

Resources support local caregivers engaged in Alzheimer's journeys

BY STEPHANIE RICHARDS

Alzheimer's. There are 5.3 million people in the United States living with the disease and 120,000 Massachusetts residents who have it or another form of dementia, according to the 2010 Alzheimer's Disease Facts and Figures report.

Behind those diagnosed with the disease are loved ones who are providing emotional and physical support...to the tune of 10.9 million unpaid caregivers nationwide, according to the same report. Caregivers looking for support or resources to help them care for a loved one with the mind crippling disease can tap into a number of local agencies and programs.

When you see signs of dementia, the first step is to get a doctor's evaluation, says Barbara Search, Director of the Sturbridge Council on Aging. There are 10 potential warning signs of Alzheimer's disease, but "the most common early symptom (of Alzheimer's) is difficulty remembering newly learned information because Alzheimer changes typically begin in the part of the brain that affects learning. As Alzheimer's advances through the brain it leads to increasingly severe symptoms, including disorientation, mood and behavior changes; deepening confusion about events, time and place; unfounded suspicions about family, friends and professional caregivers; more serious memory loss and behavior changes; and difficulty speaking, swallowing and walking," according to the Alzheimer's Association website.

Once there is a diagnosis of Alzheimer's or dementia,



the local Senior Center is a great resource that can point you in the right direction regarding referrals, medical insurance, support groups and Adult Day Care services. Sturbridge has a part-time Community Resource Coordinator position that provides such support and other Councils on Aging have outreach workers. "Caring

for someone with Alzheimer's is emotional for those involved. Most people don't know what to do or where to begin," Search said. "Councils on Aging have become 'social service agencies,' especially in towns the size of Sturbridge where there isn't one available. Most think of Senior Centers as a place for meals and recreation activities; they don't think of us as a resource for support. We are a municipal department and available to help everyone who needs assistance with social services."

Search recommends caregivers stop by their Council on Aging and pick up a free copy of a book titled, "The Caregiver's Guide," which was funded by the Federal Administration on Aging and the Massachusetts Executive Office of Elder Affairs. "The book is an excellent resource that provides information on support services for everything from Alzheimer's to vision and hearing. It's a good place to start," she said.

In addition to Councils on Aging, support for caregivers is available through the Alzheimer's Support Network (ASN) of South Central Massachusetts Inc. The all volunteer service organization began 25 years ago to respond to the needs of caregivers and provide them with local support.

That support comes in the form of things like a dedicated help line for the community~ 800.286.6640, ext. 3100. "We provide phone consultation and try to answer questions. We may also refer inquiries to evaluation case managers at Tri-Valley, Inc.(provides services to caregivers,

elderly and disabled) as they might benefit from additional resources available,” said Roger Lamontagne, LICSW, BCD, President of ASN’s Board of Directors. “We take a comprehensive approach; we want to help them to meet their needs through services are available.”

One of the first things ASN does is makes sure that a comprehensive evaluation lead to the Alzheimer’s diagnosis. “We have had individuals come to support groups and what they were really dealing with is untreated sequence depression which mimics dementia. We don’t question the diagnosis, just need to be reassured there isn’t another illness present. Also, some forms of dementia are reversible while others are not, so a comprehensive evaluation from a primary care doctor is essential,” said Lamontagne, who came to ASN in April after retiring as Director of Social Services and Care Management at Harrington Hospital.

After a confirmed diagnosis, it is essential to focus on the immediate needs for the loved one and caregiver. “Once those are determined, we assist them in developing an outline of things that need to be in place to help the caregiver handle the experience. In this process, it is important for the caregiver to sustain the relationship with their loved one and also not forsake the connection

with other family members. It’s taking the needs of everyone and balancing them in a caring and loving way,” said Lamontagne, a former caregiver himself.

One way to provide caregiver’s with encouragement is through support groups. ASN has two local caregiver support groups. There is support group that meets at 7 p.m. the first Tuesday of each month at Harrington Hospital in Southbridge. Another group meets at 6:15 p.m. the second Monday of the month at the Webster Public Library. “The groups are open to all caregivers directly involved or assisting in providing for someone with dementia or memory loss.

These free groups are led by individuals in the social service field and provide a connection for caregivers with others going through similar circumstances,” Lamontagne said. “The 90 minute sessions include current information, materials and a topical discussion. Each one can stand on its own and can be a supportive experience for caregivers; we want them to be comfortable. They can come and just sit and listen. The majority find value in coming...it serves as a new sounding board for them. Often we have seasoned caregivers who continue to participate and they offer wisdom from their experience. Every session can stand on its own.”

A wealth of materials are also available from ASN

such as articles and books that are an asset to caregivers. In addition to “The Caregiver’s Guide,” another book is available focusing on advanced directives like a health care proxy. “A Guide for a Better Ending” is put out through a Worcester area partnership. “It is important to do these things prior to crisis,” Lamontagne said. “Life planning is advantageous to everyone...it gives a peace of mind once things progress.”

In 1989, ASN started a Community Respite Services Program which was one of the first in New England to provide respite for Alzheimer caregivers. Services are provided through a contract with Accord Adult Day Center, which recently moved to a 12,000 square foot expanded facility in Dudley. “Accord is a state of the art program. Over the years, they have increased their ability to provide respite services,” Lamontagne said. “It has grown as needs have increased. For us, it is setup to serve 20-30 families a year.”

For a membership in ASN (\$15), caregivers can take advantage of the Respite Program which provides two days a month of care at Accord for their Alzheimer’s family member. ASN will put \$50 per day toward the cost of care once eligibility is determined. The majority of the fee is covered by grant monies from the George Wells

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Foundation of the Bank of America Philanthropic Management Group, with added dollars from fundraisers or memorial gifts. Tri-Valley, Inc. also has a Respite Scholarship program to supplement what is provided if needed.

The Accord Adult Day Center, which employs about 15 people, is unique in that it provides for the social and medical needs of clients. "Our primary objective is constant attention of the client to support caregivers. Respite gives relief and recharges the batteries of caregivers to give them a break. We are a locked facility with pressure doors, so clients have freedom to roam but are safe," said Joe Rizzo,

who owns Accord with his wife Lisa. Both have a background in the field as Lisa is a nurse and Joe was a long term nursing administrator for 25 years.

Rizzo said he saw a shift in nursing home care toward providing for clinical as well as social needs. "We keep clients safe, give them the medical attention they need discreetly and provide activities to help them. Our facility has a homey atmosphere with warm colors inside. Clients get exercise, keep up with current events, have home cooked meals and can participate in activities like bingo, crafts, baking or even virtual bowling. There is so much excitement as they throw balls and knock down virtual pins; everyone roots for each other. We also have a hair dresser and coffee shop," he said. "Family members with loved

ones who have Alzheimer's or dementia tell us they see a transformation after being here. They get stimulation from being around others and participating in the activities. It is more interaction than they get day to day."

Clients can be dropped off and spend the day at Accord from 8 a.m. to 4 p.m. Rizzo said they currently serve 39 clients through programs with ASN, MassHealth providers and other agencies. They are seeking approval to expand that number to 70-80 clients as they see an expanding need for Adult Day Care programs. "We also have plans to fence in the outside area which will have a garden and walking trails, so clients will be safe but can enjoy the outdoors. In addition, we want to put whirlpool tubs inside for clients that require bathing and get approval for an overnight

Respite program, allowing families to do things like go on vacation while their loved one is cared for.” In addition to Accord, Adult Day Care programs are available in areas like Worcester and Wilbraham, according to Search. Home care agencies also provide services and nationwide programs like PACE are available at Overlook (run by Fallon) in Charlton and Worcester. “The goal of Elder Services is to keep people home as long as possible. It is economical and what most people want. There are programs like Enhanced Adult Foster Care and Caregiver homes to do that.

There are also resources available to pay people to be caregivers when certain qualifications are met,” she said. Resources Sturbridge Council on Aging (Senior Center) 480 Main St., Fiskdale; 508.347.7575; www.town.sturbridge.ma.us Alzheimer’s Support Network (ASN) of South Central Massachusetts 800.286.6640, ex. 3100; www.alzsupportnet.org Alzheimer’s Association 800.272.3900; 24 hour helpline, 7 days a week; www.alz.org Accord Adult Day Center (Adult Day Health Program) 10 Cudworth Road, Webster; 508.949.3598; www.accorddaycenter.com Tri-Valley, Inc. (Elder Services) 10 Mill St., Dudley; 508.949.6640; www.tves.org