



BEING A CAREGIVER: WHAT'S YOUR PLAN?

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Huntington's Disease
Society of America

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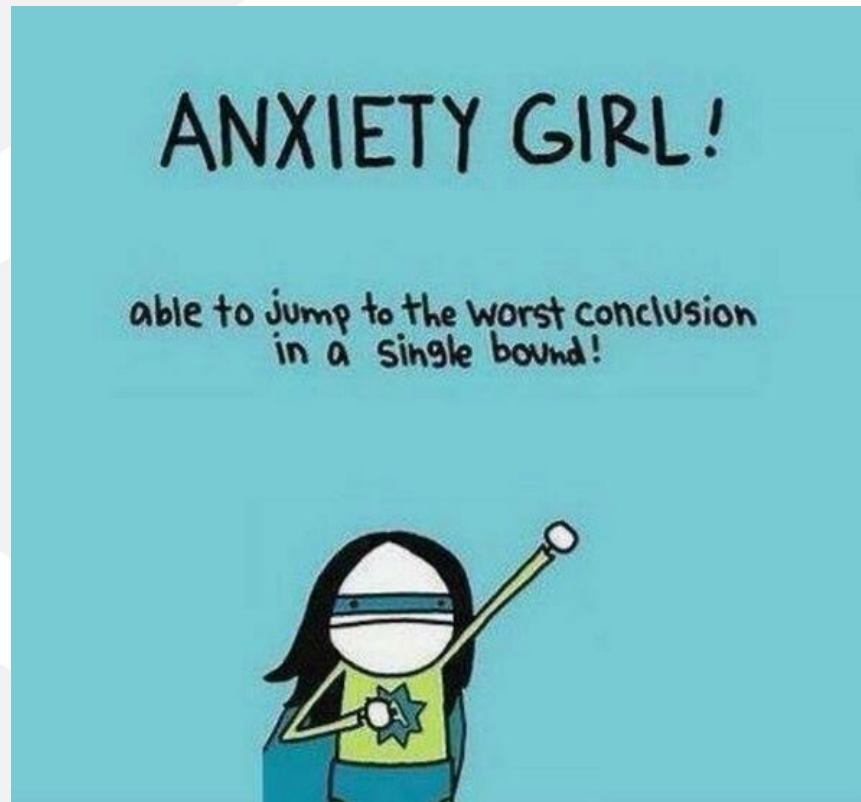
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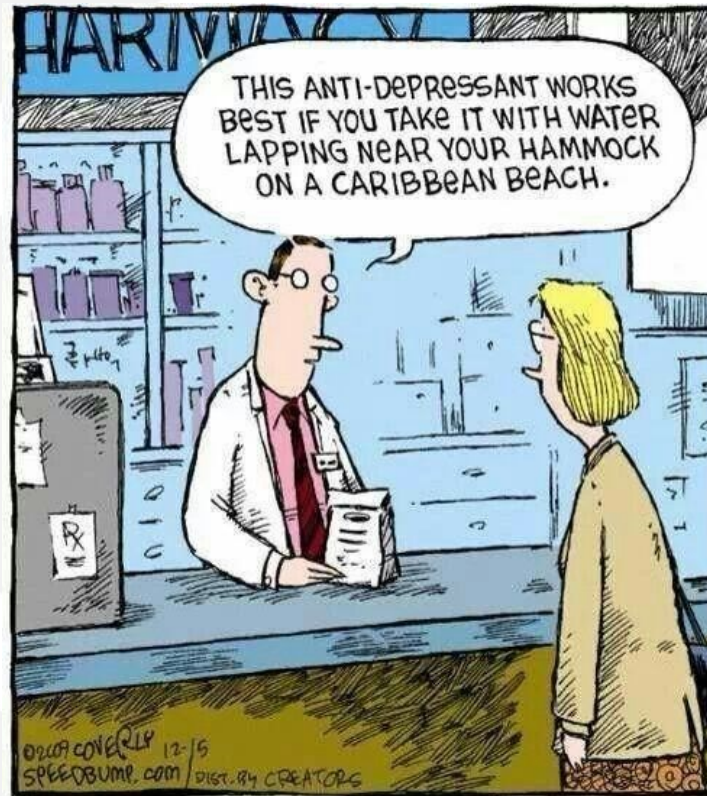
No Need to Define My Caregiver Stress...

**MY MIND IS LIKE
SOMEONE EMPTIED
THE KITCHEN
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ONTO A TRAMPOLINE**

No Need to Define My Caregiver Stress...



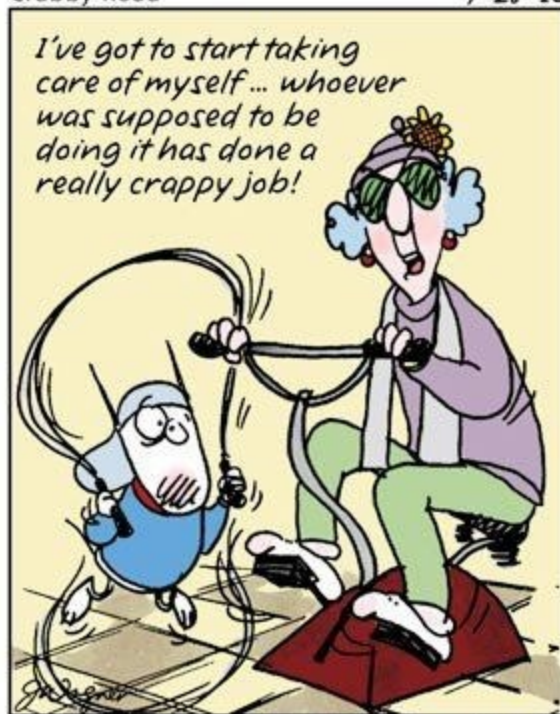
No Need to Define My Caregiver Stress...



I've Got It Covered Quite Nicely, Thank You...(or not)

Crabby Road

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HOW ABOUT YOU?

Why Caregiver Health Matters

- Changing family structures (Caregiver Family Therapy, Qualls and Williams)
 - Intergenerational family structure has shifted from a branching tree to a beanpole
 - Longevity – 3-5 generations alive at once
 - Declining fertility rates – fewer members of each generation available to provide care
- AS a result family caregivers are:
 - In caregiving roles for longer periods of time
 - Sometimes caring for more than one person
 - Performing more complex caregiving tasks

Why Caregiver Health Matters

- Caregiving facts (Medical Family Therapy and Integrated Care, McDaniel, Doherty, and Hepworth):
 - Almost one third of the US population provides care for an ill, disabled, or aged family member
 - More than two thirds of caregivers are employed outside the home
 - 40-70% have clinically significant depressive symptoms

Why Health as an HD Caregiver Matters

- Genetic component
 - Symptom-spotting – Anticipation of the disease in others
- Earlier onset than many other diseases
 - Must also work, in order to avoid financial ruin
 - Caregiving and child-rearing often combined
- Greater number of younger caregivers, including teenagers
 - An abnormal role for those stages of life
 - Some at-risk – “Am I staring at my future?”

Why Health as an HD Caregiver Matters

- Decisions regarding the “regulation of information” (Rothing et al, 2014)
 - Balancing the need to protect with the need to disclose
 - Who should be told what, and when?
 - Both inside and outside the family
- Lack of knowledge and experience by health care providers (Domaradzki, 2015)
 - “I feel like I know more than the doctors”
 - Limited access; insufficient resources
 - “A general sense of struggle with the system”

Why Health as an HD Caregiver Matters

- Greater loss of social relationships (McCabe et al, 2009)
 - Behavioral disturbances
 - Increased caregiver isolation in later stages due to a lack of resources to lighten caregiver burden
- Exceptionally long trajectory of care
 - HD may manifest itself many years before the official diagnosis
 - Early signs often more neuropsychiatric in nature
 - For some, caregiving can last almost 30 years, including the prodromal period

BEING A CAREGIVER: WHAT'S YOUR PLAN?

- To what extent have you established an unapologetic mindset of self-care?
- What sustaining habits and routines have you developed for the long haul?

A Framework for Healthy Self-Care

- Balancing too much information and not enough information
- Balancing denial and reality
 - “There is a grace in denial. It is nature’s way of letting in only as much as we can handle.”
Elizabeth Kubler-Ross
 - “Don’t put your head in the sand – ostriches get their backsides shot off all the time.” Dr. Cheryl Woodson, To Survive Caregiving

A Framework for Healthy Self-Care

- Balancing grace and truth
 - Grace – Going easy on ourselves and our loved one; showing compassion when things are tough
 - Truth – Facing the realities so that we can make good decisions; moving toward the problem, not away from it
- Balancing living one day at a time and looking down the road in preparation for the future
 - Anticipatory planning

A Framework for Healthy Self-Care

“The process of balancing starts with awareness of the trade-offs inherent in caregiving...Commitment of extraordinary care to one person almost always means someone [or something] else gets less. Although caregiving trade-offs are inevitable, the consequences should not be blatantly harmful to any family member.”

Sara Honn Qualls and Ashley Williams, Caregiver Family Therapy

Self-Care: Get Practical

- “The 11th Commandment – Thou shalt organize, organize, organize!” Dr. Cheryl Woodson, To Survive Caregiving
 - Start a medical book of notes or use an online tool
 - Record patterns of behavior change
 - Always carry a copy of the medication list
 - Make use of identification bracelets and cards for wallets
 - Complete advanced directives
- What does this have to do with caregiver self-care?

Self-Care: Get Practical

- Communicate – Look at yourself as an educator
 - Who needs to know what, and when?
 - Family
 - Friends
 - Providers – create a partnership, because you have information they need!
- What does this have to do with caregiver self-care?

Self-Care: Stay Connected

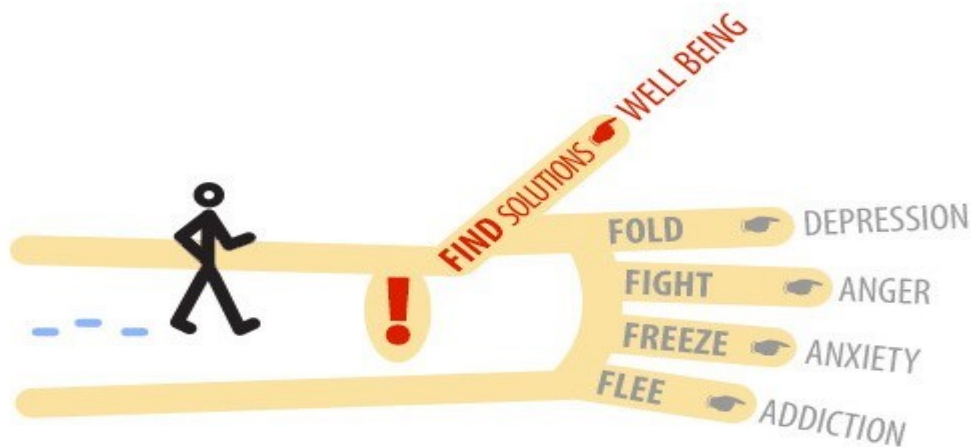
- Your relationship with your loved one:
 - The main predictor of caregiver burden is the history of the quality of the relationship
 - Ask periodically, “What aren’t we talking about?”
 - What conflicts need to be addressed? What affirmations need to be given?
 - What does it mean for you to “end well” with your loved one? This question is relevant NOW, not just during the late stage of the disease

Self-Care: Stay Connected

- Your relationships with others:
 - Be aware of the risks of isolation
 - Dilemma:
 - Which ones do I keep?
 - Which ones do I put on hold?
 - Which ones do I end?
 - Try to preserve at least a couple of key connections
 - Educate about your needs – when to talk “HD” and when not...

Self-Care: Tend to Your Emotional Well-Being

- Manage your difficult emotions with problem-solving that brings solutions (Dr. Susan Heitler, Prescriptions Without Pills)



Self-Care: Tend to Your Emotional Well-Being

- Pay attention to your level of denial and avoidance (Domaradzki, 2015)

“One of the most frequent coping strategies of dealing with HD is denial. Although caregivers experience serious distress they avoid talking about HD both within and outside the family...

...While in some cases avoidance may be effective, in the long run it increases carers' anxiety, negatively influences one's relationships...and may prevent them from seeking and/or accepting help.”

Self-Care: Tend to Your Emotional Well-Being

- Know when it is time to grieve and understand what that looks like for you
 - Acute grief
 - Chronic grief
 - Anticipatory grief
- The chronic illness cycle:
Crisis/Loss → Upset/Grief → Adaptation/Stability
....and repeat...

Self-Care: Tend to Your Emotional Well-Being

- Find your “hermit spot” and use it daily
- Practice gratitude
 - Establish a weekly routine but be careful, not too much! Dr. Mark Holder, University of British Columbia
- ‘Savor the Positive’ exercise – What has been the best moment of today?
 - Even awful days have best moments

Self-Care: Tend to Your Emotional Well-Being

- Discover the comfort of mindfulness strategies
 - Deep breathing
 - Breathe in through your nose
 - Breathe out through pursed lips
 - Mantras
 - “I don’t like it, but it is, and I’ll do the best I can”
 - Visualizations
 - Take yourself to a place in your mind that only you can go

Being a Caregiver: What's Your Plan?

- How would you describe your current plan of care for yourself?
- What works well and especially nourishes you?
- Where are the red flags that tell you something needs to be addressed?

Being a Caregiver: What's Your Plan?

- What ONE thing do you want to do, or will you decide to do that will better preserve yourself for the long haul?
 - Is it achievable?
 - Is it action-specific?
 - KEY: On a scale of 1-10 what is your confidence level in achieving your goal (anything less than 7 indicates a poorer chance of succeeding)?

(Chronic Disease Self-Management Program, Stanford University)

Being a Caregiver: What's Your Plan?

- Remember, even a small step is a step
- “Resilience is the ability to bring heaven into hell and not let fear run the show.” Maria Sirois, Psychologist
- “When we are no longer able to change a situation, we are challenged to change ourselves.” Victor Frankl, Holocaust Survivor, Neurologist, and Psychiatrist

THANK YOU!

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