


# CAREGIVER STRESS & COPING

## The Journey Through Caregiving


### We become caregivers through a variety of reasons such as:

- Choosing caregiving as a professional occupation
- Lifelong mate becomes disabled or chronically ill
- Care recipient needs short term support to recuperate from an illness
- A loved one needs care at end of life



The following questions can serve as a guide for families trying to make good decisions about the future care of their loved one.

1. What housing options are possible? Will your loved one move in with a family member, or will the family member move in with the dying loved one?
2. Who will be the principal caregiver?
3. What involvement will siblings have in providing care?
4. Which responsibilities of care can be shared? By whom? (Supervising medications, shopping, doctors, day care, etc.)
5. Is communication open and honest between caregiver and the elderly person?



The following questions can serve as a guide for families trying to make good decisions about the future care of their loved one, cont:

1. Do family members share feelings and information?
2. What is the person's financial situation?
3. What are the sources of income for the elderly loved one? (Social Security, private pension, annuities, stocks, interest, IRA's, CD's)
4. Is their current medical coverage adequate?
5. Has anyone consulted an eldercare attorney?
6. Has the elderly person transferred any assets?
7. How do you feel about having someone die in your home?
8. How do you feel about caring for the personal needs that your loved one will need?

(Adapted Caregiver Guide)



## The varying needs of care recipients may include:

- Companionship
- Medication supervision
- Running errands such as groceries/mail
- Transportation to an appointment
- Bathing
- Dressing
- Walking
- Use of toilet



## Stages of caregiving include:

1. Preparation for the role.
2. Completing the tasks and responsibilities of caregiving.
3. Detachment from various levels of caregiving.



## Six sub-stages that caregiving can be broken down into:

1. The Expectant Caregiver
2. The Freshman Caregiver
3. The Entrenched Caregiver
4. The Pragmatic Caregiver
5. The Transitioning Caregiver
6. The Godspeed Caregiver



## How did you get put in the caregiver role?

- Your choice
- Perceived obligation
- Attachment or relationship to that older adult
- Your ability to deal with the situation
- You perceived it as your responsibility
- Your spouse needs care
- A child born with a birth defect



## Caregiver stress can be caused by any of the following:

- Care receiver's behavior and attitude
- Physical and emotional components of care
- Adjusting to work and caregiving
- Care receiver's financial problems
- Adjustments of caregiving within the family



## Warning signs that may indicate high stress include:

- **Physical.** Headaches, appetite or weight changes, feeling tired all the time, changes in sleep habits, muscle aches, getting sick often, stooped posture, sweaty palms, neck pain, weight gain or loss.
- **Emotional.** Anger, sadness or crying spells, irritability or short temper, worry or anxiety, discouragement, trouble relaxing, emptiness or loss of direction, looking for magic solutions, inability to concentrate, frequent mood swings.
- **Behavioral.** Increased use of drugs or alcohol, trouble concentrating, avoiding decisions, low productivity, forgetfulness, boredom, over-reacting, acting on impulse, changing jobs often.
- **Relationships.** Problems with marriage or children, intolerance of others, fewer contact with friends, nagging, lowered sex drive, loneliness, resentment.

(Adapted Jolly, 1996, & Caregiving: Stress Management and Burnout Prevention)



## Healthy choices for dealing with stress may include:

- Exercise
- Get enough sleep
- Eat proper food
- Take time for hobbies
- Ask for support from our families, friends, or community resources
- Take care of your physical appearance
- Accept that there are events you cannot control
- Stop smoking
- Set realistic goals and expectations
- Be forgiving
- Communicate feelings



## Things the care receiver can do for the caregiver to relieve stress:

- If you can possibly do it for yourself, do it, and be happy that you can.
- Express good manners... say thank you for the smallest things. Everyone wants and needs to be appreciated.
- Do your part to boost the entire family's morale.
- Your caregiver has a life other than caring for you, so rejoice when they have an opportunity to "go" without you.
- Laugh when things become tense. Many times that is all one can do.
- Be agreeable to change. Things cannot always be done like they once were.



## Things the care receiver can do for the caregiver to relieve stress:

- Smiling is a real upper for the one who does the smiling as well as the one who receives it.
- Think before you complain and ask yourself, “Will this help?” Chances are your complaints only agitate the condition and anyone within earshot.
- Look at your disease or disability head on, and do what is necessary to make your life and that of your caregiver as pleasant as possible.
- Never be demanding and remember no one is a slave to another person. Compassion and understanding go a long way.
- Practice patience and moderation in all things.
- Demonstrate your love in every possible way. Let it radiate to all God’s creatures.

(Loffin, 2001)



## Barriers to managing stress include:


- Trying to solve too many problems at once makes change overwhelming.
- Blaming others, “the system,” or “fate” prevents action.
- The buildup of stressors in our lives may affect our judgment and our initiative.
- Using drugs or alcohol as substitutes for resolving problems increases stress.
- A negative outlook makes us believe nothing can change.

(Jolly, 1996)




## Causes of caregiver burnout may include:

- Demands from care receivers and others in the environment.
- Apparent helplessness of the care receiver's condition.
- Unreasonable burdens put on yourself.
- Role confusion.
- Lack of control over money, resources, etc.
- Conflicting policies and procedures when trying to access support services.




## Symptoms of caregiver burnout include:

- **Withdrawing from friends, family, and other loved ones.**
- **Losing interest in activities previously enjoyed.**
- **Feeling blue, irritable, hopeless and helpless.**
- **Experiencing changes in appetite, weight, or both.**
- **Experiencing changes in sleep patterns.**
- **Getting sick more often.**
- **Feeling you want to hurt yourself or the person for whom you are caring.**
- **Becoming emotionally and physically exhausted.**
- **Being irritable.**



## Steps you can take to prevent caregiver burnout include:

- Find someone you trust, such as a friend, co-worker or neighbor, to talk to about your feelings and frustrations.
- Set realistic goals.
- Be realistic about your loved one's disease.
- Don't forget about yourself because you're too busy caring for someone else.
- Talk to a professional.
- Take advantage of respite care services.
- Know your limits and take a reality check of your personal situation.



## Steps you can take to prevent caregiver burnout include, cont:

- Be honest with yourself about your capabilities and goals.
- Educate yourself.
- Develop new tools for coping.
- Stay healthy by eating right and by getting plenty of exercise and sleep.
- Accept your feelings.
- Join a caregiver support group.
- Contact your area Agency on Aging or local chapter of AARP for information on services available in you area



## Coping skills for caregivers include:

### Stress Management

- Exercise.
- Talk to someone about worries, concerns.
- Know your limits. Set limits.
- Make time for fun.
- Know what you have to do. Do one thing at the time.
- Know it's O.K. to cry.
- Avoid self-medication.

(Adapted Haigler, 1998)



## Coping skills for caregivers include:

### Time Management

- Know that some time will be spent on activities beyond your control.
- Make a daily "to do" list.
- Do the most important/difficult things first.
- Save up errands to do at once.
- Take along a small task if you go somewhere you know you will have to wait.
- Do an appraisal of the things you must do. Delegate what you can. Forget what is unnecessary.

(Adapted Haigler, 1998)



## Coping skills for caregivers include:

### Decision Making

- Define and clarify the issue.
- Set up criteria that any solution or decision should meet. For example: there is enough time; it is affordable.
- Select the best possible solution for everybody involved.
- Design a plan of action.

(Adapted Haigler, 1998)




## Coping skills for caregivers include:

### Life-style Management

- Exercise.
- Eat right.
- Get enough rest.
- Take time to relax.
- Maintain a sense of humor.
- Get regular medical and dental check-ups.
- Develop and use a support system.

(Adapted Haigler, 1998)



## To qualify for services under the Medicaid Waiver for the Aged and Disabled program, and individual must be:

- A Medicaid recipient (meets income eligibility requirements)
- Screened at nursing facility level-of-care
- At least 65 years of age or disabled by Social Security Disability criteria
- Capable of directing his/her own care
- Living in his or her own home or apartment (not in a dormitory or other group housing)
- Able to have his or her service/care need(s) met within scope of the Waiver

(Adapted Home & Community Based Services: North Dakota's Medicaid Waiver for the Aged and Disabled)



## SPED program criteria:

- Liquid assets of less than \$50,000.
- Inability to pay for services.
- Impaired in four Activities of Daily Living (ADLs) involving basic needs such as bathing, dressing, toileting, etc. OR in five Instrumental Activities of Daily Living (IADLs) that require a higher level of cognitive or physical ability to perform such as driving, managing money, shopping, etc.
- Impairments must have lasted or are expected to last three months.



## SPED program criteria, cont:

- Is not eligible for Aged & Disabled Waivers
- Is not living in an institution, dormitory, or congregate housing.
- The need for service is not due to mental illness or mental retardation.
- Is capable of directing own care or has a legally responsible party.
- Has needs within the scope of covered services.

(Adapted Home & Community Based Services: Services Payments for the Elderly and Disabled (SPED) program & Expanded-SPED program)



## Expanded SPED Criteria:

- Receives or is eligible for Medicaid
- Receives or is eligible for Social Security Income (SSI)
- Is not severely impaired in the ADLs of toileting, transferring, eating.
- Is impaired in three of four IADLs: meal preparation, housework, laundry, or taking medications.



## Expanded SPED Criteria, cont:

- Has health, welfare, or safety needs, including supervision or structured environment, otherwise requiring care in a basic care facility.
- Is not living in an institution or dormitory.
- Has needs within the scope of covered services.

(Adapted Home & Community Based Services: Services Payments for the Elderly and Disabled (SPED) program & Expanded-SPED program)



## Tips for interviewing in-home provides include:

1. What training does the candidate have?
2. What is the candidate's work history and experience?
3. Describe your needs; ask if the candidate is capable of performing these tasks.
4. Does the candidate have the skills or knowledge to meet your special care needs?
5. Does the candidate have any allergies or other medical/physical health related problems that may interfere with your specific care needs?
6. If the candidate will be providing you with transportation, verify his/her driver's license and insurance and ask if their vehicle is safe.



## Tips for interviewing in-home provides include, cont:

1. If the candidate will be driving your vehicle, verify his/her driver's license and check with your auto insurance agent about coverage in case of accidents.
2. If food preparation is needed, ask if the candidate has experience cooking for others.
3. Ask what the candidate's expectations are regarding vacation and time off.
4. If you have pets, ask if the candidate is agreeable to providing care for them.
5. Ask the candidate for references.
6. At the end of the interview, tell the candidate when you will get back to him or her.

(Adapted In-Home Services: Selecting a Non-Agency Provider)



## The written agreement may include:

1. Who is responsible for the payment of transportation cost, meals, Social Security and other fringe benefits.
2. Rate of pay, days and hours of employment, days off, vacations, and whether or not you will be withholding taxes
3. Schedule of tasks and set working hours.
4. How and to whom the provider will communicate any change in your condition or behavior.
5. A statement of confidentiality that prohibits the provider from discussing any personal information about you.



## The written agreement may include, cont:


1. How medical emergencies will be handled. Include names and telephone numbers of emergency contacts.
2. A requirement that all receipts accompany all purchases made on your behalf.
3. A clarification of the provider's responsibilities regarding meal preparation, routine housework, laundry, etc. when you have family/friends as daytime or overnight guests.
4. Your preference regarding smoking in your home.
5. How much notice each party should give when one decides to discontinue services.

(Adapted In-Home Services: Selecting a Non-Agency Provider)




## Questions to consider when choosing a doctor:

1. Does your loved one have a primary care physician?
2. How far do you have to travel to receive health care services?
3. Does your loved one's doctor presently reflect the skills necessary to continue to meet an increasing need for care?
4. Within your community, are there doctors who have an empathetic understanding of the care recipient's personality and aging process?
5. How are medical emergencies handled?
6. What method of communication does the doctor prefer?
7. Who will answer my questions if the doctor is unavailable or if it is after hours?




## Plan what you will say before you meet with the doctor...

1. Write down issues and questions that you wish to discuss.
2. Allow adequate time to communicate and allow everyone time to state their views regarding the care of their loved one.
3. Determine who should be present at the appointment.
4. Don't hesitate to ask for a second explanation.
5. Don't use "jargon talk" in end-of-life care.




## Plan what you will say before you meet with the doctor, cont...

1. State facts concisely: honesty promotes trust.
2. Communicate preferences of race, ethnicity, culture, and religion to the health care team.
3. Take notes during the appointment. Many issues may arise after you leave, and you may forget what was discussed.
4. Summarize the discussion.
5. Plan for the next step in the care of your loved one.



### **Listening strategies to strengthen your communication with the older adult could include:**

- Direct your full attention to the older adult when they speak.
- Provide encouragement for their opinions.
- Acknowledge and confirm their spoken words and body language.
- Use appropriate tone in your voice when you are speaking.
- Assure older adults they have been heard.
- Decrease disturbing noises and activities within the environment.



### **Factors that affect what kind of care your loved one will need:**

- The level of care necessary now and in the future.
- Family preferences
- Monetary resources
- What services are offered within your community.
- Is your relative ambulatory, or non-ambulatory (requires a wheelchair or walker or other walking aid)?
- Does your loved one want a private room?