Late Effects from Cancer and Survivorship Care Planning

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Who are Survivors?
“anyone who has been diagnosed with cancer from the time of diagnosis through the balance of his or her life”

What is Survivorship?
Dealing with the unique needs of survivors after active treatment ends
Cancer Survivorship

12 million cancer survivors now alive 5 years after diagnosis (3-4% of total population)

Estimated Number of Cancer Survivors in the US from 1971-2007

- 20 million by 2020

Cancer Survivorship

Cancer survivors by diagnosis:

- 66% of those diagnosed today with cancer will be alive in 5 years
- For children under 19 years of age, 78% will be alive in 5 years
I’m a survivor—so what’s next?
Needs of Survivors
Lance Armstrong Foundation LIVESTRONG™ Poll
N=1020

• 53% reported secondary health problems
  – Chronic pain (54%)
  – Sexual dysfunction (58%)
  – Relationship difficulties
  – Fertility issues
  – Fear of recurrence
  – Depression
  – Financial & job related concerns

• 49% reported
  – Non-medical cancer related needs not met

Assessment of Risk

Acute Long-Term Late Effects

RADIATION  CHEMOTHERAPY  SURGERY
Common Issues Facing Survivors

Medical Problems:
- Cardiovascular disease
- High triglycerides/cholesterol
- Diabetes
- Osteoporosis / osteopenia
- Hypothyroidism
- Premature menopause
- Pulmonary (lung) function
- Lymphedema
- Urinary incontinence
- Infertility
- Neurologic problems (balance, neuropathy, memory)
- GI (diarrhea, constipation, reflux)
- Dental impairments
- Increased risk of 2nd cancers

Symptoms and Functions:
- Restricted social and physical activities
- Memory loss, cognitive concerns
- Muscle and joint stiffness, weakness, cramps or pain
- Sexual dysfunction
- Fatigue / lack of stamina
- Distress and worry

Psychosocial Issues
- School
- Work
- Insurance
- Relationships
Beyond Cancer to Wellness: What do cancer survivors need?

• Resources for survivorship problems that arise and a realistic description of recovery from cancer

• A comprehensive evaluation after completion of cancer treatment, so you can understand the long-term physical and emotional problems that you may face following cancer treatment
Survivorship Programs: What are they?

- Dedicated programs that provide clinical care, advocacy, educational activities and access to research
- A bridge between acute oncology and primary care to assist patients and primary health care providers to work together to manage the survivor’s ongoing health care needs
Survivorship Program Services

• Coordination of care
• Referrals for counseling services, physical and occupational therapy, nutrition, social work, vocational and rehabilitation therapy and other sub-specialties as needed
• Educational information on physical, emotional and daily living issues specific to cancer survivors
• Navigation to locate community and web-based resources
• Educational classes and events
Survivorship Clinical Evaluations
Include:

- Cancer Treatment Summary/Survivorship Care Plan
- Screening of medical history and current needs
- Physical examination and lab tests focused on long-term and late effects
- Guidelines and recommendations for follow-up monitoring, including for healthy lifestyle and general health maintenance
- Subspecialty referrals as needed
- Communication back to primary oncologist and primary care provider
Survivorship Treatment Summary and Care Plan (1)

• **Diagnosis:** Cancer type, stage, histology, date and age at diagnosis

• **Care Providers:** Treatment facility and oncology health care providers and PCP with contact information

• **Treatment details:** Chemotherapy, with selected cumulative doses, radiotherapy doses and fields, surgical procedures, blood product exposures
Survivorship Care Plan (2)

- **Complications** on/off treatment with long-term implications

- Associated *potential risks* of treatment including second cancers or specific organ toxicity with screening and follow-up recommendations

- Sent to survivor and healthcare providers
Where to get a Survivorship Care Plan

- Your oncologist or a survivorship clinic
- **American Society of Clinical Oncology**
  - [http://www.cancer.net/patient/Survivorship/ASCO+Cancer+Treatment+Summaries](http://www.cancer.net/patient/Survivorship/ASCO+Cancer+Treatment+Summaries)
- **Journey Forward’s Survivorship Care Plan Builder**
  - [http://www.journeyforward.org/](http://www.journeyforward.org/)
- **LIVESTRONG Care Plan**
  - [http://www.livestrongcareplan.org/](http://www.livestrongcareplan.org/)
- **SCCA Survivorship Clinic**
  - [www.fhcrc.org/survivorship](http://www.fhcrc.org/survivorship)
What else can you do?
This is your new “normal”, get used to it and make the best of it…
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Final Comments: the 3 ‘P’s of Survivorship

• Be *proactive* for your health: get informed about what you have been through and treated with

• Be *preventative*: follow standard guidelines for screening (pap smears, mamograms, lipid testing, colonoscopy, etc)

• Be *physical*: exercise is critical
Exercise and Thrive Program

• 10-week strength and fitness and nutrition program for cancer survivors

• YMCA of Greater Seattle
  – Program offered at 13 locations
  – Significantly reduced rates of membership for survivor and family for duration of program

• Extending program to more Y’s locally and regionally
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