



Cancer Care on the Continuum

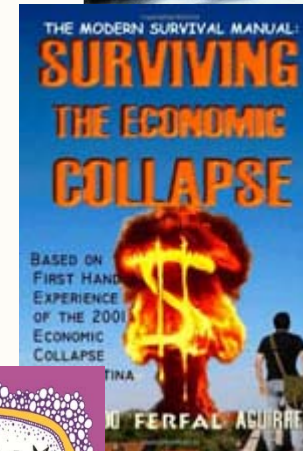
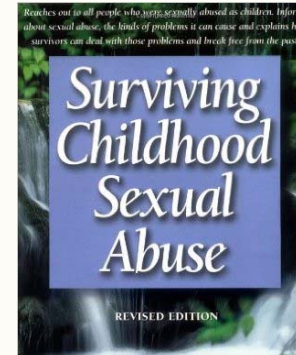
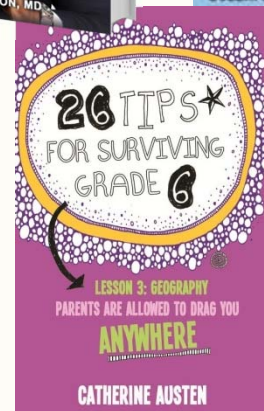
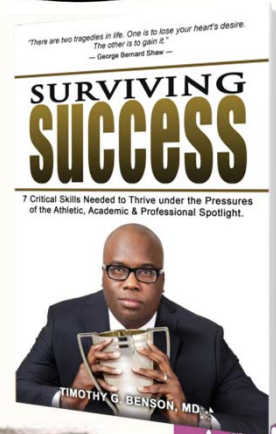
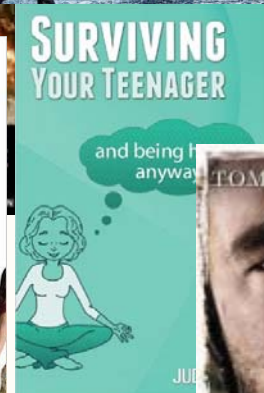
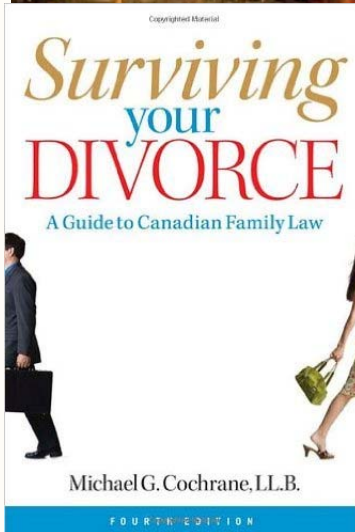
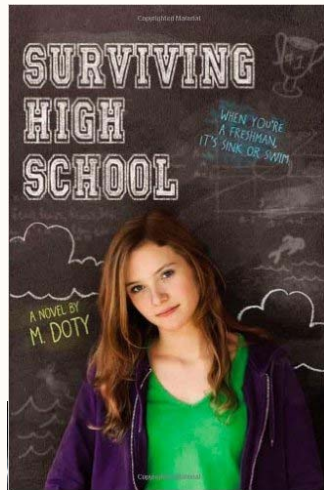
2016 Radiation Oncology Conference for
Therapists & Dosimetrists
September 10th, 2016

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Grayslake Cancer Centers - Lake Forest/Grayslake, IL

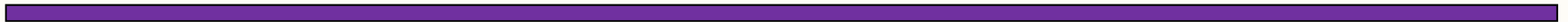
Goals of this session

- Define 'Cancer Survivor'.
 - Describe at least 3 challenges Cancer Survivor's face.
 - Describe how cultural competency and therapeutic presence are exhibited by radiation therapists/dosimetrists..
 - Describe 3 ways you can provide support to caregivers.
 - Describe compassion fatigue and 3 ways it impacts the cancer professional's ability to treat/care for patients.
-

Being a "Survivor" means....



How do **YOU** define Survivor?



Standard Definitions

- To remain alive or in existence.
- To carry on despite hardships or trauma; persevere.
- To remain functional or usable.
- To live longer than; outlive.
- To live, persist, or remain usable through.
- To cope with (a trauma or setback); persevere after.



Facing Challenges

Defining challenges:

- *Positive challenges – i.e. relationships, children, career changes, education, moving, etc.*
- *Negative challenges – loss of abilities, relationships, disappointments, etc.*



All of us are survivors of something

- What life challenges have you faced before?
 - *Personal, family, friends, career, health*
 - How did you meet those challenges?
 - *Strengths*
 - *Skills*
 - *Supports*
 - What did you learn from the challenge?
 - *About yourself*
 - *About others*
 - *Were there any benefits from the experience?*
-

How did these challenges affect
your daily living?

- Impact on daily schedule of activities
- Impact on relationships
- Impact on life goals



“You have cancer.”



What defines a Cancer Survivor?

1. Someone who has no cancer after completion of treatment.
2. Someone living with, through, and beyond cancer.
 - Includes people currently on treatment either to reduce the risk of reoccurrence or to manage the disease over time.
Cancer defined for many as a chronic disease.
 - Survivorship starts at diagnosis



Cancer Survivorship in the US

14.4 million children and adults with a history of cancer were alive on 1/1/14.

This number **does not** include:

- In situ cancers (non-invasive cancer) of any site except urinary bladder.
- Basal cell and squamous cell skins cancers.

64% were diagnosed 5 or more years ago.

15% were diagnosed 20 or more years ago.

46% of Survivors are 70 years or older.

5% are younger than 40 years old.

By January 1, 2024 estimated survivors = 19 million

Challenges of Cancer Survivors

- ✓ Physical
- ✓ Sexual/reproductive
- ✓ Relationship
- ✓ Work-related
- ✓ Financial
- ✓ Spiritual
- ✓ Emotional



How do cancer survivors adjust?

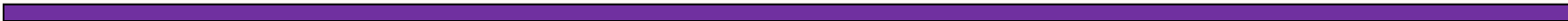
- Normal = ?
- It may take a while to develop or happening quickly.
- Some people make changes in their life to reflect what matters most to them now.
- You may find your meaning by yourself or with the help of others (i.e. family, friends, counseling, support groups, informal networks.)



Fear of Recurrence

Triggers for anxiety:

- Follow-up visits to doctors.
- Anniversary events (date of diagnosis, surgery or end of treatment).
- Birthdays
- Illness of a family member
- Symptoms
- Personal reminders – i.e. food or places you went during treatment.
- Depression occurs but tends to improve within 2 years
- Anxiety is less predictable and can be a concern 10 years after diagnosis.
(psychcentral.com/news/2013/06/09)



Dealing with Anxiety

- Information is Power
- Express Feelings
- Positive attitude
- Relaxation techniques
- Stay Active
- Control what you can
- Focus on Faith and Spirituality





How do we support
Survivors?



The American College of Surgeons

S3.2 “The cancer committee develops and implements a process to integrate and monitor on-site psychosocial distress screening and referral for the provision of psychosocial care.”

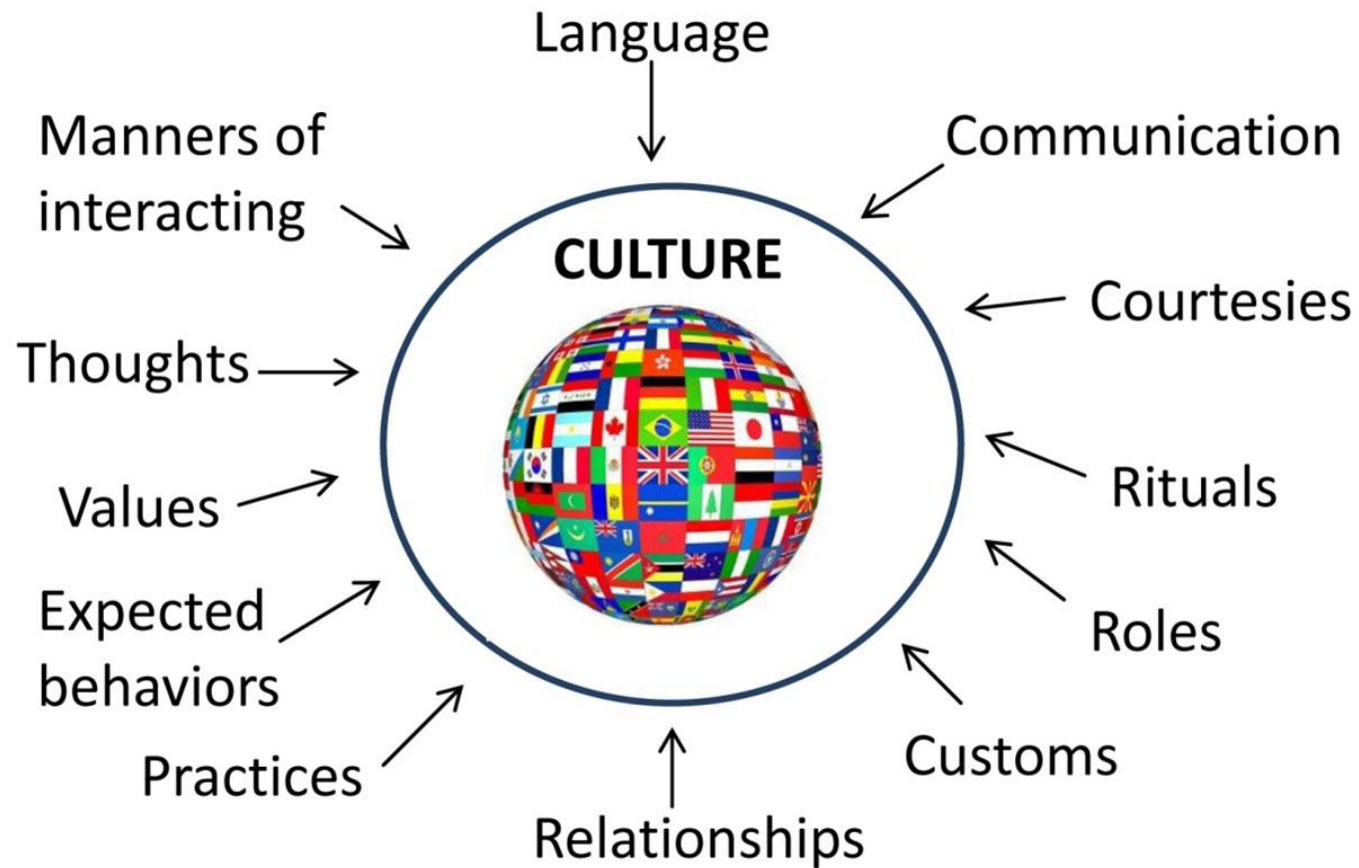
Wagner, L. Spiegel, D. & Pearman, T.P. (2013). The American College of Surgeon’s Commission on Cancer’s new screening standards for integration of psychosocial care/distress management into routine care. Journal of the National Comprehensive Cancer Network, 11(2), 1-8.



Cultural Considerations

- Culture is **defined as the dynamic and multidimensional context of many aspects of the life of the individual**. It includes gender, faith, sexual orientation, profession, tastes, age, socioeconomic status, disability, ethnicity, and race (Wells, 2000).
 - Culture competency, or cultural awareness and sensitivity, is **defined as the knowledge and interpersonal skills that allow providers to understand, appreciate, and work with individuals from cultures other than their own. It involves an awareness and acceptance of cultural differences, self awareness, knowledge of a patient's culture, and adaptation of skills** (Fleming and Towey, 2010).
 - Lack of cultural competence of health care providers is one of the reasons groups such as gay and lesbian individuals, the disabled, lower socioeconomic groups, ethnic minorities, and immigrants receive inadequate medical care (American College of Obstetricians and Gynecologists, 2011).
-

Cultural Considerations in Providing Support



Cultural Competency

Health care providers should be sensitive to the unique needs of the community they serve.

When serving a large Latino population:

- ❖ Spanish speaking health care providers, such as hospitalists, physician assistants, patient care techs, housekeepers, and resource ambassadors.
- ❖ Translation services on a television monitor to facilitate difficult conversations where the patient can feel safe and respected.

Cultural competency is **vital** to the patient-provider relationship. In increasing our awareness of our patients' cultural values, we can foster trust and build a supportive relationship.

Therapeutic Presence

- Presence has been **described as one of the most therapeutic gifts a therapist can offer a client to be fully present and fully human with another person has been viewed as healing in and of itself** (Shepherd, Brown and Greaves, 1972).
- Therapeutic presence is defined **as bringing one's whole self to the engagement with the client and being fully in the moment with and for the client, with little self-centered purpose or goal in mind** (Craig, 1986; Hycner, 1993; Hycner and Jacobs, 1995; Kempler, 1970; Moustakas, 1986; Robbins, 1998; Webster, 1998).
- Providing support to our patients **means putting aside expectations, beliefs, preconceptions, categorizations, theories and plans of how the session should go, to enable them to approach the client with a sense of openness and curiosity** (Geller and Greenberg, 2012).



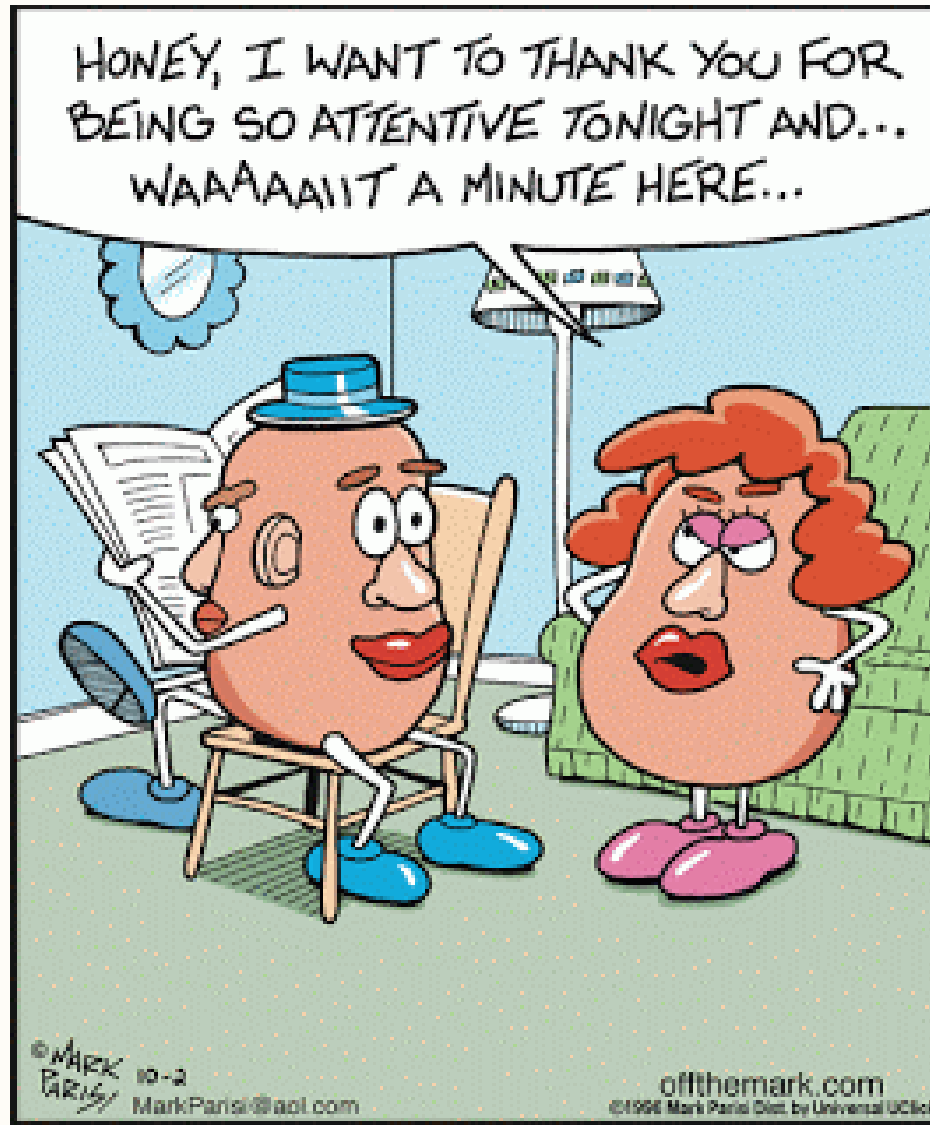
Therapeutic Presence?

LOS ANGELES TIMES

PEANUTS CLASSICS By Charles M. Schulz



Therapeutic Presence?



Helping Survivors Find Meaning

1. Examine life patterns

- *Is the Survivor doing what he/she wants or what others expect?*
- *Are there changes the Survivor has wanted to make but been afraid?*
- *Is the Survivor happy with what he/she is doing or just “used to it”?*

2. Suggest Keeping a journal

- *Express feelings in a safe/private way.*
- *Clarify thoughts.*
- *Process feelings at your own pace.*
- *Different styles of journaling: make lists, write letters, prayers, dreams, reflections, blessings.*



3. Consider New Relationships

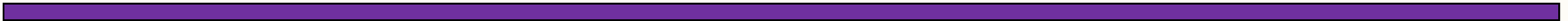
- *Meet other survivors*
- *Help those in need*

4. Focus on Wellness

- *Keep follow-up appointments.*
- *Communication with MD regarding medications and side effects when tax cancer as a chronic disease.*
- *Explore other wellness programs:
i.e. massage, Reiki, yoga, meditation.*

5. Re-examine Faith/Spirituality

6. Be part of a research study



Having Cancer means.....

“After treatment for breast cancer, I knew my life had changed forever....Nothing could ever be the same. I was very sad at mylosses, but I felt I had been given the gift of a new life.”

“I feel good that I’ve found ways to cope. I also feel better able to handle any future problems that might come up. I have new skills, and I now know I have strength.”

“I used to be goal-oriented, knowing what I was doing and what I intended to achieve during a given period. Now that is history; I take it day by day.”



“As long as I was in treatment, I was killing the cancer. (After treatment) I was waiting for the other shoe to fall.”

Judy, breast and thyroid cancer survivor, 45.

“Cancer is just a part of life and we always have hope.”

Anonymous

The Dynamic Duo (Trio or more)

- Treating the cancer survivor
- and their caregivers.



What defines a Caregivers?

- The person who will be helping the patient manage their treatment and/or care.
- This person can be a relative, significant other, or friend.
- For purposes of this discussion, the caregiver does not get paid for their assistance.



What do Caregivers do?

- They help on average with 4.4 out of 7
- Instrumental Activities of Daily Living (IADLS)
- including:
 - transportation (83%)
 - housework (75%)
 - grocery shopping (75%)
 - meal preparation (65%)
 - managing finances (64%)
 - arranging or supervising outside services (34%).



– *Caregiving in the U.S., National Alliance for Caregiving in collaboration with AARP, November 2009.*

Caregivers as a Group

- 1 in 4 adults in the United states provide care to a family member or friend. That is approximately 50 million people.¹
 - 86% care for a relative; 36% care for a parent.
 - 7 of 10 caregivers take care of someone age 50 years and older.
-

- 66% of caregivers are female.
- The average age of a caregiver is 48.
- 7% of caregivers are caring for a person with cancer.

- *Memorial Sloan-Kettering Cancer Center, A Guide for Caregivers – Memorial Sloan-Kettering Cancer Center revised 2011.*
- *Caregiving in the U.S., National Alliance for Caregiving in collaboration with AARP, November 2009.*



Caregiving=Stress



A national survey of 1,002 men and women conducted by the Cancer Support Community revealed that approximately **80%** of cancer caregivers experience high levels of emotional distress.

(CSC survey, 2009 STAR Campaign)

Caregivers =

vital partner in the care of the cancer patient and we need to provide support and direction for them.



Encourage Sharing of Feelings

- In a recent Stress in America survey, 55% of caregivers reported feeling overwhelmed by the amount of care their ill or aging person requires.
- Common feelings may include anger, frustration, guilt, anxiety, & depression.
- Discuss friends, family, clergy that are available to person.
- Support groups or mentoring programs.
- Oncology Social Workers at their local hospital or cancer center.
- Mental Health professionals
- Caregiver organizations and websites

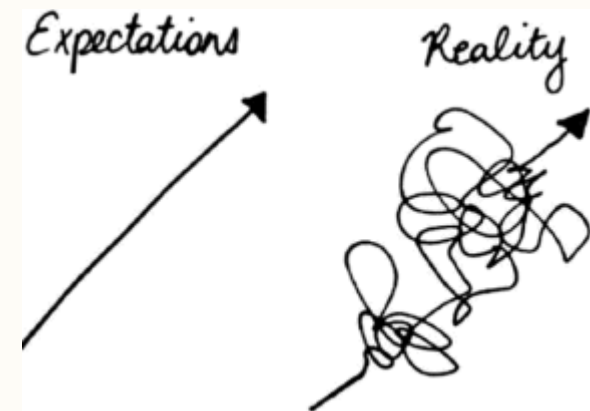
– American Psychological Association “Our Health at Risk”. www.apa.org/news

Encourage Education

- Information and resources related to diagnosis.
 - Speak in a language they understand
 - *Minimize medical terms/jargon*
 - How much is too much? Caregiver driven.
 - Moderation may be the key.
 - Direct to reliable websites, information sources.
-

Encourage Realistic Expectations

- Acknowledge that change is occurring.
- Help prioritize.
- Encourage organizing of materials and tasks.
- Slow down and listen.



Encourage Self-Care

- 1 in 6 caregivers report that care giving has had a negative impact on their health.
- Ways to decompress: walk, read, listen to music, call a friend, watch tv/movie, write in a journal, maintain hobbies.
- Plan for breaks. This may take practice.
- Be purposeful in self-care.
- Keep doctor appointments.
- Eat well, sleep well, exercise.
- Learn/Practice relaxation techniques (i.e. meditation, yoga, deep breathing.)



Encourage Acceptance of Help

- This is a challenge for many.
- Most people who offer really want to help.
- Be ready with concrete things for others to help you with.
- Can provide emotional support as well without having to “express” the need. (i.e. churches, communities, co-workers).



Encourage “Normal” (whatever that means).

- Try to maintain some of the daily routine realizing that a “new normal” is evolving.
- Continue to plan whatever activities you can.
- Find familiarity as the “new normal” evolves. It need not be completely new.



The positives of Caregiving

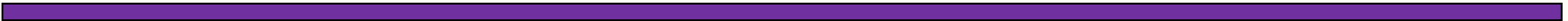
- 😊 Can result in a sense of satisfaction and confidence. Shows inner strength.
 - 😊 Can enrich lives.
 - 😊 Can draw some families closer together and closer to the person who is in need.
 - 😊 Can open doors to new friendships and personal relationships (i.e. support groups, medical professionals, new networks).
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The impact on the Health Care Provider

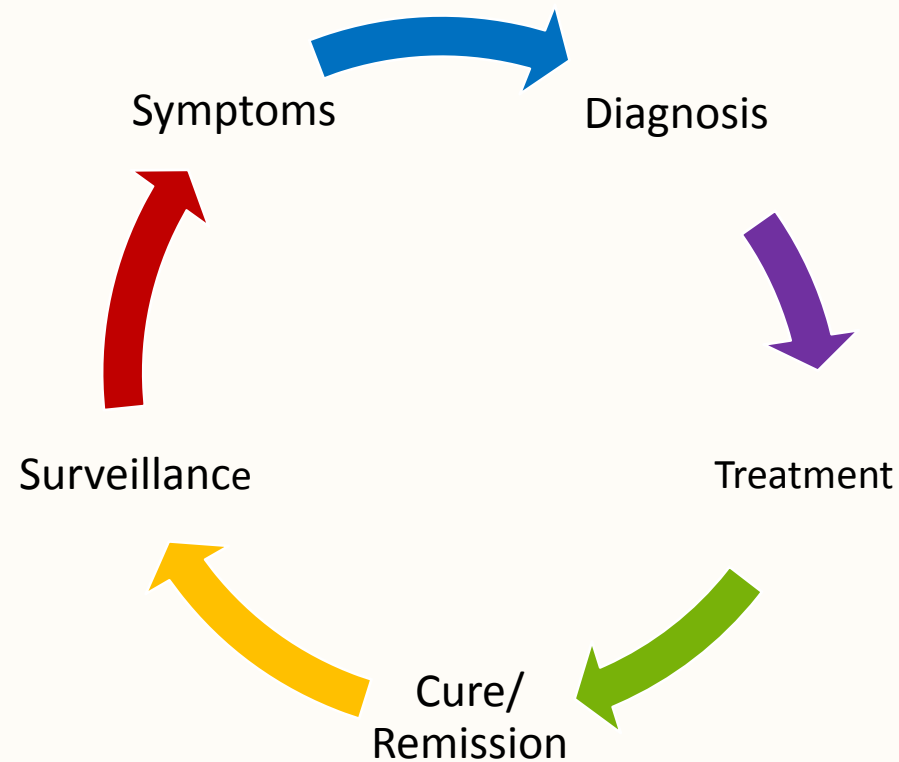
“The expectation that we can be immersed in suffering and loss daily and not be touched by it is as unrealistic as expecting to be able to walk through water without getting wet”

(Remen,1996)

Running on Empty: Compassion fatigue in health professionals By Françoise Mathieu, M.Ed., CCC. Rehab & Community Care Medicine, Spring 2007



Recurrence:
“When our best isn’t good enough.”



Professional Expectations

"Individuals who are drawn into healthcare careers may be more likely to develop compassion fatigue, based on their drive for perfection and to do their best for their patients. If you work in an environment where despite your very best efforts patients for whom you provide care will not survive, there is a set up for developing a sense of 'there is nothing I can do anymore.'"

"Compassion Fatigue: Impact On Healthcare Providers Of Caring For The Terminally Ill." *Medical News Today*. MediLexicon, Intl., 2 Apr. 2009. Web.
12 Jun. 2013.

Signs of Compassion Fatigue

- ✓ Physical and emotional exhaustion
 - ✓ Change in the ability to feel empathy for their patients, their loved ones and their co-workers.
 - ✓ Dreading working with certain patients.
 - ✓ Increased cynicism at work
 - ✓ Loss of enjoyment of career
 - ✓ Depression, secondary traumatic stress and
 - ✓ Stress-related illnesses/absenteeism
 - ✓ Dread of working with certain patients
 - ✓ Increased anxiety or fear
 - ✓ Increased use of alcohol or drugs
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The most significant impact of compassion fatigue on the Health Care Professional:

“it attacks the very core of what brought us into this work:
our empathy and compassion for others.”





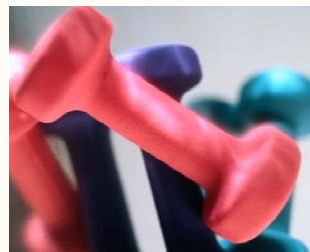






Managing Compassion fatigue

- Share your feelings with others
- Exercise
- Eating well
- Sleeping
- Find activities and relationships outside of work that you enjoy.



IT'S A GOOD DAY TO
TAKE CARE OF YOURSELF
(SO IS EVERY OTHER DAY).



Cancer Survivor-Caregiver-Provider



Talk about your experience.



Take care of yourself.



Seek enjoyment.



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Questions?





Thank You!
