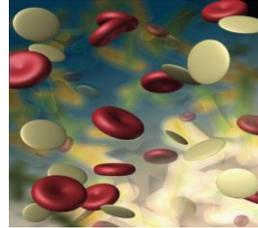


## Survivorship Care Planning

What's Next In Your Journey.

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Stem Cell Transplantation and Cellular Therapy  
Survivorship Program  
4/20/2018



### The Journey



### Tips to reduce stress

- ▶ Organize
  - ▶ Where does it go
  - ▶ Keep a calendar
- ▶ Keep copies your records
- ▶ Write it down when you think of it
- ▶ Record important health care discussions
- ▶ Delegate to family and friends
- ▶ Ask for help

### Definition of 'Survivor' for those with Bone Marrow Failure Disease

- ▶ **One who has been diagnosed with (cancer) from the time of diagnosis through the balance of that person's life**
  - ▶ The National Coalition of Cancer Survivors (2009) definition includes
    - ▶ the patient family,
    - ▶ caregivers and
    - ▶ friends

## Stages of Survivorship

- ▶ Acute
  - ▶ Diagnosis and Treatment
- ▶ Intermediate
  - ▶ Close medical monitoring and personal physical recovery
- ▶ Long Term
  - ▶ Ongoing surveillance, personal re-integration

## Impact of Disease and Treatment During Treatment

- ▶ Disease Symptoms
- ▶ Medication Side Effects

## Impact of Disease and Treatment Late or Long-term Effects

- ▶ Late or Long Term effects of disease and treatment can be seen months to years after treatment
- ▶ Late or Long Term effects occur because the treatment (immunosuppressive medication, chemo, radiation) can cause damage to normal cells as it is fighting the disease.
- ▶ Some people never experience late effects

## Potential Late/Long-Term Effects

- ▶ Neuropathy (numbness, tingling or pain usually in fingers, toes, feet)
- ▶ Memory, attention and focus problems ("Chemo brain")
- ▶ Depression
- ▶ Cataracts
- ▶ Dental cavities
- ▶ High blood pressure
- ▶ Heart or Lung problems
- ▶ Diabetes

- ▶ Hypothyroidism (decreased function of the thyroid gland)
- ▶ Osteoporosis (thinning of bones or low bone density)
- ▶ Infertility (inability to get pregnant or get someone pregnant)
- ▶ Sexual function issues (no desire for sex, inability to be aroused, erectile dysfunction, vaginal dryness)
- ▶ **Fatigue**
- ▶ Late infections (may be due to delay in recovery of your immune system or damage to other organs)

## Impact on Quality of Life

- ▶ Low self esteem
  - ▶ Role changes
  - ▶ Body Image changes
- ▶ Psychological distress
- ▶ Occupational disability
- ▶ Change in social and marital relationships
- ▶ Limitations in routine daily tasks
  - ▶ Recreational activities, employment
- ▶ Sexual dysfunction
- ▶ Cognitive impairment
- ▶ Sleep difficulties

## Impact on Personal Finances

- ▶ Job related changes
  - ▶ Medical Insurance
  - ▶ Reduction or loss of income
  - ▶ Added expenses
- ▶ "FINANCIAL TOXICITY"

How do I know my risk factors for late effects?

Who should guide my life long follow up?

## Treatment Summaries Survivorship Care Plans

- ▶ Treatment summary
  - ▶ Document that outlines all treatments (chemo, radiation, immunosuppressive medications) that you have had in chronological order, related to your disease.
- ▶ Long term follow up plan
  - ▶ Document that outlines:
    - ▶ Plan for surveillance of your disease
    - ▶ Plan for ongoing monitoring to recognize and manage long term or late effects of your disease and it's treatment.
    - ▶ Plan for risk reduction
      - ▶ Includes physical, emotional, social, spiritual aspects of life

- ▶ You will need screening tests such as blood work or xrays as well as health and social interviews and physical exams.
- ▶ When you no longer have to closely follow up with your hematologist or oncologist, it is important for you to have yearly check up's with your family/primary care health care provider.
  - ▶ Your primary care provider can do the screening tests and exams on a routine basis.
- ▶ Continue with routine dental and eye evaluations.
- ▶ Women will need to have routine women's health exams including breast and pelvic exams.
- ▶ Age related cancer screening may be advised earlier in life.
- ▶ Continue with routine health care such as infection care, immunizations, management of new or preexisting health problems like diabetes, high blood pressure.

## Life Long Attention to Your Health

▶ It is important to report unusual symptoms or new problems.

▶ *If a late effect is diagnosed and treated early, there is less chance of it creating a serious problem with your health or quality of life.*

## Prevent Infection!

- ▶ Wash hands!
- ▶ Stay away from sick folks
- ▶ Maintain a clean home environment
- ▶ Follow PET and ANIMAL safety guidelines
- ▶ Follow FOOD SAFETY guidelines
- ▶ Get a flu shot
  - ▶ Ask close social contacts to get a flu shot
- ▶ Stay away from sick kids
  - ▶ Encourage children in your family to stay up to date on vaccinations
- ▶ Pay attention to changes in your health status
  - ▶ HAVE FEVER EVALUATED IMMEDIATELY
  - ▶ If you think you are getting sick, talk to your team about it
  - ▶ Report changes, even if you think it is "probably nothing"

## Take care of your lungs!



## Eat well!

Fruits and vegetables!



Whole grains!



- ▶ Small frequent meals/snacks
- ▶ Add protein to each meal.
  - ▶ Cold foods on "bad food days"
- ▶ Eliminate processed foods
- ▶ Reduce intake of "white foods"
  - ▶ sugar, potatoes, white flour, white rice
- ▶ Limit caffeine intake
  - ▶ caffeinated and carbonated don't count as your "fluid"
- ▶ Avoid sugary drinks like commercial juices and sodas
- ▶ Drink water!

## Stay Physically Active

- ▶ Walk!



## Participate in planned exercise 5 days a week!

5-10 minute sessions during the day  
Stretching, walking, light weights, chair exercises



## Sleep!



### Manage Health Problems



### Limit or Avoid Alcohol



### Use sun protection!



- ▶ Sun screen, SPF 30 or higher
- ▶ Sun protective clothing
- ▶ UV protective sun glasses
- ▶ Exposure awareness
  - ▶ Before 11, after 5
  - ▶ Even cloudy days expose you to UV radiation
- ▶ Self skin exams

### Participate in activities that renew you spiritually and emotionally.



### Be aware of relationship stresses. Be willing to talk, ask for help.



Socialize



Keep intimacy alive.



Be alert for problems with family members



Participate in Health Screening



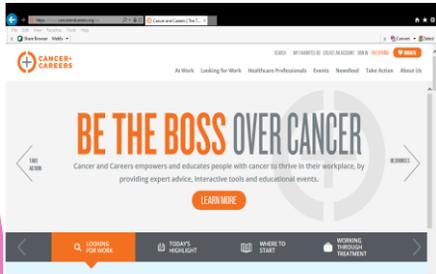
Work and treatment/recovery?



Work/School Issues

- ▶ Do you need to change the type of job?
- ▶ Do you want to go back to school?

### Cancerandcareers.org



### Cancerlegalresources.org



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