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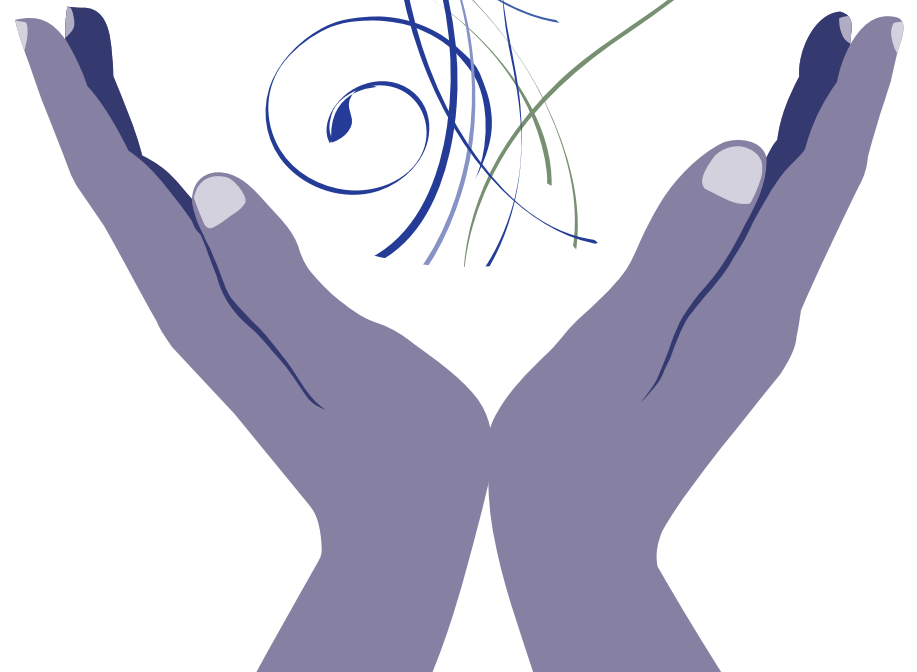
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# Respite Handbook

FOR FAITH-BASED ORGANIZATIONS



**T**ogether we  
**HEAL**  
Help Elders Aim High and Live Long

Expansion of Respite and Adult Day Services via  
Faith-based Partnerships

*By Mary Jo McKay, MBA*

Project goal is to increase the number of faith-based organizations providing respite and/or adult day services to seniors.

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## Why Should Faith-Based Organizations Offer Respite for Caregivers of Seniors?

- It gives caregivers a break from caregiving
- It meets the needs of the faith community's members
- It will assist those on waiting list for respite
- It reduces caregiver stress and burnout
- It allows the faith community's members to remain in their community
- It coincides with faith community's mission
- It gives members volunteer opportunities

In 2007, Hillsborough County Government conducted a survey which revealed that only 6% of Hillsborough County's 40+ population expected faith communities to assist them with activities of daily living. Five percent of those surveyed expected a government program to assist them and 15% did not know who would help them. Later, Hillsborough County surveyed faith-based organizations. Survey results indicated that the faith community is committed to serving their surrounding community. It also revealed that although the faith community and other local organizations have a significant number of programs for seniors, there were still unmet needs in the following areas: caregiver respite, adult day care, personal care, and end of life care.

According to estimates, by 2050, more than one out of every five people will be age 65 or older. Over 20 percent of the United States' total population will be older adults. In fact, individuals over age 85 are the fastest growing sector of our population.

Living longer can be a blessing for most of those who reach their senior years in good or fair health; however, it can be especially difficult for those with serious health concerns. It can also become a hardship for their spouses and their children who will most likely become their caregivers.

Our country's aging population will place demands on our health care system unlike ever before. This new demand will be quite challenging for government programs, community-based services, health care systems, and families.

Families, health care systems, government programs, and community-based service providers will not be able to handle the increased needs alone. Community organizations and our faith-based organizations will be an essential part of the solution.

## Who Needs Respite?

Caregivers of individuals with disabilities, chronic illnesses, and Alzheimer's disease or a related dementia are the primary users of respite services.

## Alzheimer's Disease (AD)

More than 5.2 million people in the U.S. are afflicted with dementia, of which Alzheimer's disease is the most common form. As the senior population increases, the incidence of Alzheimer's disease increases as well. It is estimated that approximately 50% of those older than 85 will have Alzheimer's disease. Currently there are 501,480 probable cases of Alzheimer's disease in Florida and 21,567 in Hillsborough County.

Alzheimer's disease is a progressive neurodegenerative disease that attacks the brain and causes nerve cells to die. It affects individuals of all races and ethnic backgrounds. Deterioration begins gradually and may last from three to twenty years. The disease affects memory, thinking, language, and eventually destroys one's ability to perform routine functions.

## Early Signs of Dementia

- Repeats themselves and asks the same thing over and over
- Forgets appointments
- Problems with paying bills
- Difficulty purchasing items
- Difficulty getting dressed
- Unable to take medications

## Diagnosis of Dementia

Individuals suspecting Alzheimer's disease or a related dementia should visit their nearest Memory Disorder Clinic for an assessment. The University of South Florida Memory Disorder Clinic located at 3515 East Fletcher Avenue, M-14, Tampa, FL 33613 (813) 974-3100 serves Hillsborough County residents. The Memory Disorder Clinic will provide a comprehensive diagnosis and assessment of strengths and weakness, suggestions for treatment of associated conditions and family support. The diagnostic team may include: neurologist, psychiatrist, psychologist, nurse, pharmacist, social worker and a speech pathologist.

## Caregivers

- At least 75% of caregivers are family members
- Average age of caregivers is 46
- Caregivers spend 69-100 hours per week providing care
- Most AD patients receive their care at home
- Average cost of AD caregiving in 2006 ranged between \$18,400 and \$36,132

## Caregiving Dilemma and Consequences

- Sleepless nights
- Little or no assistance
- A lot of time away from work
- Other responsibilities
- Caregivers may develop major health problems
- Physical problems in caregivers can include: lack of mobility, chronic medical conditions, fatigue, compromised immune functioning, and increased risk of mortality for distressed caregiver

## Respite Models

*In-Home services* usually provide companion services and assistance with activities of daily living.

**Respite Care Facilities** provide overnight, weekend, and longer stays so a caregiver can have longer periods of time off. Respite care facilities include nursing homes, residential care facilities, and assisted living facilities.

**Emergency Respite** is usually offered in nursing home, residential care facilities, and assisted living facilities. Emergency respite is usually needed when a caregiver becomes ill or must go out of town unexpectedly, or if the care recipient is a risk of abuse or neglect.

**Adult Day Services** provide a planned program that includes a variety of health, social, and support services in a protective setting during daytime hours. This is a community based service designed to meet the needs of functionally and/or cognitively impaired adults.

## Who Volunteers?

Today's volunteers come from a wider section of our society. Volunteer respite programs should recruit volunteers from the following groups:

- Retired individuals
- Unemployed middle class women
- Teenagers needing volunteer hours
- Caregivers desiring to help other caregivers
- Individuals who believe in the cause
- Members of the organization

## Selecting Volunteers

The role of volunteer caregiver is an important one. The volunteer organization has a responsibility to caregivers and care recipients to select appropriate volunteers. Organizations can improve their chances of making good volunteer selections by having volunteers complete an application which include the following:

- All possible volunteer assignment choices
- Physical or health conditions limiting their level of ability
- Prior convictions of any illegal activity
- Emergency contacts
- At least three non-family member references

## Suggested Training Topics

Volunteer respite providers have the responsibility of properly supporting its volunteers. Training is an essential component of volunteer support. The volunteer respite provider should not attempt to design a training program required for professional health care providers, but one that will sufficiently prepare volunteers for their volunteer roles. Listed below is a list of recommended training.

- Sensitivity
- CPR/First Aid
- Alzheimer's disease
- Conflict Resolution
- How to Facilitate Activities

## Activities for Individuals with Alzheimer's Disease

Activity programming is essential in caring for individuals with Alzheimer's disease. Activity programming maximizes independence for the care recipients. Activities must be based on the person's abilities, physical health, behavioral status, and personal preferences.

Most importantly, the care recipient must always be recognized with respect and dignity. Secondly, an activity has to be meaningful, it must have a purpose, be voluntary, enjoyable to the participant, and if possible failure-free.

Activities should be planned to address the needs, history, strengths, and challenges of each individual. They should reflect as much as possible the person's preferred lifestyle while providing a sense of usefulness, pleasure, success, and as normal a level of functioning as possible.

Whatever the activity, it should be:

- Environmentally conducive
- Repetitive – persons with Alzheimer's may enjoy helping with daily housekeeping routines similar to those they did in the past, i.e., folding laundry or clearing or setting the table.
- Routine – consistency in routine is calming to the person with Alzheimer's.

- Spontaneous – for someone who is anxious or restless, a spontaneous invitation to have a cup of tea or take a walk, may distract him or her and diffuse the situation.

## Nationally Recognized Volunteer Respite Programs

- Brookdale Foundation’s National Group Respite Program
- Robert Wood Johnson Foundation’s Faith in Action Program
- University of Alabama’s Support Teams

## Resources

Each state has different regulations and resources for respite care. In the State of Florida, adult day care is regulated by the Agency for Health Care Administration.

- Alzheimer’s Resource Center, 850-561-6869, [www.arc-tallahassee.org](http://www.arc-tallahassee.org)
- Mace NL & Rabins PV. *The 36 hour day*. Warner Books, 3<sup>rd</sup> edition. 2001
- Alzheimer’s Foundation of America, 1-866232-8484, [www.alzfdn.org](http://www.alzfdn.org)
- Alzheimer’s Disease Education and Referral Center, 1-800-438-4380, [www.alzheimers.org](http://www.alzheimers.org)
- West Central Florida Area Agency on Aging, 813-740-3888, ElderHelpline, 1800-336-2226
- Alzheimer’s Association Florida Gulf Coast Chapter, 727-578-2558 or 1-800-772-8672, [www.alz-tbc.org](http://www.alz-tbc.org)
- Florida Department of Elder Affairs, [www.elderaffairs.state.fl.us](http://www.elderaffairs.state.fl.us)
- Eldercare Locator, 1-800-677-1116, [www.eldercare.gov](http://www.eldercare.gov)
- USF Memory Disorder Clinic, 813-974-3100
- Johnny B. Byrd, Sr. Alzheimer’s & Research Institute, 813-396-0606, [www.byrdinstitute.org](http://www.byrdinstitute.org)
- Hillsborough County Department of Aging Services, 813-272-6630, [www.hillsboroughcounty.org/aging](http://www.hillsboroughcounty.org/aging)
- Florida Adult Day Care Association, How to Open an Adult Day Care Center in Florida, [www.fadca.org](http://www.fadca.org)

## How to Ensure Your Program’s Success

According to a Robert Wood Johnson Foundation survey of 800 of its Faith in Action Programs, the following are keys to the success of volunteer caregiving programs:

- Use volunteers to operate your program- using volunteers makes the cost of your respite services relatively inexpensive
- Hire a director with voluntary caregiving experience who can dedicate themselves to the project
- Establish a coalition or board of at least 16 members- the coalition will recruit volunteers, increase community support and awareness, and raise funds
- Establish participant and volunteer criteria
- Handle all of the logistics and legalities
- Start small and build according to need and resources
- Recruit the majority of your volunteers from your congregation or organization
- Screen, train, and supervise your volunteers properly
- Supervise volunteers frequently
- Require pre-training of volunteers
- Evaluate program frequently and do not be willing to make changes

**Attend one of Hillsborough County Department of Aging Services’ free trainings and remember, “Together We Heal” Call 813-272-6261 for additional information and to register.**

## References

Alzheimer's Association, Findlay, Diana and Judy, Hoef, Ver. *Building a Volunteer Respite Care Program: A "How To" Manual Especially for Churches*, 1993.

*Caring To Help Others: A Training Manual*, AARP, Interfaith Caregiving Alliance, United Way of America, Hospice Association of America, Alzheimer's Association, 2000.

Herrera, Carla and Pepper, Sarah. *Faith in Action: Using Interfaith Coalitions to Support Voluntary Caregiving Efforts*, 2003, Public/Private Ventures.

*Hillsborough County Aging Services Master Plan 2008-2030*, University of South Florida Center for Housing and Long-Term Care, Florida Policy Exchange Center on Aging, 2007.

*Opportunities for Working Together: Outreach to Seniors, Caregivers, Children, and Families by Religious Congregations in Hillsborough County*, Aging Research Group, 2008.

*Training for Faith-based Leaders: Caring for Persons with Alzheimer's*, Byrd Alzheimer's Institute and Alzheimer's Rural Care Healthline, 2005.

*You Are Not Alone*, Hillsborough County Department of Aging Services, 2006.

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