A Toolkit for Caregivers of Persons with Dementia

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A Toolkit for Caregivers of Persons with Dementia

Description
A collaboration with Washington County Disability, Aging and Veterans Services and 3 Pacific University occupational therapy students to create a toolkit for caregivers of people with dementia. A thorough review of existing information was categorized onto commonly cited topics of concern and condensed into a collection of easy-to-use tip sheets with valuable information to help ease caregiver burden.

Disciplines
Occupational Therapy | Rehabilitation and Therapy

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The Toolkit for Caregivers of Persons with Dementia

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Abstract

A collaboration with Washington County Disability, Aging and Veterans Services and 3 Pacific University occupational therapy students to create a toolkit for caregivers of people with dementia. A thorough review of existing information was categorized onto commonly cited topics of concern and condensed into a collection of easy-to-use tip sheets with valuable information to help ease caregiver burden.
Approximately 52 million caregivers provide 210 billion dollars worth of care in the United States annually. More than 15 million of these caregivers provide care for someone with dementia (www.alz.org).

“Dementia is a general term for a decline in mental ability severe enough to interfere with daily life…” Alzheimer’s is the most common type of dementia accounting for 60 – 80% of all dementia diagnoses. While dementia is not a natural part of aging, an increasing number of older adults are diagnosed each year. Currently, about 1 in 8 adults in the United States aged 65 years and older have a dementia diagnosis (www.alz.org).

Along with an increasing number of older adults diagnosed with Alzheimer’s disease and related dementias, comes an increasing need for resources to support those providing care.

**Objective**

An innovative practice project was completed by Pacific University Students in collaboration with Disability, Aging and Veterans Services of Washington County (DAVS). Our objective was to address an unmet need in the community and to help enhance DAVS mission which reads, “To create options to maintain the quality of life. We perform these functions to enable persons to live as independently as they can for as long as possible. We are especially concerned about the risk of persons losing their independence. Often this means helping families and caregivers” (http://www.co.washington.or.us/HHS/DAVS)

DAVS serves members of the community including older adults, caregivers, and persons with dementia. Two programs administered by DAVS were the focus of this project. The Family Caregiver program offers support to unpaid caregivers in the community, and Oregon Project Independence, a federally funded program, provides services to older adults and those with dementia. Case managers from DAVS perform home visits to assess the caregiving situation, evaluate need, and connect caregivers with resources. Resources and services offered through these programs include respite care, medical equipment, counseling, support groups, and a free 5-week family caregiver training offered several times throughout the year.

**Methods**

Preparation for this project included participation in DAVS strategic planning process for the years 2012-2015. Attendance at 1 of 5 strategic planning focus groups conducted throughout Washington County provided background on community concerns. The focus groups consisted of community members, public officials, and staff of the Health and Human Services Department. Through the focus groups, several needs related to caregiving were revealed. They included a need for resources for caregivers and care receivers as well as improved access to training and information for caregivers. Nearly every focus group participant indicated that
they currently were, have been, or will be a caregiver at some point in their lives (http://www.co.washington.or.us/HHS/DAVS).

A meeting was held with the community partner to determine their need. The community partner representative from DAVS requested a tool for caregivers offering solutions for common day-to-day needs and challenges in providing care for their loved ones with dementia. It was suggested that minimal focus be on the diagnosis and research related to dementia, but that a practical tangible tool be created that could be easily distributed.

The student team established team goals, determined the goals of the community partner, developed a timeline for the project, drafted a contract between the student team and faculty advisor, and submitted this plan for approval.

Through collaboration and ongoing interactions with DAVS, the team received feedback and was provided with resources to support information gathering. One such resource was the 5 week family caregiver training offered to members of the community through the Family Caregiver Program. The team attended these trainings which included the following topics: community resources, self-care, assistive equipment, medication management, challenging behaviors, elder law, and end-of-life planning. These caregiver trainings provided insight on the types of information provided to current caregivers, common challenges for caregivers, and community resources used by caregivers.

The team met regularly to extract and distill information from books and websites. A caregiver support group was attended, and informal interviews were conducted with caregivers.

**Outcomes**

An initial idea for a toolkit containing room specific information cards was developed using information gained, and a prototype was proposed. It was determined that a more readily reproducible tool was needed. The initial product was adapted to meet the specific needs of the community partner and the idea of a collection of tip sheets was agreed upon.

Information obtained from all sources was synthesized and translated into easy to use, readily reproducible tip sheets. DAVS was provided with a binder including 22 tip sheets providing helpful information on common challenges caregivers face. An electronic version of all tip sheets and a template was submitted for DAVS use.
Conclusion

Caregivers do not have the time to locate and sort through the immense volume of information and resources intended to provide support.

This toolkit consisting of tip sheets for caregivers is intended to be an easily accessible resource, adding to the offerings provided by DAVS to support unpaid family caregivers of persons with dementia. It will be disseminated by DAVS case managers through the Family Caregiver Program and Oregon Project Independence, as well as incorporated into the 5 week family caregiver trainings. The tip sheets will also be made available on DAVS website.

Over the next year, it is suggested that DAVS pilot the toolkit and gather data on usage and feedback from caregivers and case managers. The information can then be used to adapt the toolkit as necessary.
Introduction

Collaboration between Pacific University students & Disability, Aging and Veterans Services (DAVS) of Washington County

Family Caregiver Program – Serves unpaid caregivers in the community

Oregon Project Independence – Serves older adults & those with dementia

- Paid respite services
- Medical equipment
- One-on-one counseling
- Support groups
- Free family caregiver training

New! Toolkit for caregivers of persons with dementia
Caregiver Statistics

Informal caregivers provide more care in the home than the federal government provides in all settings combined.

<table>
<thead>
<tr>
<th>Oregon</th>
<th>United States</th>
</tr>
</thead>
<tbody>
<tr>
<td>420,000 unpaid caregivers</td>
<td>52 million caregivers</td>
</tr>
<tr>
<td>450 million hours of care</td>
<td>&gt;15 million care for someone with dementia</td>
</tr>
<tr>
<td>$4.6 billion value</td>
<td>$210 billion value</td>
</tr>
</tbody>
</table>
Dementia Statistics

“Dementia is a general term for a decline in mental ability severe enough to interfere with daily life. Memory loss is an example. Alzheimer's is the most common type of dementia.” (Alz.org)

ADRD = Alzheimer's disease and related dementia

Approximately 5.4 million diagnosed with ADRD in the U.S.

- 1 in 8 adults 65 years and older are diagnosed with ADRD
- 45% of adults 85 years and older
- Alzheimer's accounts for 60-80% of dementia diagnoses
Justification

Number or older adults =

ADRD diagnoses =

Number of caregivers =

Need for caregiver support

(13)
Relation to Occupational Therapy

Occupation = something that occupies one's time

- Caregiving is an occupation for more and more people.

- Occupational therapists help people improve performance and satisfaction in meaningful occupations.

- Occupational therapists help people maintain independence.

- Occupational therapists support the concept of aging in place.

- Occupational therapists support caregivers!
DAVS Mission

“To create options to maintain the quality of life. We perform these functions to enable persons to live as independently as they can for as long as possible. We are especially concerned about the risk of persons losing their independence. Often this means helping families and caregivers” (Washington County Disability, Aging and Veteran Services [DAVS], 2012).
DAVS Strategic Plan

Strategic Plan 2012-2015:

- Input was included from five focus groups held with community members, and an all-staff group from Health and Human Services Department.

- Applicable reported needs from focus group participants:
  - Information about resources for caregivers and recipients
  - Training and access to information for caregivers

- Caregiving: “Nearly every focus group participant indicated they have been, currently are, or expect to be a caregiver at some point” (DAVS, 2012).
Initial Developments

Attended focus group

- September 15, 2011, at the Forest Grove Community Auditorium
- Participate in the DAVS strategic planning process for 2012-2014

Meeting with Community Partner, DAVS

- Develop a tool for caregivers that provides solutions for common day-to-day needs and challenges.
- Less focus on the diagnosis and research associated with ADRD and more applicable and practical tool that is easy to distribute.
- Synthesize information from multitude of available resources.
Project Plan

- Determine goals as a student team
- Determine goals of community partner
- Timeline for project
- Develop a contract between faculty advisor and students
- Present plan to faculty advisor for approval
- Schedule meetings

**OBJECTIVE:** To address an unmet need and enhance DAVS mission.
Methods

Research and Gathering data

- Collaboration with Deborah Letourneau, DAVS
- Caregiver trainings: No Worries In-Home Care
- Caregiver informal interviews
- Attended a local caregiver support group
- Book and website review
- Synthesis of materials
## Caregiver Trainings

### No Worries In-Home Caregiver Trainings:

Five free classes for non-paid caregivers, providing information on:

- Where to find help in the community and importance of self-care
- Basic personal care techniques and assistive equipment
- Medication administration and dealing with challenging behaviors
- Elder law
- Hospice and end-of-life planning

### Connecting with Caregivers Allowed:

- Insight to relevant needs and concerns of current caregivers
- Resources currently available to the caregivers
- Connect with caregivers as a resource and learn what additional resources they use
Initial Product

At bath time...

- Incorporate preferences (timing, products)
- Bath seat at tub height & non-slip mats
- Control environment: lighting, music, room & water temp
- Supplies in reach
- Extra towels for warmth and modesty

Tips:
Place a colorful towel on the bath seat to increase contrast for better depth perception and to ease anxiety.
Findings

- Overwhelming amount of information
- Caregivers need assistance at all times, but may not have time to search it out.
- Common areas of challenge for caregivers were identified.

Easy-to-use Tip Sheets were created
Dementia Caregiver Toolkit

Contents

Planning
- Preparing the Home
- Planning Ahead
- Jobs to Share with Family & Friends
- Caring for the Caregiver
- Dementia Care Services
- Home Medical Equipment

Communication
- Communication Strategies 1
- Communication Strategies 2
- Communication Strategies 3: Cueing

Daily Care
- Bathing
- Grooming & Hygiene
- Dressing
- Toileting
- Incontinence
- Eating & Feeding
- Activities

Behaviors
- Wandering & Exit Seeking
- Pacing & Shadowing
- Repetition: Talking, Asking, & Movements
- Sleep Distubance
- Sundowning
- Rummaging & Hiding
- Getting Rid of Clutter 1
- Getting Rid of Clutter 2

A toolkit consisting of practical tip sheets for unpaid caregivers of people with dementia. Developed by Pacific University, master of occupational therapy students in collaboration with Disability, Aging, and Veterans Services of Washington County.

Washington County Disability, Aging and Veteran Services
180 E. Main Street, Suite 226
Hillsboro, OR 97123-4026
Phone (503) 846-3060
Fax (503) 846-3065
www.washington.or.us/HHS/DAVS

Alzheimer’s Association 24 hour helpline 1-800-272-3900
General Guidelines

- Adjust water heater temperature.
- Always have working fire extinguishers & smoke detectors.
- Lock or disguise hazardous areas w/cloth, paint, folding doors.
- Install locks above or below eye level.
- Discard toxic plants.
- Dark rugs may be perceived as holes.
- Use night lights or install floor level lighting in hallway, bedroom, & bathroom.
- Remove firearms; consult local law enforcement for instruction.
- Consider moving bedroom to main floor.

Kitchen

- Make commonly used items easily accessible (toaster, coffee maker).
- Remove clutter from tables & counters (sugar, seasonings, napkins).
- Ensure all seating areas are well lit.
- Install fire-safety burner covers on range.
- Install hidden gas or circuit breaker on stove and/or remove knobs.
- Install child safety locks on cabinets.

Bathroom

- Install door to swing out to help prevent a blocked door in the event of a fall inside the bathroom.
- Remove bathroom and bedroom door locks.
- Install an accessible shower.
- Apply textured stickers on slippery surfaces.
- Install grab bars at tub, shower, vanity, and toilet.

Stairs

- Secure carpets and rugs with non-slip backing or adhesive tape.
- Install railing at all stairways.
- Install a gate at the top and bottom of stairs.
- Add contrasting color on floor in front of doors and steps to help anticipate step up/down.

Dementia Caregiver Tip Sheet

Preparing the Home

Alzheimer’s Association 24 hour helpline 1-800-272-3900
Intended Use

- Caring for the caregiver
- Create easy-to-use helpful hints and ideas for caregivers of people with ADRD.
- DAVS case managers will provide the caregivers with the tip sheets relevant to their situation.
- Toolkit will be provided to family caregiver training attendees.
- DAVS was given an electronic version of the tip sheets to reproduce as needed.
Our idea will revolutionize caregiving.

- Caregivers need simple, practical applications for caring for their loved one. Our tip sheets will fill the gap that currently exists between the overwhelming amount of information and the overworked caregiver.
Opportunities for Continued Services

Pilot Program

- Document how the tip sheets are being used.
- Record caregivers response and comments.
- After a year of the pilot program, evaluate effectiveness with surveys for caregivers and case managers.

Other Ideas

- Have information readily available and easily accessible to caregivers.
  - Provide tips sheets on website and at training classes.
- Card idea shown earlier can be further developed.
Acknowledgements

Nancy Krusen, PhD, OTR/L, faculty advisor

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Melinda Reed, RN, Owner of No Worries In-Home Care

Caregivers:

Joan Lane

Elaine Loving
Questions

Alzheimer’s Association website (www.alz.org)


Photo Credits

3. Caregiver.jpeg. Retrieved on April 26th from eastidahoaging.com