Caring for the Caregivers: Tools for Supporting Caregivers in Rural Areas

2016 AgrAbility National Training Workshop
Fort Collins, Colorado
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Care Giving

Caregiver: a person who gives direct care, help and protection to someone.

from Marriam-Webster Dictionary

Care Giving: compromising a part of your life to assist someone with theirs.

from raconline.org
Care Giving

- Caregivers number close to 54 million
- Most caregivers are women ages 40-70
- 1 in 5 adults provide voluntary care to adults
Rural Caregivers

- 22% of rural caregivers use visiting nurse/aide
- 4% of rural caregivers use respite services
- 3% of rural caregivers use adult day care center
Rural Awareness (Stressors)

- Difficult to attract and retain medical & social service professionals
- Inadequate federal funding
- Geographic dispersion (long distances b/t residence & service locations)
- Lack of in-home & community-based options
- Low population density
- Isolation
- Poverty
Rural Awareness (More Stressors)

- Limited family capacity to share duties
- Difficulties in getting training & education while securing care
- Emigration of youth
- Limited access to agencies & outreach programs
- Limited available & reliable transportation
- Distance & time
- Standard of living
Cultural Component

Tendency
• Close connection to home
• Self-reliant
• Strong sense of duty/responsibility

Downside
• Reluctant to leave
• Less open to accepting help
• Caregivers less likely to seek help
  – Stigma
  – Feel obligated to be self-reliant
Disability Awareness (Stressors)

- Work still has to get done
- Reluctance to enter a sick role
- Access to health care limited by resources and insurance as well as demands of farming
Farm Awareness (Stressors)

- Long working hours and seasonal deadlines
- Fatigue
- Isolation
- Worry about survival of the family farm
- Tensions of handling on-farm and off-farm work
- Inability to control external factors
Depression & Adults

• Apathy
• Withdrawal from family, community
• Changes in grooming & hygiene habits
• Changes in sleep pattern
• Changes in appetite
• Negative mood
• Elimination of activity
• Slowed thinking and responding
• Increased complaints of physical ailments with no identifiable sources
Farm Awareness (More Stressors)

- Working side-by-side with family members
- Coordinating the division of labor
- Agreeing on management practices
- Difficulties associated with intergenerational farm transfers
Expectedations of a Caregiver

- Providing more assistance in all venues of life than average family member
- Knowing someone depends on your care for their well-being
- Helping with basic daily activities like personal hygiene and transportation
Roles of a Caregiver

• New duties or roles/loss of traditional duties
• Communicator & broker with all involved parties
• Meeting caregiver’s own needs
• Caring for themselves
• Increased responsibilities on farm
• Caring for family, children, grandchildren
• Community responsibilities, e.g. church
• Caring for home
Emotional Effects

- Changes in degree of personal freedom
- Changes in pace of life
- Role changes - doing things not preferred
- Feelings of burden and being overwhelmed
- Reduced social interaction
- Decrease in income
- Survivor’s guilt
- Hopelessness that other options do not exist
- Belief that caregiver has to do it all
- Victimization by care receiver
- Fear that others will view caregiver as neglectful
- Feelings of anger, weariness and resentment towards care receiver
Caregiver Needs

- Social and emotional support
- Accurate assessment of their needs
- Financial assistance for healthcare expenses
- Supportive work environments (e.g. flex time)
- Understanding that family support/help is not always available for caregiver
Caregiver Needs Cont’d

• Finding time for oneself
• Managing emotional & physical stress
• Balancing work (farm) & family responsibilities
• Maintaining care receiver safety
• Identifying easy activities for caregiver & receiver to do together
• Talking with healthcare professionals
• Making end-of-life decisions
End-of-Life Decisions

- Law student contributed heavily to this section of original work
  - Information is presented from an elementary approach, i.e. basic information so as not to overwhelm but gives consumers items to consider
  - Covers topics such as writing a will, advance medical directives, dying without a will, services for seniors
  - Also covers topics such as Medicaid, DRS, SSI/SSDI, Medicare
Effects of Care Giving

- Strain
- Burden
- Role fatigue
- Role overload
- Stress/Perceived stress
- Burnout
- Depression
Caregiver Burnout

- Despair regarding care receiver’s condition
- Feelings of inadequacy in fulfilling duties
- Minimal down time
- Strained family relationships
- Negative, tense, sarcastic communication
- Reduced social interaction
- Reluctant/hesitant to accept help
- Destructive thoughts
- Destructive coping mechanisms (e.g. overeating, drinking)
- Exhaustion & resentment
Meeting Caregiver Needs

- Basic support, information, education & services, especially respite care
- Comprehensive, coordinated long term care system
- Valid & uniform assessment tool for collecting information on individualized aspects of caregiver situation
  - Highlight areas of difficulty
  - Identify appropriate types of services & support
Meeting Caregiver Needs

- Accessible community services
- Visibility of community service providers
- Community & family recognition of care giving is a job and requires compensation
Coping Strategies

- Staying healthy - balanced eating, rest, exercise
- Asking for help
- Support group
- Education - about health issue/disability, care giving skills, others’ experience and tips, etc.
- Prayer
- Meditation
- Humor
Communication

Communication is key for care giving. Caregiver may also have to communicate with people they have never had to talk with before.

– Communicate about oneself; self awareness
– Communicate with person receiving care
– Communicate with the person's family members
– Communicate with healthcare providers
– Communicate with social services
– Communicate with farm partners & associates
Communication with Outside Parties

- Communicate when rested
- Take notes
- Ask for clarification
- Repeat back
- Ask questions
• What helps you be kind, gentle & clear
• Be specific in expressing appreciation
• Praise me openly & often;
• Provide me with constructive criticism
• Provide privately and as needed
• Do what you can for yourself
• Place yourself in the other party’s shoes
• Both parties be open to suggestions
• Every task you do is one less for the other person

tips from Breaking New Ground Resource Center
Interventions

What’s being done?

- Funded projects can test effectiveness of methods for sharing information, education & tools with caregivers
- Video conferences & telemedicine network set-up at rural hospitals, clinics, libraries & community colleges
- Workshops, webinars and conference calls
- In-person meetings
- Town-hall forums bringing elected officials, service providers & caregivers together
Assistive Technology (AT) is any device or service used to perform tasks that would otherwise be difficult or impossible to do because of a disability or limitation.
Alternative Alarm Clocks

Sunrise Alarm Clock

Sonic Alert Bed Shaker
Medicine Reminders

CADEX 12 Alarm Meds Reminder Watch

Saf-V Vibrating Pill Box
Portable Assistive Technology

Uplift Cushion

Freedom Portable Shower
AT for the bathroom

Bathtub Lift
AT for Grooming
AT for Eating and Drinking

Utensil Cuff

Liftware Weighted Spoon
AT for Eating and Drinking

Farmer Biball
www.biballs.com

Easy Fill

Foogo Sip Cup

Ergo Handled Utensils
AT for Dressing

Leg Loop
Leg Lift

Collar Button Extender

Button Hook Zipper Pull Combo
Adaptive Clothing

IZ Adaptive Clothing
Adaptive Clothing

Snap Back Dress

Velcro Closure Shirt

Buck & Buck
AT for Communication

- Proloque2go App
- Lightwriter AAC Device
Hearing related AT

Pocket Talker Pro
Assistive Listening Device

HearAll Phone Amplifier

Serene Cell Phone Signaler
Sign Language Apps

Marlee Signs app

Sign4Me 3-D Signed English Translator app
Vision related Apps

AFB AccessNote App and Braille Note

Tap Tap See app

“orange bucket”
AT for Eye Gaze Communication

Speakbook

Megabee Handheld Writing Tablet
AT for Remote Communication

Two Way Radios

Baby Monitors (apps on iphone)
Personal Alarms and Pendants
Safety & Medical Alert Bands

- Safety Tats
- Design-a-Band
- Vital ID Medical Wrist Band
USB Devices for Information Sharing

Key 2 Life USB Bracelet

Swiss Army Knife with USB
Lifts and Transports

Patient Lifts

Folding Chair Transport
AT Solutions for Mobility

- PVI Multifold Portable Ramp
- Gait Belt
- Car Swivel Transfer Disk
AT for Relaxation & Massage

Environmental Sound Machine

Theracane
Resources

- National Family Caregivers Association
  www.nfcacares.org
- Extension- Family Caregiving
  www.extension.org/family_caregiving
- Today’s Caregiver (quarterly magazine)
  www.caregiver.org
- Rosalynn Carter Institute for Caregiving
  www.rci.gsw.edu
Resources

• West Virginia Assistive Technology System  
  www.cedwvu.org/programs/wvats

• West Virginia AgrAbility  
  www.wvagrability.org

• Northern West Virginia Center for Independent Living  
  www.nwvcil.org

• EEOC Best Practices for Workers with Caregiving Responsibilities  
  www.eeoc.gov/policy/docs/caregiver-best-practices.html

• Breaking New Ground Resource Center  
  www.agrability.org