**Role of Faith Communities in Dementia Care and Support**

**Respite Ministry, Montgomery Alabama**

Project Background, Description and Major Activities

In 2012, the Senior Pastor and congregants at the First United Methodist Church in Montgomery, Alabama, identified the need for a day program for persons with dementia and their families in the area. With full support from the congregation, in an effort to fill this gap in services, the Director began a research of adult day respite programs. Five adult programs, all in Methodist churches, were found in the state. Most of these were volunteer-based and seemingly very successful. The Director worked for almost a year on a startup plan for a similar program in the Montgomery First United Methodist Church. The first event was a lecture from local experts speaking on Alzheimer’s and Parkinson’s diseases. The lecture was well attended and demonstrated the high level of interest and the great need for this kind of program within the community. The First United Methodist Church responded to the need by including adult day services, known as the Respite Ministry, in the budget and provided initial start-up funding of $50,000. The Church supports the salary of the program director and one part-time assistant who administer the program. The current director has a Master’s degree in gerontology, and the assistant has a background in teaching.

Beginning with two participants, the Respite Ministry now operates from the Montgomery First United Methodist Church with some twenty participants a day for four hours each day from mid-morning until early afternoon, including a hot lunch. The Ministry provides a four hour non-stop program of physical and mental exercises in the context of socially interactive activities for participants who have memory loss due to Alzheimer and other forms of dementia and related debilitating conditions. The total number of different participants is about forty a week. Participants pay $30 per day, if they are financially able. The Respite Ministry solicits donations and maintains a scholarship fund for those in need. Since the beginning of the program, the Respite Ministry has awarded over $60,000 in scholarships.

The program is primarily volunteer-based. Volunteers undergo a background check and are required to attend a four hour training course developed by the Respite Ministry. The training covers the basics of Alzheimer’s disease and communicating with people with dementia. The program had fourteen volunteers in the first training class. By the end of first year, there were seventy-five volunteers and twenty participants. Currently, the program has 120 volunteers from eight churches and two synagogues. The Respite Ministry Director’s experience in recruiting volunteers indicated that many people from the baby boomer generation are a good fit—they have skills, are looking for a purpose, and are not looking to be paid. The Respite Ministry has served over 175 people in four years and the Ministry’s volunteers provide over 10,000 hours of service per year. The volunteers engage in and help participants in the activities and feel a sense of community and family involvement and responsibility. Perhaps most importantly for all, volunteers and participants, the program is fun and full of humor and life with dignity and respect for every participant and volunteer. Volunteers and participants become a family with all of the attachments and responsibilities associated with being a family.

Participants may attend the Respite Ministry one, two, three, or, four days a week. Participants, as feasible and helpful, often ae encouraged to and behave as volunteers in assisting and encouraging, even cajoling, other participants. An observer would notice little, if any, differences in the participation in activities between volunteer and participants. Participants and volunteers sit together in the group, everyone with matching name tags on, so that nobody is identified as an “Alzheimer’s patient” or as a “volunteer.” Participants are involved and included as in a natural community and family. Sessions are called “classes” as a part of a life-long learning program. Volunteers and participants contribute to making the program work from activities, to serving food, assisting with drinks, and helping fellow participants navigate the classroom and activities. The Director believes this integrated family structure of the program is an important part in the success of the overall program.

Attendees may be and are at different stages of disability due to memory loss, yet there are only two main criteria for participation. Participants must be able to use the restroom independently, and they must be able to function in a group setting. Sessions offered by the Respite Ministry may include activities such as: gardening, crafts, community services, reminiscing, exercise, adapted floor games, intergenerational programs, art therapy, pet therapy, and socialization activities. There are also faith based and spiritual activities, all which are offered to participants but are not required activities. Spiritual activities may include prayers, devotionals, fellowship activities, service projects. The Ministry provides a chapel devotional service designed for Respite participants. The Side by Side Choir,(volunteers, caregivers and participants) meets and practices regularly in ten week sessions to make formal public presentations.

The Side by Side Choir helps demonstrate a more inclusive community that is welcoming to people with special needs and their families. These families are thus able to participate more fully and feel a sense of belonging. This brings caregivers into the faith community as an act and commitment of care and support.

Once a person is not receiving benefit from attending the Respite Ministry, the Director discusses changes in the person’s abilities with the primary caregiver and refers caregivers to home healthcare services or the Area Agency on Aging.

Caregivers are supported through Respite Ministry activities as well. The Ministry provides caregivers with support through a caregiver support group, information regarding available resources, and the opportunity for personal time away during the day to address their own needs. The support group is led by an experienced counselor and provides attendees with information regarding available community resources, nursing home options, and information on Alzheimer’s disease, including how to manage difficult behaviors. The Ministry has also begun a weekly yoga class open to all caregivers and volunteers. While the participants are in the day program, caregivers may utilize this time to be in community and meditation.

Bereavement services, in the form of a thirteen part video series called: Grief Share, are available for caregivers and family members. Caregivers are also welcome to attend sessions, lunch, and church services with participants. These activities support the efforts of the family to keep the loved one in the home environment, and contribute to the quality of life of the participant as well as the family.

The Respite Ministry is a community project open to people of all faiths. Currently the Ministry has Protestant, Jewish, Catholic, Episcopalian, and, Buddhist participants, and are open to others. The Methodists Church believes inclusion is an essential value of being Methodist, and it is part of the mission of the First United Methodist Church.

Identifying Community Needs and Outreach

After identifying the lack of resources for families caring for a person with Alzheimer’s and related conditions, the Church began to identify families in the congregation who could benefit from the program. The Church contacted these families via phone or email to determine their level of interest for a support group. Twenty-one people attended the first support group meeting, so the Senior Pastor knew the Church needed to develop a community for people with Alzheimer’s disease and dementia to be together. The resulting program is the Respite Ministry. The Church’s Senior Pastor actively works to get people from the community into the respite program and has contacted other denominations for outreach. With a high level of community trust in the church, this helps enrollment and fosters a feeling of good will towards the project within the congregation. Along with a foundation of trust within the community, this trust gives caregivers reassurance that their loved ones will be properly cared for in their absence. To spread word of the Respite Ministry, the program director had a professional video made, which can be shown to caregivers interested in the program, and, at various caregiver and professional conferences. The program director also shares the video with other churches in the area so they can refer their families to the Respite Ministry and with other faith communities thinking of starting their own day program. Volunteers and families now market the program by word of mouth. These types of conversations and openness among family members increased understanding and acceptance of Alzheimer’s and dementia and aided in the growth of the program.

Project Successes/Challenges

One of the greatest benefits of programs such as the Respite Ministry is that it gets participants up, dressed, keeps them motivated, and helps them build a routine. Alzheimer's disease and dementia can be very isolating, affecting the family, the caregiver, and the person with the disease. The Respite Ministry provides a fun and positive environment for participants, as opposed to having someone in the home with little social interaction or stimulation. It is believed that participation in the program can stimulate thought, memory, movement and help build relationships with other participants and volunteers. Institutional care is very expensive, typical costs for nursing home care in Alabama are $5810 per month. ("Alabama Skilled Nursing Home Facilities - view all skilled nursing home facilities in AL", 2016) An average cost of a nursing facility or Alzheimer’s unit runs well over 70K a year. The Respite Ministry has made respite care affordable for families and family members feel the program allows them to keep loved ones at home longer. The average cost of Respite per year is roughly 6K a year with the participant coming four days a week for 50 weeks.

Some of the biggest challenges of the Respite Ministry are convincing caregivers of the benefits of the program and to accept help. Often a caregiver, wanting to give their family member with dementia a choice, asks if they want to attend the program and that person will decline. The caregiver may accept this response and never try the program. In an effort to overcome this challenge, the Respite Ministry is in communication with local neurologists to ask them to refer to the program. The Ministry also works with a nurse practitioner who writes a “prescription” for program attendance for at least 2 days a week, which often makes both the person with dementia and the family caregiver more accepting. Another challenge is that the program does not provide transportation. While the church does have a bus available for program use, hiring and training a driver, arranging for volunteer bus monitors, and figuring out a route is difficult. Some volunteers will offer to pick up participants, but on a “friend offering a friend a ride” basis.

The Respite Ministry became a catalyst for other Alabama communities to start their own similar programs, including: the First United Methodist in Dothan, Canterbury in Birmingham, Jewish Services in Birmingham, and Auburn United Methodist in Auburn.

While Respite does not formally measure program outcomes, caregivers anecdotally report improvement in participant’s mental state and quality of life, in addition to the benefit to care partners and families. The UAB Memory Center is confident that Respite is producing clinically measured improvement in retarding loss of memory and is currently organizing to measure clinically the impact of Respite volunteer model on participants.

Lessons Learned and Advice for Future Faith Based Projects

Faith communities have the capacity to provide respite since they already have many of the resources needed for such a program including availability of facilities, stability of finances, and a wealth of volunteers. The Respite Ministry, in particular, is also not expensive to operate because it is run by volunteers, there is no incentive to make a profit since it is sponsored by the church, and there is no overhead other than food and the salary of the director and one assistant. To replicate this work, a community could develop a program that has a smaller or larger scope than the Respite Ministry. This particular respite program also serves as an outlet for volunteers. Most likely congregants in other locations can provide a source of untapped talents that can be put to good use through a respite program. “Everybody just feeds off each other. I’ve got volunteers who have never volunteered a day in their life, and now they are addicted to this and come all of the time. They just feel so needed. They are needed for the caregivers or the participants. People can’t imagine an Alzheimer’s ministry being happy. There’s humor and joy that people can’t imagine in a ministry like that.” (Johnson, 2016)

Respite Products That Other Organizations Might Use:

* *Job Description, Respite Director*.
* *Consent Form.*
* *Field Trip Form.*
* *Medical Form.*
* *Policy & Procedure Manual.*
* *Start-Up Checklist.*

Products may be requested by contacting Patty Yuen at: pyuen@rti.org.

References

*Alabama Skilled Nursing Home Facilities - view all skilled nursing home facilities in AL*. (2016). *Skillednursingfacilities.org*. Retrieved 17 May 2016, from http://www.skillednursingfacilities.org/directory/al/s

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