

## The Caregiving Journey . . .



Vicki L. Schmall, Ph.D.

Gerontology Specialist  
Professor Emeritus  
Oregon State University



## 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...

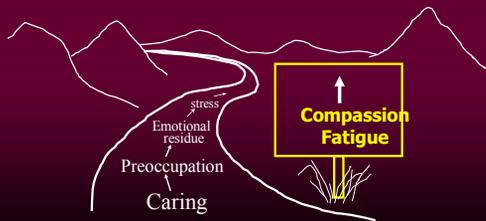
And the reasons why...

### 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



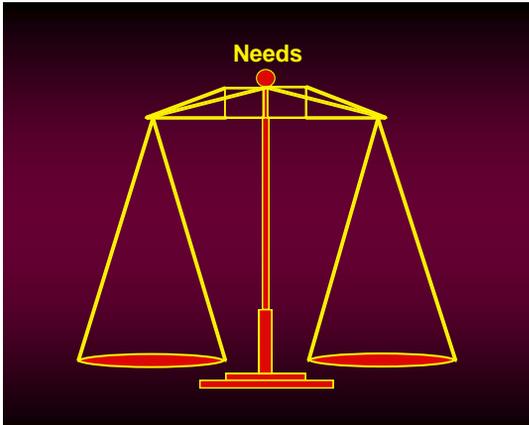
When we suffer from compassion fatigue, we experience a frozen heart!

- 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 caregiving**
  - 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!



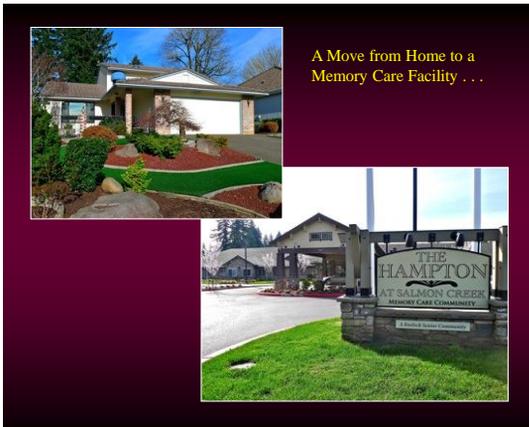
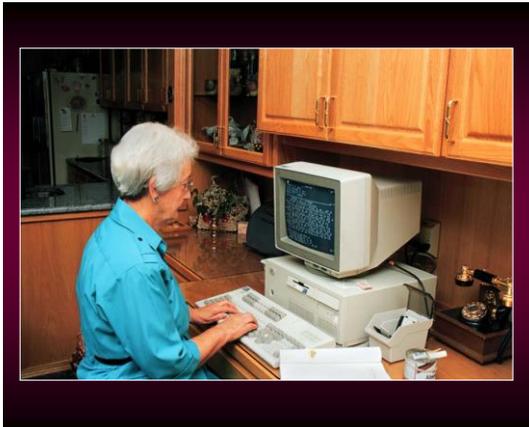
Be Open to Changing Your Caregiving Situation



A Personal Story . . .

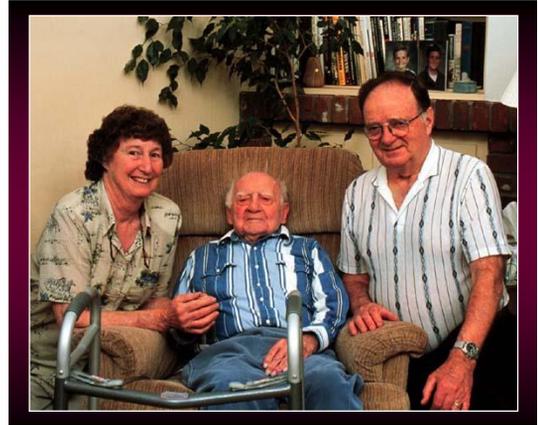


My Parents . . .  
Grant & Iona



Two months later... Dad falls! ... It's related to the beatings from Mom.





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



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

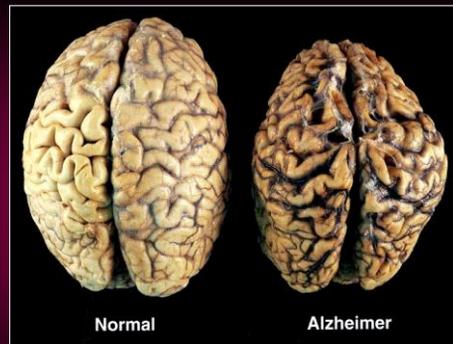
- Have time for YOU packed in it?
- Have attitudes that make for healthy caregiving?
- Have a life separate from caregiving?
- Say good things about yourself to yourself?
- Focus on what you’ve done well?
- Ask for and accept needed help?
- Know the resources—family, friends, community, long term care—available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

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

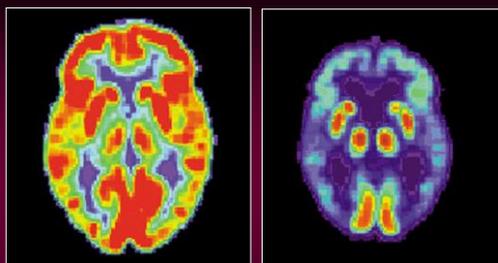
## Communicating with someone who is memory impaired



## 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”?

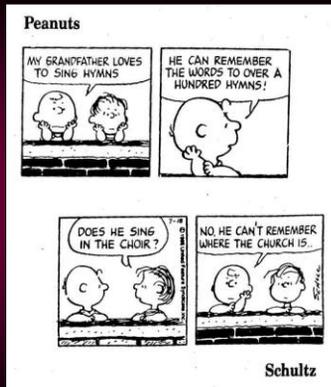
The “Little White Lies” . . . “Therapeutic Lies”



- “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



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