REACH INTO INDIAN COUNTRY: CAREGIVER SUPPORT FOR DEMENTIA CAREGIVERS

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University of Tennessee Health Science Center and Memphis Veterans Affairs Medical Center
“Our caregivers changed from viewing the issues with their loved ones as huge problems into thinking proactively by addressing small parts of the issues. The book helped them to break thing down into a doable level. The program in our experience was very user friendly.”

Program Coach – Cherokee Community
REACH INTO INDIAN COUNTRY

- Resources for Enhancing Alzheimer's Caregivers Health in Tribal Communities (REACH into Indian Country)
  - Implement a proven dementia caregiving behavioral intervention
  - Funded for three years by the RX Foundation
  - Focus on the fit and utility of the intervention in Tribal communities
Resources for Enhancing Alzheimer's Caregivers Health in Tribal Communities (REACH into Indian Country)

- Education, support, and building skills (problem solving, stress management, mood management)
- Helps dementia Caregivers manage their loved one’s dementia and their own stress and coping
- Four sessions between the Caregiver and a Program Coach (more if needed)
- Sessions are individualized to the Caregiver’s and Patient’s specific concerns
- A Caregiver Notebook provides suggestions and strategies
REACH IC Material – Caregiver Notebook

- **Caregiver Notebook**
  - Structures the intervention
  - Educational material (care recipient’s condition, safety in the home)
  - Stress and coping topics (health, well-being)
  - Behavior/Issue topics
  - Primary resource for now and after intervention ended
  - Given to Caregiver by Program Coach

I really, really liked the notebook. It was well organized; the patients were very receptive to it.

Program Coach
### SECTION 1

**BEHAVIORAL ISSUES**

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CAREGIVING RISKS

- Psychological health
  - depression, anxiety, PTSD, burden, stress, morale, life satisfaction, marital satisfaction, resilience, grief

- Physical health
  - morbidity, mortality, blood pressure, insulin levels, impaired immune systems, CVD, health care use for both

- Caregiving/social
  - time spent on caregiving, social support, isolation, validation, efficacy, frustrations, safety
CAREGIVING RISKS

• Inability to provide care for loved ones
  – Caregiver may not be in the loop
  – Medication errors
  – Lack of follow through on provider recommendations
  – Neglect
  – Burnout

• Not taking care of self
  – Caregiver health status
  – Morbidity, mortality
  – Lack of caregiver assessment
  – Isolation
SUCCESSFUL CAREGIVER INTERVENTIONS

- **Common topics needed by all**
  - Disease and course
  - Safety
  - Caregiver physical well-being
  - Caregiver emotional well-being
  - Social support
  - Management of patient concerns

- **Targeted to**
  - Specific needs of the dyad
    - Through assessment

- **Multicomponent Focus on**
  - Education
  - Support
  - Skills building
    - Problem solving
    - Cognitive restructuring
    - Stress reduction
    - Communication
COMPONENTS OF THE PROGRAM

- Problem Solving
- Positive Thinking
- Stress Management
PROBLEM SOLVING STEPS

1. Determine problem (patient, caregiver, family)
2. Define/operationalize (frequency, duration, intensity, characteristics)
3. Assess previous attempts to address
4. Set goals and determine realistic outcome
5. Develop Target Behavior/Issue plan
   - Determine appropriate topic in Caregiver Notebook
   - Review materials with Caregiver
6. Review and troubleshoot plan
   - Barriers
7. Assess plan
8. Modify, if needed
PROBLEM SOLVING

• Problems: Increased dependence in dressing, unable to choose appropriate and clean clothing, increased agitation

• Possible solutions:
  – Medication
  – Attendant
  – Lay out clothes
  – Simplify tasks
  – Limit choices
  – Cue, prompt
  – Modify environment
Pause for a moment, breathe, focus on the breath. Know that you are OK, in this moment.
SIGNAL BREATH

- Focused Breathing
- Simple and Portable
- Prioritizes Stress Management

Step 1: Rate your level of tension

Step 2: Take a deep breath and hold it for 3 or 4 seconds

Step 3: Breathe out slowly while saying a word or phrase to yourself, such as “relax,” “peace,” or “calm down.”

Step 4: While exhaling, let your jaws, shoulders, and arms go limp

Step 5: Repeat these steps two more times

Step 6: Rate your level of tension
MOOD MANAGEMENT – COGNITIVE REFRAMING

- Managing the relationship between thoughts and feelings when the problem cannot be changed
  - Identify the situation
  - Identify current thoughts
  - Recognize current emotions/feelings
  - Challenge/replace unhelpful thoughts
  - Match milder feelings to milder thoughts
### Thought Record Example

<table>
<thead>
<tr>
<th>Step 1</th>
<th>Step 2</th>
<th>Step 3</th>
<th>Step 4</th>
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<tr>
<td><strong>Situation</strong></td>
<td><strong>Current Thoughts</strong></td>
<td><strong>Current Feelings</strong></td>
<td><strong>Challenge &amp; Replace</strong></td>
<td><strong>New Feelings</strong></td>
</tr>
<tr>
<td>My sister was supposed to help me and didn’t come</td>
<td>She always does this to me I shouldn’t depend on her</td>
<td>Trapped, Stressed, Disappointed, Angry, Sad</td>
<td>She’s been there for me in the past</td>
<td>Less trapped, Understanding, Annoyed, Hopeful</td>
</tr>
<tr>
<td>I never have time for myself</td>
<td>My day is ruined</td>
<td></td>
<td></td>
<td></td>
</tr>
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</table>
STRESS MANAGEMENT: SKILLS BUILDING

- Additional stress management techniques
  - Power of Music
  - Pleasant Events
  - Stretching
  - Guided Imagery/Visualization
## Eligibility
Caregivers are usually a family member or someone with a significant personal relationship who provides substantial, necessary, regular or long-term care of a person with dementia receiving services at your organization.

## Enrollment and Risk Priority
The Interventionist completes Caregiver Assessment forms (Demographics and Risk Priority Inventory). The Interventionist explains the program to the Caregiver and sets a date for Session 1.

## Intervention Sessions
The Interventionist will complete

**Active Intervention Phase**
- Four core sessions with the Caregiver over two to three months
- Additional sessions if necessary based on goal attainment, Caregiver need/desire, or Interventionist clinical judgment for Active Intervention Phase

**Discharge from Active Intervention Phase**
- Obtain closure to Active Phase by reviewing previous sessions and ways to contact Interventionist if problems arise

**Maintenance Intervention Phase**
- If problems arise, Interventionist works with Caregiver on additional problems/stress issues
REACH PROGRAM –
PUTTING IT TOGETHER TO HELP THE CAREGIVER

• Active Phase
  – Four individual core sessions over 2-3 months
  – Face to face or by telephone
  – Optional additional sessions based on caregiver need, desires and goal attainment, and REACH Coach judgment

• Maintenance Phase
  – Additional problems/stress issues as needed

• Key Tools
  – Risk Assessment
  – Program Coach Manual
  – Caregiver Notebook

• Focus
  – Education
  – Problem solving
  – Mood management
  – Stress reduction
PROGRAM INITIATIVES

- Community Specific Modifications to Program Format
- Expanded Training Opportunities
- Provided additional support staff
- Soliciting Community Wide Feedback
CONTINUING EDUCATION (CE)

• For Nursing CE: To obtain a CE certificate you must registered, attend the activity in its entirety and submit a completed electronic evaluation form.

• The electronic evaluation link will be provided to registered participants and must be completed within one week of the educational activity.

• The Indian Health Service Clinical Support Center will mail CE Certificates to those Nurses who successfully complete the criteria for receiving CE.

• This activity is designated 2.75 contact hours for nurses.
UPCOMING TRAINING DATES

September 25, 2017 2:00 pm to 5:00 pm ET
October 6, 2017 11:00 am to 2:00 pm ET
October 17, 2017 2:00 pm to 5:00 pm ET
November 17, 2017 11:00 am to 2:00 pm ET
November 29, 2017 2:00 pm to 5:00 pm ET
December 14, 2017 11:00 am to 2:00 pm ET
BECOME A REACH PROGRAM COACH

- Access to these resources to help you help your caregivers

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https://www.uthsc.edu/prevmed/memphis-caregiver-center/index.php
REACH Into Indian Country:
Caregiver Support for Dementia Caregivers

Reach Community
Resources for Enhancing Alzheimer’s Caregivers Health—Indian Country
Talking Points

- Introduction
- REACH IC in Arizona
- Marketing the Program
- Who Are the Caregivers?
- Partnering for Success
REACH IC in Arizona

- Trained 24 participants through ITCA-AAA, Region 8 (Caregiver Coordinators, Senior Service, Health Services, CHR’s, CHN’s)
- Certification/reporting requirements reviewed
- Training location – local Hotel, Breakfast & Lunch
- REACH IC Trainer provided 2 – 3 day training
- Staff trained and certified on-site
- REACH IC Trainer provided follow-up training
- REACH IC Training available by webinar

Reach Community
Resources for Enhancing Alzheimer’s Caregivers Health—Indian Country
Marketing the Program

- Engage leadership, community professionals to support program
- Identify target groups for training (Caregiver Coordinators, Senior Services, Health Services, CHN’s, CHR’s, staff that work with caregivers)
- Flyer, Community Newspaper, Public Service Announcements (PSAs), Displays at Health Fairs
- Support Groups, Health Fairs, Elderfests
Who Are the Caregivers?

- An adult family member, or other individual, who is an informal provider of in-home care to an individual with dementia or memory loss.
Partnering for Success

- Develop programming unique to the character of the Tribal community and regional setting
- Traditions and Culture
- Family caregivers, care recipients, & extended family
- I.H.S., Health Services & Community Providers
Partnering for Success
Tribal Staff Collaborating
Lunch is Served!
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