

# 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



Huntington's Disease  
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# Our Philosophy: We Believe in the Power of:

Genetic Counseling

Symptom Management

Research Studies

Support Groups

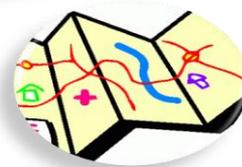
Community Outreach/In-services

Referral/ Social Service Resources

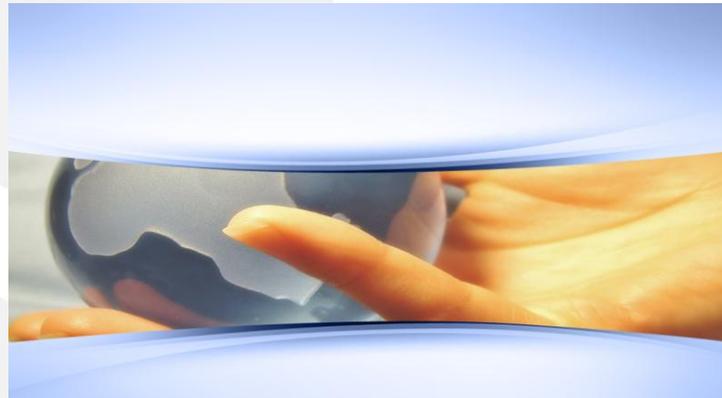
**Caregiver Support**



# 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*



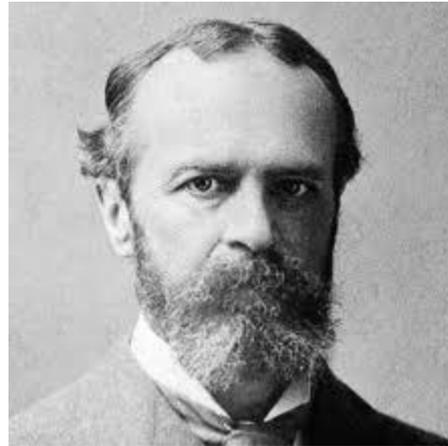
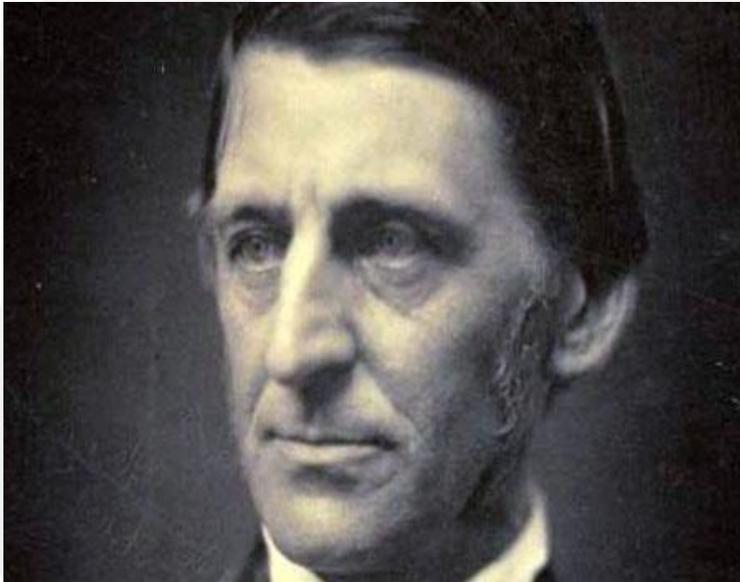
**Annual Spending in  
Billions of Dollars**



# 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



# TOP 5

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.

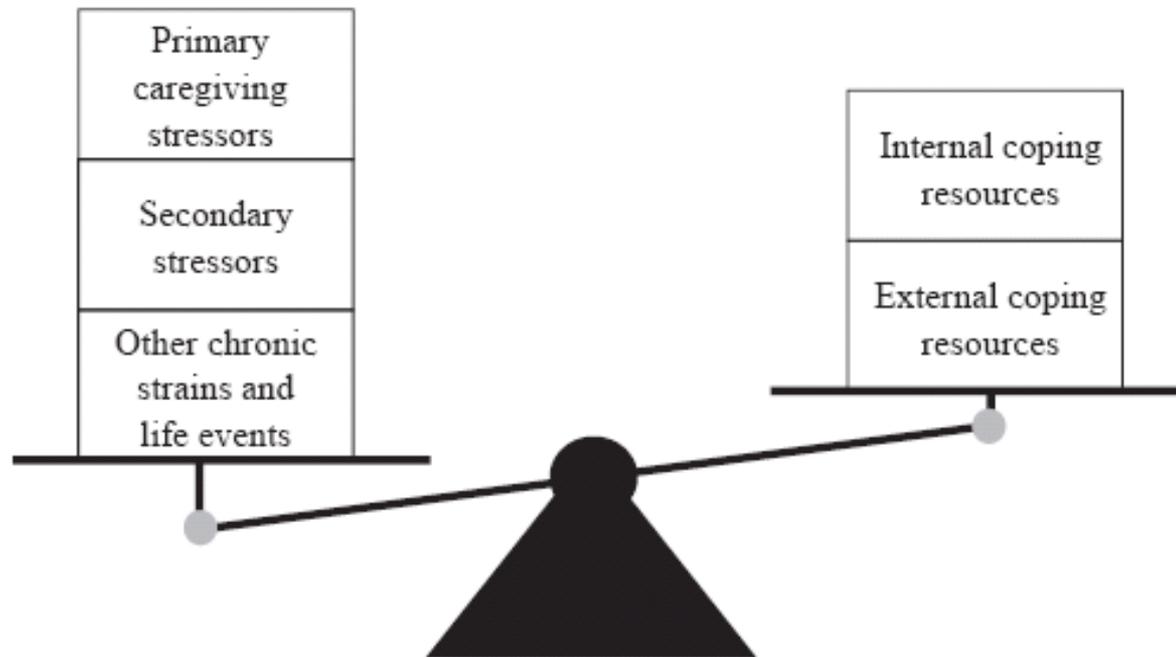
Stress is a reaction to an event rather than the event itself.



## 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

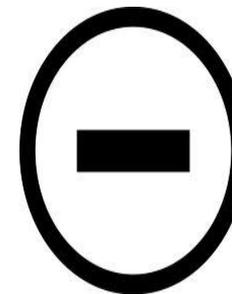
Unreasonable Expectations

Depression

Exhaustion

Apathy

Illness



## Credits

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

Emotional Surpluses

High self-esteem

Energy

Self-confidence

Courage

Healing old wounds

Friends

Solitude

Love

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

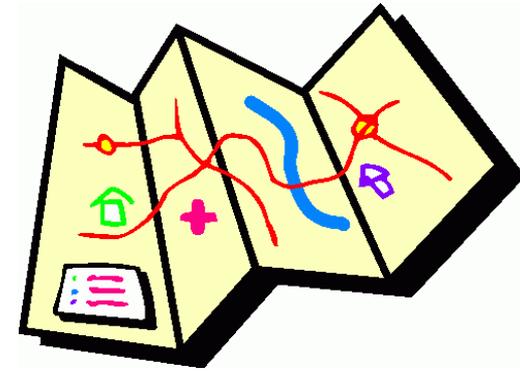
- Being constantly tired, sad or depressed
- Feeling helpless and alone
- Eating more or less than usual
- Feeling distracted or “spacey”
- Skipping favorite activities or turning down invitations
- Drinking alcohol to deal with pressure
- Thinking about death
- Losing interest in caregiving



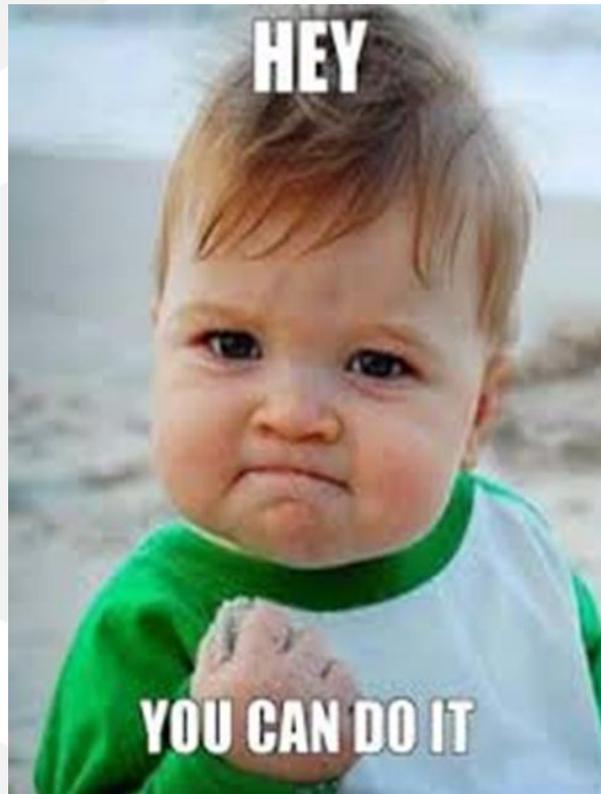


- Playing sports/ exercise/dancing
- Listening to music
- Eating Healthy
- Outdoors
- Naming your worries and thinking of them a tape that you refuse to play in your head
- Humor
- Social life
- Support Group
- Journaling/Awareness
- Expressing Gratitude (Worksheet)

- **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**







YOU  
CAN  
DO  
IT!

— ROB SCHNEIDER



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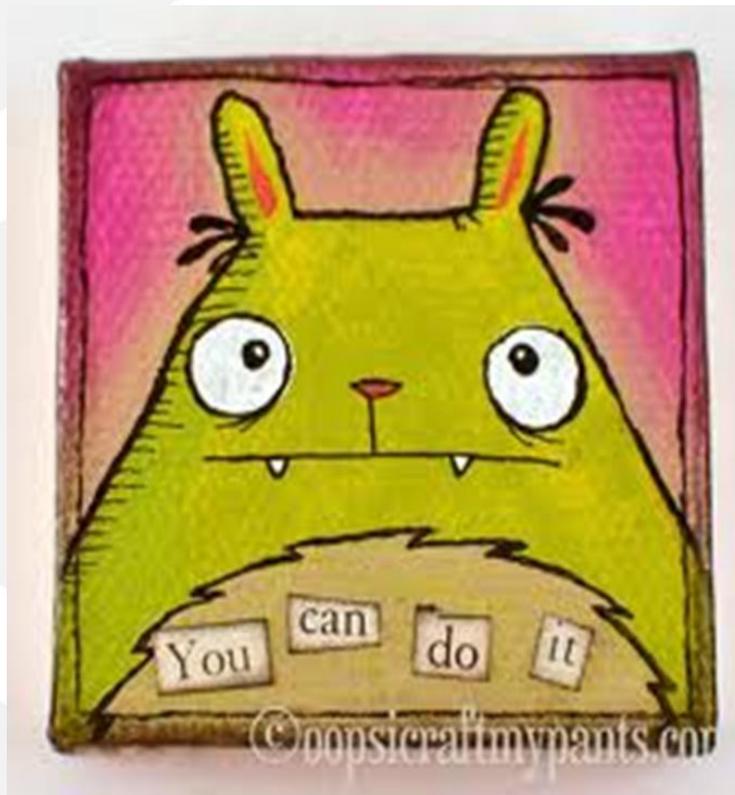




**KEEP  
CALM  
YOU  
CAN  
DO IT!**



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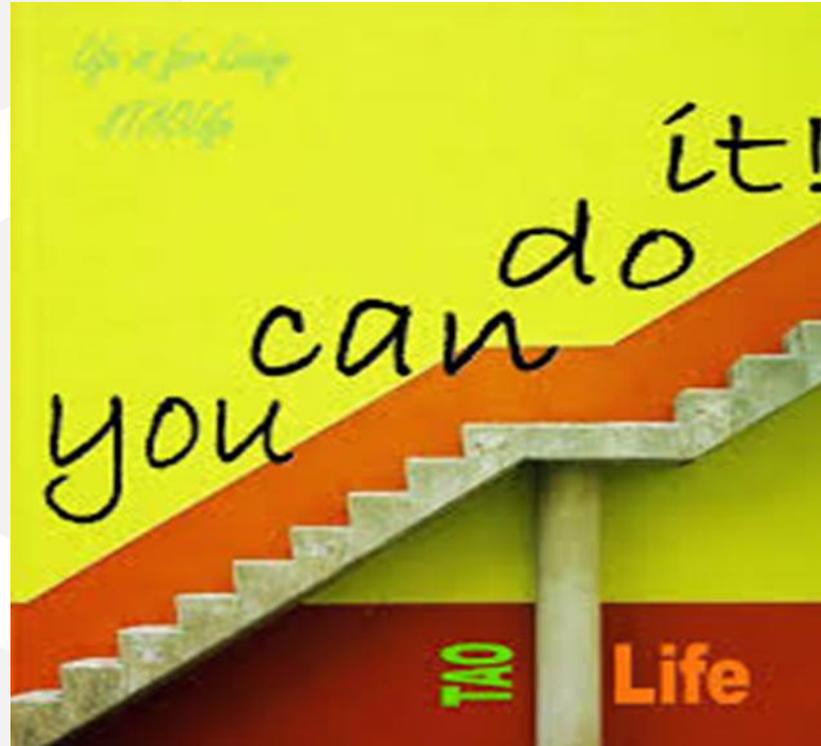


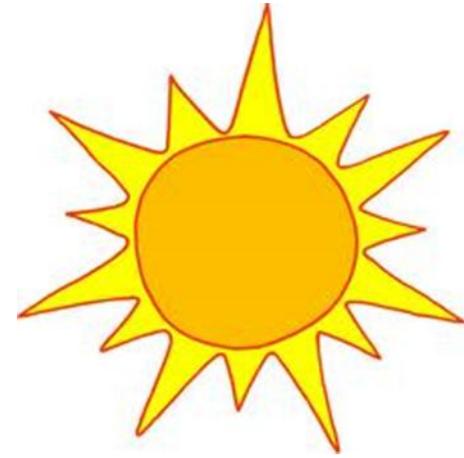
# YOU CAN DO IT











YOU CAN DO IT



YOU  
CAN DO IT!

**You can do it!**



YOU CAN DO IT



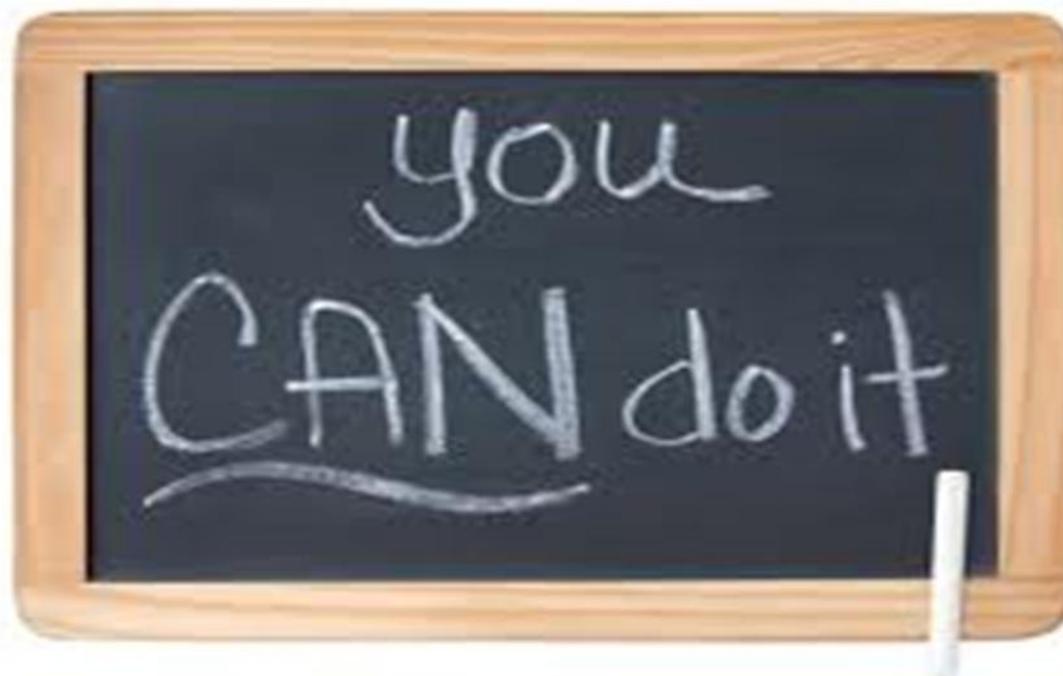
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You can  
do it.



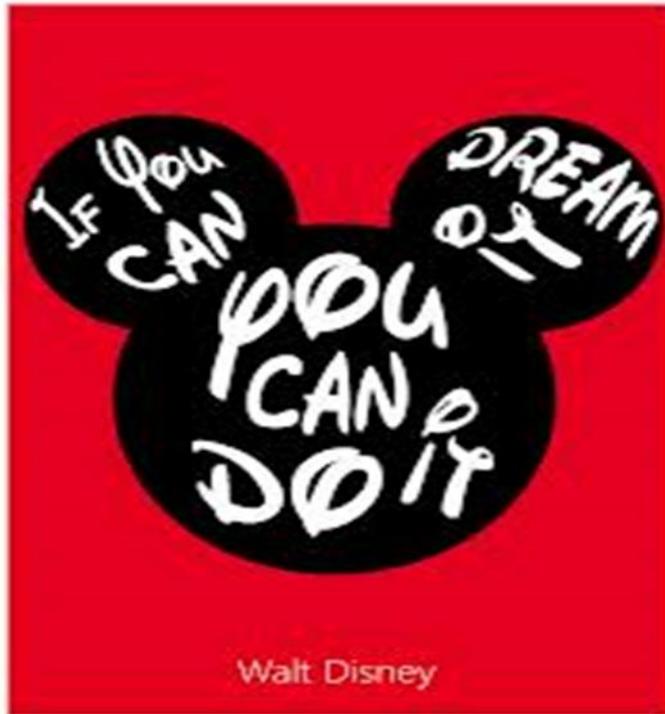




YOU  
CAN  
DO IT!













**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!







Don't Worry.

**... YOU CAN DO IT!**







YOU CAN DO IT

**YOU CAN  
DO IT!**

# References

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