

Myths & Meaning During Survivorship

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Overview

- **Case Example**
- **Domains of Quality of Life**
- **Types of Core Conflicts in Survivorship**
- **Finding the “Middle Space” and Meaning**

Case Example: “Ron”

- **Background:**

- 68-year-old married man with two adult children and several grandchildren
- Retired professor

- **Medical History:**

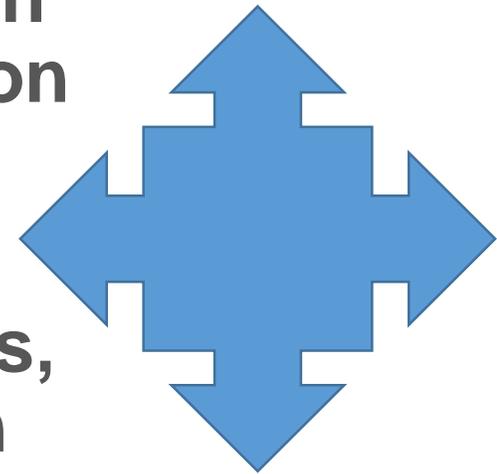
- Diagnosed with glioblastoma
- Completed surgery, radiation, and now taking oral chemotherapy

- **Presenting Concerns:**

- Distress about how to manage changes in cognition and functioning
- Worry about the effects of cancer on family
- Anxiety about how to cope with future uncertainty: “living in limbo”

Case Example: “Living in Limbo”

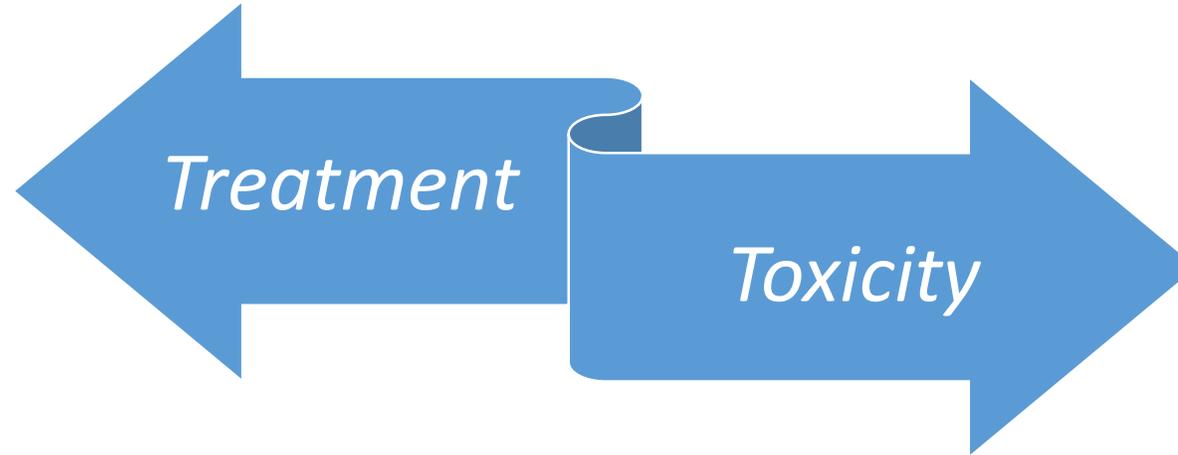
- Any intermediate, indeterminate, or transitional state
- For many with brain cancer, limbo is the ongoing state of uncertainty that begins after diagnosis with respect to what the future holds and which direction to take in life
- The limbo experience may cause significant stress, and at times, symptoms of anxiety and depression



Domains of Quality of Life



Physical



Minimize or ignore symptoms and side effects

Feel like failure for reducing chemotherapy or needing to stop clinical trial

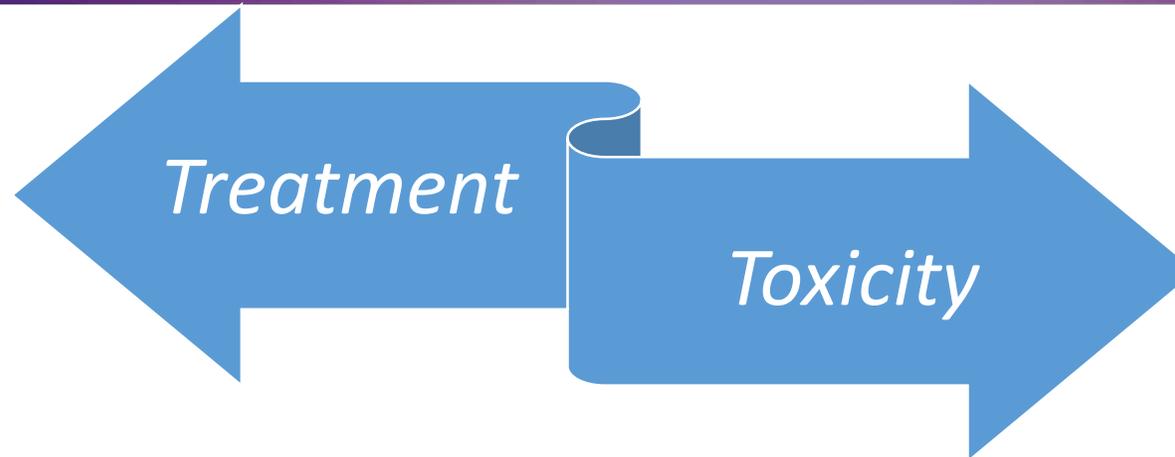
Don't disclose side effects to care team

Perceive side effects as harmful

Misinterpret symptoms as recurrence or progression

Avoid treatment or seek a lot of reassurance from care team, internet, loved ones

“Middle Space”



When possible, try to perceive side effects as chemotherapy working to try to stop cancer

Work with care team to clarify concerns about symptoms and side effects to optimize adherence

Engage in symptom management strategies, such as relaxation techniques

Example: Relaxation Training

- Deep, Diaphragmatic Breathing
- Progressive Muscle Relaxation
- Mindfulness Meditation



Emotional

Shutdown

Overwhelm

“Everything is fine; I am one of the lucky ones.”

Always have to stay positive to ‘fight’ the cancer

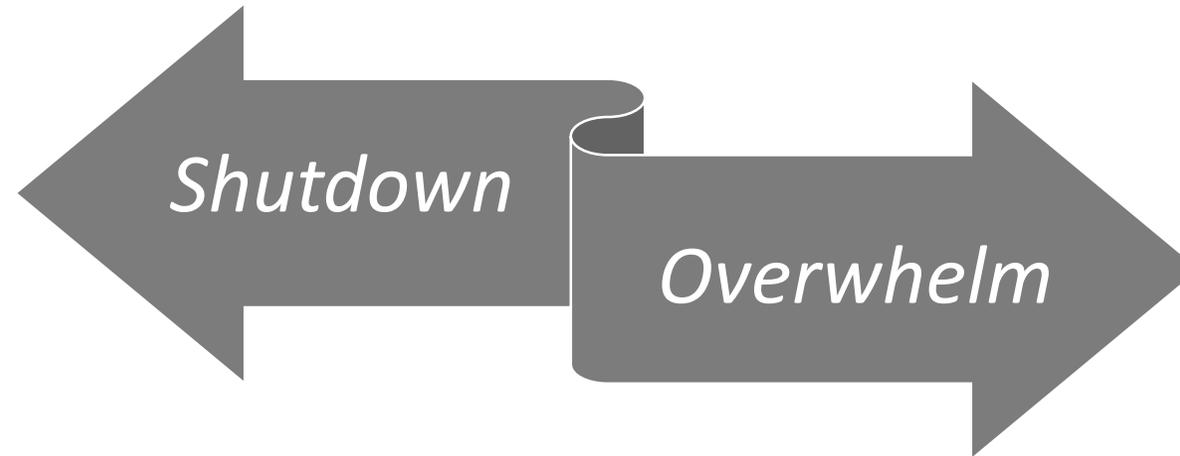
Avoid triggers of thoughts and feelings about cancer

“I have lost all hope.”

Become anxious/depressed and consumed with negative thoughts about cancer

Disengage from meaningful life activities and relationships

“Middle Space”



Acknowledge the vacillation between moments of sadness and grief along with gratitude and hope

Consider ways that life goals may have changed and continue to engage in activities and relationships that matter to you

Try to cultivate positive emotions

Example: Positive Emotions

Pick a word below that calls to you and spend the next minute thinking about how your day would be different if you cultivated more of that state:

Inspiration	Humor	Peace	Joy
Optimism	Gratitude	Acceptance	Freedom
Courage	Healing	Connection	Openness
Energy	Love	Hope	Serenity



Social

Breadwinner

Burden

Shield loved ones from the effects of cancer

Feel responsible to maintain same roles with family and friends as before diagnosis

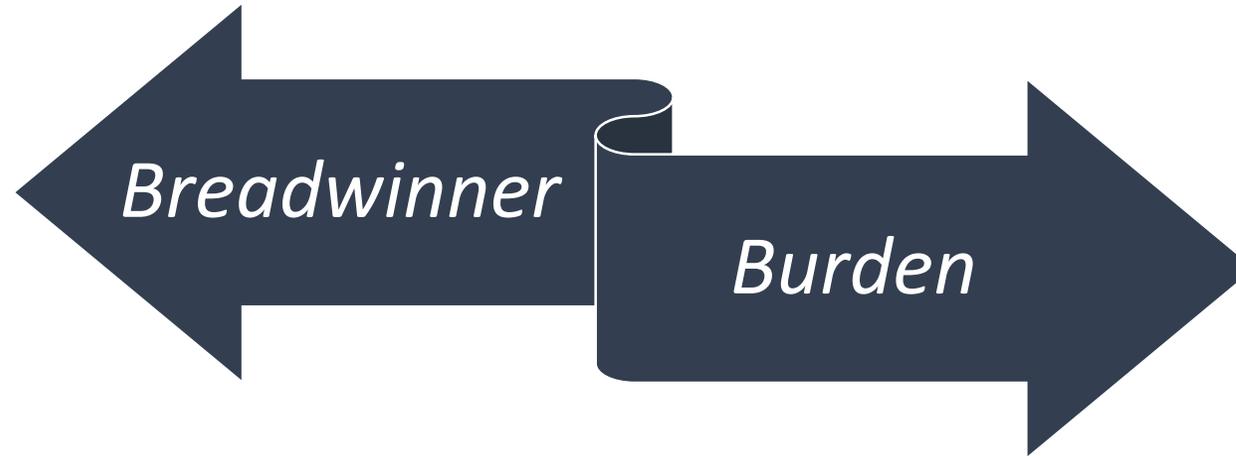
Put on 'strong' face for others

Consider oneself as a "burden" to family and friends

Perceive that one's identity has been reduced to being only a "cancer patient"

Feel distressed by seeking support from others

“Middle Space”

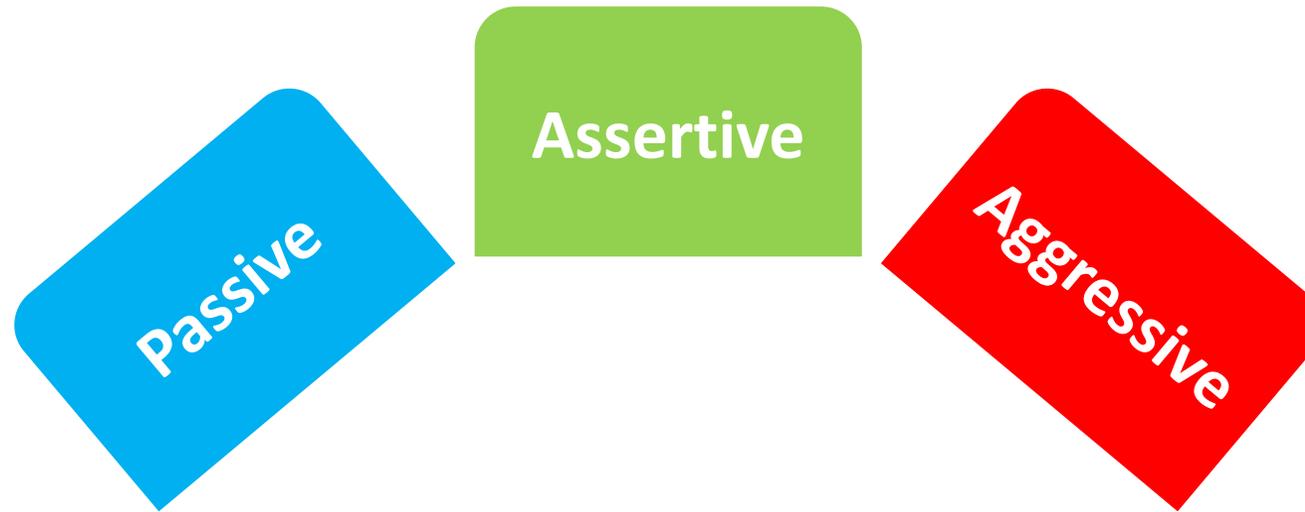


Consider perspective of how you would respond if roles were reversed

Acknowledge and affirm one's value and identity across all life domains

Use effective communication skills to call upon people based on who best meets different support needs (informational, emotional, practical)

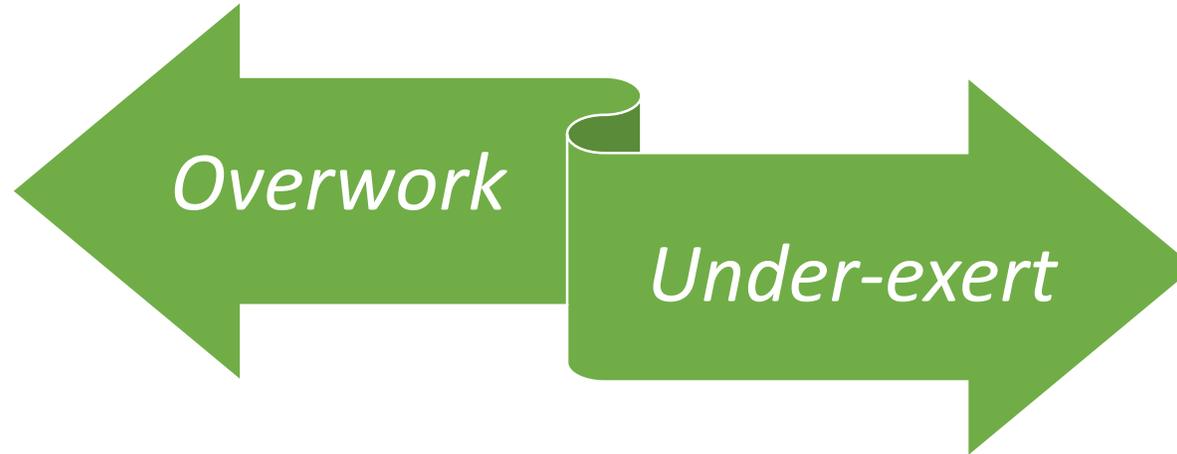
Example: Assertive Communication



The three “Fs” for effective communication:

- Statement of *Fact*
- Statement of *Feeling*
- Statement of *Fair Request*

Functional



Ignore changes in functioning or fluctuations in energy

Try to achieve too much in one day

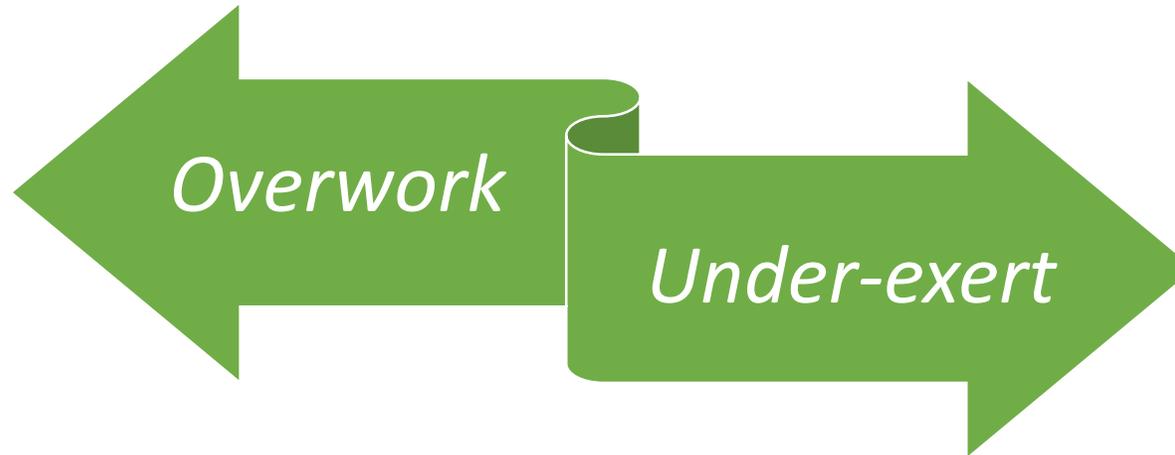
Prioritize responsibilities and life tasks over self-care

Become overwhelmed by changes in functioning and fatigue

Withdraw from physical activity and become deconditioned

Fall behind on responsibilities and life tasks

“Middle Space”



Proactively monitor fluctuations in energy within and across days

Incorporate self-care activities in every day, not just attend to demands

Modify and pace activities to help conserve energy and to accomplish more over time

Example: Activity Pacing

Prioritizing activities

- Identify most important tasks
- Differentiate responsibilities from pleasurable activities

Planning activities

- Categorize activities in terms of physical demand
- Brainstorm ways to modify activity (duration, intensity)

Pacing activities by time

- Alternate between physically stressful and non-stressful activities to avoid overexertion

MONDAY



3:30pm

TUESDAY



3:30pm



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Existential

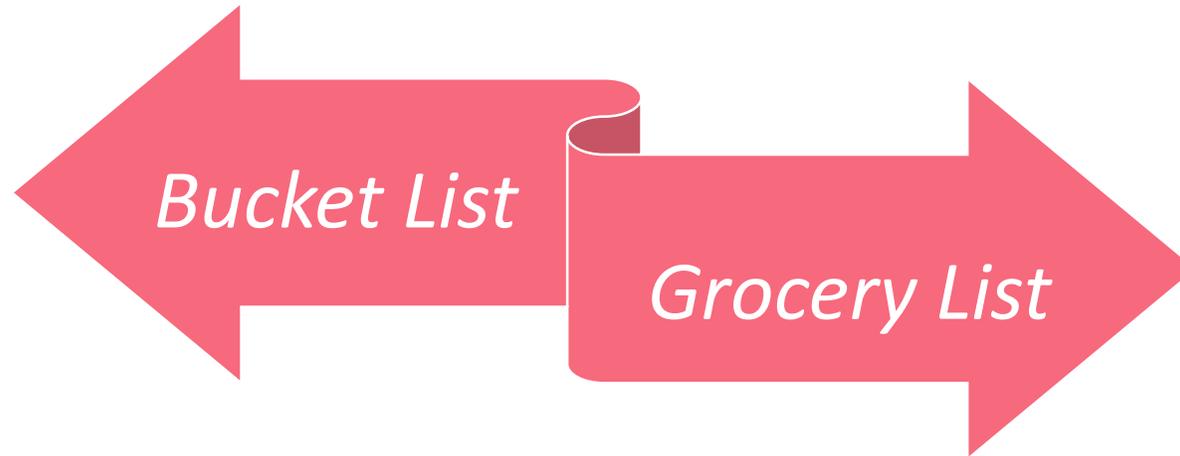
Bucket List

Grocery List

Have a heightened sense of urgency and meaning because of cancer diagnosis with uncertain expectations about prognosis and future

Must still attend to life's day-to-day (and sometimes mundane) needs in which family, work, and other priorities have not changed

“Middle Space”



Recognize false dichotomy of life events as being either meaningful or mundane

Take time to be reflective about your life, accomplishments, relationships, and existential questions that matter most to you

Affirm lifelong values while incorporating new goals

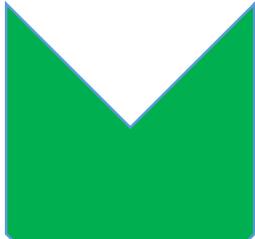
Example: Finding Meaning

1. List 1 or 2 experiences when life has felt most meaningful to you.
2. Ask yourself, “who am I?” Before cancer? After cancer?
3. When looking back on your life, what are the most significant memories, relationships, traditions etc. that have impacted you?
4. What are the most meaningful roles, activities, or accomplishments that you are proud of?
5. List three ways in which you connect with life and feel most alive.

Revisit the Case of “Ron”



Summary



- Try to pull back from extreme thoughts and behaviors



- Recognize and affirm one's full self



- Identify and cultivate what matters most to you

Thank You!

“You can’t
stop the waves
but you can
learn to surf”
~ Jon Kabat-Zinn



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