# The Challenges of Cancer Survivorship: Psychological Understandings & Strategies

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### The Challenges of Cancer Survivorship: Psychological Understandings & Strategies

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Wallis Annenberg Director's Initiative in Psychosocial Oncology

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#### Survivor Challenges

- Disruption in Life Plan
- Living with the "New Normal"
- Fear of Recurrence
- Continuing Medical Follow-up
- Making Meaning out of "Your Story"
- "Time"



#### Challenge: Disruption in Life Plan

- Cancer alters the course of ones life
- Dependent on developmental phase
- School/work/career/retirement
- Family planning/family life
- Requires
  - adjustment
  - resetting of priorities
  - altering goals
- Psychological consequences = Loss
- Need for adjustment



#### Disruption of Life

- Understand what happened
- Take time to grieve the loss
- Write about experience
- If pause button ....
- Psychotherapy
  - Process events and losses
  - Proactive action to restart life

#### Challenge: The "New Normal"

- Immediate disruptions of treatment end
- Life gets going back to "Normal"
- Living day to day with the changes



#### Challenge: The "New Normal"

- Physical symptoms
- Emotional changes
- Cognitive dysfunction
- Social changes
- Psychological adaptation
  - Grief and loss
  - Acceptance of changes
  - Ongoing fears
- Heightened sense of vulnerability



#### Challenge: Fear of Recurrence

- Prevalent in Cancer Survivors
  - Kornblith, Herndon ,Zuckerman et al. Comparison of psychosocial adaptation of advanced stage Hodgkin's disease and acute leukemia survivors. Ann Oncol, 9, 1998.
- Ranges 5%-89%
  - Ronson, Body. Psychosocial rehabilitation of cancer patients after curative therapy. Support Care Cancer 10, 2002.
- Described as largest concern of breast cancer patients
  - Spencer, Lehman, Wynings, et al. Concerns about breast cancer and relations to psychosocial well-being in a multiethnic sample of early stage patients. *Health Psychol* 18, 1999.
- Persists at least up to 9 years post TX
  - Mishel, Germino, Gil et al. Benefits from an uncertainty management intervention for African-American and Caucasian older long-term breast cancer survivors. *Psychooncology* 14, 2005.

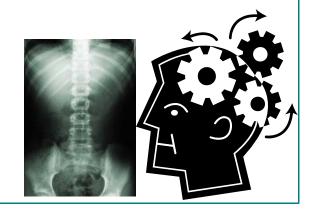


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#### Challenge: Fear of Recurrence

- Does Cancer Still Exist?
  - In the body?
  - In mind?





#### Fear of Recurrence

- Fear depletes your energy reserve
- Fear steals valuable time
- Fear distracts you from living fully
- Fear steals the present
- Fear keeps you in the past and in the future
- Fear perpetuates itself
- Fear is wasted energy



#### Fear of Recurrence

Does NOT prevent recurrence



#### Fear of Recurrence: Understand the Triggers

- Aches and pains
- Scans and doctor visits



#### Fear of Recurrence: Understand the Triggers

- Anniversaries
- Friends/families diagnosed or recur



#### Fear of Recurrence: Understand the Triggers

Media





#### Cancer as Foreground, Cancer as Background



"Someone likened cancer to a pink elephant, and the pink elephant initially is right there in front of your face, you know... and then as you get better, the pink elephant maybe goes to another room. And then as you get much better, the pink elephant goes down the street, but it's always there and you always know it's there. And, I think that, as you approach appointments, the pink elephant [from] down the street, you know, comes in the living room again."



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## Where does Fear of Recurrence come from?

- Cancer is a traumatic event
- Characterized by loss and crisis
- Powerfully affected by diagnosis
- Memories are created
- Our mind uses those memories, cognitions feelings to shape what happens
- Cancer is life threatening



#### Tackling Fear of Recurrence

- Cancer in the mind is ...
  - Anxiety based problem
  - Solution is to develop anxiety management specific to it



# Development of Individualized Plan to Manage Symptoms/Fear

- Who will you talk to about your concerns for emotional support?
  - Friend
  - Family
- Where will you seek medical information?
- How long will you wait before presenting symptoms to your doctor?
- Will you go on the Internet?
- Example Plan





#### Plan – Social Support

- I will talk to my best friend David because he tends to be calming and reassuring.
  - [Engage David in advance that he will serve as this resource for you]
- If David not available, I will talk to Shannon, because she listens well and supports me.
- I will not call my brother, Mike, because he freaks out and makes me anxious.





#### Plan – Medical Support & Time Frame

- Discuss with your doctor how to handle worrisome symptoms.
- If a symptom such as a cough or pain persists for two weeks I will see my doctor.
  - [Set comfort window]





#### Plan - Self Talk

- It is unlikely that this is cancer.
- I was screened \_\_\_\_ months ago and things were fine.
- If I have this in two weeks I will go to my doctor.
- I can always go to my doctor sooner if I need reassurance.
- There are 10.5 million cancer survivors, I am one of them.
- I have a lot of inner resources.
- I have people that I can rely on.
- I have a doctor that I can count on to help me with this.
- I can call my friends, who always helps me to feel better.
- I'm going to stop thinking about this, until two weeks have passed.
- I'm going to do something that I enjoy.
- I'm going to write this all down in my journal and leave it.



#### Plan – Distraction Techniques When I am feeling worried I will

- Exercise
- Meditate
- Use relaxation
- Television/Movie
- Work
- Read
- Social Activity
- Religious practice and prayer

#### Challenge: Medical Follow-up

- Medical follow-up is long term
- Medical environment is trauma trigger
  - Heightens worry about recurrence
- Communication with Medical Team is often difficult

#### Post Traumatic Stress Disorder (PTSD)

 Intense fear, helplessness or horrors resulting from an extreme traumatic stressor and symptoms fall into three clusters





#### Post Traumatic Stress Disorder (PTSD)

- Reexperiencing Symptoms relives trauma, flashbacks, memories, uncontrollable thoughts feelings images (intrusive thoughts & memories most common)
- Avoidance -- of situations that bring back memories of event (may get detachment and emotional numbness)
- Hyperarousal -- usually as consequence to trigger includes insomnia, irritability, increased psychophysiological arousal decrease in concentration alertness, startle response

#### Post Traumatic Stress Disorder (PTSD)

Prevalence in Cancer – Approximately 10%

range in studies is 0-60% depending on how measured

Reexperiencing Symptoms 36-72%

intrusive thoughts and memories most common

Hyperarousal symptoms 11-27%

Avoidance symptoms 7-80%



# Develop Strategy for Medical Appointments



#### Before You See Your Doctor

- Develop a list of bullets that you want to convey
- Write out a medication list
- Write a list of questions in order of priority
- Identify potential referral needs
- Take memory aides
  - Paper & pencil
  - Tape recorder
  - A second set of ears (social support)
- Take Care Plan





#### Planning Appointments

- Arrange to have scans early in week
- Plan & schedule follow-up visit with physician for results at time of scan





#### Cognitive Frame

- See your doctor as an integral part of your well-being
- Understand that communication is a two lane highway
- Make certain you communicate about your whole self
  - Physical & Psychological
- Recognize limitations in physician ability to communicate
  - But do not be deterred
  - Initiate interaction
- Don't get distracted talking about your physician's life
- The appointment IS about YOU





## At the Doctor Visit – Managing the Appointment

- Provide summary of your current status and most pressing issues
  - Cover medical and psychological issues
  - Bring up concerns
- Inform physician that you have a list of questions
- If all questions are not answered, let physician know
- Ask to schedule another visit





#### After the Visit

- Write summary of recommendations made by physician
- List of things to do to follow-up





#### Challenge: Make Meaning of "Your Story"

- Develop a narrative about your experience
- What were the hardest parts?
- What did you get from this experience?
- Assess your Post-Traumatic Growth



#### Your Six Word Cancer Journey Story

- How many words would it take to say all the ways that going through cancer has touched you?
- What would you say if you had six words only?
- Ernest Hemmingway wrote of his life:

"For sale: Baby shoes, never used."



#### Six Word Cancer Journey Story

- My children need me. Must live. Marcia Britvan
- Wait, wait. I'm not done yet. Anonymous
- Thirteen years and still here. Wow. Marcia Britvan
- Lived a good life. Wanting more. -- Sally
- Not the same as before cancer. Marcia Britvan
- So much Hope, keep spirits high. -- Annette
- Much help. Good life. Give back. Anonymous
- I will get well, I promise. -- Annette
- The best is yet to come. Anonymous
- Had much trauma. Have much joy. Anonymous
- Chemo: done. Radiation: done. Freedom done! Anonymous
- Feeling good again, much to do. -- Annette



## Six Word Cancer Journey Story

- If you would like to submit yours to me for posting on our web site, please send them to:
- SimmsMannCenter@mednet.ucla.edu
- Title it: Six Word Story for Anne
- Please tell me how you want to be identified:
- First Name, Last Name, Anonymous

#### Post Traumatic Growth

- PTG follows an initial period of turmoil and distress
- Over time, many individual develop a growing sense of enrichment and satisfaction that appears to exceed prior levels



### Post -Traumatic Growth

- "Growth"
  - Individual undergoes a stage in their personal development that extends beyond their previous functioning





#### Post Traumatic Growth

- Relationships with friends and family are stronger
- More emotionally connected
- Greater feelings of closeness
- Improvements in quality of marital relationships
- Importance of awareness of one's importance to others
- Increased feelings of compassion for others/felt more deeply
- Renewed appreciation for life





#### Post Traumatic Growth

- New set of priorities or changes in goals
- Shifts in life, school, family how they relate to themselves
- Many feel they have grown stronger, giving new resources and skills to tackle life's problems
- May feel more competent
- Empowerment to make changes

## Challenge: "Time"

- Takes on new meaning
- Awareness of the possibility of a condensed life
- Requires work to move from the past
- Requires work to stay out of the future
- The challenge is to live "Now"





## Strategy for Being in the Present: Ask Questions that focus on Now

- Do I have cancer today?
- What can I do today that gives my life meaning?
- What am I feeling now?
- What am I grateful for at this moment?
- Who do I have in my life right now?
- What are my current strengths?
- Am I living today as I want to be living?
  - If not, what can I do to change that

## Flexible and Multiple Coping Strategies

- Individual Counseling
- Medication
- Reframing/Restructuring Cognitions
- Problem-solving
- Relaxation/Meditation
- Peer Support
- Yoga, Qi Gong
- Writing Give it form
- Art
- Focus on Wellness Nutrition, CAM, Exercise



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#### Three Wishes

- Cancer could be prevented
- Cancer could be cured for everyone
- Cancer patients and their families receive optimal integrated medical and psychosocial care throughout the continuum of care



# Thanks to the Wallis Annenberg Director's Initiative in Psychosocial Oncology

The Annenberg Foundation **for** 

Supporting the leadership of the Center in direct services, training and educational programs to improve quality of life for patients with cancer and their family members

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FOR INTEGRATIVE

## Thanks to the Simms/Mann Family Foundation for

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