Charting a New Course: Exploring Life Opportunities

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Facing a serious illness invites us to reprioritize & reflect upon what matters most.

Living with a history of transplantation 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.
Exploring the Impact of Transplantation Upon Quality of Life

- Physically
  - Less energy
  - Symptoms & side effects
- Socially (We’re not in this alone)
  - Illness is a shared experience
  - Dating & mating
- Psychologically
  - Coping
- Spiritually
  - Importance of making moments matter
Negative Repercussions

- Over/Under-Eating
- Substance Use/Abuse
- Self-Flagellation
- Shame/Blame/Guilt
- Sarcasm/Anger/Hostility
- Hopelessness/Helplessness
- Frustration
- Fatigue
- Depression/Apathy/Despair
- Anxiety/Worry
- Emotional Distancing/Detachment
Perspective Matters!

- Do we believe that ultimately there is the potential for “good” to come from each difficulty?
  - Will our 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!
Key Question Becomes…

What matters the most Right Now?
To Thine Own Self Be True…

- 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.

- Set aside time for…
  - Self Assessment
  - Introspection
  - Reflection
  - Meditation
  - Prayer

- Learn what is most important to you

It’s never too late to grow!
When Facing a Health Crisis…

- Have a “plan” (and a series of “back-up” plans)
- Address “unfinished business”
- Increase your tolerance for ambiguity
- Utilize strategies to minimize suffering (the arts, music, journaling, poetry, etc.)
- Seek “anticipatory guidance”
- Mobilize your network of support (especially important when coping with chronic health concerns)
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*” (Use positive self-talk: Reframe experiences when possible)
Personal Coping Strategies

- Address your personal roadblocks
- Increase your tolerance to ambiguity
- Develop an “attitude of gratitude”
- Be Brave! (Take risks)
- Weigh passion vs. practicality carefully and 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...
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
Coping Strategies

- Adjust expectations
- Periodically reframe and reprioritize
- Debrief and de
grief
- 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
Take Care of Business to Minimize Regrets

- Honor Ancient Wisdom:
  - “Hope for the best, but prepare for the worst”
- Manage logistics
  - What do others need to know or 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)
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*. 
Focus on Practical Concerns: Where the Rubber Hits the Road
Finances: Plan ‘A’ versus Plan ‘B’

Realistic Need vs. “Re-Vision”

- **Basic needs** (Maslow’s Hierarchy)
- **Medical expenses** (out-of-pocket and planned future expenses)
- **Other debt** (consumer credit, loan modifications, Bankruptcy)
- **Long-range planning** (Dreams vs. Goals vs. “Experiences”)
Insurance: Managing Financial Risk

How much is enough?

- **Health** (chronic disease management, prevention and treatment)
- **Life** (re-insurability, risk-sharing, cash accumulation, early pay-out)
- **Disability and Long-term Care Planning**
- **Other family** and household members
New Considerations:

- **Decision-making** and Estate Planning, Advanced Directives, Probate

- **Social Security** and its effect on benefits
  - Part-time vs. Full-time, Field specific versus “Any field”
  - Field, function or role change
  - Affect on health insurability, other benefits
Legal: New Status (cont)

- **Re-Employment Access and Accommodation (“Right to Work”)**
  - **JTPA - Job Training Partnership Act of 1982**: A United States federal law passed on October 12, 1982 by the United States Department of Labor during the Reagan administration. The law was the successor to the previous federal job training legislation, the Comprehensive Employment & Training Act (CETA). It was repealed by the Workforce Investment Act of 1998 during the Clinton administration. (Pub.L. 97-300, 29 U.S.C. & 150, et seq.)

- **“Voc. Rehab.” - Vocational Rehabilitation**: Services offered to those wanting to participate in the Labor market work force who have special concerns such as: disability or dislocation. Administered through the United States Federal Office of Health and Human Services at the state level. Each state varies on how these services can be accessed by phone, internet or in person. Some states, such as Arizona, have streamlined “One Stop” Centers which offer Voc. Rehab support at the same location that Unemployment Benefits applications are available, Job Service registration and coaching is offered, and other state-run support services are obtained.
Services may include:

- Diagnostic evaluation, interest & aptitude testing
- Skills training
- College or vocational training
- Vehicle or housing modifications
- Assistive and Rehabilitative Technology
- Consulting advice and incentives for employers
- Job placement assistance for workers
Vocation: Redefining Purpose

- Creating a balance between passion and pragmatism
- Re-visioning meaning and purposeful activity
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.
- Reconnect with/create traditions that are most meaningful to you.
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)