



## Coping with Alzheimer's

Ever have a dream where you were hopelessly lost and trying to find your way home? Or that someone was chasing you and intending to harm you? Perhaps you screamed, sat up suddenly and for a few moments didn't know where you were.

Ever get caught in a torrential downpour while driving or in a snowstorm so blinding you couldn't see the lines on the road or the taillights of the car in front of you? Maybe you felt panic rising within you as you try to find the edge of the road.

Ever go to a party or meet someone in the grocery store and you just couldn't remember their name or if they are a former classmate or co-worker? You might have been a bit embarrassed and maybe the other person graciously helped you out.

Life for a person with Alzheimer's disease or another dementia may be filled with these types of challenges and emotions every day. A person with dementia experiences problems with memory, decision-making, self care and communication. They experience anger, depression, frustration and embarrassment. Often they are afraid, lonely and reluctant to ask for help. As the illness progresses they are not able to express themselves.

The caregiver of someone with dementia may feel they are in a bad dream that never ends. "If only I could wake up and things would be back to normal." They experience the same feelings as the person who is ill along with guilt for having those feelings. Their 24 hour responsibilities result in isolation especially as the illness progresses.

Community Caregivers continues to address the needs of both persons with dementia and those who care for them. Services such as respite visits offer the caregiver's precious time to themselves. The number of volunteers providing this service has grown along with the requests for service. The respite team has developed from a short list to thirty strong and about 24 are active at any given time. Some clients are matched for a weekly visit while others call on an as-needed basis.

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## 6<sup>th</sup> Annual Community Caregivers Golf Tournament

Once again the Community Caregivers golf tournament was a huge success! This annual fund-raising event was held at Orchard Creek Golf Course on June 21<sup>st</sup> and by all accounts the golfers had a great time. The highlight of the day was the fabulous weather, a close second the delicious chicken and rib dinner for which Orchard Creek has become famous.

After a scramble format for 18 holes of golf, the players enjoyed a cocktail hour, dinner, raffle and live auction. All proceeds go to help Community Caregivers deliver services to our neighbors in the Towns



of Guilderland, Bethlehem, Berne, Knox and Village of Altamont.

Special thanks go to our sponsors: Adirondack Environmental Systems, SEFCU, Atlas-Copco, Times Union, Orange Motors and Wells Fargo Advisors. The continued support of sponsors and the 136 golfers who participated is most appreciated. The live auction featured many great items including foursome of golf with carts at Leatherstocking in Cooperstown; two VIP tickets to LPGA tour event at Locust Country Club, Pittsford, NY, foursome of golf with carts at Pinehaven Country Club and foursome for golf with carts at Albany Country Club. Pat Bulgaro, auctioneer extraordinaire,



did a fabulous job of 'encouraging' the bidding by reminding everyone of the many services our volunteers provide each and every day.

An event like this doesn't plan itself, so we thank co-chairs, Elaine Roemer and Regina DuBois and golf committee members, Steve Walter, Midge Bulgaro, Bernadette Fuller, Arnie & Judy Rothstein and Nancy Kuhl.



Plans for the annual gala are underway to be held on Saturday, November 6 at Albany Country Club. For more information about volunteering or donations, please call 456-2898.

## From the Executive Director



In the July issue of their magazine AARP announces a new trend in volunteering. They report that more and more Americans are making time to serve others. Interestingly the biggest jump is in the number of people – 66% – who prefer to help people on their own. Rather than volunteer with an organization many folks like the personal reward of helping someone nearby in their own neighborhood or community.

That article made me smile because Community Caregivers must be a trend-setter. We offer the best of both worlds in volunteerism: Our volunteers get to have maximum flexibility, direct interaction with neighbors; the immediate satisfaction of seeing needs be met. And they get all the benefits of being part of an organization: someone else to coordinate the services, training, coaching, insurance coverage and no guilt!

At Community Caregivers we are on top of other trends too. As we face the dramatic demographic shifts in our region we are preparing to serve more people. You have read the news stories: In our region the population of people over age 60 will increase by 40% in the next five years. More of us will live longer but with more chronic illness and disabilities. To prepare Community Caregivers is looking at how to meet those needs and how to help family caregivers care for those they love.

Our mission, established 16 years ago: “to enable individuals of all ages to maintain their independence, dignity and quality of life” is needed now more than ever. We need your help too. You can lend a neighbor a helping hand by giving us your volunteer hours, expertise and yes, dollars too. Thank you for all you do and all you continue to share as we build our caring community.

Sincerely,

Diane Cameron, *Executive Director*

## Drive Someone Happy!

We need more volunteer drivers to bring our clients to medical appointments, to shop for groceries and pick up prescriptions. Our services are provided at no charge to elderly and people of all ages who are unable to drive. Requests for rides have increased dramatically and we need your help.

Becoming a volunteer is easy! Attend a brief meeting and fill out a volunteer form. Learn how the program works and our staff will get you started on helping your neighbor.

*YOU decide when and how often you volunteer.*

Our service area includes Bethlehem, Guilderland, New Scotland and the Hilltowns of Altamont, Berne and Knox. YOU decide how far you will drive and in what locations. Destinations include these areas as well as Albany and Schenectady.

**Call 456-2898 and say, “I WANT TO DRIVE SOMEONE HAPPY.”**

## Meet Our Summer Interns



Delaney Chmura is from Loudonville and is a sophomore at the University of Wisconsin–Madison. She is an undergraduate intern at Community Caregivers this summer.

Samantha Cathers, who lives in Delmar, is a graduate student at the School of Public Health, SUNY–Albany. She is interning in the Community Caregivers program for the summer.



## Community Caregivers Can Give You a Break.

Full-time caregivers must balance time for the care of their family member and caring for their own needs. It can be a very demanding balancing act, especially when caring for someone with dementia, a chronic illness or in end-of-life situations – and when the need for care is 24/7.

This is when *the caregiver is in real need* of care –time away from the care responsibility, if only for a few hours, to deal with personal needs and relaxation. Respite offered by Community Caregivers Volunteer Respite Services can help by providing a caring presence so individuals and families can enjoy a break from their caregiving responsibilities. Our volunteer respite caregivers are experienced in dealing with those who need care in these situations.

If you're a caregiver in need of a break, call us and ask about our respite services. If you want to volunteer for our Respite Team, we'd love to meet you.

Call Mary Morrison – 456-2898

## Coping with Alzheimer's, *continued from page 1.*

The monthly support group for caregivers of people with dementia recently held its 18<sup>th</sup> monthly meeting. Attendance has grown from one courageous participant to a steady group of 10-12. Support group members report that being with others who understand their journey is the main reason for attending the meeting. They also benefit from a variety of guest speakers who provide information about the disease, legal matters, stress relief and exercise.

Community Caregivers also hosts educational seminars that are open to the public. Our volunteers and clients often attend programs on topics such as The Basics of Alzheimer's disease, Communicating with a Person with Dementia and Legal & Financial issues for Caregivers.

Our lending library has also grown in numbers of materials as well as numbers of borrowers. In addition, we maintain a resource file of relevant educational materials to distribute to clients on intake visits, to support group members and to our staff and volunteers.

– Linda Laudato

## Who Helps Community Caregivers Help Our Neighbors?

In addition to your donations, we receive funding from private foundations and government funds. Here are some of the funders that have helped us this year:

- Albany County Department for Aging: *Friendly visitor and assurance services*
- The Albert J. and Elsbeth Field Foundation: *One-time help for disabled seniors confined to home*
- The Equinox–Albany Community Foundation Fund of the Community Foundation for the Greater Capital Region: *Helping hand services*
- New York State Department of Health: *Helping hand and neighbors programs*
- New York State Office for the Aging: *Dementia programs*
- SEFA: *State employees helping Community Caregivers provide basic services*
- SEFCU: *Improved technology*
- Stewart's Holiday Match: *Family services*
- Town of Berne: *Rural transportation for seniors in Berne*
- Town of Guilderland: *Services to seniors in Guilderland*
- United Way of the Greater Capital Region: *Reducing hospitalization and keeping seniors in their homes*
- William Gundry Broughton Charitable Private Foundation: *Recruiting volunteers and clients*

## You Can Help Community Caregivers to Help More Neighbors Now and in the Future.

This time of year we are reminded to revisit our financial planning goals. When you meet with your financial advisor please consider making a planned or deferred gift for Community Caregivers. Three of the many options are:

### A Gift through Your Will:

Some of our supporters generously name Community Caregivers as a beneficiary in their will. It is a way to sustain the caring work we do and to provide for others who will need our services later. You can give a specific dollar amount, a percentage of your estate, or the remainder after providing for your family.

**A Gift of Life Insurance:** You may name Community Caregivers as the beneficiary of a life insurance policy. Many people have a second life policy through their employer or one that is paid off. These policies can be designated to support our work.

**A Gift with Income:** There are also planned giving vehicles that can provide income to you or a family member and later become gifts to charity. Charitable gift annuities and gifts via a trust are examples. You may also be eligible to designate part of your retirement account as a later gift and enjoy tax savings now. Talk to your accountant or financial advisor about what is best for you.

*For a confidential conversation about these options please call Diane Cameron, Executive Director, at 456-2898.*

## You Can Also Volunteer.

*You can drive* disabled, elderly, and non-driving persons for medical appointments, visits to family in nursing homes, etc.

*You can* either accompany a client who needs assistance or do the shopping for such items as food, prescriptions, or personal items.

*You can prepare and deliver* simple meals for individuals and families temporarily unable to provide for themselves, including delivering food from local food pantries.

**Call 456-2898 to learn what YOU can do.**

# “We Need to Talk.”

by Diane Cameron

Those of us who work in aging services do a lot of talking. We talk about medication and money and housing and hospitals; we talk about caregiving and caregivers and finances and politics. But the thing we don't talk about often enough is talking.

We rarely talk about how critical talking is in tackling the issue of aging with dignity. Of course we say the words; we say that seniors must talk to their families, and we offer brochures that tell seniors what to tell their kids and what children should ask parents. We remind caregivers to speak up and ask for what they need. But then we quickly move on to other topics because, we too, are uncomfortable with talking.

Many of us have suggested that families use holiday gatherings to start the conversations about things like living wills and money and how they want to live later. But we forget to mention how many times you have to try that conversation before it “takes.”

Talking is where those of us who work with seniors fail. Despite the many fall prevention workshops, we who work in aging are falling down on the job because we are just not talking enough about talking. Why?

We are talking about feelings---messy and uncomfortable feelings. The realm of emotions is gray and most of us prefer black and white. We'd rather talk about aging protocols and best practices and we can get very worked up about Medicaid and nursing homes, but we regularly avoid the one thing that can make a big difference in the dignity of people's lives: Talking and listening and talking some more.

“Aging in Place” is the current buzzword. At a recent workshop sponsored by the Albany Guardian Society, we talked about the services available, the options for money and housing and caregiving help. But the sad truth is that none of those strategies are viable unless spouses and parents and children are talking about this hard stuff frankly, directly, and repeatedly. The bottom-line of aging in place is this: You must talk to the point—and well past the point—of being rude, boring and annoying. And that is not easy for a senior to do unless we as providers back them every step-- and every word-- of the way.

Denial, as they say in AA, is not a river in Egypt. It is the central issue in aging. We're Americans; denial about aging and death is built into us. We need to be frank about this: The only healthcare fact you need to know and that all research confirms is this: You will age; you will become less able and you will die. Given that, who do you need to talk to?

These conversations are not easy or comfortable, but if you want to have a say on the last years of your life then talk about that now. There is no time for family planning in a crisis.

Here is what I learned from years of being a family care giver: You think you'll get some warning; you think aging will happen gradually kind of like the way your hair gets gray, a little at a time. But no. It's very fast. One phone call, one bit of blood, one screech of the tires, one slow motion slide as your foot goes the wrong way on a scatter rug. Your life – and the life of every family member around you – is drastically rearranged. Yep, you meant to talk about healthcare proxies and end of life measures and where you would

like to live if you ever got disabled.

The family chat must happen long before you meet your discharge planner—and since we don't know when that is going to be: You have to talk now. Discharge planners are amazing professionals. Their job is hard logistically and emotionally, but they can't facilitate the conversations that seniors should be having now.

Those of us who work in aging are at fault too. We keep talking about making houses aging-friendly and “patient navigation”. But no one will ever get the benefit of those if they don't first talk and talk and talk to family.

Shame on us for not insisting that every senior have those talks. Anyone who works in aging should be saying, “Did you talk to your kids?” when they get a call from a senior, and “Have you sat down with your parents?” every time we get a call from an adult child asking about services. And we should not accept excuses like, “I can't talk to my parents about their money.” Yes you can or you'll be talking about it with a complete stranger in the cramped office of the nursing home you didn't pick.

One more big thing we need to say is, “Never say never.” At some point a family member will be your caregiver. Start talking now about whom that might be and how you can make this work best for them. If you are lucky and plan ahead, you can have a say in this – otherwise no. Don't waste time disagreeing. Who will it be?

If you had to choose which of your children you'd prefer to live with, talk about it now while everyone is calm and has time to go away and come back to the conversation again. Married children need to talk to their spouses and their kids and even their in-laws. It can take several conversations to get through those layers. If there are siblings there will be sibling issues. They don't go away because we get older and even the best families have to tread this tricky terrain.

At the end of the day – or the end of your life – the issue is not nursing homes or retirement communities – naturally occurring or manmade – but what we didn't talk about. And that is where dignity lives or dies.

It's not the ramps and rails that will derail a family; it is the emotional issues we would – literally – rather die than talk about.

*This article is reprinted from the Capital Commons Quarterly – April 2010*

## Volunteers of the Month

January	Max Chmura, Loudonville
February	Hank Williams, Guilderland
March	Quinn Family, Albany Goutos Family, Altamont
April	Tom Morrison, Albany Joe Kelly, Albany Shirley Morey, Berne
May	Margie Brague, Voorheesville