Caregiving Challenges & Rewards

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Who are caregivers?

Webster’s Dictionary – persons who provide direct care to another individual

What is caregiving?

An Art
A Profession
A Partnership
A Commitment
A Journey
Why is caregiving important?

• Approximately 45 million Americans provide unpaid care to another adult
• The value of care is estimated at 257 billion dollars per year by AARP
• Family care is the most important source of assistance for people with chronic conditions who need long-term care
• Without this informal workforce the entire care system would be in jeopardy
Caregiver Roles
How do we become caregivers?

• By choosing caregiving as a professional occupation

• When a spouse/significant other or child is disabled or chronically ill

• When a care recipient needs short-term support to recuperate from an illness, injury or surgery

• When a loved one needs care at the end of life

• When a parent can no longer live on their own
Some guidelines for making good caregiving decisions

- What are the available housing options?
- Who will be the principal caregiver?
- Will there be sibling involvement?
- What responsibilities can be shared?
- Is there open communication?
- Do family members share openly?
- What are the person’s finances, sources of income?
- What is the current medical insurance?
- Has an eldercare attorney been consulted?
- How do you feel about having a death in your home?
- How do you feel about caring for the personal needs of your loved one?
What are some potential care recipient needs?

- Companionship
- Medication Supervision
- Running errands
- Transportation
- Bathing
- Dressing
- Walking
- Toileting
Stages of caregiving

1. Preparation for the role

2. Completing the tasks and responsibilities of caregiving

3. Detachment from various levels of caregiving
Breaking down the stages

The Expectant Caregiver: You have a concern that you will become a caregiver soon... This is your time to prepare.

The Freshman Caregiver: You have been a caregiver for awhile, how is it going? Time to review your caregiving personality.

The Entrenched Caregiver: You have been caregiving for several years, does your routine provide comfort for you and for your care recipient?
Breaking down the stages

The Pragmatic Caregiver:  You have been a caregiver for more than 5 years...You have settled into your role and routine

The Transitioning Caregiver:  Your care recipient’s condition is worsening...This is your opportunity to begin to mourn for your loved one even before death

The Wise Caregiver:  Your role as a caregiver ended awhile ago...You now become a strong support and advocate for other caregivers
I'll tell you, Iggy, when you get to be my age, the mind is the second thing to go.... I forget the first thing!
Understanding caregiver stress

“Caregiver stress is a reaction to changes that require adjustments or responses and our stress level will depend on how we respond to these adjustments. All caregivers experience stress. Recognizing the stressors you can eliminate, gives you courage and enthusiasm to take control over changes that previously would have overwhelmed you.”

How did you become a caregiver?

• Personal choice
• Perceived obligation
• Attachment or relationship to care recipient
• Your personal skills/abilities to deal with the role
• Your spouse needs care
• Your child is born with a challenge/disability
I took one of those memory courses. Now I can walk up to people I haven't seen in years and insult them by name!
Causes of caregiver stress

- Physical and emotional components of care
- Care recipient’s behavior and attitude
- Physical and emotional health of caregiver
- Adjusting to work and caregiving
- Financial Problems
- Adjustments to caregiving within the family
Warning signs of high stress

- **Physical:** Headaches, appetite changes, change in sleep habits, chronic pain
- **Emotional:** Angry, sad, irritable, worried, discouraged, looking for magical solutions, mood swings
- **Behavioral:** Increased use of drugs or alcohol, forgetfulness, boredom, acting impulsively
- **Relationships:** Problems with marriage, intolerance, less contact with friends, lowered sex drive
Managing your stress

- Exercise
- Enough sleep
- Proper diet
- Take time for hobbies
- Ask for support
- Take care of physical appearance
- Accept that there are things you cannot control
- Research & utilize respite care
- Set realistic goals/expectations
- Be forgiving
- Find someone to confide in/communicate your feelings
Barriers to stress management

• Trying to solve too many problems at once

• Blaming others, the “system,” fate, why me?

• The build-up of stressors may affect judgment and initiative

• Using drugs or alcohol as substitutes for resolving problems increases stress

• A negative outlook makes us believe nothing can change
Caregiver burnout

“Caregiver burnout is a state of physical, emotional, and mental exhaustion that may be accompanied by a change in attitude, from positive and caring to negative and unconcerned. Burnout can occur when caregivers don’t get the help they need, or if they try to do more than they are able physically and financially.”

Causes of caregiver burnout:

• Demands from care recipient/others
• Hopelessness of care recipient’s condition
• Unreasonable burden put on yourself/need to fix it
• Role confusion
• Lack of control over finances/resources
• Conflicting policies in accessing support services
Symptoms of caregiver burnout

• Withdrawal from friends and family
• Losing interest in previously enjoyed activities
• Feeling hopeless, helpless
• Weight and appetite changes
• Changes in sleep pattern
• Getting sick more often
• Thinking about hurting yourself or the one you care for
• Emotionally and physically exhausted
My computer doesn't work! The hard drive crashed! What do I do?!

Did you back up?

Why? Is it gonna blow?!
Preventing caregiver burnout

- Find someone you trust to talk about feelings & frustrations
- Set realistic goals, accept you may need help and ask for it
- Be realistic about your loved one’s disease
- Take time for yourself/self-care is NOT a luxury
- Talk to a professional therapist, social worker, clergy
- Take advantage of respite care services
- Know your limits/listen to your body
Preventing caregiver burnout

• Be honest about your capabilities/goals

• Educate yourself...the more you know the more effective caregiver you will be

• Develop new coping tools, lighten up, don’t forget to laugh

• Stay healthy, eat right, exercise, sleep

• Accept your feelings, negative feelings are normal

• Join a caregiver support group

• Contact your local Area Agency on Aging, or disease specific agency for information and support & educational materials
I'll have a cheeseburger, large fries, black coffee...

I'm starting to think retesting seniors for driving isn't a bad idea!
I'm not saying your mother is senile but she just vacuum bagged the cat!
Caregiver coping skills

Stress Management
• Exercise
• Know and set limits
• Have some fun
• It is OK to cry
• Avoid self-medication

Time Management
• Make a “to do” list
• Do the most important/difficult things first
• Delegate what you can
• Forget what is unnecessary
Caregiver coping skills

Decision Making
• Clarify the issue
• Establish criteria, consider time & affordability
• Best solution for all involved
• Plan of action

Life-style Management
• Exercise
• Eat right
• Rest
• Relax
• Maintain a sense of humor
• See your physician/dentist
• Develop and use a support system
APPARENTLY YOU’VE NEVER HEARD OF THE TRUTH-IN-ADVERTISING LAWS, SPORT.
Rewards of caregiving

Positive emotions: Caregivers report 3x more positive emotions than negative emotions related to caregiving, 96% report feeling “loving,” 90% report feeling appreciated, 84% report feeling proud

Relationship rewards: Increased closeness with care recipient, other caregivers and their support network

Renewed sense of purpose and meaning: Many find it meaningful to care for a family member or friend making caregiving a life-enriching experience

Spiritual Growth: Caregiving can help to clarify one’s beliefs and deepens one’s sense of their own values
Rewards of caregiving

Logistical Savvy: Caregivers learn how to help with medical care. They also learn about interacting with the medical community, legal services and financial planning. These services will be helpful in the future.

Self-Confidence and Self-Esteem: All of the above promote self-confidence and self-esteem.

Post-traumatic Growth: A positive psychological change can be experienced as a result of a struggle with a highly challenging situation.
One family’s caregiving journey
Learn about resources in your area, attend conferences and workshops offered by agencies involved in health care and older adult services.

Take advantage of all respite care opportunities, this benefits your loved one and you.

Talk to family members that you anticipate caring for, find out about their wishes.

Attend an area support group - sharing with others who are experiencing similar circumstances may be the best thing you can do for yourself.

Care for yourself as well as you care for your loved one, discuss your health including your stress levels with your Primary Care Physician.

Seek out a professional counselor for help if you need it.

Remember, you are only one person and you cannot do this alone.

Keep your sense of humor, if yours is sapped, cultivate a “funny” friend.
"Yesterday's the past, tomorrow's the future, but today is a GIFT. That's why it's called the present."
Area caregiver resources

• Pinal-Gila Council for Senior Citizens, Area Agency on Aging Region V, 1-520-836-2758 or 1-866-293-9393
• Alzheimer’s Association, Desert Southwest Chapter, Tucson Region 520-322-6601 - 24 hr. helpline 1-800-272-3900
• American Parkinson’s Disease Association, Arizona 520-626-5055 or 1-866-897-1261
• www.caregiver.com (information on many other groups in the area)
• University of Arizona – Tucson Community Stroke Support Group 520-626-2901
• Catalina Community Services – 3535 E Hawser, Tucson, AZ 520-826-0009
• Cenpatico – 24 hour Crisis Line – 1-866-495-6735 (Behavioral Health)
• Adult Protective Services – 1-877-767-2385
Resources used in this presentation

• A Celebration of Caregiving, Lee Schulz 2007
• Caring for the Caregiver, Dr. David Coon ASU, 2012
• The Journey Through Caregiving, North Dakota State Caregiver Project, 2004
• The Emotional Challenges of Caregiving, Washington State Dept. of Health and Social Services, October 2008
• Caregiving Challenges and Rewards, A. Barry Rand, CEO, AARP, November 2012