

**LLS RESOURCES FOR PATIENTS AND CAREGIVERS**  
**LLS.ORG**

**BEATING CANCER IS IN OUR BLOOD.**

LEUKEMIA & LYMPHOMA SOCIETY

1


**BEATING CANCER IS IN OUR BLOOD.**

**UNDERSTANDING THE EMOTIONAL EFFECTS OF CANCER**


Daniel C. McFarland, DO  
Medical Oncologist/Psychiatrist  
Department of Psychiatry and Behavioral Sciences  
Memorial Sloan Kettering Cancer Center  
New York, NY

LEUKEMIA & LYMPHOMA SOCIETY


2

 **DISCLOSURE**  
*Understanding the Emotional Effects of Cancer*

**Daniel C. McFarland, DO** has nothing to disclose.

**BEATING CANCER IS IN OUR BLOOD.** 

3

 Memorial Sloan Kettering  
Cancer Center

**Understanding the Emotional  
Effects of Cancer**

**Daniel McFarland, DO**  
**Memorial Sloan Kettering Cancer Center**  
**1/29/2020**

4

## Overview

- Emotions at diagnosis/recurrence
- Understanding emotional symptoms (distress, anxiety, depression)
- Spirituality
- Body Image
- Post-traumatic stress
- Fear of recurrence
- Survival Guilt
- Recommendations

5

## Diagnosis

- Coming to a diagnosis...-the waiting game
  - trail of doctors, nurses, hospitals, (invasive tests), and receiving information
- Pathology
  - Molecular data
- Treatment considerations-recommended treatment – best treatment – trial options? etc...
- Cancer 'education'
- Lifestyle changes

6

## Diagnosis-figuring it out...

- Information handling: “big picture versus need details”
  - ‘I want to know everything’
  - ‘need to know basis’
- Managing sources of information
- Disclosing, ‘circle of trust’
- Irony of needing to support family and friends
- Living with constant uncertainty

7

## Emotional Effects of Cancer

- What’s a ‘normal’ reaction?
- Coping reserve and resiliency
  - Stress, appraisal, and coping
- Usual ‘go to’ coping mechanisms?
- Loss/gain of function

8

## NIH-Feelings and Cancer

- Overwhelmed
- Denial
- Anger
- Fear and Worry
- Hope
- Stress and Anxiety
- Sadness and Depression
- Guilt
- Loneliness
- Gratitude


NCI 2020.

9

## Emotional Effects of Cancer-Distress

- The National Comprehensive Cancer Network 'Distress Screening'
- Definition of Distress in Cancer
  - *"Distress is a multifactorial unpleasant experience of a psychological (i.e., cognitive, behavioral, emotional), social, spiritual, and/or physical nature that may interfere with one's ability to cope effectively with cancer, its physical symptoms, and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis"*
- The practical, familial, emotional, spiritual, and physical

10

 Memorial Sloan Kettering  
Cancer Center

**NCCN DISTRESS THERMOMETER**

Instructions: Please circle the number (0–10) that best describes how much distress you have been experiencing in the past week including today.

Extreme distress

10

9

8

7

6

5

4

3

2

1

No distress

0

**PROBLEM LIST**  
Please indicate if any of the following has been a problem for you in the past week including today.  
Be sure to check YES or NO for each.

YES	NO	Practical Problems	YES	NO	Physical Problems
<input type="checkbox"/>	<input type="checkbox"/>	Child care	<input type="checkbox"/>	<input type="checkbox"/>	Appearance
<input type="checkbox"/>	<input type="checkbox"/>	Housing	<input type="checkbox"/>	<input type="checkbox"/>	Bathing/dressing
<input type="checkbox"/>	<input type="checkbox"/>	Insurance/financial	<input type="checkbox"/>	<input type="checkbox"/>	Breathing
<input type="checkbox"/>	<input type="checkbox"/>	Transportation	<input type="checkbox"/>	<input type="checkbox"/>	Changes in urination
<input type="checkbox"/>	<input type="checkbox"/>	Work/school	<input type="checkbox"/>	<input type="checkbox"/>	Constipation
<input type="checkbox"/>	<input type="checkbox"/>	Treatment decisions	<input type="checkbox"/>	<input type="checkbox"/>	Diarrhea
			<input type="checkbox"/>	<input type="checkbox"/>	Eating
			<input type="checkbox"/>	<input type="checkbox"/>	Fatigue
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with children	<input type="checkbox"/>	<input type="checkbox"/>	Feeling swollen
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with partner	<input type="checkbox"/>	<input type="checkbox"/>	Fevers
<input type="checkbox"/>	<input type="checkbox"/>	Ability to have children	<input type="checkbox"/>	<input type="checkbox"/>	Getting around
<input type="checkbox"/>	<input type="checkbox"/>	Family health issues	<input type="checkbox"/>	<input type="checkbox"/>	Indigestion
			<input type="checkbox"/>	<input type="checkbox"/>	Memory/concentration
			<input type="checkbox"/>	<input type="checkbox"/>	Mouth sores
<input type="checkbox"/>	<input type="checkbox"/>	Depression	<input type="checkbox"/>	<input type="checkbox"/>	Nausea
<input type="checkbox"/>	<input type="checkbox"/>	Fears	<input type="checkbox"/>	<input type="checkbox"/>	Nose dry/congested
<input type="checkbox"/>	<input type="checkbox"/>	Nervousness	<input type="checkbox"/>	<input type="checkbox"/>	Pain
<input type="checkbox"/>	<input type="checkbox"/>	Sadness	<input type="checkbox"/>	<input type="checkbox"/>	Sexual
<input type="checkbox"/>	<input type="checkbox"/>	Worry	<input type="checkbox"/>	<input type="checkbox"/>	Skin dry/itchy
<input type="checkbox"/>	<input type="checkbox"/>	Loss of interest in usual activities	<input type="checkbox"/>	<input type="checkbox"/>	Sleep
			<input type="checkbox"/>	<input type="checkbox"/>	Substance use
			<input type="checkbox"/>	<input type="checkbox"/>	Tingling in hands/feet

**Family Problems**

**Emotional Problems**


**Spiritual/religious concerns**

Other Problems: \_\_\_\_\_

Version 3.2019, 05/06/19 © National Comprehensive Cancer Network, Inc. 2019. All rights reserved.  
The NCCN Guidelines® and this illustration may not be reproduced in any form without the express written permission of NCCN.

DIS-A

11

 Memorial Sloan Kettering  
Cancer Center

## Consequences-Emotional Effects of Cancer

- Quality of Life
- Interference with cancer treatment (treatments, delays, communication)
- Impacts the ability to cope with cancer
- Relationships:
  - Primary, familiar, friends, acquaintances
  - Interpersonal styles and values
  - Stressor
    - Can strengthen, strain, or weaken relationships
  - Transformation
  - Relationship with self (self image/identity/roles)

12

## What does anxiety or depression feel like?

### Anxiety

- Extra worry, can't relax and feel tense
- May notice
  - Fast heart beat
  - Headaches, muscle aches
  - Appetite disturbance or diarrhea
  - Shaky, weak, dizzy
  - Tight feeling in throat/chest
  - Sleep disturbance
  - Hard to concentrate

### Depression

- Sadness that doesn't go away
- Emotionally numb
- Sense of guilt or feeling unworthy
- Helpless or hopeless (loss of meaning)
- Moody, short temper, irritable
- Crying (long periods of time or many times per day)
- Focused on worries and problems
- Little or no interest, enjoyment
- Thinking about self harm

NCI 2020.

13

## Emotional Symptoms: Distress, Anxiety, Depression

- Common
- Co-occur
- Recur
- Treatable
- Red Flags
  - Functional loss
    - Getting to doctor's appointments
    - Relationship stressor
  - Physical symptoms
    - Insomnia
    - Anorexia
    - Physical ailments
  - Substance Abuse
  - Self harm
  - Suicidal thoughts

14

## (Post)Traumatic Stress

- Disorder versus symptoms
- Core symptoms of PTSD
  - Intrusive persistent negative thoughts
  - Avoidance type of behavior
  - Hyper-arousal and reactivity (vigilant)
- Cancer is considered a traumatic event (Diagnostic Statistical Manual-V)
- Associated with distress, depression, other anxiety disorders
- Cancer –related PTSD is 12.6% while up to 20% may have symptoms
- Risk factors:
  - prior trauma, pre-existing psychiatric conditions, poor social support , limited financial resources
  - advanced disease, invasive treatments, not remembering during key cancer experiences, persistent intrusive re-experiencing

Cordova et al. Lancet Psychiatry 2017.

15

## (Post)Traumatic Stress

- What aspect of the cancer experience might constitute a traumatic stressor?
  - Period of heightened anxiety following abnormal finding on self, laboratory test, screening procedure, routine imaging, clinical exam
  - Undermines assumptions of invulnerability, predictability, and control
  - Series of acute and chronic challenges (e.g., medical complications)
  - Life threatening
    - Diagnosis versus other time points
  - *"Diagnosis and treatment of cancer pose a cascade of physical, emotional, practical, and social demands on the individual and their support network"*
- Treatment

Cordova et al. Lancet Psychiatry 2017.

16



## Post Traumatic Growth (PTG)

- Cancer has potential for both negative and positive psychological outcomes
- Positive relationship between growth and stress
- Refers to the cognitive process through which those who've encountered a traumatic event positively re-interpret and find meaning in the event
- Mildly correlated with PTSD in cancer, perhaps to a certain point (curvilinear relationship)

Tedeschi RG, Calhoun LG. J Trauma Stress. 1996.

17

## Body Image Discomfort

- Body Image: *An image of one's own body created in the mind*
- Changes throughout treatment and recovery
- Physical changes versus perceptual changes
- Negative feelings about one's body affects:
  - Self image
  - 'betrayal'
  - Confidence (self esteem)
  - Relationships
  - Intimacy
  - Role
- Cancer and treatment specific issues
  - Can persist
- Impedes post traumatic growth

Muzzatti et al. Support Care Cancer 2017.

18

## Fear of Cancer Recurrence (FCR)

- The most prevalent unmet supportive care need in cancer is help with FCR
- Almost all patients experience some FCR;
  - ‘scanitis’
- Studies have shown even higher rates in caregivers
- Does not always decrease with time, even when the risk is low
- Intrusive thinking and preoccupation with checking (for cancer)
- Negative impact on QOL, psychological adjustment, ability to establish goals
- Interventions –few validated approaches
  - Risk perception modification
  - Self regulation of illness model –focuses on adaptive coping
  - Acceptance and Commitment Therapy (ACT)-cognitive flexibility

Thewes et al. Support Care Cancer. 2012.

19

## Survivor Guilt

- Connection and identification with a community and surviving a situation that others have not
- Comparing ones’ life to the lives of others who have died
- Struggle to justify existence (fairness)
- Deep sense of injustice
- Majority endorse survivor guilt
  - Distinct from depression (self esteem)
- Five themes:
  - Mentioning death of others
  - Questioning ‘why not me?’
  - Role of passage of time on emotions experienced
  - Demographic and clinical characteristics
  - Strategies for managing

Perloff et al. J Psychosoc Oncol. 2019.

20

## Dealing with Emotional Effects from cancer – Susan's Story

- Susan is a 75 year old retired school high school teacher. She lives alone but has several friends close by with whom she plays Bridge and two adult children who live out of the state. She underwent a stressful divorce 10 years ago but is financially secure through retirement/savings. Does not drink or use any drugs.
- She was diagnosed with CLL at age 65 and then diagnosed with Diffuse Large B Cell Lymphoma (DLBCL) 8 years later and underwent 6 cycles of R-CHOP.
- Initially, she was nervous but could garner the support she needed to get through her months of treatment. She had difficulty sleeping, eating, concentrating at times, and always felt 'on edge'. Treatment left her with fatigue and neuropathy.
- She used to only get nervous before her scans (all NED) but is now nervous and irritable most of the time. She is having trouble sleeping again but doesn't want medication or to see her doctors/nurses. She no longer enjoys playing cards, seeing friends or family and prefers solitude. Interests have diminished.

21

## Susan's Story

### Red Flags ?

- Change in pace and tenor of her anxiety symptoms
- Social withdrawal
- Not engaged with medical team (Avoiding?)
- Physical symptoms
- Previous stressors
- Protective: finances

### Possible Reasons?

- Anxiety
- Fear of recurrence
- Depression
- Post traumatic stress

22

## Susan's Story

- She needs a medical assessment along with a thorough/comprehensive evaluation into her recent psychological symptoms.
- Susan's medical work up is fine.
- On further discussion, she says that this time of year is difficult for her due to a previous loss. She is unsure of how to cope with the added stress of worrying about cancer and feels overwhelmed.

23

## Dealing with Emotional Effects from Cancer

- Alignment with medical team
  - Addressing physical symptoms (e.g., sleep)
- Familial/relationship stressors may add to cancer stress
- Psychologically stressful times in the past -what helped? What didn't?

24

## Susan's Story

- Susan starts getting better sleep with the help of Cognitive Behavioral Therapy-Insomnia in addition to as needed lorazepam
- She finds a therapist through LLS in her area and benefits from obtaining another perspective on her cancer journey. She discovers that she feels constrained about her emotions. Everyone wanted her to act 'positive' and she never had a chance to express how she was truly feeling after her diagnosis and through treatment. She harbors anger at those around her who indicated (nonverbally) that they weren't willing to listen to her feelings even though they had been present.

25

## Coping with Emotion and Cancer

- Express your feelings
- Look for the Positive
- Don't blame yourself for cancer
- Don't try to be upbeat if you're not
- YOU choose when to talk about your cancer
- Be as active as you can
- Look for things you enjoy
- Look at what you can control
- Find ways to help yourself relax

NCI 2020.

26

## Spirituality

- **Religion:** viewed as specific set of beliefs and practices associated with organized religion or denomination
- **Spirituality:** recognized as encompassing experiential aspects, whether related to engaging in religious practices or a sense of peace/connectedness.
  - >90% express belief in God
  - >70% identify religion as important
- 77% think physicians should take spiritual needs into consideration
- 37% wanted religious beliefs addressed more frequently
  - Spiritual/religious needs not met by medical system
- Intensity of spiritual distress correlates with depression but not pain or perceived severity of illness.
- Affects coping and quality of life
  - Less distress
- Prayer

27

## Hope and Gratitude

- Maintain as much normalcy as possible (routine)
- Don't limit things you like to do
- Look for reasons to have hope. If it helps, write them down or talk to others about them
- Spend time in nature
- Reflect on personal beliefs
- Listen to stories about people with cancer who are leading active lives
- The surprising solace in simplicity

28

## Conclusion

- Unique interface of cancer meaning and life trajectory
- Enormous task and complexity
- Capacity for coping and resilience
- Attention to symptoms and functioning
- Support and perspective go a long way

29



### Q&A SESSION

*Understanding the Emotional Effects of Cancer*

- **Ask a question by phone:**
  - Press star (\*) then the number 1 on your keypad.
- **Ask a question by web:**
  - Click “Ask a question”
  - Type your question
  - Click “Submit”

Due to time constraints, we can only take one question per person. Once you’ve asked your question, the operator will transfer you back into the audience line.

**BEATING CANCER IS IN OUR BLOOD.**





30

**LLS EDUCATION & SUPPORT RESOURCES**

- **Information Specialists**  
Master's level oncology professionals, available to help cancer survivors navigate the best route from diagnosis through treatment, clinical trials and survivorship.  
– EMAIL: [infocenter@LLS.org](mailto:infocenter@LLS.org)  
– TOLL-FREE PHONE: 1-800-955-4572
- **Caregiver support:** [www.LLS.org/caregiver](http://www.LLS.org/caregiver)
- **Free education booklets:** [www.LLS.org/booklets](http://www.LLS.org/booklets)
- **Free telephone/web programs:** [www.LLS.org/programs](http://www.LLS.org/programs)
- **Live, weekly online chats:** [www.LLS.org/chat](http://www.LLS.org/chat)
- **LLS Community:** [www.LLS.org/community](http://www.LLS.org/community)

**BEATING CANCER IS IN OUR BLOOD.**


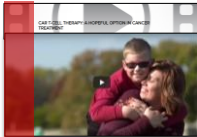
LEUKEMIA & LYMPHOMA SOCIETY

31

**LLS EDUCATION & SUPPORT RESOURCES**


- **LLS Patient Podcast, *The Bloodline with LLS***  
Listen in as experts and patients guide listeners in understanding diagnosis, treatment, and resources available to blood cancer patients: [www.thebloodline.org](http://www.thebloodline.org)
- **Education Videos**  
Free education videos about survivorship, treatment, disease updates, and other topics: [www.LLS.org/educationvideos](http://www.LLS.org/educationvideos)
- **Patti Robinson Kaufmann First Connection Program**  
Peer-to-peer program that matches newly diagnosed patients and their families: [www.LLS.org/firstconnection](http://www.LLS.org/firstconnection)


32




**LLS EDUCATION & SUPPORT RESOURCES**



- **Free Nutrition Consults**  
Telephone and e-mail consultations with a registered dietitian:  
[www.LLS.org/nutrition](http://www.LLS.org/nutrition)




- **What to Ask**  
Questions to ask your treatment team:  
[www.LLS.org/whattoask](http://www.LLS.org/whattoask)



- **Other Support Resources**  
LLS community, blogs, support groups, financial assistance, and more: [www.LLS.org/support](http://www.LLS.org/support)

33

**UPCOMING BLOOD CANCER CONFERENCES**




**BLOOD CANCER CONFERENCES**

To register or to view the BCC schedule, visit [www.LLS.org/BCC](http://www.LLS.org/BCC).

Texas Blood Cancer Conference Hyatt Regency Hill Country Resort San Antonio, TX <b>February 8, 2020</b>	Florida Blood Cancer Conference Ft. Lauderdale Marriott Harbor Beach Resort & Spa Fort Lauderdale, FL <b>February 29, 2020</b>
--	--

BEATING CANCER IS IN OUR BLOOD.



34

