What does survivorship mean?

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Definition

• Survivorship
  - The state of being a survivor

• Survivor
  - A person who survives, especially a person remaining alive after an event in which others have died
  - A person who copes well with difficulties

• Survive
  - Continue to live or exist, especially in spite of danger or hardship
[sur viv or]
to beat the odds, one with great courage and strength, a true inspiration
Estimated Number of HCT Survivors in the United States, 2009-2030

CIBMTR Analysis

- ~110,000 BMT survivors in the US in 2009
- ~500,000 BMT survivors by 2030

Number of BMT Survivors, Thousands

Number of HCT Survivors Is Increasing
So now what?

Cancer
Been there
Beat that
Goals for Survivorship Care

• EMPOWER you to take ownership of your care and long term health
  - Provide you with information Tools
  - Motivation to staying healthy
  - Tools to be successful
Goals for Survivorship Care

- EDUCATE you about late effects and survivorship
- Surveillance for disease recurrence
- Surveillance, prevention and treatment of late complications
- Screening and prevention of second cancers
- Routine health maintenance
- Psychosocial support
- Rehabilitation
- Financial counseling
- Reintegration into society (return to work/school)
Cardiovascular Disease

- Heart attack, stroke, chest pain, blood clots
- Increased risk post transplant
  - Chemo/radiation
  - Medications
  - Metabolic syndrome
    - High blood pressure, diabetes, high cholesterol
How to screen for CVD risk

- Health history
- Family history
- Cholesterol
  - At least every year but more often if starting treatment
- Blood pressure monitoring
  - Each clinic visit or at least yearly
Modifying the modifiable

- Diet
  - Mediterranean or DASH diet
  - Less than 2.4 grams salt per day
- Exercise
  - Goal 30 minutes aerobic daily
- Healthy weight
- Maintaining healthy cholesterol
- Managing blood pressure
  - Goal <140/90
# Heart healthy diets

## The Mediterranean Diet

- **Wine:** In moderation
- **Poultry, Eggs & Dairy:** Moderate portions daily to weekly
- **Fish & Seafood:** Often, at least twice a week
- **Vegetables, Fruits, Whole Grains, Olive Oil, Beans, Nuts, Legumes, Seeds, Herbs & Spices:** Base all meals on these foods

### Savor meals with loved ones and be active every day.

## The DASH Eating Plan

Use this chart to help you plan your menus—or take it with you when you go to the store.

<table>
<thead>
<tr>
<th>Food Group</th>
<th>Servings Per Day</th>
<th>Serving Sizes</th>
<th>Examples and Notes</th>
<th>Significance of Each Food Group to the DASH Eating Plan</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grains*</td>
<td>4</td>
<td>6-8</td>
<td>1 slice bread, 1 oz dry cereal, 1/4 cup cooked rice, pasta, or cereal</td>
<td>Major sources of energy and fiber</td>
</tr>
<tr>
<td>Vegetables</td>
<td>3-4</td>
<td>4-6</td>
<td>1 cup raw leafy vegetable, 1/4 cup cooked vegetables</td>
<td>Rich sources of potassium, magnesium, and fiber</td>
</tr>
<tr>
<td>Fruits</td>
<td>3-4</td>
<td>4-6</td>
<td>1 medium fruit, 1/4 cup dried fruit</td>
<td>Important sources of potassium, magnesium, and fiber</td>
</tr>
<tr>
<td>Nuts, seeds, and legumes</td>
<td>3 per week</td>
<td>4-5 per week</td>
<td>1/2 cup or 1 oz nuts, 2 Tbsp peanut butter</td>
<td>Rich sources of protein and magnesium</td>
</tr>
<tr>
<td>Fats and oils</td>
<td>2</td>
<td>2-3</td>
<td>1 tsp soft margarine, 1 tsp vegetable oil</td>
<td></td>
</tr>
</tbody>
</table>
Bone Health

- Decreased bone density
- Vitamin deficiency
- Post menopausal
- Decreased activity
- Underlying disease
  - ie: multiple myeloma
- Radiation
- Steroid use
Screening for bone health

- Bone density test every 2 years
- Vitamin D level every year
Treatment of osteopenia and osteoporosis

- Oral and IV medications
  - ie: bisphosphonate (alendronic acid and zolendronic acid)
- Vitamin D supplements
  - Minimum 2000 units vitamin D daily
    - More if deficiency found
- Weight bearing exercise
  - Heel-striking exercise
Endocrine function

• Glands that regulate a lot
  - Sexual function
  - Sleep
  - Metabolism
  - Growth
  - Mood
  - Etc..

• Can be affected by chemo, radiation, steroids, medications post transplant
Diseases of endocrine dysfunction

- Diabetes
- Depression
- Anxiety
- Infertility
- Menopause
- Decreased sexual desire
- Insomnia
- Fatigue
Screening the endocrine system

- Screen for symptoms of abnormal function
- Labs yearly
  - TSH, Fasting blood sugar or HbgA1c, Testosterone, LH, FSH
Chronic graft versus host disease

- Unique complication of allogeneic hematopoietic cell transplants
- Affect different organs: skin, GI tract, liver, lungs, eyes, mouth, vagina, vulva, muscles, connective tissues, fascia
- Affects quality of life and can impact daily activities
- Increases risk of blood clots
- Increases risk of second cancers
- Treatment can increase all late effects of transplant
Symptoms of cGVHD

- Skin and joint tightness
- Muscle pain/cramps
- Dry, itching, burning eyes
- Dry mouth with or without sores
- Low appetite, weight loss, bowel changes
- Shortness of breath, dry hacking cough
- Vaginal dryness, pain with intercourse
Treatments for cGVHD

- Topical steroid: cream for skin, beclomethasone and budesonide for GI tract, oral steroid rinses
- Systemic steroids: IV solumedrol or oral prednisone
- Ibrutinib: targets the B-cells
- ECP (extracorporeal photopheresis): twice weekly treatments at transplant facility
- Other medications that have been tried:
  - Ruxolitinib (oral)
  - Rituximab (IV)
  - Bortezomib (SQ or IV)
Steroids

- Weight gain
- Decreased bone density
- Anxiety
- Insomnia
- Irritability/moodiness
- Muscle loss
- Weight gain in abdomen
- Diabetes
- Metabolic syndrome
Second Cancer

- Breast cancer
- Squamous cell carcinoma
  - Mouth, throat, skin, esophageal
- Colorectal cancer
- Cervical cancer
Screening for second cancer

- Mammograms yearly
- PAP exams yearly
- Colonoscopy every 10 years
  - Unless there are polyps or history (personal or family) and then more often
- Prostate cancer screening
  - Starting at 40 with primary care provider
- Regular dental exams
  - Every 6 months even those without teeth
What to report

- Abnormal skin lesion
- Bleeding with intercourse
- Pain with intercourse
- Blood in stool
- Abdominal pain
- Difficulty swallowing or feeling like food gets stuck
- Lump in breast or leaking from nipples
- Mouth sore
- Difficulty urinating
- Blood in urine
Anxiety and depression

- Post traumatic stress disorder
  - Difficulty getting out of bed
  - No enjoyment in activities
  - Difficulty sleeping
  - Increased fatigue
  - Sleeping all the time
  - Unable to interact with friends and family
Tell someone!

• Rule out a physical cause
• Connect you to social workers, psychiatry, psychology, support groups
Treatment Summary

- Diagnosis and treatment (prior to transplant) summary
- Transplant information (e.g. preparative regimen, donor source, etc.)
- GVHD status and treatment
- Infection history
- Any complications or readmission
- Review of clinical trials patient has been or is currently enrolled on
- Any ongoing treatment/maintenance
<table>
<thead>
<tr>
<th>Follow-Up Item</th>
<th>How Often?</th>
<th>Who's Responsible?</th>
<th>Due Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Immunizations</td>
<td>6 months, 8 months, 10 months, 12 months and 24 months post-transplant</td>
<td>Infectious Disease</td>
<td>Start 6 months post-transplant</td>
</tr>
<tr>
<td>Eye health</td>
<td>Yearly</td>
<td>Ophthalmology</td>
<td>Start at 1 year, then yearly and as needed. May need to see ophthalmology at Cleveland Clinic if signs of GVHD</td>
</tr>
<tr>
<td>Oral/Dental Care</td>
<td>Every 6 months</td>
<td>Local Dentist</td>
<td>Start 6 months post-transplant</td>
</tr>
<tr>
<td>Lung health- pulmonary function tests</td>
<td>Yearly</td>
<td>BMT program</td>
<td>Start at day 100 then 1 year post-transplant or more frequently if needed</td>
</tr>
<tr>
<td>Bone health- bone density scan</td>
<td>Every 2 years</td>
<td>BMT program</td>
<td>Start 1 year post-transplant or sooner if needed (eg: on steroids)</td>
</tr>
<tr>
<td>Liver health</td>
<td>Each visit</td>
<td>BMT program</td>
<td>Labs done with each visit. Ferritin at one year post transplant</td>
</tr>
<tr>
<td>Kidney health</td>
<td>Each visit</td>
<td>BMT program</td>
<td>One year post-transplant</td>
</tr>
<tr>
<td>Endocrine health- TSH (HbgA1c if diabetic)</td>
<td>Yearly</td>
<td>BMT program</td>
<td>Fasting labs at 6 months post discharge.</td>
</tr>
<tr>
<td>Cardiovascular health- blood pressures, lipid panel, fasting glucose, height and weight</td>
<td>Every 3-6 months</td>
<td>BMT program</td>
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Promise me you’ll always remember:
YOU ARE BRAVER THAN YOU BELIEVE,
STRONGER than you seem, smarter than you think and twice as BEAUTIFUL as you’d ever imagined.

IHadCancer.com
Every life deserves world class care.