHD at all. GVHD can be mild, moderate or severe. There are treatments for GVHD, but in some patients GVHD may not respond to treatment.

# Complications of transplant – Acute GVHD



Zeiser R, et al. 2017 NEJM

# Complications of transplant – Acute GVHD



Zeiser R, et al. 2017 NEJM

# Complications of transplant - GVHD

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- Treatment:
  - Immunosuppression (suppression of the body's immune system and its ability to fight infections and other diseases) with corticosteroids forms the basis of therapy in both acute and chronic GVHD. Other medications that lower the immune response are also used. Treatment may be either outpatient or inpatient. Treatment decisions are determined by the severity of the patient's symptoms and concerns about complications.
  - Over the past few years, we have gotten 3 new medications to treat GVHD

# Complications of transplant – Nausea and Vomiting

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- Many transplant related treatments can cause nausea and vomiting. Nausea, also called feeling “queasy” or “sick to your stomach,” is that unpleasant feeling you have when you are going to throw up. Vomiting is throwing up what is inside your stomach through the mouth. Nausea and vomiting can happen together, or one can occur without the other
- Any side effect that can make eating or drinking difficult increases the risk for health complications and poor quality of life
- Your healthcare team can provide medications to reduce or even prevent nausea and vomiting

# Complications of transplant – Nausea and Vomiting

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- TIPS TO MANAGE NAUSEA AND VOMITING:
  - Eat small meals throughout the day.
  - Eat dry, bland foods such as crackers, toast, cereal or pretzels.
  - Avoid foods that may trigger nausea, such as fried foods, spicy food and strong-smelling food.
  - Try products that contain the spice ginger (such as ginger ale, ginger gum or ginger tea). Some people find ginger products help relieve nausea.
  - Drink plenty of water and fluids. If you vomit, try sipping water, ginger ale or sports drinks to stay hydrated. It may help to drink small amounts throughout the day, rather than larger amounts less frequently.
  - Stay sitting up after meals. Avoid skipping meals. An empty stomach can make nausea worse.
  - Wear comfortable, loose-fitting clothing.
  - Ask your doctor about complementary therapies that may help relieve your nausea. Some patients find acupuncture, therapeutic massage, deep breathing, hypnosis, meditation and other relaxation techniques help relieve nausea. Ask your healthcare team before trying these therapies

# Complications of transplant - Infection

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- Transplant patients are more likely to get infections because of their weakened immune systems
- Important to know the signs of infection:
  - Fever of 100.4°F or greater
  - Chills
  - Sweating
  - Abdominal pain or loose bowel movements/diarrhea
  - A burning feeling when you urinate
  - A severe cough or sore throat
  - Unusual vaginal discharge or itching
  - Redness, swelling or tenderness, especially around a wound, sore, pimple, intravenous (IV) catheter site or vascular access device
  - Bleeding gums or white patches in the mouth

# Complications of transplant - Infection

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- TIPS FOR PREVENTING INFECTIONS

- Wash your hands often and thoroughly with soap and water, especially before eating or after using the bathroom. If soap and water are not available, use a liquid or gel hand sanitizer.
- Take a warm (not hot) bath, shower or sponge-bath every day
- Take care of your nails by keeping them short and dry. Avoid manicures, pedicures and artificial nails.
- Use an electric shaver instead of a razor to prevent cuts.
- Use an extra-soft toothbrush to clean your teeth and gums.
- If you have a port or catheter, clean and care for it by following your healthcare team's instructions.
- Clean your rectal area gently but thoroughly after each bowel movement. Ask for medical advice if irritation or hemorrhoids are a problem.

# Complications of transplant - Infection

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- TIPS FOR PREVENTING INFECTIONS

- Avoid crowds. If you must be in a crowd, wear a mask, especially in waiting rooms
- Avoid all people (including family and friends) who have contagious diseases such as colds, flu, measles or chickenpox.
- Wear gloves when gardening or cleaning up after young children or others, especially if you are cleaning up waste or bodily fluids.
- Avoid activities that put you at risk for cuts, burns or other injuries
- Wash hands thoroughly before and after handling food.
- Wash fruits and vegetables under running water before peeling or cutting. Keep raw and cooked foods separate.
- Always store food within one hour of purchase or cooking—or as soon as possible
- Be careful when eating at restaurants and shopping for food. Buy only from vendors with high grades in health department inspections. Avoid food buffets and salad bars.
- Avoid foods associated with foodborne illness. These foods include
  - Unpasteurized beverages and cheeses
  - Raw food, such as sushi
  - Premade foods at grocery or convenience stores
  - Foods that contain raw eggs such as cookie dough
  - Water from a well, unless tested and/or boiled appropriately

# Complications of transplant: Financial Health

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- A bone marrow, stem cell or cord blood transplant is an expensive medical procedure. The cost will depend on:
  - The transplant center you choose
  - The type of transplant you will have
  - The length of your hospital stay
  - Complications that may arise
- It's important to plan, in advance, how your medical and routine expenses will be covered while you undergo treatment.



# Complications of transplant: Financial Health

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- Our of pocket expenses:
  - You may also have deductibles and co-pays that add to your out-of-pocket expenses. Prescription drugs, wigs and medical devices may or may not be covered by your plan.
  - Additionally, dental work if frequently need prior to transplant and is not paid for by insurance.
  - Ask the financial coordinator, pharmacist and/or social worker at your transplant center to help you estimate your out-of-pocket expenses for medical treatment. If you have been assigned a case manager by your insurance company, he or she can help you estimate out-of-pocket expenses as well.

# Complications of transplant: Financial Health

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- It is important to organize your household expenses. You'll want to plan for how your financial obligations will be managed in your absence:
  - Who will pay your monthly bills?
  - Who will manage health insurance issues?
  - Who will pay your taxes?
  - Do you need to make special arrangements with your bank so that the person paying your bills has access to your funds?
- It is better to set up a plan in advance, than wait until you fall behind on your bills.
- You can go to [www.bmtinfonet.org/resource-directory](http://www.bmtinfonet.org/resource-directory) for information on resources for financial assistance for transplant.
- Your transplant center may have access to funds from local sources to help patients with transplant-related expenses, as well

# Complications of transplant: Mental Health

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- Your mental health is important
- Depression, anxiety and stress can take a toll on your physical health
- Cancer treatments such as chemotherapy and other drug therapies as well as radiation to the brain can cause changes in cognitive (thinking) function.
- These changes may affect concentration, memory and the ability to multi-task. Many cancer patients experience cognitive effects of treatment to some degree.
- For most, these cognitive problems last only a short time and improve after treatment ends. Others, however, may have long-term cognitive changes
- Examples of cognitive problems:
  - Memory problems, such as forgetting things that you usually have no trouble recalling
  - Difficulty finding the right word
  - Difficulty processing thoughts quickly
  - Trouble understanding what people are saying
  - Difficulty following instructions
  - Difficulty learning and recalling new information

# Complications of transplant: Mental Health

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- TIPS TO MANAGE COGNITIVE EFFECTS

- Take notes and write to-do lists.
- Use a calendar, daily organizer or mobile app to keep track of appointments, activities and important dates.
- Organize your home and work spaces by making sure everything has a place. Get rid of clutter.
- Do one task at a time. Avoid multi-tasking. Be patient with yourself and allow extra time to accomplish each task.
- Minimize distractions and put electronic devices (such as your cell phone) away when working.
- Exercise your brain by reading or doing crossword puzzles, or start a new hobby such as painting or journaling.
- Exercise your body
- Avoid alcohol and other substances that alter your mental state.
- Manage stress. Take care of your mental health by finding ways to relax such as deep breathing or meditation.
- Ask for help. Be honest with family members and friends so they can understand and help you remember things and complete tasks.

# Healthy Habits – Mental Health

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- Try to reduce stress by doing things you enjoy such as spending time with family, being outdoors, journaling, reading, meditating or any activity you prefer.
- If you are anxious or depressed and feel as though you can no longer manage your daily activities, talk to your healthcare team.
- If you are anxious or depressed and feel as though you can no longer manage your daily activities, talk to your healthcare team. You may benefit from professional counseling and/or medication

# Healthy habits for living well

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- Developing healthy lifestyle habits is important for everyone undergoing transplant.
- During cancer treatment, healthy lifestyle habits can make treatment more tolerable, help you to manage side effects, and decrease the risk of complications such as malnutrition and infection.
- After transplant, healthy lifestyle habits can help you recover faster and decrease the risk of disease such as other cancers, heart disease, and diabetes.

# Healthy Habits - Nutrition

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- Nutrient-rich foods give your body the fuel it needs for healthy function and disease prevention. Good nutrition also supports a healthy weight and body size.
- The American Heart Association recommends a plant-based, heart-healthy menu that includes
  - A variety of fruits and vegetables
  - Whole grains { Proteins such as lean meats (chicken, turkey), fish, eggs, low-fat dairy, beans, nuts and soy
  - Healthy fats such as olive oil, avocado, nuts and seeds.
- The American Institute for Cancer Research recommends that two thirds of the food on your plate should be vegetables, fruits, whole grains or beans

# Healthy habits – Physical Activity

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- Benefits of physical activity include
  - Weight management
  - Increased energy
  - Improved mobility
  - Better mood
  - Decreased risk of disease.
- The American Institute for Cancer Research recommends that you get at least 150 minutes (about 20 minutes a day) of moderate activity (such as walking, swimming, stretching, yoga, etc) or 75 minutes of vigorous physical activity (such as jogging, swimming, dancing, biking, etc.) per week.
- You may need to start slowly with short periods of exercise every day and then gradually increase the time until you are exercising for 150 minutes per week. If mobility is an issue, you may benefit from seeing a physical therapist

# Healthy Habits - Continued

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- **Avoid tobacco**
  - Smoking increases the risk for a number of cancers and other diseases such as heart disease. Smokeless tobacco such as chewing tobacco or snuff also increases the risk of oral cancer and disease. E-cigarettes do not contain tobacco but do contain chemicals and substances that may cause organ damage, diseases and possibly cancer
- **Limit alcohol intake**
  - Heavy drinking and/or binge drinking increases your risk for liver disease, pancreatitis, certain cancers and alcohol abuse disorders. Alcohol also may harm your health by interacting with medications that you are taking
- **Use sun protection**
  - Avoid direct sun when possible
  - Wear a broad-spectrum sunscreen (UVA and UVB) with SPF 30 or higher and reapply every 2 hours.
  - Wear a hat, protective clothing, and sunglasses to further protect skin.

# Living Well with Transplant

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# Living well – Quotes from Blood Cancer patients!

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“Stay strong and keep moving forward. Find the positive in every day. Be your own best patient advocate. Accept, learn and focus on present. Learning to live a different life. Patience, positive attitude, hope and faith. Test to test, I will survive! I don't look back only forward. Meditation, mindfulness, wellness, faith, nutrition and optimism. Finding the joy while living with uncertainty. Blessed to be doing so well! Eye opening needed learning and healing. Watchful waiting can be watchful worrying. Scary, expensive, grateful, blessings, hope, faith. Thank god for stem cell transplants! Extraordinarily grateful, I love my life. Diagnosed; frightened; tested; treating; waiting; hoping. I'm more generous, impatient less often. Embrace your treatment day after day. Strength you never realized you had. Challenging to our hearts and minds. Life is what we make it. Live life in a beautiful way”

# Living well with transplant

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- Questions/comments?