

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



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Care Giving



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

from Merriam-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

Expectations 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

Communication between Caregiver & Receiver



- 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

What is Assistive Technology (AT)?



Reacher

Assistive Technology can be 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

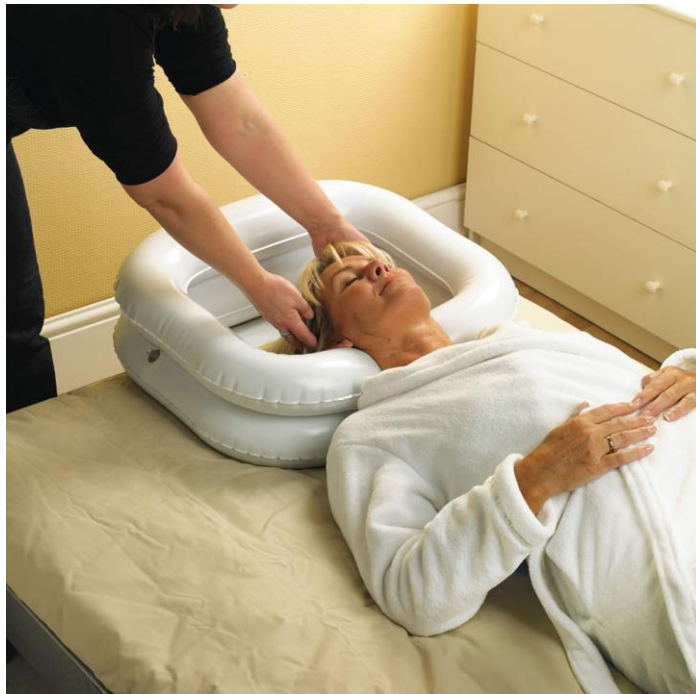
AT for the bathroom



Bathtub Lift



AT for Grooming



AT for Eating and Drinking



Utensil Cuff



Lifeware Weighted Spoon

AT for Eating and Drinking



Farmer Biball
www.biballs.com



Easy Fill



Foogo
Sip Cup



Ergo Handled
Utensils

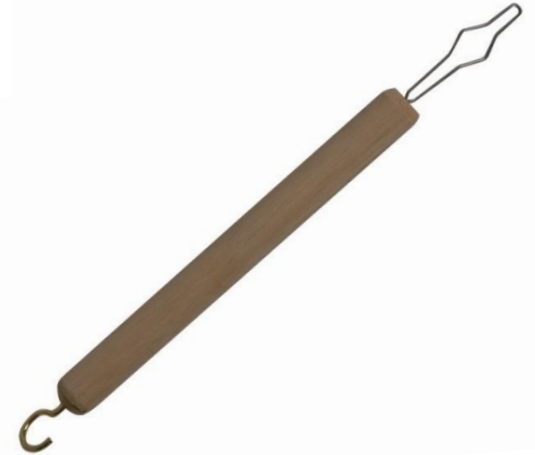
AT for Dressing



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



Textured Talkable 2



Cheap Talk 8



Gotalk 4

AT for Communication



Proloquo2go 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

“orange
bucket”



Tap Tap See app

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
- Farmer, V. (2000). *Honey, I Shrunk the Farm*. McCleery & Sons.
- Davis, M., Eshelman, E., McKay, M. (1995). *Relaxation & Stress Reduction Workbook*. New Harbinger Publication: Oakland, CA.

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