Survivorship Care Planning in YOUR Real World: Promoting YOUR HEALTH and WELLNESS

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Topics:

1. Context: the big picture of cancer survivorship
   ✓ Who are survivors, what needs to they have?

2. How does survivorship care planning meet these needs?

3. What can YOU DO to meet your survivorship needs?
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1. Context: the big picture of cancer survivorship
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Cancer Survivors in the United States

41% lifetime cancer risk
1 in 2 men
1 in 3 women

5-year relative survival rate:
- 80% of children
- 69% of adults
  if diagnosed 2006-2012
Cancer Survivors in the United States

**16.9 million in January, 2019**

USA:
- 67% diagnosed 5 or more years ago
- 45% diagnosed 10 or more years ago
- 5 year survival:
  - 90% for breast cancer
  - 97% for prostate cancer

41% lifetime cancer risk

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Cancer Survivors are ALL OF US.
We will have cancer
or people we love will have cancer.
Survivorship is about living life as healthy as possible and as well as possible with and beyond cancer.
Surviving and Thriving:

Comes in many shapes, sizes, needs and capabilities
Cancer Survivor Challenges

Wellness & PsychoSocial
- Mental health
- Employment
- Education
- Social interactions/support
- Chronic symptoms: Fatigue, Cognition, Insomnia, Neuropathy
- Lifestyle
- Physical function

Environment & Finances
- Family / Caregiver function
- Access to health & resources
- Insurance
- Financial toxicity

Organ Function
- Cardiac
- Endocrine
- Musculoskeletal
- Genitourinary
- GI/Hepatic
- Neurologic
- Pulmonary

Subsequent Malignancies
- Recurrent cancer
- New cancers

Fertility & Reproduction
- Fertility
- Health of offspring
- Sexual functioning
Prevalence of health conditions in childhood cancer survivors in St. Jude Lifetime Study

Clinical testing of late effects in 1713 adult survivors of childhood cancers

Median age at diagnosis: 6 yrs (range, 0-24)

Median age at study: 32 yrs (range 18-60)

Median time from diagnosis: 25 yrs (range 10-47)

By age 45 years it is estimated that…….

95% will have ≥ 1 chronic health condition

80% will have a serious/disabling or life-threatening chronic health condition

Figure showing cumulative prevalence of any chronic condition and serious/life-threatening chronic condition over age.

Hudson et al, JAMA, 2013
Surveyed > 3000 cancer survivors

Rechis et al. LIVESTRONG Survey Report, 2012
Percent of survivors who report

Physical Concerns

- Energy: 59%
- Concentration: 55%
- Sexual Function: 46%
- Neuropathy: 42%
- Pain: 34%
- Incontinence: 22%
- Mouth and Teeth: 20%
Percent of survivors who report

Emotional Concerns

- Fear of Recurrence: 80%
- Grief and Identity: 68%
- Appearance: 62%
- Family Members: 51%
- Sadness & Depression: 51%
- Relationships: 31%
Fear of Recurrence

- Persists at least up to 9 years after treatment
  
  Mishel et al. *Psychooncology* 2005

- Fear of Recurrence can impair clinical care and quality of life
  - Avoidance of health care visits
  - Increased health care use and emergency room visits
  - Impairs quality of life
  
  Lebel et al. *Supportive Care Cancer*, 2013

- Cognitive strategies (5 sessions) improve multiple symptoms related to fear
  - Attention training: it is safe to not think about worries all the time
  - Acceptance: it is ok, I can tolerate having fears and worries and still live my life
  - Mindfulness: relaxes and eases mind and body
  - Values-based goal setting
  
  Butow et al. *J Clin Oncol*, 2017
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Survivorship Care Plans

• Half of survivors do not get their recommended health care to reduce their risks of cardiac events, cancer, or other health problems

• Survivors often do not understand their health behavior risks and benefits
  – Tobacco risk is well known
  – Alcohol risks are becoming clearer
  – Healthy eating - many misconceptions
  – Exercise: CLEAR BENEFIT, need to know how to get started, how to stay motivated
  – How to manage emotions after treatment

• Survivorship care plans are mandated for all survivors:
  – Many do not get them, Many do not address healthy behaviors
Survivors do not know what they do not know

• Many survivors do not know what they need: what is ‘normal’
  – Unaware of what tests and follow up visits they should have
  – Unsure which physician specialists they should continue to see, or see for what
  – Unsure how they ‘should feel’

• Care Coordination is unclear
  – Oncologist may think primary care is doing monitoring beyond cancer surveillance
  – Primary care may think oncologist is doing cancer monitoring and preventive care
  – Survivors may not know who to see when and for what
  – If survivors look fine and are not complaining, assume all is well

• Lack access to survivorship care
  – Services are not available or survivors do not know about services
Fred Hutch / SCCA Survivorship Program

- Established in 2006 through a grant from LIVESTRONG Foundation

- Mission is to provide:
  - Clinical Care
  - Outreach & Education
  - Research
Fred Hutch / SCCA Survivorship Clinical Care:

- Nurse prepares a Treatment Summary and Care Plan
- Patient eligibility
  - Off active treatment, without active cancer
  - All ages, all diseases
- 60-90 min Survivorship Clinic Treatment Summary and Survivorship Care Plan reviewed with nurse practitioner or doctor
  - Visit billed and reimbursed as oncology follow-up
Survivorship Care Plan Goals

Personalized document from oncology clinician:

- Summary of cancer history/treatment
- Primary cancer surveillance plan
- Cancer/cancer treatment health risks
- Subsequent cancer/late effects screening
- Promote a healthy lifestyle to reduce cancer risks and maximize wellness
- Screening for/management of health conditions
- Definition of roles of involved providers
- Resources to address medical/psychosocial needs
Emphasis of the Survivorship Clinic visit is on review of the care plan, identification of referral needs and accessing community resources

Most Common Referrals after Evaluation:

PT
OT
Vocational Rehab
Specialty Consult Clinics
Psychology / Psychiatry
Social Work
Intimacy/Sexuality
Fertility

Chaplaincy
Pain
Nutrition
Acupuncture
Sleep Medicine
Cardiology
Endocrinology
Other Specialty Consult Clinics
When you go through the experience that I have been through with cancer, you feel kicked to the ground and then dropped into the wilderness once the treatment is over. A treatment summary and survivorship plan are the pieces that have been missing in my care since finishing treatment. I appreciate the Survivorship Clinic’s willingness to listen to me and add pragmatic steps to help me on my quest for a bit of my old life back!

A survivorship care plan is the next step to help us survivors regain our dignity and confidence, moving forward with a plan with our eyes open.
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Your Personal Survivorship Care Planning

1. Get your Personalized care plan from a Survivorship Provider
   - Primary cancer surveillance plan

2. Take Charge
   - Decide what you NEED for your health and wellness: Make a List
   - Decide on a plan for what YOU CONTROL
     ✓ What you can do
     ✓ What you need help to do – and Who Will Help
   - Decide what steps you will take to manage your HEALTH
     ✓ Put your health care needs on your calendar;
     ✓ keep track of your screening plan and results
   - Decide what steps you will take to manage your WELLNESS

3. 3 Ps: Prioritize, Plan, Pace
Take Charge: What do I Value? (Prioritize these)

What do I value that keeps me motivated:

– My kids: I want to be there to see them have kids
  • Get pictures of your kids in your wallet and
  • When you are tempted, take them out and look at them!

– Life! There are still a lot of things I want to enjoy:
  • I want to sky dive!
  • [be specific, what do you want to do]
  • I’m going to schedule a sky dive today for my next birthday and start getting ready

These are my Priorities, I’m going to make certain I make the time and plan the actions I need for these
My Plan for my Health and Wellness

What do I need and What are my concerns?

1. Cancer coming back
   - Make sure I do my follow-up plan from my oncologist

2. Worry about my future
   - Yes, I can control my worry
     - Call my doctor about a referral

3. What health problems should I keep track of
   - Yes, I can find out what health tracking I need

4. My wellness:
   - My lack of energy
   - My activity level
   - My eating habits
     - Focus on my wellness
     - Take charge of what I can
# My Plan for my Health and Wellness

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Survivorship Care Plan Visit

A Survivorship Care Planning visit can take care of a lot of this!
Who will support my Plan for Taking Charge?

• What health care providers can you see and discuss your plan?

• What family or friends can you share your plan with who will talk with you when you are frustrated, worried, tempted?

• Who will exercise with you?

• Who will have fun with you without tempting you to break your eating or drinking plan?
Pace

• Be realistic, what can you do in a day or a week (and still enjoy life)?

• Be Certain your Priorities are in your daily plan!

• It takes time to achieve goals

  ➢ when things are going in the right direction you feel better and are more likely to keep going
3 Ps: The Main Idea for Taking Charge of Your Health

- **Prioritize**
  - Know what you value most!
    - In the big picture
    - Every day

- **Plan**
  - Make sure what you value/prioritize happens, don’t leave it to chance
    - Big things
    - Every day
  - List your plans so you can track when you’ve done them

- **Pace**
  - Be realistic, what can you do in a day or a week?
  - Be Certain your priorities are in your daily plan!
KEY POINTS

1. Survivorship Care has come a long way
   - One plan does not fit all needs
   - You need your own Survivorship Care Plan for Health and Wellness

2. You are the expert on your wellness needs, use the 3 Ps
   - Identify your values / Priorities – these keep you motivated
   - Plan your health and wellness needs
   - Make sure you connect to those who can help – you don’t have to do it alone
   - Pace – you don’t have to do it all this week

3. Survivorship care planning can ease your mind and improve your health and wellness
THANK YOU
Questions?
Discussion