

Managing Cancer as a Chronic Disease

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But, you don't understand - I've got "incurable cancer..."

How can I be happy?!!

Myths about Happiness

- "I can only be happy if..."
- "I'll be happy when..."
- "I'd be happy if I was..."
- "I can't be happy under these conditions!"
- "I'd be happy if I were richer, smarter, younger, older, skinnier, heavier, stronger, healthier, etc...)
- "I'm too old to be happy..."

Normal Tendency...

- We tend to postpone things until things seem "better" or "safer"-
 - "Not tonight dear, I have a headache."
 - "We'll go to Europe after this is all settled."
 - "Let's wait to buy our house until the economy rebounds."
 - "I can't retire now until the market comes back."
 - "We'll do that when this treatment is over."
 - "We'll do that when the cancer is behind us."

Unfortunately, Life Offers Us *No* Guarantees...

- > Life is a dangerous enterprise:
 - War, disease, injury, earthquakes, carwrecks...
 - How do we cope with chronic disease and the risks that surround us daily and still enjoy the moment?
- We all do well to increase our tolerance of ambiguity.

But, Happiness is a Choice!

- Identify your Intention
 - Consistently and intentionally choose Happiness
- Accept Personal Accountability
 - What can I influence in this situation?
- > Reframe Problems into Opportunities
 - Ask "What can I learn from this event?"
- Create "Back-up" Plans
 - Be open to new possibilities

Happiness is a Choice!

- Cultivate "Mindfulness in the Moment"
 - Be fully present wherever you are.
- Develop Generosity
 - No matter your situation, you have gifts that are only yours to give.
- Be Internally Honest
 - Again, authenticity matters!

Managing a Chronic Serious Illness Changes Things...

- Living with cancer as a chronic illness offers us an invitation to consider the possibility of our own mortality.
- This can be experienced as a "personal earthquake," reminding us that we are not in control, and the world isn't as predictable as we once believed.

Suffering...

- Pain + Fear = Suffering
- You and your family each experience suffering uniquely your own.
- Suffering is always subjective.
- Buddhist Tradition: Suffering is related to our attachments/unmet expectations: "Pain is experienced in the present, while suffering is future-oriented."

Existential Suffering

- Meaning/purpose in life is called into question.
- Worldview is challenged.
- Coping is compromised.
- ➤ Treasured beliefs are threatened ("It's not fair!"/"I don't deserve this!").
- Shattered sense of predictably and comforting illusion of control is lost ("Now anything might happen and I feel powerless!")

Beware These Negative Coping Strategies

- > Emotional distancing/detachment.
- > Apathy/depression.
- > Sarcasm.
- > Hopelessness/helplessness.
- Generalized negativity (Anger/frustration/hostility).

Beware These Negative Coping Strategies

- Over/under eating
- > Substance abuse.
- > Self-Flagellation.
- > Blame.
- > Guilt.
- > Fatigue.

Impact Upon Quality of Life

- If our "foundation" premises/choices are not authentically made, our lives are likely filled with guilt and regret.
- "Stuck-ness" increases guilt and regrets which are associated with lowered selfesteem and increased anger, depression and anxiety (and with less pain tolerance).
- Energy and courage are required for change, but may be in short supply when living with a chronic serious illness.

Perhaps it is a Question of Faith...

- Do we believe that ultimately there is the potential for "Good" to come from each difficulty?
 - Will faith be strong enough to sustain us in times of challenge?
- Keep perspective: Remember, we choose...
 - Is our glass "half-full" or "half-empty?" (this decision makes all the difference!)

The Role of "God"

- Whether "God" is perceived as a "force without face" or a "personally experienced" entity, those living with a serious illness typically struggle with spiritual issues:
 - "Why is suffering allowed/caused?"
 - "What is the meaning of this experience?"
- Often, the goal of the struggle is to attain peace/serenity regarding these unknowns.

Cancer Invites us to Imagine...

- What would you do if you might have only a limited time to live...?
- Mortality challenges us to: Live authentically, live well, live now...!
- > Embrace the "What if..."

But It Takes Courage...

- Embrace Vicarious Learning Opportunities: We are offered opportunities to see living and dying done by experts (observe what worked and what didn't and apply it in our own life).
- We are invited to face our fears of distance, disability, disfigurement, dependence and ultimately, death.

Authenticity Matters...

- To the degree that we have our beliefs, values and actions in harmony, we seem to increase our sense of well-being and self-esteem.
- To the degree that we feel that we have used our unique talents and opportunities wisely, we minimize regrets.

Authenticity Matters

- Know who you are, what your priorities are and then- "To thine own self be true."
- Have the courage to change to better meet your needs under difficult circumstances!
- ➤ When faced with different situations... do differently! (To paraphrase Einstein: "It is unwise to expect a different result from the same action.")

To Thine Own Self Be True

Set aside time for...

- Self Assessment
- Introspection
- Reflection
- Meditation
- Prayer

Learn what is most important to you

It's never too late to grow!

The Lessons of the Labyrinth



- > Cultivate faith in the *process*.
- Seek peace & inspiration amidst apparent setbacks.

"Forced" Decision-Making

We are frequently asked to make literally "life and death" decisions with too little information and in too short a time...

Which can lead to frustration, anger and regrets...

Forgive Yourself...

- Recognize that you have made the best decision you could at the time with the limited information that you had available.
- Remind yourself to learn from "mistakes" and to be grateful for the opportunity to move forward now with greater wisdom and insight.

Goal:

Remind yourself to learn from past "mistakes" and to be grateful for the opportunity to move forward now with greater wisdom and insight, asking: "What do I do now, knowing what I know now?"

When Faced with Difficult Decision-Making:

- Request realistic information regarding risks associated with each proposed intervention.
- Identify a reasonable trial period and understand what are indicators of progress.
- Plan to periodically meet to review the changing situation.

When Facing a Health Crisis...

- Develop of "back-up plans."
- > Address "unfinished business" issues.
- Increase your tolerance for ambiguity.
- Mobilize your network of support.
- Utilize strategies to minimize suffering (the arts, music, journaling, poetry, etc.).
- Seek "anticipatory guidance."

When Facing a Crisis

- Communicate your needs
- Advocate for your comfort
- > Network
- Develop your resources
- > Learn more: *Knowledge is Power*
- Commit yourself to grow from the experience: "Benefit Finding"

Request a Family Conference to Communicate Your Values and Assist with Prioritization of Concerns...:

- Arrange to have significant others present.
- Request privacy.
- Request sufficient time for meeting.
- Request services of an interdisciplinary team whenever possible.

Goal: Individualized Care!

- Menu approach (different things "work" for different folks).
- Impact of: Culture, ethnicity, gender, age, access to resources, ability, language, environmental, social support system.
- Needs vary throughout illness (newly diagnosed, treatment, survivorship, recurrence, chronic illness, advanced illness, end of life, bereavement).

Strive for Personal Balance

- Spiritual dimension (meaning & purpose).
- Social dimension (friends & family).
- Productivity dimension (work/hobbies).
- Emotional dimension (feelings).
- Cognitive dimension (thoughts/interests).
- > Physical dimension (health/exercise).

Coping Strategies

- Remember physical self care (exercise, eat, sleep).
- Address your social needs.
- Cultivate relaxation skills.
- Use humor (daily).
- Nurture yourself (treat yourself as if you were your own best friend, lover, caregiver).

Supportive Strategies:

- Share your hopes, dreams, fears with others.
- Surround yourself with family, friends, pets.
- Enjoy the music and magic of each day.
- Reconnect with lost traditions that are meaningful to you.
- Celebrate the miracles to be found each day!
- Create a support network.

Coping Strategies

- Adjust expectations.
- Periodically reframe & reprioritize.
- Debrief & degrief.
- Accept that "it takes as long as it takes."
- Develop stress relief skills.
 - Celebrate even small achievements

Personal Coping Strategies

- Consider journaling, poetry, storytelling.
- PLAY daily.
- Recognize your own "center."
- Learn new skills.
- Distinguish when "good enough" is.
- Identify, and then *address* your own "unfinished business."

Coping Strategies

- Cultivate optimism
 - Practice "making lemonade" from life's lemons.
- Use positive self-talk: Reframe experiences when possible.
- Seek information/education to increase your competence in caregiving

Perhaps...

"Life is painful...

suffering is optional."

~Sylvia Boorstein

Personal Coping Strategies

- Address your personal roadblocks.
- Increase your tolerance to ambiguity.
- Develop an "attitude of gratitude."
- Weigh passion vs. practicality carefully & give yourself permission to follow your passion!

Personal Coping Strategies

- Cultivate various spiritual practices (such as meditation, prayer, or mindfulness).
- Increase self-awareness.
- Listen to your intuition...your own inner wisdom.
- Learn a new skill.
- Breathe...

Goal: Minimize Regrets!

- > Follow your bliss.
- Live your passion.
- Live as if it matters!
- Make meaning.
- > Seize the moment:
 - Acts of omission more often a source of regret than acts of commission.

Take Care of Business...

- Honor Ancient Wisdom: "Hope for the best, but prepare for the worst..."
- Manage logistics ("What do others need to know/do if you're not here for them?").
- Durable Power of Attorney for Healthcare
- Estate Planning
- > Wills
- Guardianship: Establish plans for who will care for those you care for (Children, Parents, Pets, Property, Possessions)

"But, what if these days will be my last?"

- Legacy Building opportunity: Be mindful of your impact: you mentor for loved ones how to handle adversity...We are more influential than we know!
 - Create memories that matter!
 - Be gentle with yourself physically, don't overextend.
 - Balance sociability with solitude.

Goal: "Living Well"

Mindfulness...

- Living authentically.
- Minimizing symptom impact to maximize opportunities to do that which matters most.
- Minimizing regrets (by consciously addressing priorities).

"Living Well"

- Legacy Work...
 - Living authentically.
 - Surrounded by those you care about and who care about you.
 - Minimizing symptom impact to maximize opportunities to do that which matters most.
 - Minimizing regrets (by consciously addressing priorities).

Transformative Potential

- If pain can be seen as a "gift" that tells us: "do something differently."
- Then, suffering too, may be a "gift" that invites us to ask:
 - "Do my beliefs still serve me?"
 - "Is my life being lived authentically?"
- These universal experiences may be essential to guide us as we grow...

Serenity Prayer...

"God grant me the serenity
To accept the things I cannot change,
Courage to change the things I can,
And the wisdom to know the
Difference."

Recommendations:

- Share your hopes, dreams, fears with loved ones and your healthcare team (don't just assume that they know what matters most to you!).
- Surround yourself with family, friends, pets.
- Enjoy the music and magic of each day.
- Expand your support network.
- Reconnect with traditions that are most meaningful to you.

"Your life is a sacred journey... And it is about change, growth, discovery, movement, transformation, continuously expanding your vision of what is possible, stretching your soul, learning to see clearly and deeply, listening to your intuition, taking courageous challenges at every step along the way...

You are on the path exactly where you are meant to be right now... And from here, you can only go forward, shaping your life story into a magnificent tale of triumph, of healing, of courage, beauty, wisdom, power, dignity and love."

~ Caroline Adams

Finally...
I came to understand that I wasn't being punished,
I was being prepared.

For Further Reflection...

- Rick Foster & Greg Hicks (1999). How We Choose to be Happy. New York: Putnam.
- Rachel Naomi Remen (1996). Kitchen Table Wisdom. New York: Riverhead.
- ➤ Ira Byock (2004). The Four Things That Matter Most. New York: Free Press.
- Roger Walsh (1999). Essential Spirituality. New York: Wiley & Sons.

For Further Reflection...

- Joel Levey & Michelle Levey (1998). Living in Balance. Berkeley: Conari Press.
- ➤ Greg Levoy (1997). Callings: Finding & Following an Authentic Life. New York: Three Rivers Press.
- Andrea Rains Waggener (2005). Healthy, Wealthy and Wise. Center City, MN: Hazelden.