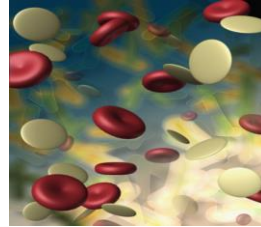


Survivorship Care Planning

What's Next In Your Journey.

Karen Stolar FNP-BC, AOCN®
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!

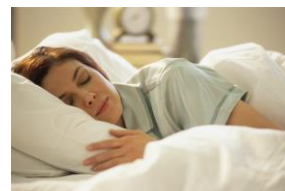


Participate in planned exercise 5 days a week!

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



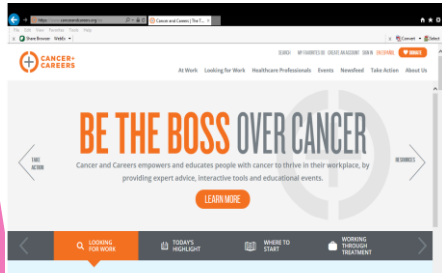
Work and treatment/recovery?



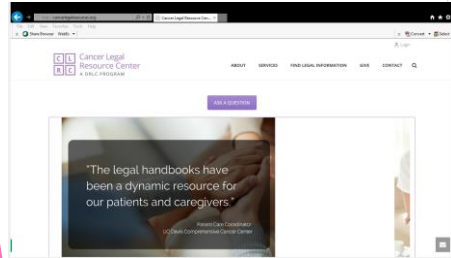
Work/School Issues

- ▶ 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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