

**Learning from  
Experience when  
Dementia is  
the Default**

*The Adventure of  
Reading to the  
Hard of Understanding*

# Contents

Competence Statement .....	3
Introduction.....	3
Terms .....	4
Research	
v Background and Symptoms .....	5
v Diagnosis and Treatment .....	6
v Dementia from the Inside .....	7
Life on a Dementia Unit	
v Interview with Michelle M .....	8
v Time Well Spent .....	11
Storyteller	
v Getting a foot in the door .....	13
v Storytelling Experience.....	14
Conclusion .....	19
Bibliography .....	20

**FX Competence Statement:**

**Can describe and explain current thinking about and treatment of dementia in the elderly and can use theories to interpret observations.**

**INTRODUCTION**

In this paper I will show how reading aloud to persons with Alzheimer's Disease and other dementias in a nursing home setting is beneficial to all concerned. My research describes ways that patients with dementia can benefit from structured activities. It includes an interview with the activities director at the facility where I read each week.

The paper gives an overview of the thinking about and treatment of dementia in the elderly at the beginning of the 21st century; it describes the work and philosophy of one person who is employed as the activity director on a dementia unit; and it concludes with my own experiences and what I have learned from them during the past eight years.

When I began reading stories at for residents of the Health Pavilion at Montgomery Place Retirement Community in Chicago, I thought it would be a volunteer effort of short duration until someone else arrived to fill the gap. I had no expectation of improving anyone's quality of life; in fact, I had no expectations of what it would be like at all. As the years elapsed, and through my studies at DePaul's School for New Learning, I have begun inquiring into what makes people successful in old age and I realize that "success" means a wide range of things. It is eye-opening to regularly spend time with people whose horizons have dwindled to the present moment, to believe that their "now" still contains their "then," and in believing that to try to be witness to the wholeness of their lives. With the help of those around them, elderly people with dementia can be successful regardless of their disease.

**TERMS**

Dementia is an umbrella term describing a variety of symptoms involving impairment and loss of intellectual and motor skills. Alzheimer's Disease and vascular dementia are the two most common types of irreversible dementia seen today. In Alzheimer's Disease symptoms begin slowly with mild forgetfulness and get progressively worse, ending with serious cognitive impairment and physical decline. Alzheimer's Disease always leads to structural changes in the brain that produce dementia.

Vascular dementia is caused by a blockage of blood supply, frequently as a result of stroke. In multi infarct dementia, a series of small strokes or changes in the brain's blood supply may result in the death of brain tissue. The location in the brain where the small strokes occur determines the seriousness of the problem and the symptoms that arise. Symptoms that begin suddenly may be a sign of this kind of dementia. (National Institute on Aging) Although vascular dementia is caused by stroke, not everyone who has a stroke develops dementia. Many people who have strokes experience only physical effects and no permanent impairment of intellectual ability.

For purposes of people living at Montgomery Place, their type of dementia is treated by appropriate medication, but those with Alzheimer's Disease and other dementias are not distinguished from one another.

## **RESEARCH**

### **Background of Alzheimer's Disease**

The disease that carries the name of Alois Alzheimer, a German physician, was first described in 1906 when he presented the case history of a 51-year-old woman suffering from a strange brain disorder. After the patient died, an autopsy of her brain showed the plaques and tangles that today are the definitive hallmarks of Alzheimer's Disease.

### **Symptoms**

The Alzheimer's Foundation of America website gives an extensive list of symptoms of the disease, which are divided into two categories: psychiatric and cognitive. Psychiatric symptoms include personality changes, depression, hallucinations and delusions. Cognitive symptoms are amnesia, aphasia, apraxia, and agnosia – widely feared as the Four Horsemen of the Alzheimer's Apocalypse.

- Amnesia is the loss of memory, first short-term recent memories and then long-term memories.
- Aphasia is the loss of communication skills. The loss of speaking and writing ability is called expressive aphasia. The inability to understand spoken or written words is receptive aphasia.
- Apraxia is the inability to perform motor tasks learned over a lifetime.
- Agnosia is an inability to correctly interpret signals from the five senses.

Like the changes in the brain itself, the psychiatric and cognitive symptoms are tangled together and appropriate treatment is a complicated matter.

### **Diagnosis**

Biopsychologist Nancy Andreasen emphasizes that “Early in the illness, the plaques and tangles usually form in the temporal lobes, and particularly in the hippocampus . . . As the disease progresses, the plaques and tangles become more widely dispersed throughout the brain. In severe end-stage cases they are seen throughout the cerebral cortex.” Ultimately, the “characteristic pathology [of a brain at autopsy] consists of the senile plaques and neurofibrillary tangles originally identified by Alzheimer (265).” Thus it is possible to be quite sure, but not absolutely positive, that a person has Alzheimer’s until they have it in the past tense. However, this fine distinction does not matter to the residents or the staff on the Health Pavilion of Montgomery Place. Their interest is in the quality of daily life that forms around predictable events.

### **Treatment**

While the search goes on for full understanding and meaningful treatment or a cure, few medications are indicated. Everything available in 2006 treats only symptoms, because there is no cure for Alzheimer’s. According to nursingceu.com, “Four drugs have been approved by the Food and Drug Administration (FDA) for treatment of mild to moderate AD symptoms. The current drugs of choice are donepezil (Aricept), rivastigmine (Exelon), and galantamine (Reminyl). These newer drugs have replaced tacrine (Cognex), the first drug approved by FDA for AD, which can cause liver damage. All of these drugs interfere with the action of acetylcholinesterase, an enzyme that normally breaks down the neurotransmitter acetylcholine.” At Montgomery Place, while treatment is important, and meds are always being measured and distributed, medication is only one facet of a resident’s life.

### **Dementia from the Inside**

There is an always-growing body of literature on the subject of Alzheimer's Disease, but there are few first-person accounts because the very nature of the disease makes it almost impossible for sufferers to tell their own stories. Thomas DeBaggio's memoir, *Losing My Mind: an Intimate Look at Life with Alzheimer's*, is a striking exception. A nursery-owner and journalist, DeBaggio developed early-onset Alzheimer's in 1999 when he was 57 years old. In *Losing My Mind* he describes his physical and mental decline over the course of two or three years, including the abrupt appearance of terrifying nighttime hallucinations and the gradual disappearance of letters on the page as he works on his book. His sadness at the floating alphabet, at his inability to make change at a cash register or to remember which wine he likes, at his confusion when he leaves his house, is both sharp and smooth. His anecdotes make the elegant-sounding words amnesia, aphasia, apraxia and agnosia into real, agonizing, experiences

DeBaggio speaks on behalf of all Alzheimer's sufferers as every change piles up on every other one with his awareness of what he is losing. Even as he struggles to retain his faculties, he knows at some level that there is a day in the future when he cannot stay at home with only his wife Joyce to care for him. When that happens, one can only wish him a new home in a place as caring as the facility where Michelle M works.

## **WORKING ON A DEMENTIA UNIT**

Between 1997 when I began my storytelling hours, and 2004 when I met Michelle M, there probably was an activity program on the dementia unit at Montgomery Place, but I was unaware of it. Since Michelle's arrival, there has been a parade of special events, from clown troupes and marimba bands to traveling herpetology exhibits courtesy of Lincoln Park Zoo. When I interviewed Michelle in the spring of 2005 her training was clearly reflected in her work philosophy. I was pleased to learn that during my short weekly visits I already was doing many of the things she considers appropriate and necessary for the comfort of people with dementia.

### **Interview with Michelle M**

Michelle M has worked at Montgomery Place Retirement Community since October 2003. She has a BS in Occupational Therapy and has worked in group situations, including mental hospitals. Courses for her degree in Occupational Therapy included group dynamics, individual program planning, and community service. To qualify for her present job, Michelle attended a 36-hour training program for activity directors at Oakton Community College. For inspiration she reads "Flow" by Mihaly Csikszentmihalyi.

She is the activity director for the 2nd and 3rd floors. The second floor is the Special Care floor for Alzheimer's and other dementia patients; the third floor is primarily for medical rehabilitation, and has some long-term residents who do not require specialized nursing. There are about 71 people altogether on these floors.

Michelle says that in working with people with dementia, the objective is to stimulate at every level, through voice, touch, smell and sounds, to evoke a purposeful response. Her recurrent theme is: Find out a person's here-and-now, and make them comfortable in the moment.



She says that people with dementia, and particularly Alzheimer's Disease, are aware when mental changes are happening, and they will try to stay functional (e.g., saying, "You know who I mean," or "I put it in the usual place," to compensate for word loss). Memory changes are distressing until the person gets beyond remembering that they are occurring.

### **Activities**

**"Activity is the focal point of everybody's life. Everything we do is an activity."**

- For successful activities there should be about 15 to 20 people in a group.
- Some residents will not initiate activity, but will imitate what they see being done.
- Stuffed toys offer tactile and visual stimulation. One woman communicates only when she is handling pieces of colorful, textured fabric. She is rarely coherent, but one day when Michelle wore a bright pink sweater to work, she patted and stroked the arm of the sweater and said, "It's about time you wore something pretty!"
- It is important to be aware of the possibility of overstimulation; if that happens, the resident is moved to a quieter place.
- Tossing a beach ball helps with physical coordination and alertness.
- Asking questions about the past stimulates memory. Residents enjoy talking about holidays, seasons, and how to do things, such as baking a cherry pie. (Margaret, who in her earlier life was a nursing supervisor, sometimes stands in the doorway of her room issuing instructions, saying, "You know, I've done this all my life!" Another woman, who used to be an executive secretary, was given a place at a desk near the nursing station, with a name sign, and papers she could keep in order.)

### **Caregivers**

Residents learn to trust a particular caregiver or aide, sometimes through voice, sometimes through touch, occasionally by appearance. One male resident is very responsive to men, but everyone who works on the unit is a woman. It helps that a favorite housekeeper, who works throughout the building, makes a point of pausing to visit and chat with this resident whenever the housekeeper's duties bring him to the second floor. Repetition, familiarity and consistency are watchwords for the care of people with dementia. Michelle says, "That makes sense; I'd go crazy if I had a new boss every day! We all need consistency."

### **In-Service Education**

In fall 2004, Michelle held an in-service day for everyone working at Montgomery Place, from the kitchen staff to the head administrator, to help them understand the importance of activities for people with physical and mental impairments. She wanted all workers to understand the place where they're employed. She made a booklet, "Activity: A glimpse into the purpose, therapeutic benefits, and role of Activity Staff with the Alzheimers/Dementia Population," that was given to each person who attended the in-service day. (She gave me a copy, too)

### **This is Their Home**

To **find out a person's here-and-now, and make them comfortable in the moment**, a resident is assessed at the time of arrival.

- Michelle interviews the resident if possible; otherwise she talks with family members, to learn what the person's life was like earlier
- Observation of the resident's behavior on the unit
- Variety of exposure is offered to find what a person is most responsive to: sound, sight, touch, smell, group activity, or one-on-one encounters.

- Be aware that preferences may change as the disease progresses. A person may like things now that were of no interest before (e.g., types of music, card games), or may lose interest in things that were previously important to them. It is important for a resident's family to be able to accept these changes, even if they are strange or disappointing.

Michelle's philosophy is that people who live on the second floor are residents, not patients.

"This *is* their home now," she says.

## **TIME WELL SPENT ON A DEMENTIA UNIT**

A nursing home setting is a good place for group activities that would not be available to people living with dementia at home. In a sprightly and sensitive book, *Keeping Busy: a Handbook of Activities for Persons with Dementia*, James Dowling, an activity specialist at the Alzheimer's Care Center in Gardiner, Maine, outlines practical ideas for activities suitable to persons with cognitive impairments. His chapters cover social activities, exercise, gardening, pets, spirituality, music and art, humor, word games, and even the possibilities and pitfalls of cooking. The people with whom he works are higher-functioning than the population on Michelle M's unit, but his cheerful attitude of understanding the person in their present situation is the same as hers, and some of the activities he suggests are transferable. Music, in particular, is appropriate for people with all levels of dementia.

My friend Betty Borst, who lives in an apartment on the 14th floor at Montgomery Place, often volunteers to entertain the Health Pavilion residents. She plays the piano, offering an extensive repertoire of old-time hymns and popular songs from before World War II. They sing

together; some just listen; and one lone woman gets up to dance. Betty phoned me to describe the scene, wishing everyone would dance, wondering why her audience is not more responsive. I could tell her, from my experience, that this *is* a high level of responsiveness and involvement, and she should be pleased with her success. (It's quite an honor to be asked for advice by a 95-year-old.) Music reaches people when words slide by. Working with words is a different discipline.

# STORYTELLER

## **Getting My Foot in the Door**

After my mother died in 1997 I missed her a lot, and by extension I missed the people I had met in the retirement community where she was living. I needed to find a reason to go back to Montgomery Place, to be on hand for the pulse of daily activity. After a few months my chance came in the form of a “want ad” in the *Montgomery Messenger*, the resident-written monthly newsletter. I **thought** the appeal was for someone to sit in the library on the first floor once a week and read newspapers aloud to visually impaired residents. As things turned out, the assignment involved reading to Health Pavilion residents living on the second floor Alzheimer’s and Dementia Unit.

This was quite a different kettle of fish from what I envisioned when I thought of reading about and discussing world events with people whose limitations might be visual and physical, but generally not intellectual. On my first visit to the second floor the residents were seated around a long table. I was placed at the head of the table and given a paperback large print Reader’s Digest. There was a slip of paper marking the story I was to read. It told about a dog that made friends with chickens, particularly with one chicken that then – what else? – got run over by a car. My learning curve about suitable reading material for this audience was steep. The next week, I started bringing in my own books.

On the Montgomery Place Health Pavilion, the emphasis is entirely on quality of life. There is no question that residents have advanced dementias and no effort is made to “prevent” or “cure” diseases. People are accepted and viewed for who they are in the place they currently occupy in their lives.

## **The Storytelling Routine**

Recognizable people in a recognizable setting is important and comforting to people with dementia. Early on, thanks to a tip from Bob Petite, the chaplain for all of Montgomery Place, I learned to make myself recognizable by wearing exactly the same clothes each week: black shoes, black pants, red shirt, black overshirt, small silver earrings. This made me an easy object to focus on, with a single standout color in the outfit. Monday became my own favorite day of the week, because I never had to decide what to wear.

Each week I began by introducing myself and saying how glad I was to see everyone again. The group of 15 to 25 people, ranged from completely inert and non-participant to responsive and conversational. As the years went by, many residents aged in place in good physical—and deteriorating cognitive—health. As dementias progressed to later stages the number of responsive individuals declined markedly, in my estimation a sign of excellent care.<sup>1</sup>

When I was making my choices for reading material, I knew from the start that “chapter books,” or serialized stories were out of the question. Even the most alert person with dementia is going to have trouble retaining a story line from one week to the next. Soon I learned that the least successful stories were ones with anthropomorphic characters. Those scallywags Br’er Rabbit and Br’er Fox were a dud every time, even in the sprightly version of those stories retold by Julius Lester and illustrated by Jerry Pinkney. In similar vein, Aesop’s fables, which seemed to be a good choice because everyone knows at least a few of them, were a failure. With no dramatic tension, and the inevitable superiority of a moralistic mouse or crane or ant, those fables put everyone—even me—to sleep when I read them.

Overall, the greatest challenge of reading to an audience with physical and mental impairments is getting people’s attention and then keeping it. The most beautifully illustrated

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<sup>1</sup> It might also be surmised that there is an increase in good day-care facilities to which people can take higher-functioning family members.

storybook is of no use if the storyline isn't strong enough to be acted out by the storyteller, because it isn't possible to show the pictures to the whole group. By the time the last person looked at a picture, the first person would have forgotten what was going on. As a way of inviting involvement, I often asked for requests, and occasionally I got them. One day a lady asked if I knew "You Are My Sunshine." I said I did, and the following week I brought a CD with the song on it. She was delighted. We all sang the parts we knew—mainly the chorus—and immediately after it ended, she said, "That was very nice, wasn't it? Do you know that song, what's it called, 'You Are My Sunshine'?" I said I certainly did, and that I would bring it in next week.

For a time, when one resident wanted to hear tales from Africa, creation stories were in vogue. These are a little tricky, because the purest forms of creation stories just tell you exactly how something came to be and are short on plot. Sometimes they are violent and frightening, and I made a decision early on **never** to read a scary story that didn't have a quick, positive resolution. When I read ghost stories at Halloween, just to be on the safe side, I always first polled the audience about their beliefs concerning the supernatural. As it turned out, not one person believed ghosts are real, although several did think it would be nice to meet the ghosts that are out there.

Year after year, the most popular and resonant stories were fairy tales, with "Rapunzel" the hands-down favorite. I never figured out why – perhaps because I did such a good job of acting out the few characters in the story – but the plight of the girl in the doorless tower in the wood evoked interest and sympathy again and again. Almost all my storytelling books came from my frequent visits to the Chicago Public Library (and the CPL's operating budget was met

in large part by my payment of overdue fines), but I read “Rapunzel,” and some tales from Virginia Hamilton’s *Her Stories* so many times, I bought my own copies.

Humorous poetry and wordplay were far more appreciated than I would have imagined. People liked these even more after I realized that previewing a punchline improved the enjoyment and sense of being in on the joke. Frequent repetition of funny rhymes also went over well. Jack Prelusky’s four-liners were favorites for all of us, and eventually two or three people were able to join me in “Never disagree / with a shark beneath the sea / lest you feel a sudden crunch / and discover you are lunch.” I made one set of animal poems, and another of food poems, and always promised, but never got around to, a collection of body parts poems, which was to have begun with the cautionary, “Be Glad Your Nose is on Your Face.” For Christmas 1999 I made poetry booklets (with no thought to copyright violation) and gave one to each member of the Monday Morning Story Group. Most of these booklets were lost immediately, but one lady brought hers with her faithfully each week after that, and when she died, it was in the small pile of papers on her bedside table.

During the first year, I noticed there was some confusion when I left each week, and it occurred to me that although I knew how much time had elapsed, probably everyone else in the room had no idea whether we were at the beginning or the middle or the end of the stories. To establish a regular routine, I finished each session with a group recitation of Edward Lear’s “The Owl and the Pussycat,” a story deficient in detail but awash in romance, of a bird and a cat who elope. I chose it for its fetching alliterative repetitions that made it the only poem I knew by heart. I purchased a large runcible spoon that emerged from my book bag and made a surprise appearance each week in the last verse of the poem.



Over the years, there were periods when several members of the group would know at least some of the words; other times everyone was clueless but interested in watching me perform the poem and produce the amazing runcible spoon. Most interesting to me was that **twice**, people who had no previous familiarity with the poem were able to learn part of it. One woman learned enough to sometimes take charge of leading me through the first half. Since a hallmark of Alzheimer's Disease is the progressive loss of short-term memory, I found this learning particularly delightful and did not mind that according to medical science it was impossible.

At Christmastime of the third year, I played parts of a CD with Judy Collins singing holiday music. The last song, "Amazing Grace," elicited such a strong response from the group that I decided to add it to the weekly closing lineup, right before "The Owl and the Pussycat." Four or five verses and choruses of "Amazing Grace" gave me ample time to walk around the room, to greet everyone with a touch on the arm or hand, and to see whether my gaze and smile would let me spot the person still far inside. On several occasions, someone who appeared to be catatonic woke up and looked at me and smiled back. Once, famously among the nurses' aides, a man who never made any sound at all lifted up his head, sang vigorously, and then became mute again. One lady, whose oxygen machine nearly beat my voice in volume, would pat my hand and thank me for my good preaching. Geneva invariably said, "In every thing give thanks," and I replied, "In every thing."

The people in the story telling group were completely accepting of our circumstances. It was almost a new room every Monday morning, into which we carried tenuous memories of one another. They never knew for sure who I was, and I never knew for sure that any one of them still would be alive. When I read a very good story, they sometimes clapped. When I read a story

that went nowhere, they sat and looked at me. When I asked questions, they sometimes answered and sometimes slept. They did not mind at all that I read “A Visit from St. Nicholas” in April and September, or that I twirled around to demonstrate my favorite lines, “As dry leaves that before the wild hurricane fly / When they meet with an obstacle, mount to the sky.” In turn, I never took it personally when a story fell flat or a hilarious poem met with dead silence. I don’t know what effect the story times had on them, but I know that in those hours I was free in a way I’ve never been in any other situation.

In April 2006 my turn at being the story teller ended. Changing circumstances in my life made it increasingly difficult to sustain my commitment of keeping every Mon-day morning open<sup>2</sup>. I felt that sporadic appearances might be acceptable in theory, but in practice would be difficult for both me and the residents. It was time to move along.

On the last day that I read stories at Montgomery Place, I had one of the unexpected exchanges that typified my years there. After I read a poem about a fish that rides a bicycle and bounces a ball but cannot swim, and was moving on to the next topic, a resident interrupted me, saying, “Do you like to fish? Do you go fishing often?”

I talked a bit about fishing when I was a kid, and what a peaceful afternoon you can have when you’re fishing. Then I wondered what the question meant to her, so I turned it around.

I asked, “Do you know a lot about fishing? You sound like you really know what you’re talking about.”

It turned out she did. For two or three minutes – a remarkably long time for a person with dementia to conduct a coherent soliloquy – she described good places to fish, both generally and specifically; the kinds of fish that can be caught; the best bait to use (nightcrawlers, dear, and

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<sup>2</sup> Of course, I hadn’t kept *every* Monday open for more than eight years, but I did plan my schedule around Monday mornings, and generally managed to get to Montgomery Place about 45 weeks out of every 52.

nothing else); and the taste of a freshly-caught freshly-cooked trout. She finished with a suggestion that I join her on a fishing trip in August.

*“And that’s a firm invitation,”* she said.

## CONCLUSION

The best volunteer work must occur when everyone involved gives something and everyone receives. On the surface, my visits to the dementia unit at Montgomery Place would seem to contradict that idea, since I was the one who chose the material, made the trip, read the stories and poems, and exerted 90 per cent of the energy each week. Beneath that surface, I received something every time a resident responded, laughed, clapped, sang, asked a question or joined in a poem. At an even deeper level, all of us in the Monday Morning Story Group gave and received by just being there as the selves we were on any given day. When every moment is now, the journey really is the destination, and success is marked by making the journey.

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