

First Annual  
Early-Stages Conference  
*A Conference for Persons with Dementia  
and their Caregivers*



Thursday August 23, 2008  
9:00 a.m. – 4:00 p.m.  
Legacy at the Fairways  
681 High Street, Victor NY 14564

Changing Our Image: Tools for Living with  
Alzheimer's Disease

alzheimer's  association™

*Changing Our Image: Tools for Living with Alzheimer's*

Prepared by Theresa L. Fischette, White Light Communications  
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## Welcome

### **Teresa A. Galbier, CEO of Alzheimer's Association**



### **Speech**

Albert Einstein once said. *“There are two ways to live your life. One is as though nothing is a miracle. The other is as though everything is a miracle....”*

It was ten years ago when I first was given the incredible opportunity to participate alongside some of the finest people in our community in supporting the mission of the Alzheimer's Association. Included in this group of supporters were:

- The founders of the Alzheimer's Association who, twenty seven years ago embarked upon a journey to help their families affected with the disease;
- Countless individuals who found themselves struggling with the affects of this disease and had nowhere to turn;
- Our board leadership; an amazing team of staff; a large and strong cadre of volunteers who covered a region 5333 square miles long; and
- Most of all – a group of courageous men and women who decided, in spite of facing a very difficult future, were going to live life to the fullest and experience all life has to offer with the help of support groups, educational programs, panel discussions, and now – for the first time in our community – an amazing Early Stage Conference for people with dementia hosted by people with dementia.

Today's event is a wonderful example of our enhanced responsiveness to the needs of people with dementia. It's imperative we not only continue to increase, but enhance our support for those affected by Alzheimer's disease as we continue to strategically forge ahead. Being mindful as to never becoming complacent, we owe our full attention and our untiring commitment to those we serve.

And, so we take action to continually enhance the circle of support and resources available to ensure you remain active in your communities, your neighborhoods, as well as your network of friends and family as you plan for your future.

Yes, we have fortitude; we are progressive thinkers; we join all today to continually change the image of Alzheimer's disease; and make a promise to you ... that we will continue to support you throughout your journey while aggressively searching for answers, for better treatments, and, perhaps one day soon, for a cure.

I share with you today a snapshot of our history. Twenty-seven years ago a young woman named Debra Mayberry was told her father had been diagnosed with Alzheimer's disease and that there was nothing that could be done. For those of you who've had the pleasure of meeting and knowing Debra, you know she would not accept this fate the medical establishment of the time gave her. She placed an ad in the local newspaper with the hope of attracting others who may be facing Alzheimer's disease, had nowhere to turn, but knew they did not want to face the challenge alone. In her ad, she asked others to join her at the Rochester Public Library on a spring Thursday evening to share their stories, to support each other, and to let others know they were not alone. Much to Debra's surprise, more than 20 people showed up that evening.....

Nearly twenty years ago, the Rochester New York Alzheimer's Association went into uncharted territory by being the first in the nation to begin an Early Stage Support Group. Now, 27 years later, more than 40 support groups are offered in every county of our region throughout the course of the month, with more than 220 people participating in these groups. Included are support groups for people with dementia, for care partners, for those grieving the loss of a loved one, for meaningful activities, and for partners who, together, want to prepare for what the future holds.

Two and a half decades ago, funding for Alzheimer research was essentially non-existent at the federal level. Today our government provides almost \$700 million to scientific studies throughout the world. But, it's not enough. With Alzheimer's being the sixth leading cause of death in the United States today, we must accelerate the funding of studies that will unravel the mysteries of this fatal disease today so that we will have a world without Alzheimer's tomorrow.

Even without a cure we must continue to forge ahead and serve those living with Alzheimer's today. And, so we provide a wide array of programs and services. The five core services comprise the foundation of our organization. Included are supportive services, education, care consultation, safe return, and advocacy. We encourage participation as champions; more than 1.8 million have accepted the challenge to spread awareness and concern for our cause and have signed on as champions. We will mobilize this nation by showing our strength in what's been accomplished yet know there's still much more to be done. To do this, we must empower people with dementia to participate in planning for their future.

We know many everyday champions. Two years ago our national organization produced a powerful video including a dozen champions willing to say to the American viewing audience, "I have Alzheimer's". These remarkable people came from all walks of life, throughout several communities in our country. Five years ago, another champion and a friend of the local Alzheimer's Association - Jim Ruppert - showed remarkable courage by his willingness to stand up at our 22nd annual luncheon. With

his mother by his side, he shared his extraordinary story with colleagues, peers, and all of those in attendance. The following year he shared his personal story on a first-ever panel of people with dementia at our Public Policy Forum in Washington DC. Three years later, he joined the newly-created national Early Stage Task Force to recommend policy and direction for our national effort. Included in the policy recommendation was the endorsement of a person with Early Stage Alzheimer's to the National Board of Directors. Bill Bridgewater - a professional, father, husband, and head of one of the U.S. Fortune 50 companies - accepted the endorsement and was appointed to the National Board of Directors this spring, setting an extraordinary precedent for others to follow. In spite of the difficulties he and his family are facing along with the monumental challenges a diagnosis of Alzheimer's brings, Bill shares his talents, expertise, and personal experience nationally to empower and encourage others to join him in a fight that must be fought.

Another remarkable gentleman was Frank Carlino, a Manhattan-based architect who lost everything because of his disease. Instead of quietly suffering, he testified in front of the United States Congress at the 2003 Congressional Hearing in Washington DC and boldly asked Congress to throw him a lifeline as he was drowning. For the next four years, Frank courageously travelled to our nation's capitol and to Albany, spending countless hours testifying to local, state, and national officials with the hope of seeing a breakthrough in his lifetime. But, Frank was not to witness this miracle first-hand. The New York State Coalition of Alzheimer's Association Chapters, in response to Frank's heroism and unwavering advocacy efforts, proudly keeps Frank's legacy alive today with the Frank Carlino Award, which is presented to an outstanding state-wide advocate. Our hope is the lead Jim, Bill, Frank, and all of you in attendance today have taken will be followed by millions of others to join in the formidable task of changing the image of Alzheimer's disease; thus, planting seeds of hope for generations to come.

As Albert Einstein once said, *"There are two ways to live your life. One is as though nothing is a miracle. The other is as though everything is a miracle...."* As you sit back and enjoy this incredible day the Planning Committee has prepared, you will witness many miracles as you hear courageous men and women share their stories and see but a glimpse of their world. Pay close attention to the miracles happening before your eyes. If you are at least bit touched by these stories and these amazing people as I have been and continue to be, then choose to live your life as though everything is a miracle... I know I will.....

It is now with great pleasure I acknowledge those who worked so diligently to make today a reality.....

- Anna Alger, Executive Director of the Legacy Fairways for graciously hosting today's event and for providing corporate support;
- Steve Baldwin of Xerox Corporation for generously donating the printing and production of the keepsake conference programs;

*Changing Our Image: Tools for Living with Alzheimer's*

- Our Planning Committee, which is made up of people with dementia, professionals from the community, as well as agency staff: Amy Hay, President of Comfort Keepers; Terri Fischette of White Light Communications; Todd Goddard, Director of our Learning Institute; Ralph and Ann Hendenberg; Marilyn Mould; Alan Whiting; and Audrey Brady, Resource Specialist;
- All of our wonderful volunteers, with support from Beth Barnard, Program Assistant; and
- Our twelve presenters, including our esteemed keynote speaker, Ross Stuckless

## The Planning Committee

We would like to acknowledge and thank the following individuals who made this special event possible:

### **Planning Committee**

- Audrey Brady
- Theresa Fischette
- Todd Goddard
- Amy Hay
- Ralph Henderberg
- Ann Henderberg
- Marilyn Mould
- Alan Whiting

### **Presenters**

#### **Keynote**

- Russ Stuckless, Professor Emeritus, RIT

#### **Driving**

- Frank Cagliandro, Rochester Rehabilitation
- Jim Maxwell, Testimonial
- Michael Walker, Testimonial

#### **Financial Planning**

- Kevin Best, Financial Planner

#### **Preparing for a Move**

- Jennifer Everett, Moving Memories
- Ana Uetz, LMSW

#### **Staying Active**

- Andrew Little, Pieter's Family Life Center

#### **Disclosure**

- Kelly Carson, Resource Specialist
- Gladys Hickey, Testimonial
- Marilyn Mould, Testimonial

#### **Laughter Lightens Panel**

- Terry Christiansen, Testimonial
- Patti Christiansen, Testimonial
- Barbara Gramkee, Testimonial
- Alan Whiting, Testimonial

## **Information Stations**

- Advocacy
- AD CARE
- Arts and Cultural Council for Greater Rochester
- Catholic Family Center
- A Community Place
- Eldersource
- Jewish Family Services
- Just Friends Social Club
- Learning Institute™
- Lifespan
- Livingston County Office of Aging
- Monroe County Office of Aging
- Ontario County Office of Aging
- Pieter's Family Life Center
- Preferred Care
- Resource Table™
- Seneca County Office of Aging
- Wayne County Department of Aging and Youth
- Yates County Office of Aging

## Sponsors

We would like to express our sincere thanks for the following organizations who sponsored this event:

- Legacy at the Fairways
- Story Corps
- White Light Communications
- Xerox Corporation

## Schedule of Events

<b>Time</b>	<b>Agenda</b>
9:00 – 10:00*	Registration / Breakfast
10:00	Welcome
10:20	Conference Planning Committee Introduction
10:30	Keynote Address
10:50	Introduction to Speakers
11:00	Table Discussion #1
11:45	Lunch
12:45	Interactive Stations
1:45	Table Discussion #2
2:30	Laughter Lightens Panel
2:50	Closing Remarks
3:00	Reception

\* From 9:00 a.m. through 4:00 p.m., Story Corps will be recording seven oral histories for the Library of Congress

## Keynote Address

**Russ Stuckless, Psychologist / Professor Emeritus of RIT**

### Biography



### **B.A. (1956) University of Toronto, Honors (Psychology)**

M.S. (1959) Gallaudet College, Washington, D.C. (Special Education, Deafness)

Ph.D. (1963) University of Pittsburgh, Research & Psychology, (Special Education & Rehabilitation)

1956-61 Psychologist, working in schools with deaf students, teachers and parents

1961-67 Associate Professor, University of Pittsburgh

- Numerous federally-funded research projects
- Leave of absence to U.S. Dept. of Health, Education & Welfare, Bureau of Education for the Handicapped (Kennedy Administration)

1967 Professor, National Technical Institute for the Deaf (NTID)/ RIT

- Director of Research & Training
- Special Assistant to the VP for NTID
- Research focusing on automatic speech recognition (ASR) and other support services for deaf students internationally

1997 Presently, Professor Emeritus (retired)

Other professional activities:

- Chaired R&D Center Review Panel, U.S. dept. of Education, Bureau of Education for the Handicapped
- Chaired National Task Force on Quality of Educational Services for Post-Secondary Deaf and Hard of Hearing Students
- Co-Chaired National Task Force on Educational Interpreting
- Co-chaired Programs Committee of the 17<sup>th</sup> International Congress on Education of the deaf (1990)
- Co-chaired International Convention of Alexander Graham Bell Association for the Deaf (1994)
- Seventy-five publications in referred journals, book chapters, and monographs

## **Keynote Speech**

Those of us with Alzheimer's disease know it tends to creep up on us. However, in my instance, I almost expected it. I saw my father's mind slowly change with the disease as it has the mind of my younger brother. This led me to worry about whether I was to follow. It also gives me concerns for my children and grandchildren. But of course, we must leave that pending to future medical breakthroughs.

With that having been said, I've accepted my Neurologist's diagnosis as of four years ago and continue to go on with my life at my age of 74, with one exception - in June of this year, I suddenly lost my dear wife and caregiver, Carol. But again, life does go on and I'd like to share some of my experiences to date with my Alzheimer's.

I did have one early interesting experience, which suggested to me I hadn't entirely come to grips with accepting the full fact of Alzheimer's. It was simply this: I had a dickens of a time spelling the word. I'd wake up in bed and try to spell Alzheimer's, but couldn't sleep until I looked up its spelling again and again. This went on for months until I came to realize that something in my brain was rejecting the acceptance of my disease – and only this realization brought me to where I am now.

I'd also like to share some of my other personal experiences with you as they may be quite common with you. First, we know memory loss comes with the disease, along with all kinds of problems related to conversations, including remembering telephone numbers, names, etc., we could all go on and on. Incidentally, I sometimes carry a small notebook for reference. Oh, the struggles and indignities I had with myself until I was able to open my conversations with just three words, "I have Alzheimer's". I've found some people I've talked to have already learned quite a bit about the consequences of the disease, and particularly of memory loss.

I can give you a recent example that happened just a month or two ago. Carol and I had agreed much earlier that she would take over the household bills, taxes, and other things going along with maintaining a home – even the thermostat for the furnace. That was her job! I knew nothing about the thermostat and its buttons, but I did know the telephone of our serviceman. He began to tell me about the thermostat, which I couldn't understand until I finally had to say, "I have Alzheimer's". Immediately he said, "I'll write it down for you and drop it off today".

I've learned not to cover my memory loss until it's too late; that is to say, I think it's better to indicate my Alzheimer's before I open a conversation than to bring it up in its midst.

Now there's a trick or two here. When I'm struggling for words, numbers, etc., there's often a long pause before finding it; that can be stressful in a conversation. At that point, Carol or a friend might insert the word I would be looking for; that would also bother me like being "between a rock and a hard place".

I was rejecting the help of others. This particularly hurt Carol because she was my "caregiver". And looking back, I was hurting both myself and others.

She eventually convinced me the person was in fact trying to help me in my conversation. One of the lessons she left with me was to become more gracious with people in accepting help.

I'd like to tell you a story about my Mother, Mrs. Lindsay, and me. I was six years old when I had cancer and had to have my left arm amputated. I had just started to take piano lessons at the time when Mom insisted I join our Church's Boy's Children's Choir. This involved dressing up in those choir outfits - bow ties and all. But one day after church, Mom took me aside and said, "Do you know you hurt Mrs. Lindsay's feelings today?"

"Why?" I asked.

Mom said, "She wanted to help you fix your tie, but you said you could do it yourself."

I still recall what my mother said that Sunday afternoon 68 years ago. I think it applies to all of us who have Alzheimer's - and particularly those of us who depend so much on our caregivers.

Other disappointments? Perhaps they come with the package. One of my pleasures has always been to read; particularly novels. However, I've lost some of its pleasure, because I seem to forget the characters and story in an earlier chapter. Carol and I tended to watch TV and movies since they allowed me to carry the stories along.

I still enjoy getting out and getting together with family and friends. I should mention a problem or two. I don't like eating out in a noisy environment with a lot of major movement and general confusion. So I sometimes avoid them. Yet I know at the same time I shouldn't use these as excuses for avoiding crowds.

Do I still drive a car? Yes, I do. I continue to drive with the exception of nighttime and bad weather. I must say Carol was reluctant to go along with it. After lengthy conversations, we established a few rules, which seemed reasonable to both of us, such as no lengthy trips and no driving within certain boundaries near our home.

The Importance of Caregiving. In closing, I'd like to add a few comments about caregiving. Carol and I attended Alzheimer's groups on a monthly basis and I assume I'll continue. We've met wonderful, open people, giving us all a chance to learn from one another.

Before closing though, I'd like to share with you one more thing Carol did before her heart attack without mentioning it to me. She left very specific instructions for me on the caring of our little dog, Penny; about our grandchildren's birthdays; and her diary which I have with me all the way onto December - ending with a note written "Pay Ross' Long Term Care premium notice".

If only for Carol's passing, I would have asked her to help me close this presentation on behalf of all the caregiving families, men, women, children, friends, neighbors, and others we have met. May I ask all the caregivers present here to stand and be recognized for their support? She would say, as I would also say ... "Bless you all!"

## Table Discussions & More

### Speakers

#### Barb Cacia

Barb Cacia is the Wellness Coordinator at the Pieter's Family Life Center. She brings a great deal of experience and enthusiasm to her work, teaching a variety of exercise and information classes including a series on the care and management of Fibromyalgia.

#### Kelly Carson



Kelly Carson has been a Resource Specialist at the Alzheimer's Association for two years. She graduated from SUNY Cortland with a BA in Sociology with a concentration in gerontology and has worked in long-term care for four years prior to starting with our agency. She has a passion for working with people with dementia and their loved ones and feels blessed to have the opportunity to work with so many wonderful people from our community. She grew up in Fairport and currently lives in Irondequoit with her husband Simon.

#### Kevin Best



Kevin Best is a registered representative of Lincoln Financial Advisor Corp. Securities and advisory services offered through Lincoln Financial Advisors Corp. a broker/dealer (Member SIPC) and a registered investment advisor. Kevin knows the tools, tactics and financial planning processes that can help give business owners and families' confidence in the future. Kevin has been honored as one of Rochester's Forty under 40 leaders. He is part of the firm's Private Wealth Services Group Program. Kevin founded the Blue Dot Group, a family business advisory group, and maintains an active membership in Rochester's Family Business Forum as well as

the Penfield Business Association. When he is not meeting with clients, tracking trends, connecting with business contacts or spending time with his family, Kevin enjoys golf.

### **Frank Cagliandro**



Mr. Frank Cogliandro is Director of Physical Rehabilitation Services at the Rochester Rehabilitation Center, which provides programs in driver rehabilitation, outpatient article 28 CORF physical, occupational, speech, and social work therapy, alcohol & substance abuse education and sports and leisure activities. Mr. Cogliandro has over 25 years experience in the education and rehabilitation profession. He is a regular contributor to several publications relating to traffic safety and co-author of *Handbook for Drivers of Disabled & Elderly Passengers and Developing and Maintaining an Agency Driver Safety Program*. He is the past northeast president of the Association for Driver Rehabilitation Specialists and a present Board member and past VP of the Genesee Waterways Center. Mr. Cogliandro has an ardent interest in safety issues for the older driver and people with a neuromuscular impairment and has teamed with the U of R School of medicine on related research.

### **Jennifer Everett**

Married to Dan Everett, Jennifer has three dogs and a pet duck. She is Co-Founder of Moving Memories, Senior Move Managers LLC since 2002 and is active in Monroe County as a paramedic and paramedic/EMT instructor. In addition, Ms. Everett is an educator and instructor for various state and national medical conferences and a licensed Wildlife Rehabilitate in NY. During her spare time, Jennifer and her husband like to travel and scuba dive. She also enjoys reading, gardening, and spending time with family.

## **Gladys Hickey**



Gladys was born and raised on a farm in Clyde, NY. She later completed her degree at RBI, and started working at Kodak, eventually becoming an executive secretary. Marrying Robert M. Hickey in 1951, the couple moved to West Webster. Gladys resigned from Kodak when she had her first child in 1952; as the next eight children were born (all girls!) she was a fulltime homemaker. They were, and Gladys still is, very active at St. Rita's. Volunteering for 28 years at Bishop Kearney (BK) High School, Gladys and Bob were inducted into the BK Hall of Fame in recognition of their years of service supporting the school! Still living in her home in Webster, Gladys enjoys visiting with friends and relatives, gardening and reading. She is a valued employee at her church, and is now very involved in Alzheimer's Association support groups and events. Gladys loves and prays for her 20 grandchildren and five great grandchildren, feeling lucky and very blessed with a good life and good health.

## **Andrew Little**



Andrew Little is the Director of the Pieter's Family Life Center. He has been working for Heritage Christian Services in a variety of roles for the past 10 years, including Director of Heritage Christian Stables – a therapeutic horseback riding program.

## **Jim Maxwell**

Jim Maxwell is a retired Kodak employee beginning in work in mechanical oversight, reporting production numbers and technical problems, then later into the responsibility of management over 30 female employees. He met the love of his life, Louise, through his sister who played matchmaker for the two. They remain deeply in love and true best friends for one another. They raised a beautiful family and feel have been immensely blessed.

## **Marilyn Mould**



Marilyn graduated from Syracuse University with a degree in music. She has always loved music, playing both the trumpet and piano, and now takes recorder lessons weekly. She was married and raised a family of three. While she was a stay at home mother during her children's formative years, she spent many years as a typist for a CPA.

## **Ana Uetz**



Ana Uetz is from Webster, New York. She attended Nazareth College of Rochester, where she received her Bachelor's degree in Social Work, and earned work experiences as an intern at Gilda's Club of Rochester and Catholic Family Center's Kinship Care Resource Network. After her undergraduate work, Ana enrolled in the Greater Rochester Collaborative MSW Program at SUNY Brockport and Nazareth College, where she earned her Master's degree in Social Work and work experience as an intern at the Jewish Home of Rochester, working in the adult day health care program and long-term care. Ana has been a Resource Specialist for the Alzheimer's Association since 2007.

## **Michael Walker**



Michael S. Walker was born Ohio in 1931 and raised in Indiana. After serving four years in the US Air Force at the end of the Korean War, Mike attended John Carroll University in Cleveland, Ohio, on the GI Bill. Upon graduation in 1963, he came to Rochester to work at Eastman Kodak Company. He spent 34 years as an engineer at Kodak Park, retiring in 1997. Mike's main hobbies are photography and general aviation. He became a private pilot in 1968 and owns a Cessna airplane. Mike has been married to his wife, Barbara, for almost 45 years. They have three grown children. He was diagnosed with early stage Alzheimer's disease in February, 2008.

## **Alan Whiting**

Born in Albany, NY in 1932, Alan Whiting grew up in Delmar, NY; graduated in 1954 from University of Vermont; and obtained a Master of Education Degree in 1959. He served in the military as a Infantry Paratroop Officer in Germany from 1954-1957. Mr. Whiting taught in the Rochester City School District and served as Elementary School Principal in West Irondequoit from 1966-1989. He married Jane in 1955 (deceased in 2001); has three daughters (Judith, Nancy, and Emily); and two grandchildren, Audrey and Evan. In his spare time, Alan is Co-Chair in a Volunteer program at Schools #22 and #15 (1988 -2008) under the auspices of the First Unitarian Church of Rochester.

## Table Discussions

### Driving

#### Frank Cagliandro

A panel discussion with Frank Cagliandro, Jim Maxwell, and Michael Walker about changing senses, signs of when to discontinue, and promises to friends.

#### 1. Introduction

Driving is one of the most important issues we face in our society today:

- Mobility freedom
- Control
- Get to place to place at your own time

And as we age, are we prepared to deal with our body changes and the affects it has on our ability to drive safely?

#### 2. Objectives:

- a. Understand the Department of Motor Vehicles fitness rules
- b. Understand the warning signs of driving problems
- c. Understand the benefits of a Driver Evaluation
- d. Be more prepared to ease the transition from Driver to Passenger

#### 3. NYS Department of Motor Vehicles - Section 502 – Requirements for Licensing

“The applicant shall furnish such proof of identity, age, and fitness as may be required by the commissioner.”

- Age
- Vision acuity
- Condition causing unconsciousness which now includes Dementia & Alzheimer's
- Hearing Impairment & Heart Condition
- Lost use of leg, arm, foot, hand, or eye

4. Why Dementia and Driving is a Difficult Topic?

- Different from later in life body, visual, and mental changes a person with Alzheimer's disease is gradual and unpredictable.
- A person with dementia is unable to apply deductive reasoning of the critical mental changes related to driving.
- Often critical functions are overlooked by family and friends because driving is a learned behavior and long term driving memory remains.

Let's look at an example

**Example:**

A person who drives the same route everyday to and from the grocery store for many years has retained the long term memory of the driving route. Since it is a routine, he/she remembers which intersections have a stop sign or traffic light.

If there is road construction, the person is asked to change their driving pattern and driving judgment as well as multi-task – all begin to diminish.

5. So should every person with Alzheimer's Disease stop driving? No! However, consider a professional driver evaluation to look at critical driving indicators.

- Attention span
- Visual perception
- Processing information
- Short term memory retention

6. Adaptive Driving Aids that might help prolong driving:

- Back-up sensors
- Wide review mirror
- On-Star or like service
- Wide side mirrors
- Satellite road maps with voice direction
- Raised seats

7. What are some of the warning signs?

- Gets lost and has difficulty or was unable to return home
- Is easily distracted when driving
- Hits the curb or other fixed objects
- Experienced increased agitation when driving
- Is confused with gas and brake or other vehicle devices

- Does not anticipate possible driving hazard
  - Uses a co-pilot
8. How do I ease from Driver to Passenger?
- The most affective method is limit driving to short familiar places and let your spouse, family member, or friend drive all other times.
  - Gradually let others drive you; tell them what kind of driver you would like them to be.
  - When you're the passenger, communicate your concerns with their driving.
  - Help the driver with directions.
  - Talk to your friends and neighbors; build a Transportation Club.
9. Driver Rehabilitation Services
- Locations: Rochester, Buffalo, Syracuse, & Utica
- Driver Evaluation Service
- Knowledge assessment
  - Functional assessment
  - Vision assessment
  - Cognitive assessment
  - Driving performance assessment
10. Driving Evaluation Outcomes
- a. Valid driver license and no driving adaptations needed; return to driving. See you in the next ? months
  - b. Minimum standards were met, but could benefit with some driver education to improve on some weak areas
  - c. It's time to discuss transportation alternatives

Thank You & Let's be Safe on our Roadways!

## **Michael Walker**

Hello. My name is Michael Walker. I live in Greece, NY and I have Alzheimer's Disease. I have agreed to participate in this first-ever Early Stage Conference: Changing Our Image.

Six months ago, I knew there was something wrong when I was unable to use the words I needed to use. Initially, I thought it would go away but, of course, with time it became worse. I became angry and frustrated with myself. I finally realized I must see my doctor. I was diagnosed with Alzheimer's Disease in February of this year.

The neurologist recommended I make an appointment for an evaluation of my driving. I have always been a safe driver and thought I would pass the test with flying colors. I didn't pass. Giving up driving privileges was devastating. I was also a private pilot for 35 years and have my own airplane. In addition to not being able to drive a car, I am now unable to fly the plane myself. That hurts even more!

I have been blessed with good health for most of my life. I had glaucoma for more than 10 years and received radiation treatments for prostate cancer in 2004. Having the Alzheimer's diagnosis was a triple whammy. I asked myself, "Why me?" I had a spell for awhile of not being very happy. I soon realized I can't sit around and mope. Each day I must do the very best I can.

I learned along the way there are things that help. My doctor prescribed Aricept, with the results being almost magic. The people from the Alzheimer's Association have been very helpful and understanding. My wonderful wife, Barbara works part-time. Fortunately, she has an understanding boss and she makes arrangements for taking me wherever I need to go. She is a great chauffeur. Friends offer to fill in where necessary.

I focus on my hobbies: playing the guitar, drawing and painting, as well as keeping up with the news in the newspaper and on television. My wife and I eat dinner out once a week and attend RPO concerts and plays at GEVA. Although our three children all live out of state, they have been very supportive and have scheduled more frequent visits. My son, Tim is also a private pilot and during his visits he takes me flying. That pleases me very much.

## **Jim Maxwell**

Good Morning/Good Afternoon. My name is Jim Maxwell and I have Alzheimer's disease. This came to light during a discussion with my primary care physician, Dr. Bernard Farnand, when he suggested that I have the disease. At first, this was very concerning to me. But in discussing this with my wife, Louise, we learned much to our great joy that this did not mean my life was ending.

Today, I am here to talk to you about my experiences with driving and how I came to stop. I know giving up driving for many people is a big challenge; however, this was not a difficult decision for me to make. I gradually gave this up driving because my coverage with our insurer was not good anymore. I was actually happy to give up driving because I have never had any problems on the road and I never wanted any. I had driven all my life without an accident. My wife, Louise, is a marvelous woman and excellent driver. When I need to get somewhere we go together, always, thank the Good Lord. Louise was in agreement that I should stop driving and very supportive of this decision. She never made me feel as though driving me was an imposition, we enjoy driving together and do it for fun as well as when we have to.

Louise is my rock, my dear love and I trust her completely. Because of this love and out of this love I want to be sure to keep us safe and she wants to do the same for me.

## **Financial Planning**

### **Kevin Best**

At the completion of this session the learner will be able to:

- Explain legal capacity, understanding legal documents.
  - Identify ways related to finding a lawyer and financial planner.
  - Discuss important information to bring to a meeting.
  - Indicate typical expenses and financial resource options.
1. Determining Legal Capacity
    - A. Important to determine whether or not person with Alzheimer's disease or other dementia able to understand explanation of legal documents
    - B. Have discussion as early as possible with the individual who has the disease regarding what their wishes are
  2. Understand Legal Documents
    - A. Power of Attorney – individual authorizes an agent to legally make decisions when individual no longer competent
    - B. Power of Attorney for Health Care – makes decisions regarding health care
    - C. Living Will – person with Alzheimer's disease expresses decisions on use of artificial life support
    - D. Living Trust – ensure management of property
    - E. Will
    - F. Guardianship/Conservatorship
    - G. Health Care Proxy
  3. Find a Lawyer and a Financial Planner
    - A. Consider lawyer who practices elder law, estate planning attorney
    - B. Seek assistance from professional financial advisor or financial planner
    - C. Check credentials/references
    - D. Questions to ask:
  4. Information Important to Bring to Appointment
    - A. Itemized list of assets with current value – include names on accounts or ownership documents
    - B. Copies of estate planning documents
    - C. Copies of recent income tax returns
    - D. Life insurance policies and cost values of policies
    - E. Health insurance policies
    - F. Stock and bond certificates
    - G. Bank and brokerage account information
    - H. Pension/Retirement information
    - I. Social Security
    - J. Rental income

- K. Deeds or mortgage papers or ownership statements
- L. Monthly/outstanding bills

5. Typical Expenses

Consider expenses, income and payment method

- A. Costs
- B. Look at Current Income – Considerations

6. Financial Resources – Possible Options

- A. Health care coverage
- B. Medicare and any other plan individual may have such as Preferred Care Gold or Blue Cross/Blue Shield Senior
- C. Disability insurance
- D. Long term care insurance
- E. Life insurance

7. Personal Resources

- A. Employment
- B. Employee benefits
- C. Retirement benefits
- D. Personal savings, investments and personal property
- E. Government assistance

8. Family Medical Leave Act

More information on this topic may be obtained from the Resource Specialist at the Association at (585) 760-5400 or 1-800-272-3900.

## **Preparing for a Move**

### **Jennifer Everett of Moving Memories**

Jennifer Everett of Moving Memories addresses the emotional aspects of downsizing, our connection with our belongings, and how to make a successful transition.

#### ***Why are our things so emotionally connected to us?***

They have been part of your life and even small things that reflect special memories can be very difficult to part with. What seems trivial to one person may be very important to you.

My family doesn't understand how precious these things are to me, they are connected to my memory.

#### ***I don't know when I will be moving, why is it important for me to go through my things now?***

The earlier you start sorting the better. Depending on where you may be moving to the space and storage options may be limited. Starting early gives you the time to reflect in personal memories and decide what you can bring that is most important to you. Most importantly you are not "rushed" and can truly evaluate what you want to bring with you.

#### ***I know I should start, but there is so much, where should I begin?***

We recommend starting small and for short periods of time (2-3 hours). We also suggest not starting with your primary everyday items. Start with items that are not used on a daily basis. Generally items that are used daily will all be moving with you and may need to be reduced in size or amount.

#### ***What should I do when I start to get too upset/emotional?***

Stop, take a break. When starting the downsizing process many times items will be uncovered that have not been seen or looked at for years. This can cause memories that can be joyful or sad. Talking and sharing the story can help. Staff who assist you should understand these emotions and know when it is time to stop and start again the next day.

#### ***My family says they want to help, but they really don't have the time.***

Families are busy in today's world. Saying they can help and sometimes getting them to actually commit time can be challenging. We suggest setting a date and requesting they come and help at a certain time, like an appointment. If they cannot come there are alternatives out there to help you.

***My children are fighting over who gets what.***

Be firm and all explain that you will decide when you are ready. This can be very hard as sometimes legal issues arise. Moving coordinators can only make suggestions and are not readily trained mediation. A moving coordinator may have to step out of the situation until it is resolved.

***What do most people hang on to?***

Photos, decorations, and clothes, we also find that many people do not want to part with furniture pieces. This can be difficult as many times during down sizing decisions on what furniture can fit into the new home. Beautiful furniture sets can be very difficult to split up.

***How do you decide if it is something to keep, store, give to family/friends, give away or trash?***

Complex question:

- If you plan to keep it, where will it be placed and will it fit where you plan.
- Does the location your going to have storage? If so many times it is a very small area.
- Storage off site can be expensive and if you are storing it off site, will you truly ever use it again is a question to ask yourself.
- Give to family or friends: Are you sure they want it, and when will they come and actually take the items.
- Donation: Many organizations can be pretty “fussy” on what they will actually take and everything is not easily donated.
- Estate Sale: Is there enough in the home left after you leave to have sale? Estate sale companies usually charge a flat fee of \$1000.00 - \$1200.00 or \$600-700.00 plus 25% of the sale. Financially that is not always the best option. That said some people are willing to have the sale just on the premise of they do not want to throw out their stuff.
- Trash: sometimes this is the most financially reasonable option, not the easiest for the individual person to do.

***What if my family member doesn't want my oriental carpet, how do I make sure it has a good home?***

The sad truth is you may not find someone that wants it. Generally with an item like an oriental carpet you can find a buyer or home for it if you are patient. Other items that fall into that category are: china, silver, crystal. Many of the younger generation are not collecting these items anymore and have no use or do not want them.

***How can I get creative and keep some of the things I just can't part with, but that know will not fit in my curio cabinet or on a shelf.***

Store them someplace close and every few weeks rotate the items on display. That way you have an activity to complete and you get to see your cherished items. Ask a family member if they can store a few items for you.

***What special recommendations do you have for most people with memory impairments when organizing their current home to better suite their needs or setting-up their new home?***

De-cluttering is our biggest recommendation, the less visual stimuli around decreases confusion. We do not recommend "changing" everything, especially with memory loss. In fact we recommend that when moving you try to set up the new home the same as close to the previous one as possible. I.e.: plates and cups in the same side of the sink they were before. Medications, dressers and closets as close to the same that is possible. Labels can be a help in orienting yourself to your new home.

(I am sure you know this, but we don't recommend that people develop necessarily new places to store things, just more of the de-cluttering aspect and ensuring the things they use most are easily assessable, possible labeled, possibly in plain sight, in the area that would make sense for them to find it their. We do not promote turning the house upside down and starting completely new storage/organizational structure, but instead minimizing distractions, accumulation, and making the ability to participate in any number of activities easier- such as writing a letter, watering plants, putting away dishes, etc. This is a balance, organizing and minimizing while keeping things the same, why the person with dementia would expect to find an object).

***What should I make certain is accessible, and what is okay to store out of sight.***

All safety items should in plain site. Medications must be accessible if they are self administered. Out of site items really have to be the choice of the person, some assistance or recommendations can be given but the person that uses the items generally knows best what they need on a daily basis.

***Because I have dementia, I can loose track of a project I am working on, how will organizing and cleaning through some of the things I don't really need help me?***

Less clutter and over stimulation will be better for any person. For our memory impaired family members it is easier to find something if there are not too many options of places to look. Signs and labels of where items are left can be helpful also.

***What are my options for organizing and downsizing?***

You can start the process on your own. We find many times people are overwhelmed and do not know "where" to start. A family member or close friend may be able to help. Professional organizers and Downsizing specialists are available to help.

**What should I do to ensure the people (organizers/movers/estate sales rep.'s) who come into my home to help me (if not family) are trustworthy?**

Insured, reputable individuals only. Ask for referrals and make sure to call the referrals. If someone is trying to force you to do what they think is best for your items remember they are your belongings and you have the ultimate say in what happens to your belongings.

**What is your experience with how people adjust to the transition? What should I expect right away? What about a few months down the line?**

Emotional trauma, fear, confusion are common. Expect to feel like "I cannot find a thing!" It will get easier as you go. By 30-60 days you should be oriented to your new home. Make sure to work with a company that will remain on call for you. Instead of getting frustrated and mad about not being able to find something, give them a call. Many times you can be directed where to find the items over the phone. If that cannot be achieved the company should be able to send someone back over to help you find it.

*Feel free to include other information that may be helpful to the audience. There will not be a facilitator directly asking you these questions directly, instead it is my hope that you would respond to these common concerns in your presentation. Because these are "Table Discussions", at the audience may have some questions, so I would allow for about 10 minutes of questions. This gives you about 35 minutes to speak, prior to questions.*

## **Ana Uetz, LMSW, Alzheimer's Association**

Ana Uetz of the Alzheimer's Association discusses how to make a successful transition to a new home.

Although most people are hopeful they will be able to remain at home throughout the disease process, situations occur where it is no longer possible. Your safety, first and foremost, is important in determining the appropriateness of your living arrangement. Therefore, sometimes it is the best choice for you to move out of your home to ensure a safer environment as well as a way to maintain your quality of life. However, this transition is often difficult and extremely emotional for all individuals involved.

### **Stay Involved**

- Communicate with family members as to the importance of your involvement in the decision-making process for moving
- Express your needs, wants, and desires regarding the move
  - Allow your feelings to be heard
    - Are you afraid?
    - Fear is often at the root of resistance to moving to a new home
    - Fear is a common feeling when discussing moving in with a family member or to a health care facility.

- Keep in mind you have dealt with big adjustments and transitions in the past and that there are people who care about you and who will help you adjust to your move
- Do you want to move?
  - Why or why not?
- Is your family member's home adapted to support your needs?
- Identify your needs
- Select the time of day you feel most calm and willing to talk about this decision with your care partner and/or family members involved
- It is okay and common to feel upset if you did not initiate a conversation about moving from your home to a loved one's home or to a health care facility
- Be patient with your own feelings and with family members' feelings
  - Why is this topic being discussed if you did not initiate it?
- Discuss alternative housing options with family and others who are involved
- Express your feelings and encourage family members to remain honest with you about their concerns; be honest with your family members about your own concerns about your health and safety
- Discuss having your family members arrange your new room similar to how your former room was arranged.

As difficult as this may be for everyone involved, it is important to remember the decision has been made for a reason and your health, safety, and well-being are most important to maintain.

### **Preparing To Move (To a Family Member's Home or to a Health Care Residence)**

- It is important for you to choose which personal belongings are important to you to bring to your new home
- Decide which items are most meaningful to you
  - Favorite arm chair, blanket, robe, etc.
  - Include pictures of yourself when you were younger (childhood to twenties) as well as pictures of family members
- Ask for help from family, friends, or an organization who can help you go through belongings and organize what is most valuable and necessary to bring with you to your new home
  - Talk to family members about setting up your new room prior to your arrival.
  - Try to rearrange the furniture so the room is set up similar to your former room, including where personal belongings are placed in drawers
  - Label doors and drawers with words or pictures to help assist you in finding your belongings after moving in
  - Label photographs with the names of the people in them to aid you in identifying family members and friends

## **Adjusting to a Move to a Loved One's Home**

- If you are moving into a loved one's home, be sure to sit down with them and create an activities calendar for you. It is important for you to socialize so as not to feel isolated
- An activities calendar gives you something to look forward to each day as well as offers a reference point to your schedule during the week
- Continue to participate in activities to stimulate your mind and keep you active, mentally and physically. Examples of activities, which may interest you include:
  - Crossword puzzles
  - Gardening
  - Yard work
  - Looking through photo albums or watching a home video
  - Knitting
  - Reading
  - Journaling
  - Painting
  - Attending an adult exercise class
  - Going to a museum or art gallery
  - Attending a support group for individuals with dementia
- Structure is important for a person who has a dementia diagnosis. Having a structured day will help you remain active and socialize with others
- Participate activities to prevent or decrease isolation, increase socialization, and enhance your quality of life

## **Adjusting to a Move to a Health Care Residence**

- If you are moving into a health care residence (such as an assisted living facility), the residence often has a monthly activities calendar with a variety of activities and events offered daily
  - This will help you meet new people, make new friends, and continue to stimulate your mind daily
  - Getting to know your neighbors in the health care residence will help you form new bonds and will provide support networks for adjusting to your new home
- Although it can be discouraging if your family members do not visit every day, your move can be an overwhelming and emotional transition for them too
- It is important to make a family member's visit meaningful for both of you:
  - Encourage your loved one to bring old photos, or even new ones to give you an update on how other family members are doing
  - Play your favorite music when they come
    - Encourage them to bring old music cassette tapes or CDs of your favorite music on them
  - Go for a walk outside with your family member on nice days
  - Take them to the dining hall to have a snack together
  - Introduce your family member to any new friends that you have made

## **Disclosure**

### **Kelly Carson**

A panel discussion with Kelly Carson, Marilyn Mould, and Gladys Hickey about feelings upon receiving diagnosis, about sharing the news with family and friends, etc.

When first diagnosed with dementia, there are many decisions for the person to make. One of the major choices is who to tell. Once that is decided, it is then when and how to tell family and friends. Today, I would like to talk with all of you about some of the emotions people go through upon receiving the diagnosis; the emotions their loved ones may experience; and how you may benefit from sharing your diagnosis with others. I will also touch on the community's perception of what dementia is and how we can all work together to help enlighten others about what living with dementia really means.

I would first like to start off by stating I do not claim for one second to know what it is like to be diagnosed with dementia. People who have been diagnosed often share (and rightfully, so) one cannot truly understand unless he or she has experienced something similar. Therefore, I will be drawing from experiences I've had in working with people who have dementia over the past six years, as well as from literature on this topic. I do feel I have gained perspective on diagnostic disclosure through my work. At the same time though I do not want anyone to mistake my "perspective" for anything other than just that.

I also want to stress that the process of being diagnosed with dementia and the decisions made regarding who to tell are intensely personal. Each person who is diagnosed has his or her own unique factors affecting how he or she processes this information, including their spiritual and cultural beliefs, personality, family support, previous life experiences, and cognitive ability. Because each person navigates through this experience differently, there cannot be a "cookie cutter" answer for how to go about making these choices. There is no right or wrong response. What I review today are common responses based on those we work with at the Alzheimer's Association, as well as a generalized view of how sharing your diagnosis may be helpful to you. I encourage anyone here who feels they are really struggling with their diagnosis and/or are fearful of telling others to speak with a Resource Specialist from the Alzheimer's Association or a trusted loved one. This may help you identify what in particular you are struggling with and what steps could be taken to address this.

It is the viewpoint of the Alzheimer's Association that the person being diagnosed with dementia has the right to know about the diagnosis. At times, family members decide not to tell their loved one because they are trying to protect them. I have heard family members say, "My mother would not be able to keep going if she knew she had Alzheimer's disease" and "What is the point of telling him?" The point is most people who have dementia are aware and have been aware for some time they have been and are experiencing changes. Many people share they felt they were "going crazy", and finding out that there is a medical cause for what is happening can be a relief. Other important reasons why telling the person is vital are to give them the opportunity to

make decisions about advance care planning and legal/financial matters as well as to participate in exploring treatment and future care options.

When deciding how to convey the news to the person who has been diagnosed, I encourage loved ones and the health care professionals involved to discuss how best to share this information with the person. Shape the discussion to fit the person's emotional state, medical condition, as well as their ability to remember and make decisions. Also review family dynamics and cultural values. Ideally, close family members should participate in this discussion to provide much-needed emotional support. Health professionals involved in the diagnostic process should also be present to provide information and answer questions. Consider the person's preferences to select the type of setting where the person would be the most comfortable. It may be helpful to identify the time of day best for the person, and in most cases, it is better to have more than one meeting; especially if there is a lot of information to review. Even if the person is unable to recall what was discussed, he or she may remember people cared enough to come together on his or her behalf.

A person receiving the diagnosis may respond in a number of ways. Therefore, it is important to stay flexible and to adapt to his or her reactions. It is normal to have an emotional response, and many may express anger, fear, and/or sadness. Some may not fully understand the meaning of the diagnosis or may initially deny it. If this occurs, accept the reaction and do not attempt to "convince" the person at that time. The topic can be approached again at another time. Others may be more receptive, and may ask for and appreciate additional information. If this is the case, consider visiting the Alzheimer's Association for information and details on local resources.

After receiving the diagnosis, people often experience a variety of emotions similar to Elizabeth Kubler-Ross' *Stages of Grief*. These stages include denial ("this isn't happening to me!"), anger ("why is this happening to me?"), bargaining ("I promise to pray every day if..."), depression ("I just do not care anymore about what happens to me."), and acceptance ("I'm ready to address this and move forward with my life."). The term, *stage*, is really arbitrary as people experience these emotions in different orders and for different lengths of time. Some move quickly to acceptance while others struggle with moving past one particular emotion, such as anger. Some might not experience each of these emotions, while others might revisit emotions more than once. Regardless of how a person experiences this process, it is important to remember that with any loss or series of losses, it is natural to grieve. It is also important to consider loved ones of the person with dementia may also be grieving and may very well experience similar emotions.

Most people diagnosed with dementia express wanting to have the power to decide who they tell, when those individuals will be told, and how. There is no blueprint for this, and again, it is a very individual process. Those who have decided to tell their loved ones have shared there are several benefits. First, telling loved ones provides them with the opportunity to be there for you. If they know what the diagnosis is, they can educate themselves and hopefully will gain a better understanding of what you are experiencing. This will better prepare your loved ones to assist and support you now and in the future. Sharing your diagnosis with your loved ones also provides them with the opportunity to seek support for themselves. Another reason why people with dementia might choose to share their diagnosis is so their loved ones understand they may say or do things they would not normally say or do, and that these changes are happening as a result of the disease process.

Some people choose to tell their loved ones right away, while others may wait for a time that feels "right". Just as your loved ones hopefully considered how to best share your diagnosis with you, also consider how to best share the news with them. If these decisions are difficult for you to make independently, then enlist a close friend or family member to assist you in this process. For those whose dementia prevents them from making these kinds of decisions, the same process applies for the person's immediate loved ones.

Unfortunately, not everyone may be as accepting and supportive as you would hope. This could occur for various reasons, including lack of knowledge about dementia, inability to accept the diagnosis, or fear. In these cases, the person with dementia should do whatever he needs to do to take care of himself. If this means letting go of those who are unable or unwilling to be supportive, that is okay. Surrounding yourself with people who will love you and support you no matter what is key. If you feel a lack of support from your loved ones, consider other ways to increase your support network. This could be done by attending a support group offered by the Alzheimer's Association and/or by participating in other activities in your community.

Going along with today's theme, sharing your diagnosis may not only be beneficial to you, but to your community as well. Many people still lack an accurate understanding of what dementia is. Our agency is always working towards reducing the stigma and you can assist us in raising awareness. If you are able to and feel comfortable doing so, take the opportunity to share with others that a person with dementia can still live a meaningful and happy life. Demonstrate that while you may be experiencing changes in some of your abilities, you still have many strengths; that you are no less valuable of a person. If you are interested, the Alzheimer's Association would be happy to provide you with additional opportunities for advocating for yourself and other people in the community living with dementia.

I do want to readdress the point that taking care of yourself is the most important piece of this entire process. It is crucial to identify what is important to your physical, emotional, and mental well-being as well as to take steps to maintain your happiness and health. The same applies to your loved ones. If educating others is too draining for you, do not feel charged to make this your responsibility. Give yourself permission to cut out activities that no longer make you happy. Focus on what brings you joy and

meaning to your life, whether that is spending time with your family, maintaining involvement in your church and/or community, exercising, socializing, or some other activity or interest that is important to you.

## **Marilyn Mould**

### **Diagnosis / Treatment**

- Husband noticed symptoms and became concerned
- Diagnosed four years ago via an MRI
- Been on Aricept for four years
- Slow progression

### **My Reaction**

- Surprised with diagnosis
- Didn't think I had changed; my mind works great most of the time
- Didn't dwell on diagnosis
- Lived a charmed life; didn't affect self-esteem; could accept my own frailties if others are accepting of them

### **Who I Told? When? Reactions**

- Shared my diagnosis with everyone in my life: family, friends, spiritual community
- Shared immediately; did not feel a need to hide or prepare for disclosure
- Family and friends were concerned, supportive, genuinely interested in knowing more about the diagnosis and about Alzheimer's disease

### **What Has Helped**

- Having a support system made things easier: loving husband, three caring children, wonderful friends, great spiritual community
- Focusing my attention on the care of others lessened perception of personal problems; kept my esteem intact
- Living in a supportive environment; St. John's Meadows has been rewarding
- Experiencing slow progression; allows me to adapt
- Remaining active in church and community keeps me involved
- Enjoying hobbies: playing the recorder; listening to music

### **Advise to Others**

- Confide in a friend
- Alzheimer's disease is very common
- There are many in the community still without a diagnosis
- Stay positive; you still have much to offer
- Most of all - be grateful for everything life has given you

## **Gladys Hickey**

### ***What were your initial feelings after you were given your diagnosis?***

Surprised, a little scared, but mostly acceptance. I wanted to know what I could do about it. I felt lucky that was all it was – I didn't want to have a stroke or something worse. And we had plenty of time to plan ahead for things.

### ***What did you think your boss might say or do if you told him/her?***

One boss, where I was doing filing and office work, I knew would want to let me go. That was ok because I really didn't like working there anymore. Things were a little confusing and they weren't always that nice to work with.

My other boss, at my church where I clean the kitchen, I was a little worried about, but they knew I was doing a good job so I thought it would be ok.

### ***How did you think your children would react to the news?***

I thought they would accept it. After all, what are you going to do? I knew most of my kids would help me with it, but some might be a little upset. They all knew I had been having some problems for a while.

### ***Because we are all human and handle news like this differently, I am sure some of your family handled the news differently?***

Yes, they did. Most of them asked what they could do to help. For example, helping me understand it and taking me to workshops and support groups. One of them was upset with me about it and wanted me to stop talking about it or telling anyone that I had it. I just prayed about it and did what I thought was right.

### ***How did this make you feel?***

For the most part, I felt ok about it. I thought I could tell people and talk about it if I wanted to. At the same time though, I didn't want to upset anyone.

### ***Relieved now that you knew why you were having difficulty recalling some things and that you could share this news with those who cared about you most?***

Yes, I was glad my doctor was so intelligent and picked up on it so quickly. I had been having trouble for a while and sometimes I felt upset with myself when I would forget things. Now I could find out what to do about it.

### ***Scared that those who cared about you most might take the news pretty hard and that it might frighten them?***

I knew some would be upset, but like I just said, said some prayers about it.

### ***Is there anyone you have decided not to tell?***

Not really, but I left it to my kids to tell their own children when they felt the time was right.

***Is there anyone you said you wouldn't tell, but since have?***

No.

***How have those you have shared your diagnosis with accepted this?***

Most have been surprised because I am doing so well. They appreciate I have a positive attitude about it and can tell them a lot about it from all of the research and workshops. They are all so kind; some have been very thankful for the information. I feel good that I have helped them with someone in their life who was having problems, but had not been evaluated for this.

***Often times people with dementia report that their friends make statements like, "I forget all the time too". Sometimes statements like these are comforting. Other times these statements make people with dementia feel like their well-meaning friends are slighting a very real problem they are facing. Do statements like this comfort you or upset you?***

It doesn't really matter.

***What would you tell others about how to go about having a discussion with their loved one about their diagnosis?***

First, make sure you find out a lot about it so you can feel good about what you know yourself. Go to the Alzheimer's Association and ask them for help; they are wonderful people. They have lots of books and videos, as well as support groups you can attend to learn more as well as meet other people who are having the same problems. Say some prayers and be positive. After all, what are you going to do? We are really lucky. There is so much to learn and so many things we can do about this. When you tell them, don't worry if they are upset. Just say some prayers and keep on doing what is right. Try not to get mad at anyone, just be accepting. They will learn that it is all going to be ok.

## **Staying Active**

### **Andrew Little**

Andrew Little along with staff of the Pieters Family Life Center will discuss ways individuals can maintain their physical activity as they age as well as adapt physical activity to changing life circumstances or abilities. Central to this concept is the role of the caregiver in this process. Families and professional caregivers are critical in supporting those with dementia in maintaining their physical activity. We will lay out specific strategies that caregivers can implement that will provide proven health benefits to the individuals they support as well as for themselves.

Areas covered will include:

1. The importance and benefits of being physically active- physically, mentally, socially, and spiritually.
2. Specific physical activity programs promoting cardiovascular endurance, strength, and flexibility.
3. Discuss how cardiovascular endurance, flexibility, and strength conditions are beneficial to individuals with dementia.
4. How to identify and incorporate an individual's personal interests and passions into a physical activity program.
5. Research showing the relationship between a lack of physical activity and an increase risk of dementia.
6. How increased physical activity can benefit the caregiver.
7. We will discuss the Pieters Family Life Center and all of our programs focusing on our small group, individually focused fitness, and wellness programs.

## **Wrap-up**

### **Laughter Lightens Panel**

A panel discussion on the benefits of humor, love and appreciation will feature Terry and Patti Christensen, Barbara Gramkee, and Alan Whiting. These individuals exemplify this concept by keeping an optimistic, upbeat outlook on life by remaining flexible, stopping to smell the roses, while relieving stress and drawing closer through laughter. They will share their experiences and perspectives.

## **Closing Remarks**

### **Audrey Brady**

Sixteen months ago I attended a similar conference in NYC. From that occasion, I discovered the power inside each individual in attendance; their thirst for knowledge; their enthusiasm to utilize the new tools and resources discovered; and most especially, the camaraderie developed almost immediately amongst the group. I can assuredly say I have taken witness to those same themes and so much more.

It is the mission of the Alzheimer's Association to support people with dementia and their care partners in innovative ways to meet their evolving needs while funding research to one day develop a cure for Alzheimer's disease. It is this commitment and the inspiration of that momentous day in April of last year that fueled the engine to drive today's event. However, it is the effort expended by those donating their time and experience that brought us here to this rich occasion. For this, I would like to thank you for being a part of this important day.

I would like to personally share my appreciation for the dedication and contributions of the Planning Committee, the presenters, the underwriters, today's docents, and last-but certainly not least -You! There is an energy permeating from your participation and interest. The support from the community agencies in attendance today and your engagement in their offerings will strengthen what we can do together and display the true meaning of community. I am very grateful to have had honor of getting to know some of you and look forward to those of you I will get to know better as a result of today. Many have shared they were unaware of the wealth of resources available in our very own neighborhoods. Others have shared the connections they have made as a result of finding someone else in the same situation and have made a vital connection. There are also those who have shared their personal growth through education and narratives presented today.

I encourage you all to reach out and continue a relationship with us and the other community partners you may have met today. There is so much inside each and every one of you. I am honored to have had the opportunity to know some of you, and look forward to meeting those of you who will take advantage of the myriad of programs and services the Alzheimer's Association provides. Thank you once again for making this first ever conference for people with dementia such a momentous day!

## Information Stations

### Overview

Information stations have been designed to provide you with a variety of resources.

### **ADCARE: Alzheimer's Disease Care, Research and Education Program**

The Alzheimer's Disease Research Program and the Memory Disorders Clinic of the University of Rochester Medical Center were established in 1986 at the University of Rochester. Located at Monroe Community Hospital, AD-CARE and the Memory Disorders Clinic provide services for families affected by dementia and related memory disorders. Advancement of clinical research is a fundamental mission of the AD-CARE program. We participate in a number of national and worldwide studies, offering individuals with memory problems the opportunity to become involved in current research initiatives. Many of our clinical studies include cutting edge medicines that may not be available to the general public. Specialists who have expertise in dementia treatment and research direct the day-to-day activities of our clinical studies. We conduct studies concerning:

- Early memory problems or cognitive impairment
- Diagnostic tools used for Alzheimer's disease
- All stages of Alzheimer's disease
- Behavioral disturbances in persons with dementia

For more information regarding current studies, please call (585) 760-6550.

### Advocacy

The Alzheimer's Association develops, implements and advocates for initiatives that take into consideration the needs of persons with dementia and their caregivers within our local communities as well as at the State and Federal levels. Advocacy is a major component of the Alzheimer's Association mission. Advocates are people with Alzheimer's and related disorders, caregivers, friends and families whose voices together are a powerful tool for change and hope of a future without Alzheimer's. For more information, email Senior Vice President Sharon Boyd at, [sharon.boyd@alz.org](mailto:sharon.boyd@alz.org) and log on to [www.actionalz.org/](http://www.actionalz.org/) to become a champion!

### Arts and Cultural Council for Greater Rochester

The Arts & Cultural Council for Greater Rochester is the local arts agency for the Rochester, New York metropolitan region. It is our mission to develop, promote and strengthen the cultural industry for the benefit of the people of the Rochester region. The Arts Council directly serves the cultural community— artists and cultural organizations— as well as the community at large.

## **Catholic Family Center**

Rooted in love, justice, and trust, a respect for the dignity and of life and spirit of hope, Catholic Family Center partners with people- especially the venerable and those facing poverty- to help them achieve their full human potential. Offering a wide variety of services including:

- STAR-Provides non-medical home support to frail elders including grocery shopping, transportation, friendly visiting, essential errands, banking, occasional yard work and chores. Within STAR is ESTRELLA - services provided to Hispanic older adults utilizing bilingual volunteers.
- PATHS (Professional Assessment and Treatment of Homebound Seniors) - provides in-home assessment and counseling to homebound older adults experiencing symptoms of anxiety and/or depression which interfere with their daily activities.
- HomeWorks-program provides very low cost scheduled and emergency in home repair, cleaning, and maintenance services to seniors (60+) and disabled people throughout Monroe County.
- Expanded In-home Services for the Elderly Program (EISEP) assists older adults who need minimal assistance with housekeeping and/or personal care and non-institutional respite services through various social adult day programs. EISEP services are intended for long term, non-medical situations. EISEP also matches each client with a case manager who helps determine what help is needed and provides on-going guidance to the client and family.

## **The Community Place of Greater Rochester, Inc. (CPGR)**

CPGR provides our burgeoning senior population with both group and individual programs and services designed to help the young-at-heart get more from their golden years. Programs and services include:

- The Senior Centers
- Frail and Elderly Case Management
- Foster Grandparent Program
- Senior Companion Program: Companion volunteers provide a variety of services including transportation for grocery shopping and doctor's appointments, caregiver respite, meal preparation and socialization.

For additional information, contact Katy Allen, director, Aging Services, at 585-288-0021 or [kallen-caballero@communityplace.org](mailto:kallen-caballero@communityplace.org)

## **Just Friends Social Club**

The Alzheimer's Association Just Friends Social Club is a partnership between the Alzheimer's Association and Just Friends Senior Center of Catholic Family Center. The program provides people in the early stages of dementia and a family member or friend an opportunity to socialize within a safe and nurturing environment with others.

Just Friends Social Club meets twice each month and provides:

- A variety of activities and social events on and off site
- Social interaction
- Catered dinner
- Transportation as needed
- Companionship as needed

Pre-registration is required. To register, please call Ana Uetz, Resource Specialist, at 585-760-5408.

## **Learning Institute™**

In 2000, the Alzheimer's Association established the Learning Institute to ensure that the information about Alzheimer's disease it provides has been rigorously corroborated by the most advanced clinical and scientific research findings and meets the highest standards of accuracy. The Learning Institute™ provides dementia specific and general caregiving educational programs and consultative services for professional and non-professional caregivers, businesses and the community. Faculty of the Learning Institute™ includes well respected clinicians, researchers and physicians in the field of dementia care.

## **The Importance of Education for Family Caregivers**

More than 7 out of 10 people with Alzheimer's disease live at home, where family and friends provide almost 75 percent of their care. The challenges posed by a family member with Alzheimer's disease, such as personality and behavioral changes, can overwhelm the unprepared caregiver. The Learning Institute's educational programs for families and non-professional caregivers provide participants with strategies to cope with the complexities of caring for a person with the disease. Participants also gain the knowledge and skills necessary to successfully partner with physicians and other health care professionals in order to provide the highest-quality dementia care possible.

## **The Value of Professional Caregiver Education**

The Learning Institute™ professional education programs are designed to bring to health care, residential care and community service organizations specialized training in dementia care. This enables facilities to provide the quality of care that consumers are demanding. Health care administrators recognize that providing staff with continuing education and with opportunities to refine their skills, not only enhances the facility and the quality of care provided, but also reduces stress and ensures retention of an invaluable workforce. Nurses, CNAs, Activities Directors and many other professionals in the field are demanding Alzheimer's specific training. To be better prepared to respond to the increased challenges of their employment, healthcare professionals want to learn about the latest standards of care and they seek to gain a better understanding of the disease process and its unique clinical challenges.

## **Education Programs**

The Alzheimer's Association Learning Institute™ offers a variety of ongoing educational programs targeted to specific audiences- health care and social services professionals, individuals with the disease and their families, and the general public—as well as customized speaking engagements and consultative services. The Learning Institute™ programs are held at different locations throughout the Alzheimer's Association's nine county region. The Institute also offers web-based, interactive training. Some educational programs offer continuing education (CE) credits. All Learning Institute's educational programs are evaluated against national benchmarks.

- The Leader in Dementia Education
- On Site Education for Professionals
- Train the Trainer© Catalog
- Promotional Packages
- Developmental Disabilities & Dementia Education
- Online Courses
- Business & Community Education Workshops
- Consultation Services
- Activity Assessment Services
- Volunteer Training

## **Lifespan**

Lifespan offers older adults and their caregivers a wide array of free and fee-based non-medical services to help you take on the joys and challenges of aging. Some of their programs and services include:

- Elder Abuse Prevention Program
- Eldersource: Eldersource has four eldercare specialists providing advice and information by telephone AND we also have professional care managers who can meet with you in person. In our care management role, we get to know you, your family and your unique eldercare situation. We make home visits to assess your situation, make recommendations for care, and we can help implement our recommendations.
- Financial management
- Long-term Care Insurance Education and Outreach
- Health Insurance Information Counseling and Assistance
- Ombudsman
- Guardianship
- Geriatric Addition
- HEAP: Home Energy Assistance Program
- Home Safe Home Program

Please call 585-244-8400 or visit us at [www.lifespan-roch.org/](http://www.lifespan-roch.org/)

## **Memories in the Making®**

The Alzheimer's Association is proud to offer Memories In The Making® (MIM) a program of creative art expression for people with Alzheimer's disease. Memory in the Making offers art as a means to enhance communication, increase self-esteem and provide sensory stimulation for participants. We have several participating programs that are currently offering Memories In The Making®. Please call 585-760-5400 for the most current listing.

## **Offices of the Aging: Monroe, Livingston, Ontario, Wayne, Seneca, and Yates**

It is the mission of the New York State Office for the Aging (NYSOFA) to help older New Yorkers to be as independent as possible for as long as possible through advocacy, development and delivery of cost-effective policies, programs and services which support and empower the elderly and their families, in partnership with the network of public and private organizations which serve them.

### **Pieter's Family Life Center**

The Pieters Family Life Center is designed to serve the health and wellness needs of those with and without disabilities, and promote community inclusion in a bright, open active environment for people of all ages.

- A fitness room with universally accessible equipment and the region's only HydroWorx 2000 pool;
- Affordable memberships, starting at \$15 a month;
- A qualified staff that specializes in treating neurological conditions, back pain, arthritis, strains, and sports injuries;
- Traditional therapies such as speech, physical, and occupational, in collaboration with Unity Physical Therapy & Rehabilitation;
- Creative therapies like massage, art, music, and dance;
- Multi-purpose gymnasium for sports and recreational programs like basketball, volleyball and more;
- Creative studios for arts and cultural activities like painting, music, and dance;
- A wide range of programs for children, adults, and seniors including aerobics, movie nights and family support groups;
- The Garden Café with free wireless Internet; and
- Kitchen space for nutrition and cooking classes!

Contact us for more information at (585) 487-3500  
[info@heritagechristianservices.org](mailto:info@heritagechristianservices.org) or visit us at 1025 Commons Way, Rochester, NY, 14623.

## **Preferred Care Gold's' SilverSneakers® Fitness Program**

Members of Preferred Care Gold plans can participate in the SilverSneakers® Fitness Program **at no additional cost** and take advantage of a number of fitness benefits. The SilverSneakers Program, as featured in TIME Magazine, includes classes and use of equipment and other programs at a safe, warm, friendly fitness center in your area, a fun group exercise class designed to increase strength, flexibility and energy (you can share some laughter while you're there), and social events at which you can make new friends with some great people! For more information about the Program, Gold members please call Preferred Care Member Services, Monday - Friday, 7:00 am - 8:00 pm, (585) 327-2480 or (800) 665-7924 Eastern Time, TTY users may call (585) 325-2629 or (800) 252-2452 or log onto the [www.preferredcare.org/featured/silversneakers.html](http://www.preferredcare.org/featured/silversneakers.html)

## **Resource Center™**

### **24-Hour Help Line**

Information and reliable guidance is provided 24 hours a day, seven days a week by calling 800-272-3900.

## **Information and Referral**

The Association provides information about Alzheimer's disease. It also helps individuals, families and professionals learn about, and receive referrals to services and resources offered in the community.

## **Care Consultation**

The Association provides services to assist consumers and their families in planning for, and dealing with, all aspects of the illness experience. Components of care consultation include: assessment of needs, assistance with planning and problem solving, the development of an action plan, and provision of support.

## **Ann Lib Kozel Counseling Program**

The Alzheimer's Association offers fee-based counseling services designed to assist individuals and their families in planning for, and dealing with changes brought about throughout the disease process. For those experiencing financial hardship a sliding fee scale is available thanks to the generous support of the Kozel family in honor of their mother and sister. Counseling is provided by Masters prepared social workers with expertise in dementia-specific issues.

## **CareLine**

CareLine is a program in which a trained volunteer provides support to a caregiver in the community by telephone. When a caregiver is enrolled in the program, he or she is linked with a volunteer. The volunteer will then contact the caregiver, and together they decide when and how often to talk. The service can continue for as long as the caregiver needs the service. Both parties are only given each other's first name, and the same volunteer will follow the caregiver throughout the service unless otherwise requested.

## **Marie C. and Joseph C. Wilson Library**

The Alzheimer's Association library has an extensive collection of print and other media resources including family caregiving skills, best clinical practices, and inspirational coping techniques. In total, the library holds over 400 books on the innumerable topics related to dementia and 150 other tools, such as memory boxes and DVD's on supporting a person with dementia in their activities of daily living. While these resources are all available for lending, we also have a small collection of notable books for purchase. For your convenience, we can mail books and DVD's directly to your home or business.

## **MedicAlert and Safe Return<sup>®</sup>**

Medic Alert + Safe Return is a nationwide identification, support and enrollment program that provides assistance and access to vital medical information when someone with Alzheimer's disease or related dementia wanders or becomes lost locally or far from home. Assistance is available 24 hours a day, every day, whenever a person is lost or found. The program also provides education on techniques to prevent wandering behavior for families and caregivers and education for emergency responders and law enforcement on ways to approach and respond to the individual who has wandered.

## **Project Caregiver Connect**

The Alzheimer's Association has received a Legislative Initiative to connect families caring for a loved one with Alzheimer's disease to supportive services in Chemung, Livingston, Monroe, Ontario, Schuyler, Seneca, Steuben, Wayne and Yates counties. Services begin with an in-home assessment completed by the Alzheimer's Association. From the home assessment a written Plan of Services will be developed that may include the following services at no cost:

- Care Consultation
- Counseling
- Hands-On Education: Dementia Care Specialists come into the home and demonstrate care techniques to caregivers in areas they are struggling.
- Home Safety Assessment: To identify potential safety hazards in the home. Assessments are completed by an occupational therapist. (Each consulting occupational therapist has received special training from the Alzheimer's Association on dementia care.)
- MedicAlert®+ Safe Return®
- Respite

## **Support Groups**

The purpose of a support group is to provide an opportunity for persons with dementia, family members, friends or care partners the opportunity to meet regularly for mutual emotional support and to exchange coping skills with one another in matters relating to dementia. We have a variety of support group types:

- Caregivers
- Persons with Dementia
- Early Stage Support Group (For persons with dementia and their care partners)

## **Respite**

The Alzheimer's Association has five different types of respite care for families caring for a loved one with Alzheimer's disease. Respite services are short-term and intended to provide the caregiver with a break from their caregiving role, as well as offer an opportunity for the caregiver to meet his/her own personal needs. Respite is provided by a Dementia Care Specialist (DCS) from a licensed home care agency who has been approved by the Alzheimer's Association.

## **Volunteering**

Join the more than 35,000 volunteers whose services are critical to every program and initiative of the Association. Call 585-760-5400 to find out the most current volunteer needs.

## Resources by County

### **Chemung County Resources**

#### **Caregiver Support Group:**

##### ***Elmira***

Meetings are held on the second Wednesday of each month from 1:30- 2:30 pm at the Stafkings Health Care office, which is located at 221 W. Church St. in Elmira

#### **Additional Local Resources:**

##### **Chemung County Office for the Aging**

607.737.5520

425 Pennsylvania Avenue

PO Box 588

Elmira, NY 14902-0588

##### **Medicaid**

607.737.5309

Chemung County DSS

Human Resource Center

425 Pennsylvania Avenue

PO Box 588

Elmira, NY 14902-0588

##### **Long-term Care Ombudsman**

Kim Salisbury

607.737.5520

Email: [ksalisbury@co.chemung.ny.us](mailto:ksalisbury@co.chemung.ny.us)

**Home Care Services:**

**Americare**

703 East Church Street  
Elmira, NY 14901  
(607) 732-3502

**CareGivers**

1300 College Avenue, Suite 3  
Elmira, NY 14901  
(607) 733-4504

**Family Services**

1019 East Water Street  
Elmira, NY 14901  
(607) 733-5696

**Home Sweet Home Care**

728 West Broad Street  
Horseheads, NY 14845  
(607) 739-1447

**Stafkings**

221 West Church Street  
Elmira, NY 14901  
(607) 734-3646

**Adult Housing & Assisted Living:**

**The Barton Home**

301 Grove Street  
Elmira, NY 14905  
(607) 733-6151

**\*Bethany Village**

3005 Watkins Road  
Horseheads, NY 14845  
(607) 739-8711

**Cogswell's Rest Haven**

958 Lake Street  
Elmira, NY 14901  
(607) 734-8728

**The Falls Home**

117 Schuyler St.  
Montour Falls, NY 14865  
(607) 535-7165

**Tioga Living Center**

37 N. Chemung St.  
Waverly, NY 14892  
(607) 565-6228

**Woodbrook**

1250 Maple Avenue  
Elmira, NY 14904  
(607) 734-7741

**Social & Medical Model Day Programs:**

**Bethany Village Adult Social Day Care**

3005 Watkins Road  
Horseheads, NY 14845  
(607) 739-8711

**Elcor Health Services DayTyme Program**

48 Colonial Drive  
Horseheads, NY 14845  
(607) 739-3654 ext.254

**Pathways Adult Dynamics**

130 West Water Street  
Painted Post, NY14870  
(607) 936-0111

**Overnight Respite:**

**Bethany Village**

3005 Watkins Road  
Horseheads, NY 14845  
(607) 739-8711

**Three Rivers Long Term**

Health Care Facility  
101 Creekside Drive  
Painted Post, NY 14870  
(607) 936-4108

**Skilled Nursing Facilities:**

**Arnot-Ogden Medical Center Residential  
Health Care Facility**

600 Roe Avenue  
Elmira, NY 14905  
(607) 737-4100

**\*Bethany Village**

3005 Watkins Road  
Horseheads, NY 14845  
(607) 739-8711

**Chemung County Health Center--Nursing Facility**

103 Washington Street  
Elmira, NY 14901  
(607) 737-2001

**\*Elcor Nursing Home**

48 Colonial Drive  
Horseheads, NY 14845  
(607) 739-0304

**St. Josephs Hospital--Skilled Nursing Facility**

555 East Market Street  
Elmira, NY 14902  
(607) 733-6541

\* Dementia Unit

## **Livingston County Resources**

### **Caregiver Support Groups**

#### ***Dansville***

Meetings are held on the 1<sup>st</sup> Monday of every month from 7:00- 8:30pm at the Noyes Memorial Hospital, Conference Center, which is located at 111 Clara Barton.

#### ***Geneseo***

Meetings are held on the 2<sup>nd</sup> Tuesday of every month from 1:00- 2:30pm at the United Methodist Church, located at 4520 Genesee Street.

### **Additional Local Resources:**

#### **Livingston County Office for the Aging**

585.243.7520

8 Murray Hill Drive

Mt. Morris, New York 14510

#### **Medicaid**

585.243.7300

Livingston County DSS

3 Livingston County Campus

Mt. Morris, New York 14510-1699

#### **Long-term Care Ombudsman**

Marie Frey

585.244.8400 ext. 114

Email: [mfrey@lifespan-roch.org](mailto:mfrey@lifespan-roch.org)

### **Home Care Services:**

#### **CareGivers**

5297 Parkside Drive

Canandaigua, NY 14424

(585) 394-6090

#### **Catholic Charities**

10 Chapel Street

Mt. Morris, NY 14510

(585) 658-4466

**Lifetime Care Home Health**

3111 Winton Road South  
Rochester, NY 14623  
(585) 214-1000 or (800) 598-4995

**Livingston County Home Health Agency**

2 Livingston County Campus  
Mt. Morris, NY 14510  
(585) 243-7209

**Adult Housing:**

**Alpine Manor**

2714 Poplar Hill Road  
Lima, NY 14485  
(585) 346-5880

**Elijah House of Leicester**

134 Main Street  
Leicester, NY 14481  
(585) 382-3530

**King's Daughters and Sons Home**

26 Health Street  
Dansville, NY 14437  
(585) 335-2540

**Morgan Estates**

4588 Morgan View Road  
Geneseo, NY 14454  
(585) 243-6000

**Nunda Community Home, Inc.**

4 Massachusetts Street P.O. Box 516  
Nunda, NY 14517  
(585) 468-5500

## **Skilled Nursing Facilities**

### **Avon Nursing Home**

215 Clinton Street  
Avon, NY 14414  
(585) 226-2225

### **Conesus Lake Nursing Home**

6131 Big Tree Road, Box F  
Livonia, NY 14487  
(585) 346-3001

### **Livingston County Campus**

Skilled Nursing Facility  
11 Murray Hill Drive  
Mt. Morris, NY 14510  
(585) 243-7200

### **Livingston County Nursing Facility**

4223 Lakeville Road / 4600 Millennium Drive  
Geneseo, NY 14454  
(585) 243-3340

### **Morgan Estates**

4588 Morgan View Road  
Geneseo, NY 14454  
(585) 243-6000

## **Medical Model Day Program:**

### **Livingston County SNF**

#### **Adult Day Health Program**

11 Murray Hill Drive  
Mt. Morris, NY 14510  
(585) 243-7219

**Overnight Respite:**

**Avon Nursing Home**

215 Clinton Street  
Avon, NY 14414  
(585) 226-2225

**Conesus Lake Nursing Home**

6131 Big Tree Road, Box F  
Livonia, NY 14487  
(585) 346-3001

**\*Livingston County Center for Nursing and Rehabilitation**

11 Murray Hill Drive  
Mt. Morris, NY 14510  
(585) 243-7800

\* Dementia Unit

**Monroe County Resources**

**Monroe Caregiver Support Groups**

***Brockport***

Meetings are held on the 2nd Thursday of every month from 7:00-8:30 pm at the Brockport Methodist Church, which is located at 6787 Fourth Section Road.

***Fairport***

Meetings are held on the 1<sup>st</sup> Tuesday of every month from 1:00-2:00 pm at the Church of the Assumption, which is located at 20 East Avenue.

***Gates***

Meetings are held on the 3<sup>rd</sup> Monday of every month from 1:00-2:30pm at the Gates Town Hall, which is located at 1605 Buffalo Road.

Meetings are held on the 3<sup>rd</sup> Wednesday of every month from 6:00-8:00pm at Seabury Woods, which is located at 110 Dalaker Drive.

***Greece***

Meetings are held on the 2<sup>nd</sup> Tuesday of every month from 7:00-8:00pm at Crimson Ridge, which is located at 1 Treeline Drive Conference.

Book Discussion Group (using the book "Creating Moments of Joy" by Jolene Brackey)  
Meetings are the 2<sup>nd</sup> Tuesday of every month from 1:30 – 3:00pm at Park Ridge Living Center, which is located at 1555 Long Pond Road.

**Henrietta**

Meetings are held on the 3<sup>rd</sup> Tuesday of every month from 6:00-7:30pm at Monroe Community Hospital, 3<sup>rd</sup> Floor, Alzheimer's Association Education Room, Faith Building, which is located at 435 East Henrietta Road.

Meetings are held on the 4<sup>th</sup> Wednesday of every month from 4:00-5:00pm at Monroe Community Hospital, Fireside Lounge, 6<sup>th</sup> floor, Faith Building, which is located at 435 East Henrietta Road.

**(For People with Dementia)** Meetings are held on the 3<sup>rd</sup> Tuesday of every month from 6:00-7:30pm at Monroe Community Hospital, 3<sup>rd</sup> floor, Alzheimer's Association, which is located at 435 East Henrietta Road.

**(For People with Dementia)** Meetings are held on the 1<sup>st</sup> Thursday of every month from 1:00-2:00pm at Monroe Community Hospital, 3<sup>rd</sup> Floor, Alzheimer's Association, Education Center, which is located at 435 East Henrietta Road.

Meetings are held on the 1<sup>st</sup> Thursday of every month from 1:00-2:00pm at Monroe Community Hospital, 3<sup>rd</sup> Floor, Alzheimer's Association, Abiuso Conference Room, which is located at 435 East Henrietta Road.

**Irondequoit**

Meetings are held on the 3<sup>rd</sup> Thursday of every month from 1:00-2:00pm at St. Cecilia's Church, which is located at 2732 Culver Road (Between 104 and E. Ridge Rd.)

**Penfield**

Meetings are held on the 3<sup>rd</sup> Wednesday of every month from 7:00-8:30pm at Penfield Library & Community Center, which is located at 1985 Baird Road. (Ask Information desk for room location)

**Perinton:**

Meetings are held on the 3<sup>rd</sup> Thursday of every month from 6:30 – 8:00pm at Perinton Park Manor, which is located at 7 Chardonnay Drive, Fairport.

**Pittsford**

Meetings are held on the 2<sup>nd</sup> Wednesday of every month from 12:30-2:00pm at Pittsford Library, Fletcher Steele Room, which is located at 24 State Street.

**Rochester**

Meetings are held on the last Monday of every month from 9:30-11:00am at St. Bernard's at Park Place, Building 5, which is located at 2260 Lake Avenue.

Meetings are held on the last Tuesday of every month from 4:30 – 5:30pm at St. Ann's, which is located at 1500 Portland Avenue.

**Webster**

Meetings are held on the 3<sup>rd</sup> Wednesday of every month from 4:00 – 5:00pm at Cherry Ridge, which is located at 900 Cherry Ridge Boulevard.

**Additional Local Resources:**

**Monroe County Office for the Aging**

585.753.6548

111 Westfall Road

Rochester, NY 14620

**Medicaid**

585.753.6298

Monroe County DSS

111 Westfall Road

Rochester, New York 14620

**Long-term Care Ombudsman**

Marie Frey

585.244.8400 ext. 114

Email: [mfrey@lifespan-roch.org](mailto:mfrey@lifespan-roch.org)

**Certified Home Health Agencies (CHHAs):**

**Home Care of Rochester**

85 Metro Pk

Rochester NY 14623

(585) 272-1930

[homecarerochester.com](http://homecarerochester.com)

**Lifetime Care**

3111 Winton Rd. S

Rochester NY 14618

(585) 214-1000

[lifetimecare.org](http://lifetimecare.org)

**Visiting Nurse Service**

2180 Empire Blvd.

Webster NY 14580

(585) 787-2233

[vnsnet.com](http://vnsnet.com)

**Licensed Home Care Services Agencies (LHCSAs):**

**All Metro Health Care**

**3300 Monroe Ave.**

Rochester 14618

(585) 381-6240

**American HomePatient/PrimaCare**

1851 Empire Blvd.

Webster 14580

(585) 787-0100

**Angels in Your Home (Hilton East)**

231 East Ave.

Hilton 14468

(585) 392-7171

[hiltoneast.com](http://hiltoneast.com)

**CareGivers**

2260 Lake Ave.

Rochester 14612

(585) 458-2150

[caregivershomecare.com](http://caregivershomecare.com)

**Companion Care of Rochester Inc.**

465 Blossom Rd.

Rochester NY 14610

(585) 546-1600

**Interim Healthcare**

347 East Ave.

Rochester NY 14604

(585) 454-4930

[interimhealthcare.com](http://interimhealthcare.com)

**Maxim Healthcare Services**

311 Alexander St.

Rochester NY 14604

(585) 454-3550

[maxhealth.com](http://maxhealth.com)

**NurseFinders**

Loehman's Plaza  
Rochester NY 14618  
(585) 271-6960  
(Note: facilities care only)

**Rural / Metro**

177 University Ave.  
Rochester NY 14605  
(585) 546-2393

**Serenity Homecare, Inc.**

3897 Rush-Mendon Rd.  
Mendon NY 14506  
(585) 624-4550  
bridgesofmendon.com

**Sibley Nursing Service**

1100 University Ave.  
Rochester NY 14607  
(585) 454-1700  
excellusbcbs.com

**Signature Care (Visiting Nurse Service)**

2180 Empire Blvd.  
Webster NY 14580  
(585) 787-2233  
vnsnet.com

**Traditions in Caring**

1580 Elmwood Ave.  
Rochester NY 14620  
(585) 241-9580  
traditionsincaring.com

*Note: Collaboration by 5 nursing homes.*

**Unity Care at Home**

1477 Long Pond Rd.  
Rochester NY 14626  
(585) 368-7324  
unityhealth.org

**Unlimited Care**

1465 Jefferson Rd.  
Rochester NY 14623  
(585) 272-8800

**We Care Home Nursing Service**

1678 Empire Blvd.  
Webster NY 14580  
(585) 671-1920

**Westside Home Care**

80 Clinton St.  
Brockport NY 14420  
(585) 637-7215

**Long-Term Home Health Care Programs (LTHHCPs):**

**Unity Park Ridge at Home**

(585) 368-6342  
unityhealth.org

**Visiting Nurse Service (VNS)**

(585) 787-2233  
vnsnet.com

**Adult Housing:**

**\*Alterra Clare Bridge**

159 Sullys Trail  
Pittsford, N.Y. 14534  
(585) 249-9990

**ATRIA – 2 locations:**

*Greece*

150 Towngate Road  
Rochester, N.Y. 14626  
(585) 225-3010

*Penfield*

2006 Five Mile Line Road  
Penfield, N.Y. 14526  
(585) 381-0282

**Bridges of Mendon**

3897 Rush-Mendon Road

Mendon, N.Y. 14506

(585) 624-4550

bridgesofmendon.com

**Cornerstone**

435 East Henrietta Road

Rochester, N.Y. 14620

(585) 424-7300

depaul.org

**\*Crimson Ridge Gardens**

1 Treeline Drive

Rochester, N.Y. 14612

(585) 720-9310

crimsonridgeseniorliving.com

**Crimson Ridge Meadows**

3 Treeline Drive

Greece, N.Y. 14612

(585) 720-9330

crimsonridgeseniorliving.com

**Grande Vie Senior Living Community**

2140 Five Mile Line Road

Penfield, N.Y. 14526

(585) 381-0680

grandevie.com

**\*Grande Ville Senior Living Community**

555 Maiden Lane

Rochester, N.Y. 14616

(585) 621-6160

grandeville.com

**\*Heather Heights of Pittsford**

160 W. Jefferson Road

Pittsford, N.Y. 14534

(585) 264-1600

heatherheights.com

**Hilton East Assisted Living Community**

231 East Avenue  
Hilton, N.Y. 14468  
(585) 392-7171  
hiltoneast.com

**Jonathan Child**

399 Colvin Street  
Rochester, N.Y. 14611  
(585) 436-9462  
fsr.org

**Landing of Brockport**

90 West Avenue  
Brockport, N.Y. 14420  
(585) 637-3140  
emeritus.com

**Parkside**

420 Main Street  
East Rochester, N.Y. 14445  
(585) 586-8010  
depaul.org

**Perinton Park Manor**

7 Chardonnay Drive  
Fairport, N.Y. 14450  
(585) 425-0210  
emeritus.com

**Ranier Grove at Cherry Ridge**

900 Cherry Ridge Road  
Webster, N.Y. 14580  
(585) 697-6700  
stannscommunity.com

**\*Rochester Presbyterian Home**

256 Thurston Road  
Rochester, N.Y. 14619  
(585) 235-9100  
rph.org

**The Shire at Culverton**

2515 Culver Road  
Rochester, N.Y. 14609  
(585) 467-4544  
shireatculverton.com

**West Side Manor**

1404 Long Pond Road  
Rochester, N.Y. 14626  
(585) 225-7210  
emeritus.com

**Westwood Commons**

50 Union Square Boulevard  
North Chili, N.Y. 14594  
(585) 293-2060  
depaul.org

**Woodcrest Commons**

4455 W. Henrietta Road  
Henrietta, N.Y. 14467  
(585) 334-1800  
depaul.org

**Enriched Housing:**

**Brentland Woods**

(Episcopal SeniorLife Communities)  
3831 E. Henrietta Road  
Henrietta, N.Y. 14467  
(585) 321-1490  
episcopalseniorlife.org

**Castle Point at Baywinde**

200 Kidd Castle Way  
Webster, N.Y. 14580  
(585) 872-8100

**Danforth Towers East**

(Rochester Housing Authority)  
140 West Avenue  
Rochester, N.Y. 14611  
(585) 697-7180 or (585) 436-9400  
rochesterhousing.org or fsr.org

**Glenmere at Cloverwood**

(Rochester Friendly Senior Services)  
1 Wheatley Terrace  
Pittsford, N.Y. 14534  
(585) 248-1234  
cloverwood.org

**The Hamlet**

(Unity Health System)  
1471 Long Pond Road  
Rochester, N.Y. 14626  
(585) 723-7820  
unityhealth.org

**\*Heather Heights**

160 W. Jefferson Road  
Pittsford, N.Y. 14534  
(585) 264-1600

**Hudson-Ridge Towers (Rochester Housing Authority)**

401 Seneca Manor Drive  
Rochester, N.Y. 14621  
(585) 697-7180 or (585) 266-5610  
rochesterhousing.org or fsr.org

**Jonathan Child**

(Family Service of Rochester)  
399 Colvin Street  
Rochester, N.Y. 14606  
(585) 436-9462  
fsr.org

**\* The Landing of Brockport (Emeritus Certified Assisted Living Communities)**

90 West Avenue  
Brockport, N.Y. 14420  
(585) 637-3140  
emeritus.com

**Laurelwood at the Highlands  
(Strong Health System)**

300 Hahnemann Trail  
Pittsford, N.Y. 14534  
(585) 389-1630  
stronghealth.com

**The Northfield (Fairport Baptist Homes and  
Family Service of Rochester)**

4560 Nine Mile Point Road  
Fairport, N.Y. 14450  
(585) 377-1810  
fsr.org

**Village at Park Ridge**

1471 Long Pond Road  
Rochester, N.Y. 14626  
(585) 723-7810

**\*Sage Harbor at Baywinde**

(Baywinde Senior Living Community)  
100 Kidd Castle Way  
Webster, N.Y. 14580  
(585) 872-8100  
baywinde.com

**\*Seabury Woods (Episcopal SeniorLife Communities)**

110 Dalaker Drive  
Rochester, N.Y. 14624  
(585) 426-4950  
episcopalseniorlife.org

**Summit at Brighton**

200 Summit Circle Drive  
Rochester, N.Y. 14618  
(585) 442-1950

**\*Wolk Manor (The Jewish Home)**

4000 Summit Circle Drive  
Rochester, N.Y. 14618  
(585) 442-1950  
jewishhomeroch.org

\* dementia unit.

**Skilled Nursing Facilities:**

**\*Aaron Manor**

100 St. Camillus Drive  
Penfield, N.Y. 14526  
(585) 377-4000  
aaronmanor.com

**Baird Nursing Home**

2150 St. Paul Boulevard  
Rochester, N.Y. 14621  
(585) 342-5540

**\*Blossom Health Care Center**

989 Blossom Rd.  
Rochester, N.Y. 14610  
(585) 482-3500

**\*Blossom North, LLC**

1335 Portland Avenue  
Rochester, N.Y. 14621  
(585) 544-4000

**Blossom South, LLC**

1175 Monroe Avenue  
Rochester, N.Y. 14620  
(585) 442-0450

**Brightonian Nursing Home**

1919 Elmwood Avenue  
Rochester, N.Y. 14620

(585) 271-8700

**Crest Manor**

6745 Pittsford-Palmyra Road

Fairport, N.Y. 14450

(585) 223-3633

bhcg.com

**Edna Tina Wilson Living Center**

700 Island Cottage Road

Rochester, N.Y. 14612

(585) 368-6100

unityhealth.org

**\*Episcopal Church Home**

505 Mt. Hope Avenue

Rochester, N.Y. 14620

(585) 546-8400

episcopalseniorlife.org

**\*Fairport Baptist Home**

4646 Nine Mile Point Road

Fairport, N.Y. 14450

(585) 377-0350

fairportbaptisthomes.org or rahsa.com

**\*The Friendly Home**

3156 East Avenue

Rochester, N.Y. 14618

(585) 381-1600

friendlyhome.org

**Hamilton Manor**

1172 Long Pond Road

Rochester, N.Y. 14626

(585) 225-0450

lattaroadnh.com

**\*Highlands at Brighton**

5901 Lac de Ville Boulevard

Rochester, N.Y. 14618

(585) 442-7960

stronghealth.com

**\*Highlands Living Center**

500 Hahnemann Trail

Pittsford, N.Y. 14534

(585) 383-1700

highlandsatpittsford.org

**\*Hill Haven**

1550 Empire Boulevard

Webster, N.Y. 14580

(585) 671-4300

viaheath.org

**The Hurlbut**

1177 E. Henrietta Road

Rochester, N.Y. 14623

(585) 424-4770

**\*Jewish Home of Rochester**

2021 Winton Road South

Rochester, N.Y. 14618

(585) 427-7760

jewishhomeroch.org

**\*Kirkhaven Nursing Home**

254 Alexander Street

Rochester, N.Y. 14607

(585) 461-1991

kirkhaven.com

**Lakeside-Beikirch Care Center**

170 West Avenue

Brockport, N.Y. 14420

(585) 395-6052

lakesidehealth.com

**Latta Road Nursing Home**

2100 Latta Road

Rochester, N.Y. 14612

(585) 225-0910  
lattaroadnh.com

**Latta Road Nursing Home "A"**

2102 Latta Road  
Rochester, N.Y. 14612  
(585) 225-0920  
lattaroadnh.com

**Maplewood Nursing Home**

100 Daniel Drive  
Webster, N.Y. 14580  
(585) 872-1800  
maplewoodnursinghome.com

**\*Monroe Community Hospital**

435 E. Henrietta Road  
Rochester, N.Y. 14620  
(585) 760-6325  
monroecommunity.com

**Park Ridge Living Center**

1555 Long Pond Road  
Greece, N.Y. 14626  
(585) 723-7688  
unityhealth.org

**Penfield Place**

1700 Penfield Road  
Penfield, N.Y. 14526  
(585) 586-7433

**\*St. Ann's Home**

1500 Portland Avenue  
Rochester, N.Y. 14621  
(585) 697-6000  
stannscommunity.com

**\*St. John's Home**

150 Highland Avenue

Rochester, N.Y. 14620  
(585) 271-5413  
stjohnshome.com

**\*Shore Winds Nursing Home**

425 Beach Avenue  
Rochester, N.Y. 14612  
(585) 663-0930

**Unity Living Center**

89 Genesee Street  
Rochester, N.Y. 14611  
(585) 368-4200  
unityhealth.org

**Wedgewood Nursing Home**

5 Church Street  
Spencerport, N.Y. 14559  
(585) 352-4810  
wedgewood.frontiernet.net

**Wesley Community**

3 Upton Park  
Rochester, N.Y. 14607  
(585) 241-2111  
thewesleycommunity.com

**Westgate Nursing Home**

525 Beahan Road  
Rochester, 14624  
(585) 247-7880

**Woodside Manor**

2425 South Clinton Avenue  
Rochester, N.Y. 14618  
(585) 461-0370

\*Dementia unit

**Medical Model Day Programs:  
Day Break at St. John's Home**

150 Highland Ave.  
Rochester 14620  
271-5413  
stjohnsseniorcommunities.org

**Daytimers at The Jewish Home**

2021 Winton Rd. S  
Rochester 14618 (Brighton)  
424-1420  
jewishhomeroch.org

**Home Connection at St. Ann's Community**

1500 Portland Ave.  
Rochester 14621 (Irondequoit)  
342-1700  
stannscommunity.com

**Independent Living For Seniors (Viahealth)**

Hudson Center, 2066 Hudson Ave.  
Rochester 14617 (Irondequoit)  
(585) 922-2800

**McAuley Center**

1437 Blossom Rd.  
Rochester 14610 (Brighton)  
(585) 922-8950  
viahealth.org

**Lifetimes at Plymouth Gardens**

1400 S. Plymouth Ave.  
Rochester 14611  
328-3590

**Meadowbrook at The Highlands**

500 Hahnemann Tr.  
Pittsford 14534  
383-1700 x 235  
stronghealth.com

**Multiple Sclerosis Achievement**

**Center at Unity**

2300 Buffalo Rd. Bldg 600 B  
Rochester 14624 (Gates)  
368-6470  
unityhealth.org

**Unity Adult Day Services at Park Ridge**

1555 Long Pond Rd.  
Rochester 14626 (Greece)  
723-7260  
unityhealth.org

**Unity Adult Day Services at Parkway**

700 Island Cottage Rd.  
Rochester 14612 (Greece)  
581-6130  
unityhealth.org

**Social Model Day Programs:**

**Caring House at Grande Vie (for persons with dementia)**

2140 Five Mile Line Rd.  
Penfield 14526  
381-0680

**Day Break Meadows at St. John's Briarwood**

1 Johnsarbor Dr. W.  
Rochester 14620  
(585) 242-7072  
stjohnsseniorcommunities.org

**Generations Elder Care**

230 Coldwater Rd.  
Rochester 14624 (Gates)  
247-3490  
generations-care.com

**Home and Heart at the Cathedral**

287 Flower City Park, Rochester 14615  
697-6086  
stannscommunity.com

**Home and Heart of Penfield**

1957 Five Mile Line Rd.  
Penfield 14526  
697-6087  
stannscommunity.com

**Lifespan Adult Day Services (for older adults with developmental disabilities)**

1900 S. Clinton Ave.  
Rochester 14618  
(585) 244-8400 x 108  
lifespan-roch.org

**SeniorsFirst Day and Respite Services at Valley Manor**

1570 East Ave.  
Rochester 14610  
770-1800

**Unity Adult Day Services at Cornerstone**

2300 Buffalo Rd. #600 A  
Rochester 14624 (Gates)  
368-6480  
unityhealth.org

**Unity Adult Day Services at St. Bernard's**

2260 Lake Ave., Bldg. 5  
Rochester 14612  
254-7990  
unityhealth.org

**Unity Adult Day Services at St. Mary's**

89 Genesee St.  
Rochester 14611  
368-3942  
unityhealth.org

**Companion Care or Housekeeping/Chore Services:**

**All Metro Health Care**

3300 Monroe Ave.  
Rochester NY 14618  
(585) 381-6240  
all-metro.com

**Assisting Angels Senior Homecare**

(585) 329-4476

**CareGivers**

2260 Lake Ave.  
Rochester NY 14612  
(585) 458-2150  
caregivershomecare.com

**Catholic Family Center**

87 N, Clinton Ave.  
Rochester NY 14604  
cfcrochester.org

**E.I.S.E.P.**

(585) 262-7060

**S.T.A.R.**

(585) 262-7050

**Comfort Keepers**

2018 Latta Rd.  
Rochester NY 14612  
comfortkeepers.com  
East side  
(585) 249-0100  
West side  
(585) 663-5730

**Companion Care of Rochester Inc.**

465 Blossom Rd.  
Rochester NY 14610  
(585) 546-1600

**Deliver-Ease**

112 Strong St.  
Rochester NY 14621  
(585) 544-6342

**Eldergard Services Inc.**

1600 East Ave.  
Rochester NY 14610  
(585) 256-3510

**Happier at Home**

31 Oak Meadow Tr.  
Pittsford 14534  
(585) 248-5021  
HappierAtHome.org

**Home Instead Senior Care**

1173 Pittsford-Victor Rd.  
Pittsford NY 14534  
(585) 663-4620  
homeinstead.com

**Homestay Companion Care**

3385 Brighton-Henr. TL Rd.  
Rochester NY 14623  
(585) 272-1311

**Lifespan Partners in Caring**

(585) 244-8400 x 128  
fiavolunteers.org

Note: Henrietta, Lima, Mendon, Rush, Honeoye Falls-Lima School District

**Seniorsfirst At Home Services**

1570 East Ave.  
Rochester NY 14610  
(585) 770-1800  
seniorsfirstonline.com

**Senior Options for Independence**

4646 Nine Mile Point Rd.  
Fairport NY 14450  
(585) 377-7830

**Senior Services**

*East side*  
(585) 454-8785  
*West side*  
(585) 584-5698

*North side*  
(585) 454-8491  
*South side*  
(585) 454-8156  
*Note: For shopping*

**Services for Seniors**

2541 Monroe Ave.  
Rochester NY 14618  
*Greece*  
(585) 723-8760  
*Brighton*  
(585) 461-1190

**Signature Care (Visiting Nurse Service)**

(585) 288-7560  
vnsnet.com

**Sisters Care**

120 Augustine St.  
Rochester NY 14613  
(585) 458-8540  
ssjrochester.org

**Traditions in Caring**

1580 Elmwood Ave.  
Rochester 14620  
(585) 241-9580  
traditionsincaring.com

**Unity Care at Home**

1477 Long Pond Rd.  
Rochester NY 14626  
(585) 368-7324  
unityhealth.org

**Vetter's Home Care, Inc.**

963 Maple Dr.  
West Webster NY 14580  
(585) 787-0836

**Transportation Options:**

**Able Medical Transportation**

(585) 756-2222

**ABVI-Goodwill**

(585) 232-1111

*Note: For visually-impaired clients*

**Apple Transportation Inc.**

(585) 427-7330

**City East Parishes Senior  
Transportation Ministry**

(585) 266-6570

**Club 24**

(585) 442-7201

**Companion Care of Rochester**

(585) 546-1600

**DOVE (Webster)**

(585) 872-7809

**Elderberry Express (Pittsford)**

(585) 248-6237

**Elderbus Transportation** (Perinton or Fairport)  
(585) 377-8117

**FISH** (Charlotte, Greece, Henrietta, Honeoye Falls, Lima, Mendon, Rush, and West Bloomfield)  
(585) 453-2370

**Genesee Transportation**  
(585) 256-1510

**Give a Life** (Lifespan)  
(585) 244-8400 x 142

**Good Samaritan Transportation** (for members of six Roman Catholic parishes through Irondequoit Senior Ministries)  
(585) 336-1777

**Handicare**  
(585) 272-1787

**Irondequoit FaithLink** (Irondequoit )  
(585) 288-4099

**Jewish Family Services**  
(585) 461-0110 x 108

**Lift Line**  
(585) 244-8330

**Medical Motor Service**  
(585) 654-7030

**Monroe Medi-Trans**  
(585) 454-6211

**Rochester Medical Transportation**  
(585) 288-3444

**RTS Buses**

(585) 654-0200 or  
(585) 288-1700

**Rural/Metro Medical Services**

(585) 423-0440

**SEM/SEAFISH- S.E. Ecumenical Ministries Friends in Service Here** (14607, 14610, 14618, 14620)

(585) 271-5350

**Services for Seniors**

(585) 461-1190

**Sisters Care**

(585) 458-8540

**STAR, through Catholic Family Center**

(585) 262-7050

**Wheelchair Express**

(585) 232-8430

**Veterans Administration Van Service (to VA clinics and hospitals)**

(585) 463-2661

**Medical Transportation for Medicaid Recipients** (After authorization by Department of Human Services)

(585) 288-4680

## **Ontario County Resources**

### **Caregiver Support Groups:**

#### ***Canandaigua***

Meetings are held on the 1<sup>st</sup> Thursday of every month from 1:00- 2:30pm, Canandaigua VA, which is located at 400 Fort Hill Road, Building 8, Room 236.

#### ***Clifton Springs***

Meetings are held on the 3<sup>rd</sup> Wednesday of every month from 12:00- 1:00pm at the Clifton Springs hospital and Clinic, located at 2 Coulter Avenue, 3<sup>rd</sup> Floor Conference Room.

#### ***Geneva***

Meetings are held the 4<sup>th</sup> Tuesday of every month from 3:30- 4:30 at the Seneca Lake Terrace Assisted Living Community, located at 3670 County Rd

### **Additional Local Resources:**

#### **Ontario County Office for the Aging**

585.396.4040 or 315.781.1320

3010 County Complex Drive  
Canandaigua, NY 14424

#### **Medicaid**

877.814.6907

Ontario County DDS  
3010 County Complex Drive  
Canandaigua, NY 14424

#### **Long-term Care Ombudsman**

Marie Frey  
585.244.8400 ext. 114  
Email: [mfrey@lifespan-roch.org](mailto:mfrey@lifespan-roch.org)

### **Home Care Services:**

#### **CareGivers**

5297 Parkside Drive  
Canandaigua, NY 14424  
(585) 394-6090

**Finger Lakes Home Care**

756 Pre-Emption Road  
Geneva, NY 14456  
(315) 781-8551

**Finger Lakes Visiting Nurse Service**

756 Pre-Emption Road  
Geneva, NY 14456  
(315) 789-9821 or (800) 253-4439

**Lifetime Care**

1120 South Main Street  
Newark, NY 14513  
(315) 331-7990

**Ontario County Certified Home Health Agency**

3019 County Complex  
Canandaigua, NY 14424  
(585) 396-4343 or (800) 299-2995

**Professional Choice**

71 Kendall Street  
Clifton Springs, NY 14432  
(315) 462-3621

**Social and Medical Model Day Programs:**

**Adult Day Health Center**

116 Lewis Street  
Geneva, NY 14456  
(315) 787-4733

**Adult Day Health Center @ Waterloo**

369 East Main Street  
Waterloo, NY 13165  
(315) 787-4733

**Brighter Day Medical Adult Day Center**

30 Fort Hill Ave.  
Canandaigua, NY 14424  
(585) 396-6644

**Adult Housing & Assisted Living:**

**Ashton Place**

190 Ashton Court  
Clifton Springs, NY 14432  
(315) 462-3140

**Clark Manor House**

318 Fort Hill Avenue  
Canandaigua, NY 14424  
(585) 394-0965

**Clark Meadows at Ferris Hills**

1 Clark Meadows  
Canandaigua, NY 14424  
(585) 393-4330

**DePaul Horizons**

3132 State Route 21 South  
Canandaigua, NY 14424  
(585) 396-3390

\* Dementia Unit

**Elijah House**

99 Gorham Street, P.O. Box 450  
Canandaigua, NY 14424  
(585) 394-5022

**Quail Summit**

1 Quail Summit  
Canandaigua, NY 14424  
(585) 396-1010

**\*Seneca Lake Terrace Assisted Living Center**

3670 Pre-emption Rd, County Route 6  
Geneva, NY 14456  
(315) 789-4162

**Skilled Nursing Facilities:**

**\*Quail Summit**

One Quail Summit  
Canandaigua, NY 14424  
(585) 396-1010

**\*Clifton Springs Hospital and Clinic Extended Care**

2 Coulter Road  
Clifton Springs, NY 14432  
(315) 462-9561

**Elm Manor Nursing Home**

210 North Main Street  
Canandaigua, NY 14424  
(585) 394-3883

**\*M.M. Ewing Continuing Care Center**

350 Parrish Street  
Canandaigua, NY 14424  
(585) 396-6045

**Geneva General Hospital**

**Living Centers North and South**

196-198 North Street  
Geneva, NY 14456  
(315) 787-4730

**Ontario County Health Facility**

3062 County Complex Drive  
Canandaigua, NY 14424  
(585) 396-4340

**Overnight Respite:**

**DePaul Horizons**

3132 State Route 21 South  
Canandaigua, NY 14424  
(585) 396-3390

**M.M. Ewing Continuing Care Center**

**F.F Thompson Health**

350 Parrish Street  
Canandaigua, NY 14456  
(585) 396-6040

**Geneva General Hospital**

**Living Centers North and South**

196-198 North Street  
Geneva, NY 14456  
(315) 787-4730

**Ontario County Health Facility**

3062 County Complex Drive  
Canandaigua, NY 14424  
(585) 396-4340

**Seneca Lake Terrace Adult Residential Community**

3670 Pre-emption Road, County Route 6  
Geneva, NY 14456  
(315) 789-4162

**Quail Summit**

1 Quail Summit  
Canandaigua, NY 14424  
(585) 396-1010

## **Schuyler County Resources**

### **Additional Local Resources:**

#### **Schulyer County Office for the Aging**

607.535.7108

336 West Main St

Montour Falls, NY 14865

#### **Medicaid**

607.776.7611

Steuben County DSS

3 East Pulteney Square

Bath, New York 14810

#### **Long-term Care Ombudsman**

Kim Salisbury

607.737.5520

Email: [ksalisbury@co.chemung.ny.us](mailto:ksalisbury@co.chemung.ny.us)

### **Home Care Services:**

#### **Americare**

703 East Church Street

Elmira, NY 14901

(607) 732-3502

#### **Bethany Village**

3005 Watkins Road

Horseheads, NY 14845

(607) 739-8711

#### **CareGivers**

2898 Westinghouse Rd. Suite 528

Horseheads, NY 14845

(607) 838-8696

#### **CareGivers**

2260 Lake Ave. Suite 1100

Rochester, NY 14612

(585) 458-2150

**Community Care of Rochester**

1609 East Main Street  
Rochester, NY 14609  
(585) 288-7560

**Metropolitan Nursing Services**

49 Court Street  
Binghamton, NY 13901  
(607) 722-1666

**Olsten Kimberly Quality Care**

30 West State Street  
Binghamton, NY 13901  
(607) 772-6542  
or  
41 Chenango Lane  
Binghamton, NY 13901  
(607) 772-8791

**Seneca County Resources**

**Seneca Caregiver Support Groups:**

***Waterloo***

Meetings are held on the 2<sup>nd</sup> Friday of every month from 1:30- 2:30pm at the Huntington Living Center, 369 E. Main St., Waterloo Health Center Conference Room.

***Seneca Falls***

Meetings are held on the 2<sup>nd</sup> Tuesday of every month from 1:00- 2:30pm at MEWS, 2 Falls St., Seneca Falls, NY 13148.

**Additional Local Resources:**

**Seneca County Office for the Aging**

315.539.1765 or  
1.800.688.7188  
1 DiPronio Drive  
Waterloo, NY 13165

**Medicaid**

1 Di Pronio Drive  
PO Box 690 Waterloo  
New York 13165-0690  
315.539.1800

**Long-term Care Ombudsman**

Kim Pfeiffer  
315.539.1767  
Email: [kpfeiffer@co.seneca.ny.us](mailto:kpfeiffer@co.seneca.ny.us)

**Home Care Services:**

**CareGivers**

5297 Parkside Drive  
Canandaigua, NY 14424  
(585) 394-6090

**Community Care of Rochester**

1609 East Main Street  
Rochester, NY 14609  
(585) 288-7560

**Genesee Region Home Care**

1120 South Main Street  
Newark, NY 14513  
(315) 331-7991

**Metropolitan Nursing Services**

49 Court Street  
Binghamton, NY 13901  
(607) 722-1666

**Monroe County LTC Program, Inc.**

349 West Commercial Street, Suite 2250  
East Rochester, NY 14445  
(585) 248-8770

**Pharm Health Infusion, Inc**

172 Alexander Street  
Rochester, NY 14607  
(585) 423-9580

**Professional Choice**

71 Kendall Street  
Clifton Springs, NY 14432  
(315) 462-3621

**Stafkings Health Care Systems**

100 Genesee Street  
Genesee Street Mall  
Auburn, NY 13021  
(315) 252-3441

**Unlimited Care, Inc.**

1465 Jefferson Road  
Rochester, NY 14623  
(585) 272-8800

**Visiting Nurse Service- Finger Lakes**

756 Pre-Emption Road  
Geneva, NY 14456  
(315) 789-9821

**Social & Medical Model Day Programs:**

**Adult Day Health Center**

116 Lewis Street  
Geneva, NY 14456  
(315) 787-4733

**Adult Day Health Center @ Waterloo**

369 East Main Street  
Waterloo, NY 13165  
(315) 787-4733

**Adult Housing:**

**The Bixby Home**

8342 North Main Street  
Interlaken, NY 14847  
(607) 532-4488

**East Main Street Apartments**

371 East Main Street  
Waterloo, NY 13165  
(315) 539-3104

**Huntington Living Center**

369 East Main Street  
Waterloo, NY 13165  
(315) 787-4920

**Seneca Nursing &  
Rehabilitation Center**

200 Douglas Drive  
Waterloo, NY 13165  
(315) 539-9202

**Overnight Respite:**

**Community Manor**

**Home for Adults**

8342 North Main Street  
Interlaken, NY 14847  
(607) 532-9549

## **Steuben County Resources**

### **Caregiver Support Groups:**

#### ***Painted Post***

Meetings are held the 4<sup>th</sup> Monday of every month from 2:30- 4:00pm at the Green Meadows @ Painted Post, which is located at 120 Creekside Drive.

### **Spousal/Partners Support Groups:**

#### ***Bath***

Meetings are held on the 2<sup>nd</sup> Monday of every month from 10:30-12:00pm at the Steuben County Health Care Facility, which is located at 7002 Mount Washington Road.

### **Additional Local Resources:**

#### **Steuben County Office for the Aging**

607.664.2298

3 East Pulteney Square

Bath, NY 14810

[www.proactioninc.com](http://www.proactioninc.com)

#### **Medicaid**

607.776.7611

Steuben County DSS

3 East Pulteney Square

Bath, New York 14810

#### **Long-term Care Ombudsman**

Vicki Grace

607.664.2298

Email: [vickig@co.steuben.ny.us](mailto:vickig@co.steuben.ny.us)

**Home Care Services:**

**Americare**

703 East Church Street  
Elmira, NY 14901  
(607) 732-3502

**Home & Health Care Services**

82 Main Street (3<sup>rd</sup> Floor)  
Hornell, NY 14843  
(607) 324-4142

**Steuben County Public Health Nursing**

3 East Pulteney Square  
Bath, NY 14810  
(607) 664-2438

**Steuben County Public Health Nursing**

7604 Seneca Road N.  
Hornell, NY 14843  
(607) 324-5560

**Steuben County Public Health Nursing**

10 West First Street  
Corning, NY 14830  
(607) 664-2438

**Social & Medical Model Day Programs:**

**Founders Pavilion Adult Day Health Care**

205 East First Street  
Corning, NY 14830  
(607) 654-2400

**Fred and Harriett Taylor Health Center**

7571 State Route 54  
Bath, NY 14810  
(607) 776-8500

**Mercycare Break**

1 Bethesda Drive  
Hornell, NY 14843  
(607) 324-6986

**The Day Club**

**Bethany Adult Social Day Care**

3005 Watkins Road  
Horseheads, NY 14845  
(607) 796-2182

**The Gathering Place**

71 Church Street  
Hornell, NY 14843  
(607) 324-9334

**Adult Homes:**

**Briarcliffe Home for Adults**

10 Howell Street  
Bath, NY 14810  
(607) 776-2829

**Cohocton Valley Home for Adults**

64 South Main Street  
Avoca, NY 14809  
(607) 566-2543

**Country Valley Home**

5946 County Route 11  
Bath, NY 14810  
(607) 776-5730

**\*Green Meadows at Painted Post**

120 Creekside Drive  
Painted Post, NY 14870  
(607) 962-5096

**Maryville Home for Adults**

7678 County Road 70  
Avoca, NY 14809  
(607) 566-2368

**Pinecrest Home for Adults**

7 Charlesworth Avenue  
Avoca, NY 14809  
(607) 566-2252

**Sue's Rest**

396 Canisteo Street  
Hornell, NY 14843  
(607) 324-3222

**Updykes Willow Ridge Quality Care Facility**

131 Hornell Street  
Hornell, NY 14843  
(607) 324-5417

\*Dementia Unit

**Skilled Nursing Facilities:**

**Absolute Center for Nursing and Rehabilitation at Three Rivers, LLC**

101 Creekside Drive  
Painted Post, NY 14870  
(607) 936-4108

**Founders Pavilion**

205 East First Street  
Corning, NY 14830  
(607) 654-2400

**Hornell Gardens, LLC**

434 Monroe Avenue  
Hornell, NY 14843  
(607) 324-7740

**Ira Davenport Memorial Hospital**

7571 State Route 54  
Bath, NY 14810  
(607) 776-8500

**\*McAuley Manor at Mercycare**

1 Bethesda Drive  
N. Hornell, NY 14843  
(607) 324-6990

**Steuben County Infirmary**

7002 Mt. Washington Road  
Bath, NY 14810  
(607) 776-7651

**Overnight Respite:**

**Green Meadows at Painted Post**

120 Creekside Drive  
Painted Post, NY 14870  
(607) 962-5096

**Hornell Gardens**

434 Monroe Avenue  
Hornell, NY 14843  
(607) 324-7740

**Wayne County Resources**

**Wayne Caregiver Support Group:**

***Newark***

Meetings are held on the 2<sup>nd</sup> Wednesday of every month in the Administrative Conference Room (2<sup>nd</sup> floor) of Newark Wayne Hospital, which is located at 112 Driving Park Avenue, from 2:00- 3:30pm.

**Additional Local Resources:**

**Wayne County Office for the Aging**

315.946.5624

1519 Nye Rd., Suite 300  
Lyons, NY 14489

**Medicaid**

315.946.4881

Wayne County DSS

77 Water Street

P.O. Box 10

Lyons, NY 14489-0010

**Long-term Care Ombudsman**

Susan Claeysen

315.946.5624

Email: [sclaeysen@co.wayne.ny.us](mailto:sclaeysen@co.wayne.ny.us)

**Home Care Services:**

**CareGivers**

5297 Parkside Drive

Canandaigua, NY 14424

(585) 394-6090

**CareGivers**

2260 Lake Ave. Suite 1100

Rochester, NY 14612

(585) 458-2150

**Expanded In-Home Services for the Elderly (EISEP)**

Wayne County Public Health

1519 Nye Road, Suite 300

Lyons, NY 14489

(315) 946-5624

**Lifetime Care**

1120 South Main Street

Newark, NY 14513

(315) 331-7995

**Interim Health Care**

347 East Ave.  
Rochester, NY 14604  
(585) 454-4930

**Nursefinders of the Finger Lakes**

2525 State Route 332  
Canandaigua, NY 14424  
(585) 393-0020

**Professional Choice**

71 Kendall Street  
Clifton Springs, NY 14432  
(315) 462-3621

**Staffing Healthcare: 2 locations**

100 Genesee Street  
Genesee Street Mall  
Auburn, NY 13021  
(315) 252-3441

106 West Utica Street  
Oswego, NY 13126  
(315) 342-1390

**Unlimited Care, Inc.**

1465 Jefferson Road  
Rochester, NY 14623  
(585) 272-8800

**Visiting Nurse Service- Finger Lakes**

756 Pre-Emption Road  
Geneva, NY 14456  
(315) 789-9821

**Social and Medical Model Day Programs:**

**Allison's Adult Care**

153 Stafford Street  
Palmyra, NY 14522  
(315) 597-2409

**Friends for a Day**

**Newark-Wayne Community Hospital**

1200 Driving Park Avenue  
Newark, NY 14513  
(315) 332-2317

**Adult Housing & Assisted Living:**

**Bickford Home**

56 Main Street  
Macedon, NY 14502  
(315) 986-5552

**Skilled Nursing Facilities:**

**Blossom View Nursing Home**

6884 Maple Avenue  
Sodus, NY 14551  
(315) 483-9118

**Newark Manor Nursing Home**

222 West Pearl Street  
Newark, NY 14513  
(315) 331-4690

**\*Newark-Wayne Community Hospital**

1200 Driving Park Avenue  
Newark, NY 14513  
(315) 332-2022

**Wayne County Nursing Home**

1529 Nye Road  
Lyons, NY 14489  
(315) 946-5673

**Wayne Health Care**

100 Sunset Drive  
Newark, NY 14513  
(315) 332-2700

\* Dementia Unit

**Overnight Respite:**

**Allison Home (Family Care Home)**

153 Stafford Road  
Palmyra, NY 14522  
(315) 597-2409

**Blossom View Nursing Home**

6884 Maple Avenue  
Sodus, NY 14551  
(315) 483-9118

**Country Manor (Family Care Home)**

8383 Ridge Road  
Alton, NY 14413  
(315) 483-6983

**Newark-Wayne Community Hospital**

1200 Driving Park Avenue  
Newark, NY 14513  
(315) 332-2022

**Wayne County Nursing Home**

1529 Nye Road  
Lyons, NY 14489  
(315) 946-5673

**Yates County Resources**

**Caregiver Support Group:**

***Penn Yan***

Meetings are held on the second Thursday of each month from 2:00-3:00 pm at ProAction Yates County Office, which is located at 417 Liberty St. in Penn Yan.

**Additional Local Resources:**

**Yates County Office for the Aging**

315.536.5515  
417 Liberty Street, Suite 1116  
Penn Yan, NY 14527

**Medicaid**

315.536.5183  
County Office Building  
417 Liberty Street, Suite 2122  
Penn Yan, NY 14527-1118

**Long-term Care Ombudsman**

Marie Frey  
585.244.8400 x114  
Email: [mfrey@lifespan-roch.org](mailto:mfrey@lifespan-roch.org)

**Home Care Services:**

**CareGivers**

5297 Parkside Drive  
Canandaigua, NY 14424  
(585) 394-6090

**Community Care of Rochester**

1609 East Main Street  
Rochester, NY 14609  
(585) 288-7560

**Metropolitan Nursing Services**

49 Court Street  
Binghamton, NY 13901  
(607) 722-1666

**Monroe County LTC Program, Inc.**

349 West Commercial Street, Suite 2250  
East Rochester, NY 14445  
(585) 248-8770

**Pharm Health Infusion, Inc**

172 Alexander Street  
Rochester, NY 14607  
(585) 423-9580

**Professional Choice**

71 Kendall Street  
Clifton Springs, NY 14432  
(315) 462-3621

**Unlimited Care, Inc.**

1465 Jefferson Road  
Rochester, NY 14623  
(585) 272-8800

**Visiting Nurse Service- Finger Lakes**

756 Pre-Emption Road  
Geneva, NY 14456  
(315) 789-9821

**Yates County Public Health**

417 Liberty Street  
Penn Yan, NY 14527  
(315) 536-5183

**Social and Medical Model Day Programs:**

**Home Away From Home**

**Adult Day Health Care Program**

418 North Main Street  
Penn Yan, NY 4527  
(315) 531-2710

**Adult Housing & Assisted Living:**

**Clinton Crest Manor**

411 Clinton Street  
Penn Yan, NY 14527  
(315) 536-8800

**St. Mark's Terrace EHP #1**

110 Chapel Street  
Penn Yan, NY 14527  
(315) 536-2440

**St. Mark's Terrace EHP #2**

36 Millard Street  
Dundee, NY 14837  
(607) 243-5215

**Skilled Nursing Facilities:**

**Penn Yan Manor Nursing Home, Inc.**

655 North Liberty Street

Penn Yan, N.Y. 14527

(315) 536-2311

**\*Soldiers & Sailors Memorial Hospital**

**Extended Care Unit**

418 North Main Street

Penn Yan, N.Y. 14527

(315) 531-2731

**Overnight Respite:**

**The Homestead**

418 North Main Street

Penn Yan, NY 14527

(315) 531-2700

## Glossary of Terms

### **Accredited facility**

An accredited facility is a nursing home, assisted living center or hospital that meets very high standards of care. These standards are set by organizations such as the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO). To stay accredited, a facility must be inspected every 18 months to three years.

### **Activity director**

An activity director plans group singing, art projects and other activities. Such activities help residents of a long-term care facility stay active, alert and sociable.

### **Activities of daily living (ADLs)**

Activities of daily living (ADLs) include eating, bathing, grooming, dressing and going to the toilet. People with dementia may need aid to perform these tasks. Questions about ADLs help decide what type of care a person needs.

### **Acute care (hospital care)**

Acute care is a medical setting such as a hospital, intensive care unit or emergency department.

### **Administrator**

An administrator runs a facility, such as a nursing home.

### **Adult day care**

Adult day care is a community program for disabled adults. In this safe setting, people can socialize, participate in activities and get health care. They are designed to meet the needs of individuals with dementia and to support their strengths, abilities and independence. Another reason to use an adult day center is to give the caregiver a break from caregiving. This helps enable caregivers return to their care responsibilities feeling refreshed and renewed. If you (as a caregiver) find yourself feeling guilty, ask yourself, "If I wear myself out to the point of total exhaustion, what good will I be to the person with dementia?" Adult day centers also offer the person with dementia opportunities to be social with others and participate in activities in a safe environment. Day care centers are open during business hours on weekdays. Some programs also run during the evenings and on weekends.

### **Adult Homes**

New York State Licensed adult homes, which may be propriety (for-profit) or not-for-profit, provide long term residential care to five or more adults unrelated to the operator. Adult homes are not required by New York State law to continue care for residents who have spent down their assets and need to apply for Medicaid. They are expected to follow criteria for admission and continued stay outlined in their regulations. Many adult homes offer private rooms with private or shared bathrooms. Adult Care Facilities do not have the capacity to provide intensive medical care. They do provide meals, housekeeping, laundry/linen service, transportation, social activities, medication management, 24-hour supervision, and some personal care.

### **Advance directive**

An advance directive is a legal document. It tells what kind of medical treatment you would like if your life is in danger and you can't communicate. Advance directives include:

- a living will that explains your wishes about medical treatments at the end of life
- a health-care power of attorney that lets you choose someone to make medical decisions for you

### **Allowable cost**

Allowable cost is the highest fee the state will pay for people on Medicaid. Other insurance plans may also set allowable costs for the services they cover.

### **Alzheimer's disease**

Alzheimer's disease is the most common cause of dementia. Over months or years, this disease cripples the brain's nerve cells. Alzheimer's disease destroys memory and learning.

### **Assessment**

An assessment of mental status is a test of a person's ability to think, feel and react to others. A doctor usually performs a mental status assessment.

### **Assistive device**

An assistive device is an aid, such as eyeglasses, a cane, a wheelchair or a hearing aid.

**Attorney (elder law)**

An elder law attorney handles general estate planning issues and counsels clients about planning for the future with alternative decision-making documents. The attorney can also assist the client in planning for possible long-term care needs, including nursing home care. Not all attorneys specialize in elder law. Your local bar association or the National Academy of Elder Law Attorneys and your local chapter can refer you to elder law attorneys in your area.

**Audiologist**

An audiologist deals with ear problems, including hearing loss, tinnitus (ringing in the ears or "head noise") and lack of balance. Audiologists provide hearing aids and other listening devices.

**Bed-bound or bed-fast**

A person who is bed-bound cannot walk or get out of bed without help from another person or a mechanical lift.

**Case management**

Case management describes the care and services planned by health care workers.

**Centers for Medicare and Medicaid (CMS)**

Centers for Medicare and Medicaid is the government program that oversees nursing home care. CMS inspects nursing homes and enforces safety rules.

**Certified nursing assistant (CNA); also certified nurse's aide**

A certified nursing assistant helps feed and care for disabled adults. To learn these skills, CNAs attend at least 75 hours of classes. A CNA works under a nurse's supervision and must keep taking classes to stay certified.

**Chaplain**

A chaplain offers spiritual counseling to people in nursing homes and hospitals.

**Charge nurse**

A charge nurse supervises the staff and residents of a floor or unit of a nursing home. The charge nurse's shift usually lasts eight hours. On each shift, day or night, a charge nurse should be available.

**Continuing care communities**

Continuing care communities provide a variety of levels of care within a senior living community or hospital based system. The advantage to consumers is that it may be easier to change from one level of care to another when needed. Most services are provided on a single campus, in adjacent facilities, or nearby. The following communities vary in size, services and cost.

**Contractures**

Contractures — shortenings of the tendons and muscles — can make the knees, arms, hands or feet curl up. Physical therapy can sometimes prevent or treat this condition. But contractures following a stroke or dementia may be permanent.

**Custodial care**

Custodial care helps a person accomplish the activities of daily living (ADLs). Custodial care can also include preparing special diets and giving medications.

**Decubitus ulcers (pressure ulcers, pressure sores or bedsores)**

Decubitus ulcers are skin sores caused by constant pressure.

**Deficiencies**

Deficiencies are problems an inspector notes while visiting a nursing home or other facility. The facility must correct any deficiencies. Otherwise, it may be fined and dropped from Medicare or Medicaid participation.

**Dementia**

Dementia is a disturbance in thinking and remembering that affects daily life. The symptoms of dementia can include changes in personality, mood and behavior. Disease and injury cause irreversible dementia. But dementia caused by drugs, alcohol, hormone imbalances, vitamin deficiencies or depression may be reversible.

**Dietician**

A dietician makes sure that a facility's residents eat a healthy, nutritious diet.

**Director of nursing services (DON)**

The Director of Nursing oversees all nursing activities. These include scheduling and making sure staff members get continuing education. The DON is a registered nurse who has graduated from an accredited school of nursing.

**Discharge**

Discharge is the release of an individual from a hospital or other facility such as a nursing home. The attending doctor must give an order for the discharge.

**Do Not Resuscitate (DNR) order**

A DNR order tells the health care facility or doctor not to revive a patient whose heart or breathing has stopped. A DNR order requires the signature of the person or a substitute (see **Advance directive**).

### **Elder law attorney**

An elder law attorney handles general estate planning issues and counsels clients about planning for the future with alternative decision-making documents. The attorney can also assist the client in planning for possible long-term care needs, including nursing home care. Not all attorneys specialize in elder law. Your local bar association or the National Academy of Elder Law Attorneys and your local chapter can refer you to elder law attorneys in your area.

### **Enriched Housing**

New York State Licensed Enriched Housing provides seniors with an apartment like setting that also provides or arranges for a package of services including: meals, housekeeping/chore services, may include medication administration, transportation, shopping, social activities, and some personal care services.

### **Family/designated representative or other caregiver**

"Family members" can include people who are important to the resident, whether or not they are related.

### **Financial Planner**

A financial planner can help the client make decisions that make the most of financial resources while at the same time help negotiate the financial barriers that inevitably arise in every stage of life.

### **Functional impairment**

Functional impairment means being unable to dress, use the toilet, eat, bathe or walk without help.

### **Geriatric care manager**

A geriatric care manager will help create a plan of care that meets the needs of the older adult and will explain what resources and options are available.

### **Geriatric psychiatrist**

A geriatric psychiatrist is trained to diagnose and treat mental disorders in older adults. These disorders include dementia, depression, anxiety and late-life schizophrenia.

### **Guardian/conservator**

A court-appointed guardian or conservator manages a resident's money and makes health care and living decisions. Becoming a guardian or conservator requires a court order.

### **Hospice**

A program that offers support for dying persons to live as fully and comfortably as they can.

### **Instrumental activities of daily living (IADLs)**

Instrumental activities of daily living (IADLs) are important daily living activities, such as cooking, shopping and managing finances. Long-term care facility

A long-term care facility is a nursing home or assisted living center designed for disabled adults.

**The Long Term Home Health Care Program (LTHHCP)** is a home care program designed exclusively to care for people with chronic needs or disabilities. Unique to New York State, this program is also called the Nursing Home Without Walls. To be eligible for the program, a person must have needs similar to a person who lives in an adult home or a nursing home. This usually means help with bathing or dressing, ambulation, meal preparation, or housekeeping chores or someone who is socially isolated or may be at risk for falls if left alone. The primary physician must agree to the plan and be willing to participate. The primary nurse functions as a case manager to arrange supervise and evaluate the plan and determine whether the person's needs can be met in a less expensive format than a nursing home. There is no cost for the initial assessment.

#### **Services Provided**

- Skilled nursing
- Home health aide service
- Therapy services

#### **Waivered Services**

Additional services called "waivered services" which are unique to the Long Term Home Health Care Program:

- Social work services
- Nutritional counseling
- Housekeeping
- Home delivered meals
- Social adult day services
- Transportation
- Respite care
- Personal emergency response system
- Home maintenance
- Housing improvement
- Moving services

### **Medicaid**

Medicaid is a government health program for low-income people.

**Medicaid-certified**

A Medicaid-certified facility can offer services to people who are on Medicaid.

**Medical director**

The medical director is a doctor who oversees medical care in a facility, such as a nursing home. The medical director may be the attending doctor for some residents and may offer emergency medical care for other residents.

**Medicare**

Medicare is a government health insurance program for people aged 65 and older and for disabled people.

**Medicare-certified**

A Medicare-certified facility can offer services to people who are on Medicare.

**Mini Mental State Examination (MMSE)**

The Mini Mental State Examination (MMSE) is a short test to measure a person's basic skills. These skills include short-term memory, long-term memory, writing and speaking.

**Minimum Data Set (MDS)**

The Minimum Data Set (MDS) summarizes information on the abilities of people who live in long-term care facilities. To keep their Medicare and Medicaid certification, long-term care facilities must submit their MDS data regularly.

**Nurse**

A nurse who works in a nursing home takes care of residents and oversees certified nurses' aides (CNAs) and custodial caregivers. A registered nurse (RN) is a graduate trained nurse who has been licensed by a state authority after passing qualifying examinations for registration. A licensed practical nurse (LPN) is a person who has undergone training and obtained a state license to provide routine care for the sick. Some states use the term licensed vocational nurse or LVN.

**Nurse practitioners (NPs) and physician assistants (PAs)**

Nurse practitioners (NPs) and physician assistants (PAs) are specially trained and may help oversee residents' care. In many states, doctor-supervised NPs and PAs write orders for treatment and medication.

**Occupational therapist (OT)**

An occupational therapist helps residents change their activities or environment so they can eat, dress and bathe. An OT may also help with other tasks, such as cooking, taking medication or driving. And OTs may guide family members and caregivers.

**Ombudsman**

An ombudsman in a long-term care facility helps residents and their families keep their rights and resolve complaints.

**Owner/operator**

The owner is the individual, agency or company that owns the facility. The owner may hire an operator to direct the facility.

**Palliative care**

Palliative care includes medical or surgical methods to ease the pain of a serious or incurable illness.

**Personal Care**

Assistance with bathing, dressing, walking, eating, supervision, emotional security and housekeeping

**Personal health record**

A personal health record (PHR) is a regularly updated collection of important health information. If you have dementia or are caring for someone with dementia, a PHR will help you work with your care team.

**Physical therapist**

A physical therapist treats physical disabilities and works with residents to improve general fitness. A physical therapist may also teach a resident how to use a walker, artificial limb or wheelchair.

**Power of attorney**

A power of attorney is a legal form that names someone to act as your substitute.

**Psychologist**

A psychologist detects and treats emotional problems. Personality and intelligence testing can help a psychologist diagnose these problems. Treatments include individual, family, and group therapy sessions. Psychologists in long-term care facilities also teach staff members how to interact with residents.

**Quality indicators**

Quality indicators describe the care in a long-term facility. For example, one quality indicator is the percent of residents whose need for help with daily activities has increased. The government's [Nursing Home Compare](#) Web site uses quality indicators to score every nursing home in the United States.

**Recreational therapist**

A recreational therapist helps residents enjoy activities. For example, the recreational therapist might offer special tools, such as large-print songsheets, to encourage participation.

**Respite care**

Respite care provides temporary relief from caregiving tasks. Such care could include in-home assistance, a short nursing home stay or adult day care.

**Social worker**

A social worker offers residents and their families therapy, support services and planning for discharge. Social workers may also teach and counsel staff members.

**Speech-language pathologist**

A speech-language pathologist tests, diagnoses and treats people with speech and swallowing problems.

**Staff-resident ratio**

The staff-resident ratio compares the number of staff members to the number of residents they care for.

**Survey**

The state health department takes an unannounced survey of each nursing home about once a year. This survey helps make sure a facility is giving good care. A nursing home must participate to keep its license. Each facility has to post its latest survey results. These required surveys differ from the surveys of the Joint Commission on Accreditation of Healthcare Organizations (JCAHO) that a nursing home may request (see **Accredited facility**).