



A Caregiver's Challenge: Living With Hope, Coping With Uncertainty

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Living with Hope, Coping with Uncertainty

- Perhaps the only thing more stressful than learning of a cancer diagnosis in oneself, is learning of it in a loved one.
- When cancer occurs, it occurs in a very real sense not just to a person within a family but to the whole family.
- The challenge for the patient and family is to find a simultaneous way to live with hope and cope with uncertainty.



Overview

- Who are Caregivers?
- Waldenstrom's as a Chronic Illness
– the Continuum of Care
- Impact on the Caregiver
- Strategies for Coping
- Discussion

Who is a Caregiver?

A caregiver is an unpaid individual (a spouse, partner, family member, friend or neighbor) involved in assisting others with activities of daily living and/or medical treatment. Formal caregivers are paid care providers providing care in one's home or in a care setting.

Who is a Caregiver?

- 65.7 million caregivers make up 29% of the U.S. adult population providing care to someone who is ill, disabled or aged.
- 52 million caregivers provide care to adults with a disability or illness.
- Caregiver services were valued at \$450 billion per year in 2009 - up from \$375 billion in 2007.

Who is a Caregiver?

- More women than men are caregivers; an estimated 66% of caregivers are female. One third (34%) take care of two or more people, and the average age of a female caregiver is 48.3 years.
- On average, caregivers spend 20.4 hours per week providing care. Those who live with their care recipient spend 39.3 hours per week caring for that person.
- Research shows that an estimated 17-35% of family caregivers view their health as fair to poor.

Care Continuum

Critical Points Along the Continuum of Care

- Diagnostic phase
- Treatment phase
- Post-treatment phase

- Recurrence
- End-of-life

Care Continuum

Diagnosis

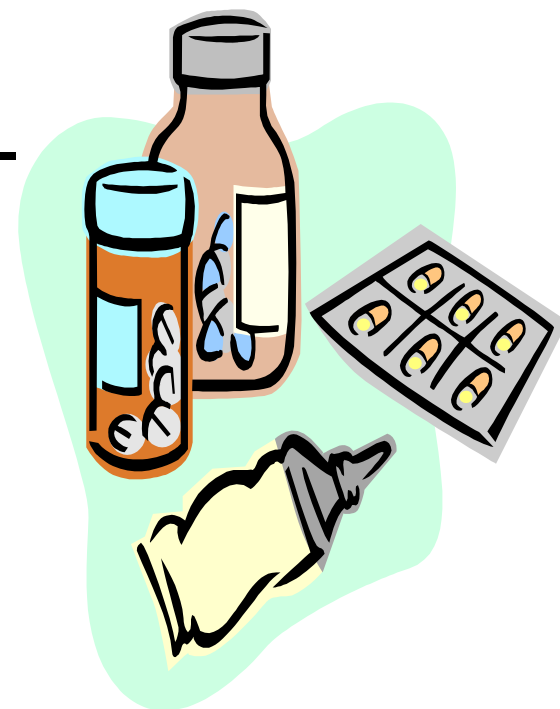
- Range of overwhelming emotions (shock, disbelief, guilt, anger, fear, confusion...)
- Information overload
- Decision-making demands
- Confronting a loved one's and one's own mortality



Care Continuum

Treatment

- Fear of the unknown (side effects, efficacy)
- Relief at “doing something”
- Transitions (work, leisure, relationships)
- Burden of care
- Loss of control



Care Continuum

Post-treatment

- Time of mixed emotions (joy and apprehension)
- Re-entry (work, friends/family, roles)
- Adjustment of expectations, perspectives and, perhaps, lifestyle



Care Continuum

Recurrence

- Despair, anger that treatment has failed despite best efforts
- Struggle to maintain hope in the face of progressive disease
- Contending with treatment plan and life decisions



Care Continuum

End-of-Life

- Palliative vs. aggressive care
- Acknowledgment (or not) of approaching death
- Can be a time of profound and precious meaning for patient and family



Impact of Caregiving

Physical

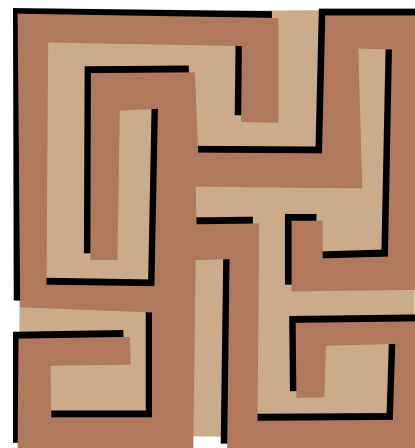
- Fatigue
- Flare ups or worsening of health problems (back pain, respiratory illnesses, acid reflux, headaches)
- Less adherence to medical regimen, visits to doctors for self care



Impact of Caregiving

Practical

- Financial pressures
- Role reversal – learning new responsibilities
- Time constraints and challenges of planning ahead



Impact of Caregiving

Emotional Wellbeing

- Distress and other intense feelings
- Depression and anxiety disorders
- Shifts in relationships
- Communication strains



Impact of Caregiving

Spiritual/existential

- Challenges to faith
- Search for meaning
- Shift in or reaffirmation of priorities



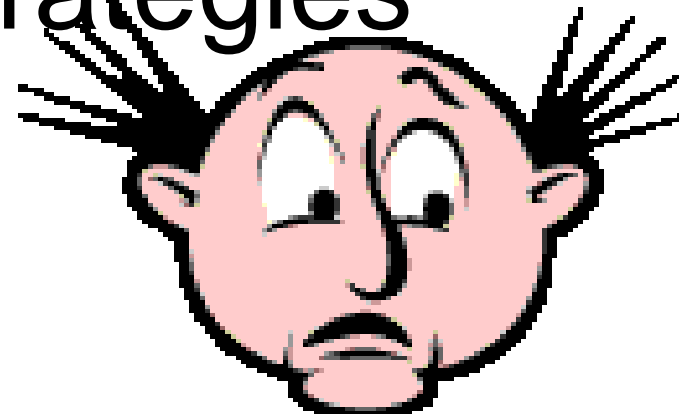
Impact of Caregiving

Benefits of the Caregiving Experience

- Deeper connection and commitment
- Clearer or reaffirmed priorities
- Awareness of strengths and capabilities
- Heightened ability to make meaning out of difficulties
- Learning whom you can count on



Coping Strategies



What doesn't work?

- Trying to “do it all”
- Putting one's head in the sand – pretending all is the same
- Pulling away from supports – isolating from others
- Not acknowledging feelings and reactions to changed circumstances – all of them

Coping Strategies

Manage stress

- Choose how to spend your time/energy
- Build your strength and endurance
- Create a supportive network
- Manage your critical self-talk
- Practice saying “no”



One plate. There. That's
enough for today.

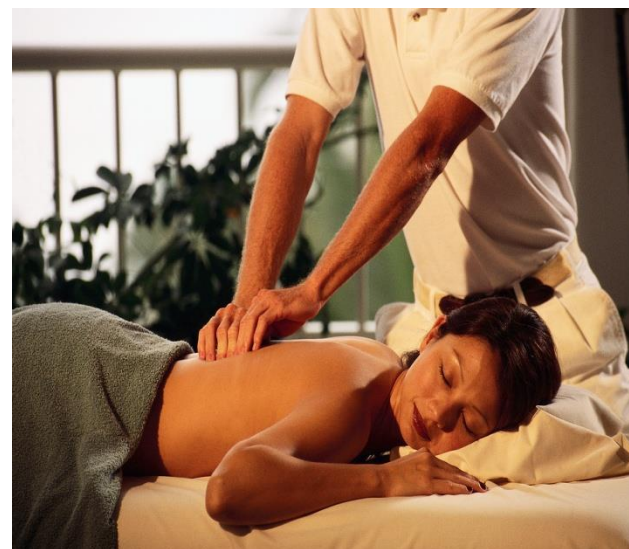


Set small goals!

Coping Strategies

Manage stress

- Learn relaxation tools
- Pay attention
- Laugh when able
- Take the long view
- Ask for help



Coping Strategies

- Relentless self care
- Examine expectations realistically (your own and others)
- Ask for and accept the specific help you need
- Seek the support of those who matter most to you and your loved one



Coping Strategies

- Let go of the need to control
- Make a point of communicating
- Focus on wellness
- Find meaning in your caregiving experience
- Set priorities so that **YOU** are on the list



Support

- Creative expression
- Individual, couples or family therapy
- Support groups with other caregivers
- Integrative medicine
- Social networking
- IWWMF, LLS, Cancer Care, NCI, Family Caregiver Alliance, National Family Caregivers Association

Support at Moffitt

- Arts In Medicine Program
- Caregivers' Weekly Support Group
- Annual Caregivers' Conference

813-745-8407

- Integrative Medicine

813-745-4630

Suggested Readings

- Denholm, Diana B., *The Caregiving Wife's Handbook: Caring for Your Seriously Ill Husband, Caring for Yourself*. Hunter House, 2012
- Holland, Jimmie & Sheldon, Lewis, *The Human Side of Cancer: Living with Hope and Coping with Uncertainty*. Harper Collins, NY, 2000
- Sheehy, Gail, *Passages in Caregiving: Turning Chaos into Confidence*. William Morrow, 2010

Caregiving – It's a Marathon Not a Sprint

Over the long haul, strive for:

- Awareness
- Balance
- Connection





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Thank you!