

Adult day service offers option for family caregivers

by Dennis Grubaugh, Illinois Business Journal
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Lisa Brennan of Collinsville, right, with her mother Patricia Ciszcon, a client in the adult day program at St. John's Community Care in Collinsville

COLLINSVILLE — While it's true that none of us is getting any younger, it's also problematic for coming generations who face the challenges of a fast-growing, aging population.

Adult day programs are becoming a big part of the answer, a means of staving off more expensive nursing care.

For Lisa Brennan of Collinsville, the care provided five days a week at St. John's Community Care in Collinsville has been peace of mind for her



and a lifeline for her mother.

"Her coming here not only gives me the opportunity to continue my career, it's also given my mom a real quality, end-of-life experience," Brennan said.

Four years ago, Brennan moved in with her 92-year-old widowed mother, Patricia Ciszcon, to help her with chores, but it soon became apparent her mom needed specialized care.

"Once I got in, I could see Mom had more needs than I thought she did," Brennan said.

"She was really struggling. So, we had a couple of assessments done, one by the state of Illinois and one by a private insurance company. Both came back with, 'Your mother has dementia and she shouldn't be left alone.' What I thought was going to be an easy solution ... put us into a tailspin."

Brennan found St. John's after her sister saw a sign advertising one of its four support groups.

"I showed up just wanting some advice. That's how it started," said Brennan, who also has an 8-year-old daughter at home.

"Mom was at a point where she didn't want to get out of her bed," Brennan said. "We started coming here, and she is engaged. Some people say she holds court. She can't hear very well, she's legally blind, but she gets an audience. She's done extremely well."

Now 96, Ciszcon comes to St. John's five days a week, enjoying programs from art therapy to therapy dogs. A beautician comes in on Wednesdays and lunch is provided

each day. A wealth of guest visitors, games and discussion sessions put the stress on socialization. Dance Party Fridays have been a real treat for many of the clients. A large, enclosed, outdoor patio and garden is also available for functions.

Nancy J. Berry is executive director of St. John's Community Care, which is one of the oldest of the senior care operations in Metro East and has locations in Collinsville and Edwardsville. St. John's has both adult day and home care services.

Adult day services differ from nursing home care in the constant stress of activities.

"We are very focused on keeping our people focused with activities," Berry said. "We have a nurse on duty if they need medications or have a medical need. Other than keeping people safe and making sure they get a decent meal, the focus is all on what can we do that's fun and rewarding."

Beyond the therapeutic benefits, adult day services provide a very real opportunity of keeping the older clients out of hospitals and nursing homes, which are far more expensive.

Studies released in recent years by the National Adult Day Services Association showed the average annual cost per person using adult day programs was \$16,900. By comparison, a year's worth of services from a home care aide was estimated at \$44,790 and a private room at a nursing home cost an average \$83,150 annually.

St. John's Community Care charges private pay clients \$10.50 an hour. Its home care services average about \$20 an hour, which Berry said is typical for the industry.

As of 2014, there were 4,800 adult day service centers in the United States, compared to 15,600 nursing homes. The Midwest was the region with the least adult day service capacity.

"And if somebody doesn't find a cure for Alzheimer's in the next 10 to 20 years, it's going to be really hard to care for everybody," said Berry.

Patti Haddick, director of home services for St. John's, speaks from the perspective of both a client and an employee. Her mother, now deceased, went to the adult day program in Collinsville.

"It allowed me to keep my job full time and not have to put her in a nursing home," she said. "I always tell people who are interested in our adult day program to let their loved ones try us for at least a month to get acclimated, and they'll learn to like us."

"One hundred percent they will like us," added Stacey Rhodes, director of St. John's

adult day programs, who defines the center as a place that provides a safe yet stimulating environment for individuals with a variety of afflictions, mostly tied to Alzheimer's or related cognitive disorders.

"The benefit is not only the client who comes here ... but also for family members who need to work or who just need to take a break from caregiving. It gives them the respite that's really needed," Rhodes said.

St. John's, 222 Goethe Ave., is an outreach ministry of neighboring St. John Evangelical United Church of Christ. It is open 6:30 a.m. to 6 p.m. Monday through Friday, which accommodates the working schedules of most people needing the service. The church conducted a capital campaign in 2001 to build the Community Care building, and clients use some of church space for functions.

St. John's Community Care has roots dating to 1985 when it was founded as St. John's Homebound Care. A second location at 1015 Century Drive in Edwardsville opened in 2013.

St. John's has two of the four adult day program operations that remain in Metro East. There are private centers in Belleville and Shiloh.

Two other nonprofit services recently closed their adult day programs, Berry said. Because St. John's has numerous funding sources, the state cutbacks have not been as significant as they have for others in the industry, Berry said. But the legislature's two-year lapse without approving a state budget has left many such services scrambling.

"It's been a real cash flow issue. The state owes us more than \$200,000 right now, and that's a lot for us," Berry said. "We're managing, because we manage well and because we do have private pay folks and because we raise money through donations, through foundations and from United Way and the Mental Health Board of Madison County. We're making it."

The state still owes St. John's Community Care money from calendar 2016 and 2017. Some money owed during that timeframe has been paid because of judicial consent decrees.

"Our folks who are Medicaid-eligible, they have to pay us for them," Berry said. "They are getting behind on that, too."

"We're in better shape than a lot of not-for-profits," she said. "We're not as dependent on the state."

St. John's adult day care and home care are both fee for service. A little less than half of participants are private pay, she said. Other patients are paid through the state, either through the Community Care Program or through the Division of Rehabilitation Services. A couple of clients are paid through Veterans Administration programs. St. John's also deals with managed care organizations in Illinois. Many states are handing off high-needs Medicaid patients to such organizations, which deal with entities like St. John's, much like HMOs do in health care.

The pay situation varies with every individual, though the approach to every patient is the same, Berry said.

"For most folks, we can find a payment source to help them, if they really are low income," she said.

Based on its square footage, St. John's has the capacity for 33 clients per day in Collinsville and 35 at its Edwardsville site, Rhodes said. Some people come in one day a week, and some come in five days a week.

Right now, there is no waiting list, but Berry says the aging population is making adult day programs an increasingly popular choice.

The one barrier is people's lack of understanding about what adult day care is, she said.

"People drag their feet. The real barrier is people accepting that it's worth giving a try," Berry said. "It's a really positive benefit both for the person who comes for the care and the family members. That's the part people don't get: They feel guilty for not taking care of Mom. That's not the point. The point is, you're going to wear out as a caregiver if you're doing it all the time. But equally if not more important: It's good for Mom."

Dads, too. St. John's clientele is almost equally split between women and men.

The adult day program has had people as young as their twenties and one as old as 100, Berry said. Most of the younger clients are either developmentally disabled or have suffered from the result of a traumatic brain injury — normally an accident. Some of the early onset Alzheimer's clients have been in their fifties.

Clients have to be at least 18 years old.

St. John's gets referrals from many sources, but word of mouth is the biggest. "We get a few from doctors and from social workers," Berry said.

"Many people use us for a stopgap," added Rhodes. "They don't know where to go or what to do and they find us." St. John's can serve as a caregiver until a family member finds other answers.

Despite the needs of an older generation, Berry is doubtful that more such centers will spring up.

“They are too hard to operate financially. Lessie Bates Neighborhood House in East St. Louis closed its adult day program because the state wasn’t paying and there is only so much you can do to keep yourselves open.”



Clients enjoy activities at St. John’s Community Care in Collinsville

(Note: This story is courtesy of the Illinois Business Journal).