Finding Your New Normal

Presented by: Crystal Ward, LSW

Robert H. Lurie Comprehensive Cancer Center
Northwestern Medicine
Agenda

1. Impact of Diagnosis
2. Emotional & Physical Reactions
3. Coping Strategies
4. Ideas from other Patients and Caregivers
5. Values Activity
6. Take Aways
Diagnosis

Onset
- Acute vs. Gradual

Course
- Progressive vs. Constant vs. Relapsing

Outcome
- Nonfatal vs. Shortened Lifespan vs Fatal

Rolland, J. (1994) Families, Illness, and Disability: An Integrative Treatment Model
Survivorship

- Estimated almost 13.7 million people in the USA are cancer survivors
- The majority of those diagnosed with cancer today can expect to be alive in 5 years
- Cancer, for many, has become a chronic, manageable illness
- More than 1 million survivors have lived >25 years after diagnosis
Common Reactions

• “I want things to go back to normal”

• “I miss the way things used to be”

• “Before cancer I...”
Everyday Changes

- New Routine
  - Appointments (Routine & Follow Up)
  - Scans, labs, Tests
  - Treatment (Chemo/Surgery/Radiation)
  - Taking medications
Family/Social Changes

• Changing Roles & Responsibilities

• Traditions/Holidays

• Friendships (gained & lost)
Identity

- Being “well” or “healthy”
- “Survivor” “Fighter” “Patient” “Victim”
- Person who has/had cancer
Practical Issues

• Work
  - Disclosure
  - Extended Leave/FMLA
  - Changing Responsibilities

• Finances
  - Insurance Issues
  - Cost of treatment
  - Loss/Decrease in Income
Cancer-related Fatigue

“A common, persistent, subjective sense of tiredness related to cancer or cancer treatment that interferes with usual functioning.”
National Comprehensive Cancer Network (NCCN)

- 60-90% of Patients
- Associated with disease or comorbid conditions
  - Increases as disease advances
  - Related to Anemia, depression, pain, insomnia
- Caused by Treatment
  - 60-93% undergoing radiation
  - 80-96% undergoing chemotherapy
  - After surgery
Typical Emotions

- Exhaustion
- Isolation
- Overwhelmed
- Altered body image
- Fear of recurrence
- Anxiety
- Anger/Frustration
- Disappointment
- Grief
Grieving the Losses

Stages of the Grief Cycle

"NORMAL" FUNCTIONING

Shock and Denial
- Avoidance
- Confusion
- Fear
- Numbness
- Blame

Anger
- Frustration
- Anxiety
- Irritation
- Embarrassment
- Shame

Depression and Detachment
- Overwhelmed
- Blahs
- Lack of energy
- Helplessness

RETURN TO MEANINGFUL LIFE

Acceptance
- Exploring options
- A new plan in place

Dialogue and Bargaining
- Reaching out to others
- Desire to tell one’s story
- Struggle to find meaning for what has happened
What is Depression?

Major Depressive Disorder* occurs when you have at least 5 of the following 9 symptoms daily for 2 weeks or more:

- A **depressed mood** during most of the day, particularly in the morning
- **Fatigue** or loss of energy
- Feelings of **worthlessness** or **guilt**
- **Impaired concentration, indecisiveness**
- **Insomnia** (lack of sleep) or **hypersomnia** (excessive sleeping)
- **Diminished interest or pleasure** in almost all activities
- Recurring thoughts of **death** or **suicide** (not just fearing death)
- Feeling **restless, agitated** or **slowed down**
- Significant **weight loss** or **gain** (more than 5% in a month)

*The Diagnostic and Statistical Manual of Mental Disorders, 4th edition, published by the American Psychological Association in 2000*
Rule out contributing factors

- Medication side effects
- Infection
- Hormonal Changes
- Low blood counts (anemia)
- Depression/Anxiety
- Nutritional deficits
- Sleep disturbances

Pearman, et al., 2013, JPSM
Incorporate Exercise

• Most strongly supported behavioral intervention for cancer patients
• Consult your physician and/or physical therapist
• 30 minutes of moderate activity most days
• Low intensity to start (walking, swimming, tai chi)
• Weight bearing exercises to strengthen bones
• Gentle stretching and breathing exercises
• Yoga: most rigorously validating fatigue intervention
Seek Support

• Share with Medical Team to rule out contributing factors

• Identify Friends & Family

• Supportive Oncology Services
  - Social Worker
  - Psychologists
  - Gilda’s Club Activities
  - Support Groups
Growth & Resilience

- Positive adjustment within 1-2 years (Stanton, et al. 2005)
- Positive life changes reported in majority of patients (Stanton et al. in Tedeschi, 2006)
- Reported benefits include:
  - Greater Compassion
  - Enhanced intimacy, relationship quality
  - Appreciation for life
  - Enhanced skills & strengths
  - Deepened spirituality

Growth & distress can, and do, co-exist
Ideas from Patients & Caregivers

• Exercise = Movement
• Keep a Journal
• Start a New Hobby
• Join a Support Group
• Become a Volunteer
• Create positive rituals for chemo/scans/appointments
• Use technology (Set reminders, care calendars, MyChart)
• Keep connected with friends and family
• Practice/reconnect with your faith
• Spend time in nature
• Disconnect from cancer (Tumor Free Tuesdays)
Values Activity
What you want to do, and how you want to do it

• What is important to you?
• What do you want your life to stand for?
• What qualities do you want to develop as a person?
• What kind of relationships do you want to build with those in your life (partner, children, parents, relatives, friends, co-workers, etc…)?
• What brings you the most pleasure (hobbies, recreation, activities for rest/relaxation, ways you have fun and enjoy yourself)?
• What life skills, beliefs, or traditions do you want to pass to the next generation?
Tools you can use: Adjusting to “The New Normal”

- Remember your values
- Keep support system close by
- Prioritize activities and tasks which give your life meaning and bring you joy
- Have Self Compassion
- Keep what works, eliminate what doesn’t
- Keep communication open and honest
  - Family & Friends
  - Medical Team

- BE FLEXIBLE!
Thank You