

The Caregiving Journey . . .



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Family caregivers to older adults . . .



Caregiving is Stressful . . .

But, it is NOT
universally stressful!

Factors Related to Higher Caregiver Stress

- Your caregiving is not voluntary
- Poor relationship existed prior to caregiving
- You have competing role responsibilities
- Care receiver exhibits behavior and emotional problems



- You view caregiving as disruptive
- You live with the care receiver
- Family members are in conflict

Caring for someone with Dementia is often the most stressful and isolating . . .



“If the levels of stress, distress and illness found in caregivers were found in any other “profession,” health agencies and worker’s compensation boards would undoubtedly be waging major prevention campaigns.”

—Nancy Guberman

For the caregiving journey, a caregiver must have good **SELF-CARE** skills...

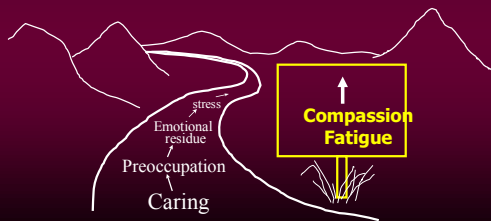
And the reasons why...

When Self-Care is neglected . . .



- Increased health problems
- Depression
- Social isolation
- Disrupted relationships
- Burnout
- Decreased quality of care!

When we don't take care of ourselves on the caregiving journey, we start "traveling down the road" to compassion fatigue



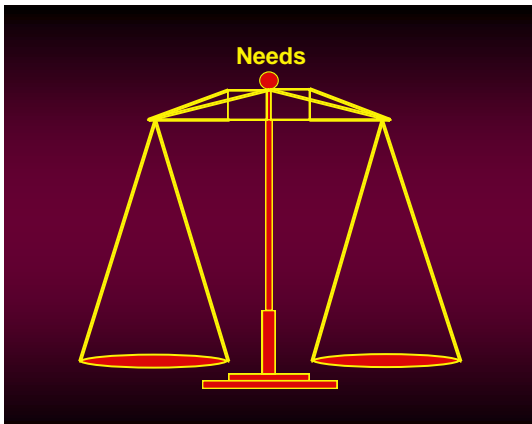
When we suffer from compassion fatigue, we experience a frozen heart!

- We are no longer able to maintain compassion
- We disconnect from others
- Our hearts become closed to the person we care for, family, & friends



Which "road" or journey will you take?





Taking care of your “heart and spirit” . . .

It's the “best gift” you can
give to your family member
who needs your care



Factors Associated with Self-Care . . .

- Having a sense of
mastery and control

- Good information
- Skill building
- Sense of confidence



Factors Associated with Self-Care . . .

- Having a sense of
mastery and control

- Good information
- Skill building
- Sense of confidence

- Having social -
emotional support

- Perceived vs. actual
support
- Value of support group



Factors associated with Self-Care . . .

(continued)



- Using a direct style of
coping

- Uses help-seeking strategies
- Uses problem solving
- Is able to reframe problems

- Finding meaning/rewards
in caregiving

- Taking breaks in care-
giving

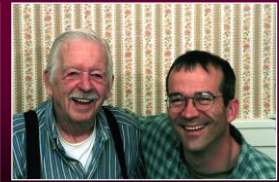
- Prevent—not treat—exhaustion
- Discretionary—not obligatory—
activities

**“Trying to do it all” or
“Doing it alone” does
NOT make for a better
caregiver . . .**

**. . . And it makes the
journey more difficult!**

Time away from caregiving — even for short periods — is needed to maintain friendships, social activities, health and overall balance in life. Once these features are lost, they are difficult to regain.

— University of Utah caregiving researchers



Impact of social isolation

- Decreased sense of well-being
- Increased loneliness
- Poorer physical health
- Poorer psychological health
- Depression

If you find yourself becoming isolated,
it's a WARNING sign!

Research studies show . . .

- Social relationships impact health as much as other lifestyle factors, e.g. smoking, blood pressure, obesity, physical activity.
- A sense of loneliness is a powerful predictor of death in longitudinal studies of older adults.
- Social relationships are a potent protective factor for health!

Benefits of Positive Relationships . . .

- Emotional support, helping one to cope with life stressors
- Enhances mood
- Provides a sense of self-worth
- Shared activities
- Better overall health and self-care

**Negative social interactions
have power . . . And, may
outweigh positive interactions!**

How to Best Express Yourself

- Use “I” messages
- Avoid “You messages”
- Any “hidden YOU messages” in your “I messages”
- Respect the rights, views, & feelings of others



Asking for



is a
sign of
strength

Benefits of Family Meetings

- Provides a forum for open communication
- Provides opportunity to express feelings, perspectives, and solutions
- Promotes shared responsibility
- Decreases the undermining of decisions



Factors Contributing to a Successful Family Meeting

- “Person of concern” is involved
- Everyone affected is involved
- Neutral territory
- Agenda is created and circulated before meeting
- Everyone speaks without interruption
- Atmosphere is non-judgmental
- Focus is kept on current issue
- Focus is on “the positive” of what people do
- Facilitated by a professional

**One's attitude makes
the caregiving journey
easier or more difficult!**

Attitude Is . . .

The way you mentally look at things



Half empty? or half full?

For Self-Care and a Healthy Caregiving Journey...

- **Avoid attitudes that block “balancing”**
 - Expecting perfection of self or others
 - “No one can provide care as well as I can”
 - “I could never...” “I would never...” “I should”
 - “It is my responsibility and mine alone.”
- **Make decisions based on “what is best”**
 - **NOT** on promises or guilt
 - **NOT** on pressures from others

**Do you ever carry
GUILT “on your
shoulders”?**

**If you experience feelings of
guilt, ask yourself . . .**

- Did I actually do something wrong or hurtful?
- OR
- Do I wish I had done something differently?



**Your emotions are
messages . . .**

**. . . Are you listening to the
messages?**



Self-Care Skills include . . .

- Accepting what you cannot change
- Letting go
- Making plans for “the worst that could happen”
- Not “borrowing trouble” from the future

**...Grant me the Serenity to
Accept the things
I cannot change,
Courage to change the things
I can, and the
Wisdom to know
the difference**



**If you worry you die
If you don't worry, you also die.
So why worry?**

— Mike Horn

Do you say things to
yourself that tend to
“pull you down”?

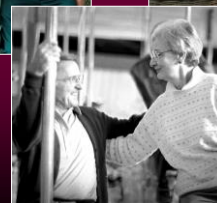
Focus on what you have
done well!



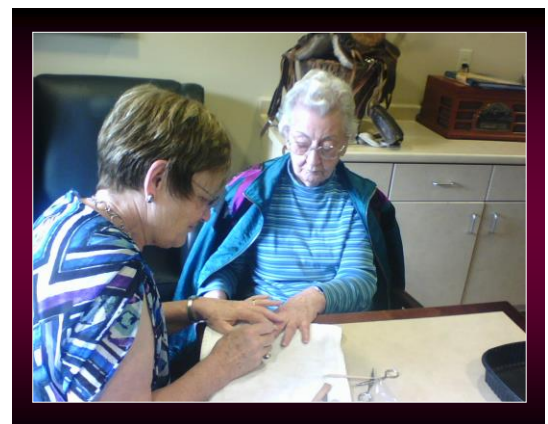
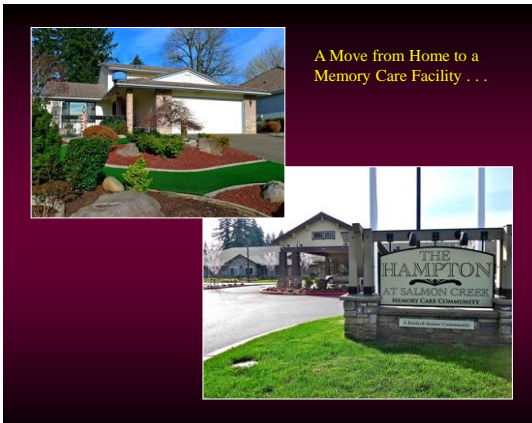
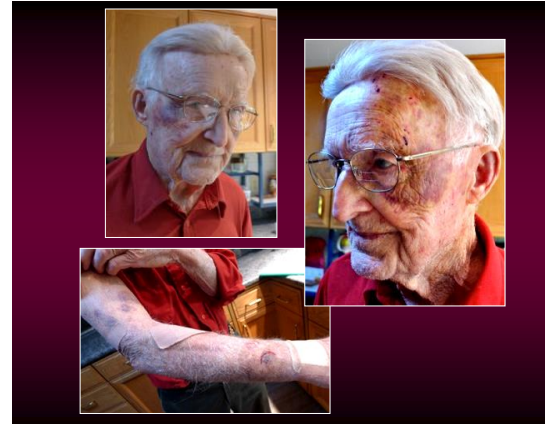
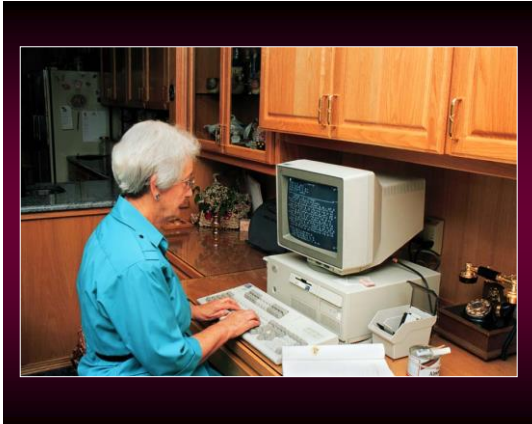
Be Open to Changing
Your Caregiving Situation



A Personal Story . . .



My Parents . . .
Grant & Iona





**To give the “best caring”
to others, we must be
CARING TO
OURSELF!**



**For your Caregiver Journey
Self-Care “bag”, do you ...**

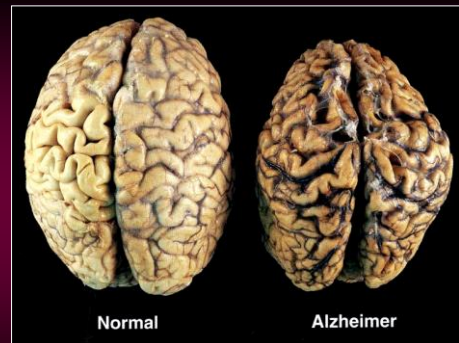
- Have time for YOU packed in it?
- Have attitudes that make for healthy caregiving?
- Have a life separate from caregiving?
- Say good things about yourself to yourself?
- Focus on what you’ve done well?
- Ask for and accept needed help?
- Know the resources—family, friends, community, long term care—available to you?

**Providing care is not for
everyone.... And that, too
is OKAY!**

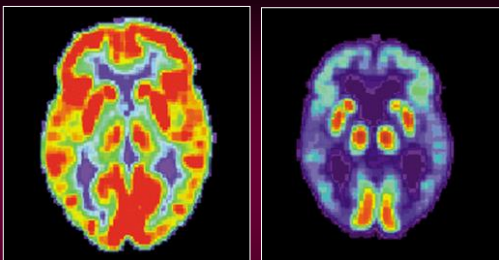
Communicating with someone who is memory impaired



Understand the world of the person with dementia



Dementia = A Damaged Brain



Normal

Alzheimer's Disease

Pet Scans of Brains

Use the "5 C's" in Working with People with Dementia



1. Calm
2. Consistent
3. Compassion
4. Caring
5. Comfort

What about “Gentle Deceptions”?

The “Little White Lies” . . . “Therapeutic Lies”



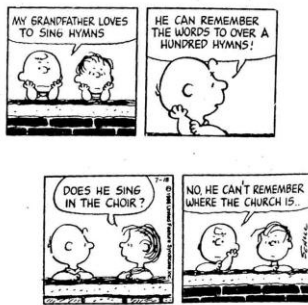
- “Grant is in rehab and it will be awhile.”
- “It’s been a long time since I’ve seen your Dad.”
- “I will now check into it.”
- “I don’t know how long you will be staying here. We will talk to the doctor.”

*What is “the truth” and it’s impact?
Whose world are you “stepping into”?*

Person loses the ability to learn and to “record” information and events



Peanuts



Schultz



Music plays . . . Bob dances and sings . . . Lisa connects with Dad

The past often becomes more “real” and lovable than the present



The person’s emotions and feelings largely remain intact!



“People will forget what you said,
People will forget what you did,
but they will never forget
how you made them feel.”

— Maya Angelou

The person cannot change.
We must change.



Being reasonable,
rational, and
logical will only
create trouble!

NEVER Argue!!



You will NEVER win an argument with a
person who has dementia

The memory-impaired person
is always right—right from
his or her point of view



Connect!
Don't correct!



You Cannot NOT
Communicate





When Verbal Communication is Lost . . .

- Non-verbal (tone, body posture, etc.)
- Feelings
- Touch
- Behavior

... SPEAK LOUDLY

... Person's Behavior Communicates



- Are you listening to what is being said?
- What is the "message" in the behavior?

Communicating with People Who Are Memory Impaired . . .

- Keep expectations realistic
- Speak in gentle tones
- Focus on feelings, not facts
- Eliminate distractions
- Simplify, simplify, simplify— e.g. use short sentences; one- step instructions
- Use person's vocabulary
- Use positive statements
- Encourage recognition rather than recall — Avoid quizzing!
- Give time to respond
- Use reminiscence
- Use multi-sensory cues
- Approach slowly, from front
- Reassure and praise
- Be kind and courteous!

The Story of the Shell and Alzheimer's Disease





Counteracting One's Own Negative Voice/Self-talk ...

- Recognize the thought
- Treat the thought as though it was said by a third person
- Dispute the thought with evidence

What will you do positive for
yourself when you return home?

On a sheet of paper, write:

- I will _____
- When _____
- My level of confidence is _____ Scale of
1 (Low confidence) to 10 (High confidence)

Share with one other person at your table

*There are only four
kinds of people in the world:*

*Those who have been caregivers,
Those who currently are caregivers,
Those who will be caregivers, and
Those who will need caregivers.*

Rosalynn Carter