Supporting Caregivers - Strategic Partners for Community Living

NPA Fall Conference 2016

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About this Session

Objective

- Provide information on:
  - Why and how to evaluate caregiver stress
  - Alternatives for reducing stress and supporting caregivers beyond home care
  - Training caregivers to increase confidence and skills

- Provide the opportunity for interactive audience discussion to:
  - Clarify strategies presented
  - Share other approaches to caregiver support through discussion with the audience
Dorothy Ginsberg

Caregiver Assessment
Why Support Caregivers – Isn’t the Participant Our Focus?

• Families have been, and continue to be, both the major “coordinators” and the “providers” of everyday long-term care.¹

• PACE is there to help, not supplant.

• Caregivers lack training for medical care and caregiving tasks

• Caregivers may unwittingly compromise the care they provide

• Often caregivers die before those they are caring for

• Extend the role of caregiver longer or indefinitely

• Loss of Caregiver may equal loss of community home

Evaluating Caregiver Stress

- Why
  - What’s stressful from the caregiver’s perspective
  - Indicators that a caregiver is approaching burnout
  - Establish a baseline/initiate strategies to prevent/reduce stress
  - Explore supports to prevent burnout
  - Acknowledge caregiver’s well being is important/valued
Evaluating Caregiver Stress

- **When**
  - Initial assessment (baseline or early intervention)
  - 6 month reassessment
  - Changes that have/will increase responsibilities or trigger areas identified as stress factors

- **How**
  - Utilize an assessment tool (see examples)
  - Meet with caregiver separately to enable an open discussion
Available Assessment Tools

- **C.A.R.E. Tool (Caregivers Aspirations, Realities and Expectations)** – See Handout
  

- **Alzheimer’s Association Assessment Tool** – focuses on Dementia
  

- **Zarit Burden Interview tools**
  
  [http://dementiapathways.ie/_filecache/edd/c3c/89-zarit_burden_interview.pdf](http://dementiapathways.ie/_filecache/edd/c3c/89-zarit_burden_interview.pdf)

- **AMA Caregiver Self-Assessment Tool**
  

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1. Authors: Nancy Guberman, Janice Keefe, Pamela Fancey, Daphne Nahmiash & Lucy Barylak
Other Caregiver Support Programs

- National Family Caregiver Support Grant outcome
  - Best Practices Conference
  - Best Practices Booklet

- Some examples:
  - Telephone Support Groups
  - Men Making Meals
  - Telecare Connections (educational videos on demand)
  - Early-onset Caregiver Support
  - Summer Sizzlers (Youth volunteers)
Additional Questions

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Family Meetings and Respite Support
Family Meetings

- Center Visit
- 30 Day Open House
- Goals Of Care
- Identifying Strengths Of Participant And Family
- Caregiver Self Care
Use of Respite

- Day Center
- In Home Companion Hours
- Overnight (Limited/Short Term)
- Assisted Living Facilities
Additional Questions

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Overview

- Review types of supportive housing options
- Goals for use of supportive housing
- Benefits associated with alternate housing options
- Challenges faced
Supportive Housing Options

- Apartments built out specifically for PACE
- Adjacent to PACE facility
- Offsite apartments
  - Shared aide housing within existing senior housing communities
- Partnership with local housing communities and shared staffing
Apartments Built Specifically For PACE

- Multiple Handicap accessible units
- One bedroom and studio apartments
- All units occupied by PACE participants
- Staffing patterns to optimize participant to staff ratios
Sample Floor Plan
Shared Aide Housing

- Use of existing senior housing
- Concentration of PACE participants in one or several senior housing communities
- Staffing these buildings with PACE homecare services
- Serves larger number of participants with fewer staff members required
Shared Staffing

- Partner with local housing communities
- Shared support staff i.e. social worker
Goals For Use

- Caregiver relief via respite
- End of life support
- Alternative to long term placement
- Community partnerships
Respite

- Allows caregiver respite without the need for participant to be temporarily placed in a facility
- Allows more flexibility with respite as there are no minimum stays required or other contractual concerns
- Continuity of care
End of Life Support

- Apartments set up for caregiver and participant
- Allows multiple family members to rotate time spent with participant
- Utilization of staff already in place to support participant and family
- Allows participants with minimal or no family support to be supported through end of life with their PACE family rather than in a nursing facility.
Alternative To Long Term Placement

- Support of participants who would otherwise be placed in a long term nursing facility
- Avoidance of nursing home allows for participants to continue to live in the least restrictive environment
Community Partnerships

- Shared aide housing uses similar concept
- The exception is that there are residents in the building that are not PACE participants
- These residents can become future PACE participants
- Often the management in these buildings become referral sources
Community Partnerships

- Many of the senior housing communities employ social workers.
- Partnering with these housing communities to share the social worker staff promotes PACE in the community and allows participants and potential participants to remain in the community.
Benefits

- Caregiver relief
- Caregiver support
- Continued community living
- Better participant care
- Staffing optimization
Challenges

- Q: But aren’t we running an assisted living?
  A: No, more like a dormitory
- Social conflict between participants
- Monitoring staff
- Recognizing the difference between housing and PACE
Conclusion

- Supportive housing allows PACE to provide continued support to caregivers and participants.
- When used correctly it helps to reduce long term nursing home placement.
Additional Questions

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The Savvy Caregiver Program
Implementation of the Savvy Caregiver Program

- CarePartners PACE in Asheville, NC (1 site location)
- Opened in March 2015
- As of 9/1/16 we have 90 participants enrolled
- Enroll an average of 6 per month
- Expanded to 2 social workers in May 2016
- 58% of our participants have a diagnosis of dementia
- 70% of our participants have a diagnosis of depression, anxiety, PTSD, or psychosis
Savvy Caregiver Program is a Project Originating from the Minnesota Family Workshop

- Designed to train caregivers in basic knowledge, skills, and attitudes to handle caregiving challenges

(Hepburn, Lewis, Sherman, & Tomatore, 2003)
Savvy Caregiver Program
Objectives

- Acknowledge the disease
- Make the cognitive shift
- Develop emotional tolerance
- Take control
- Establish a realistic care goal
- Gauge the care recipient’s capabilities
- Design opportunities for satisfying occupation
- Become a sleuth
Intervention – Program Implementation

- Two class offerings each week
  - One weekday class (Wednesday @ 230p)
  - One weekend class (Saturdays @ 10a)
- Six sessions in workshop cycle
- Class duration two hours for a total of 12 hours
- Provision of care available for PACE enrollee
- Caregiver manual, classroom instruction, group discussion, and supplementary videos
Procedures – Direct and Indirect Costs

- **Direct Expenses**
  - Savvy Caregiver Workshop Video Set $90
  - Optional online 30-day caregiver workbook $239
  - Participant Workbook $18/participant
  - Print copies of measurement tools $2/participant

- **Indirect Expenses**
  - Use of PACE center facility space
  - PACE center provision of care for persons with dementia during caregiver program hours
Assessment Tools for Pre- and Post-testing

- Revised Center for Epidemiologic Studies Depression Scale
  (Eaton, Muntaner, Smith, Tien, & Ybarra, 2004)

- Neuropsychiatric Inventory with Caregiver Distress Scale
  (Cummings, 2009)

- Caregiver Well-Being Scale
  (Tebb, Berg-Weger, & Rubio, 2013)

- Revised Scale for Caregiving Self-Efficacy
  (Steffen, McKibbin, Zeiss, & Gallagher-Thompson, 2002)
Statistics

Neuropsychiatric inventory with caregiver distress scale

- Overall caregiver distress experienced associated with Behavioral and Psychological Symptoms of Dementia dropped by 12.5%

- Distress is highest associated with apathy/indifference, depression/dysphoria, irritability/lability

- Low distress is associated with demonstration of delusions, hallucinations, anxiety, disinhibition, and aberrant motor behaviors
Statistics

Caregiver well-being scale

- Greatest difficulties with participating in events in the church or community and getting enough sleep

- Least difficulties with buying groceries, taking care of personal daily activities, and having adequate housing
Revised Center for Epidemiologic Studies depression scale

- Overall reduction in scores by 25.6% (depression experienced by the caregivers)
- Scores > 16 are clinically significant for depression
  - 5 of 10 caregivers had pre-test scores > 16
  - 4 of 10 caregivers had post-test scores >16
- Sadness, loss of interest, and fatigue all were more problematic on pre-testing with only sadness testing high on post-testing
- Appetite, guilty thoughts, and suicidal feelings were the least problematic
Revised scale for caregiving self-efficacy

- 12.72% improvement in self-efficacy for responding to disruptive behaviors in the person with dementia
- Self-efficacy for obtaining respite is the most challenging domain
Outcomes

- Understand that caregivers may overestimate abilities of person they provide care for (estimated Allen 8.2% higher)
- Reduction in depression scores by 25.6 percent
Human Experience (Anecdotal Data)

- Self-care
- Understanding of disease stages (Allen)
- Improved abilities
- Relate to other caregivers, role model
- Acceptance and recognition
- Making the most of the situation
- Desire to have had access to education earlier in the course of disease
Resources


Additional Questions

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Questions or Comments