Preparing For the Unknown: Changing Expectations of Caregiving

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Presenter Disclosures

Amy Woodard

The following personal financial relationships with commercial interests relevant to this presentation existed during the past 12 months:

No relationships to disclose or list

Huntington’s Disease Society of America
Every person has a unique blueprint for what they need to grow and be healthy, mentally, emotionally, physically and spiritually.
Collaborative Partners
Our Philosophy: We Believe in the Power of:

- Genetic Counseling
- Symptom Management
- Research Studies
- Support Groups
- Community Outreach/In-services
- Referral/ Social Service Resources
- Caregiver Support
respects dignity
Overview
There are four kinds of people in the world:
Those who have been caregivers
Those who are currently caregivers
Those who will be caregivers
and those who will need caregivers.
-Rosalynn Carter
Caregiver Impact
The Tremendous Power of Human Thought

Ralph Waldo Emerson

William James
• This will never work
• There is nothing/ no resources available
• Life is hard
• Don’t get your heart set on it
• Don’t rock the boat
• There isn’t enough to go around
• Give yourself permission to LEARN, RISK, EXPERIMENT
• Climbing is the only way to get to the top

The feeling that the higher you go the further you’ll fall…
Changing Expectations
Stress occurs whenever your mind perceives a threat to you, your loved ones, or your future and you feel you have little control over it.

Stress is a reaction to an event rather than the event itself.
Do You…

• Often fill the wants and needs of others without having your own met?

• Give yourself away and then feel taken advantage of?

• Wrestle with self-limiting fears?

• Yearn for more satisfying relationships?

• Treat yourself harshly rather than supportively?

• Wish you could communicate freely?

• Long to laugh spontaneously?
Caregiving: A Balancing Act of Stress
Building Blocks

- The Past: Building Blocks
- The Present: Opportunity
- The Future: Potential

“If only I hadn’t…”
“If they…”
“If only I’d known…”
Give Yourself Credit: Emotional Bank Account
Debits

- Unhealed Wounds
- Self-condemnation
- Overwork
- Judgment

Emotional Overdraft
Low self-esteem
Overweight
Emotional dependence
Unhappiness

Perfectionism
Isolation
Resistance
Unreasonable Expectations

Depression
Exhaustion
Apathy
Illness
Credits

- Setting limits
- Self-acceptance
- Exercise
- Listening to yourself

Healing old wounds
- Friends
- Solitude
- Love

Emotional Surpluses
- High self-esteem
- Energy
- Self-confidence
- Courage

Authenticity
- Joy
- Healing
- Fulfilling relationships
Debit and Credit Examples

Debits
“Everything is just fine”
“Overscheduling and rushing”
“Yes” (when you mean no)
“Over sitting or lots of TV”
“Concentrating on your failures”

Credits
“Being truthful about your feelings”
“Realistic goals and schedules”
“No, I’m sorry I’m not able to do____”
“Exercise”
“Concentrating on your successes”
Symptoms of Caregiver Burnout

- Being constantly tired, sad or depressed
- Feeling helpless and alone
- Eating more or less than usual
- Feeling distracted or “spacey”
- Skipping favorite activities or turning down invitations
- Drinking alcohol to deal with pressure
- Thinking about death
- Losing interest in caregiving
- Playing sports/ exercise/dancing
- Listening to music
- Eating Healthy
- Outdoors
- Naming your worries and thinking of them a tape that you refuse to play in your head
- Humor
- Social life
- Support Group
- Journaling/Awareness
- Expressing Gratitude (Worksheet)
- Not knowing where and how to start
- Waiting or trying to identify the right time to start
- Not knowing who to ask or include in the discussion
- Being confused about how systems work and what they do
- Not knowing resources available to help
- Having few or limited personal/family/community resources
- Experiencing emotional discomfort or stress when thinking about future care plans
- Being fearful or concerned about what might happen in the future
- Being too busy to plan
- Being unsure of how independent the person can be
grateful

gratitude

life
Hey
You can do it
YOU CAN DO IT!
— Rob Schneider
KEEP CALM YOU CAN DO IT!
YOU CAN DO IT!
YOU CAN DO IT!
YOU CAN DO IT
YOU CAN DO IT..
you can do it!
You can do it!

Space Kitty
YOU CAN DO IT!
You can do it!
YOU CAN DO it
You can do it.
You can do it.
YOU CAN DO IT
you CAN do it
YOU
CAN DO IT!
If you can dream it, you can do it.

Walt Disney
YOU CAN DO IT TOO
You can do it!
YOU CAN DO IT!

It is okay to fail at things in life,
But it is not okay to stop trying.
YOU CAN DO IT!
YOU CAN
DO IT!
YOU CAN DO IT
References


