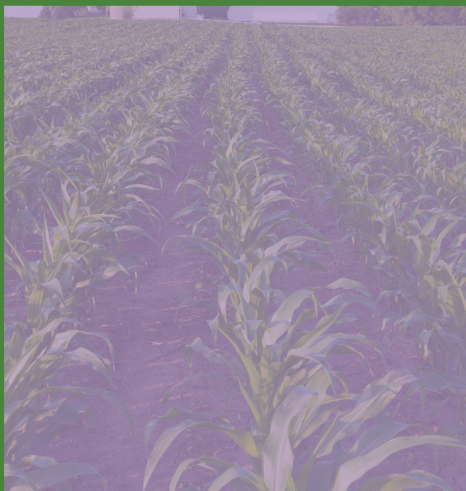
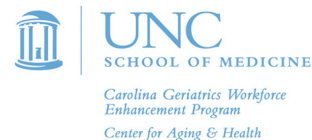
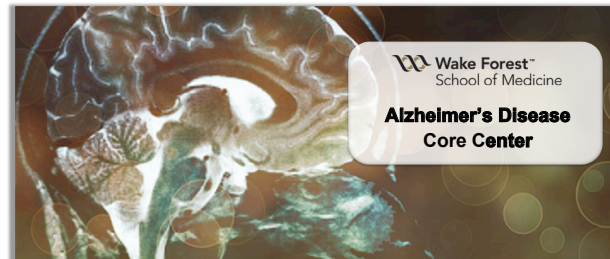




Memory Loss and
Alzheimer's Disease in
Native People





“This project is supported by funds from the Bureau of Health Professions (BHP), Health Resources and Services Administration (HRSA), Department of Health and Human Services (DHHS) under collaborative agreement #U1QHP28734, Carolina Geriatric Workforce Enhancement Program. This information or content and conclusions are those of the authors and should not be construed as the official position or policy of, nor should any endorsements be inferred by the BHP, HRSA, DHHS or the U.S. Government. The UNC Center for Aging and Health, Carolina Geriatric Workforce Enhancement Program also provided support.”

All stories except “Charlene’s Story” written by Dr. Lisa Huggins Oxendine.
Charlene’s Story written by Charlene Hunt. Design by Chad Locklear

Contents

Introduction	3
For Alzheimer’s patients, their best day typically is yesterday	4
Grandma Sarah’s Story	5
Dementia and Alzheimer’s: What’s the Difference?	6
What Cognitive Changes are Normal as We Age?	8
Charlene’s Story	9
Uncle James’ Story	11
Symptoms of Alzheimer’s Dementia	13
Dr. Frank Richardson’s Story	14
First Signs of a Memory Problem	16
Resources	18
Why is Early Detection Important?	18

Introduction

Alzheimer's is a devastating disease. American Indian people are not strangers to Alzheimer's disease. Our elders have been greatly affected by this tragic condition, and many families are faced with the struggle of understanding how to cope with caring for their loved ones who have been touched by Alzheimer's.

American Indians in North Carolina are 50% more likely to die from Alzheimer's disease compared to non-Hispanic whites. We don't understand why, but researchers are beginning to learn more about the causes and why some people are affected by Alzheimer's more than others. One possible explanation is that American Indian people have a higher risk of diabetes, and recent research has shown us that high blood sugar can impair memory and increase risk of developing Alzheimer's. We also have a better understanding of how to recognize the earliest signs of Alzheimer's disease, which allows health care providers to offer better treatments to slow disease progression and allows caregivers to begin using support resources much earlier.

This booklet is designed to help you understand more about Alzheimer's and how to recognize the early signs of memory loss. We hope this resource will help you in your journey as someone who is experiencing symptoms, or as a caregiver, family or friend of someone who has the disease.

To the Editor,

My aunt Patricia Jacobs Chavis passed on July 2, 2016. She was one of the more than 3 million Americans each year whose families suffer from Alzheimer's. I am writing this today on behalf of the Godwin, Jacobs and Chavis families because Aunt Patricia would want the world to be informed about this disease in hopes of preserving as much patient quality time as possible.

Alzheimer's is a type of dementia that causes problems with memory, thinking and behavior. Alzheimer's patients suffer from brain cell and connectors degenerating and dying. This process literally destroys memories and mental functions.

In America, Alzheimer's is the sixth leading cause of death. While most people suffering from Alzheimer's are 65 years and older, up to 5 percent of patients may experience Alzheimer's in their 40s and 50s.

Trouble in remembering newly learned info is the most common early symptom of Alzheimer's. Generally individuals do not recognize their decreased memory function, but surrounding family and friends do.

Alzheimer's patients live an average of eight years after symptoms become noticeable, but survival ranges from four to 20 years. While there is no current cure for Alzheimer's, treatments today slow dementia and improve quality of life. There are genetic predispositions toward Alzheimer's, but they are not emphatic.

It's commonly said by caregivers caught in the selfish grip of Alzheimer's that the patient's best day was yesterday. Aunt Pat would want all families to have as many cherished yesterdays as possible along the progress of the darkening night that is Alzheimer's. She would want everyone to be attuned to genetic and to behavioural symptoms. For more info, please consult <http://m.alz.org>.

Eric R. Locklear
Reprinted from The Robesonian

Grandma Sarah's Story

By the time Grandpa John Locklear died, Grandma Sarah had begun to disappear. Her disappearance wasn't literal and it definitely wasn't sudden. Her talkativeness, quick laughter and funny wit were no longer part of our interactions with her.

When she began to forget my name, I became concerned that something was going on with her memory. It wasn't an occasional mix-up due to being over seventy with 9 children, many grandchildren and a few great-grandchildren. First, she began to call me by my uncle's name. Then, in time, she didn't address me at all. I struggled with feelings of sadness and disappointment. I sometimes wondered how she could forget me. I comforted myself by remembering that whatever interfered with her memory also impacted her ability to show her love for us.

Since I was a child, she routinely talked every few days with her children and grandchildren in-person or by phone. She ended conversations with a promise to pray for us. It was fun and comforting to talk with her. Unfortunately, by the time of Grandpa's death, she rarely spoke. Even as an adult with a busy life, I enjoyed talking with Grandma. I was sad when the talks were no longer possible.

When Grandpa John told us she had been diagnosed with Alzheimer's and prescribed medicine, it was difficult to accept. Grandma had done the things that are supposed to keep a person mentally healthy. She kept herself active on the farm by walking and doing work. She solved crossword puzzles, ate nutritious foods and



saw her doctor regularly. She had no other medical problems. So, how could it be possible for her to have Alzheimer's! Still, I knew that many of Grandma's family members had been diagnosed with Alzheimer's in the past. Grandma ate health-supporting foods, exercised and kept mentally active because she knew her family history increased the risk that she would develop the disease. So, she controlled the things that she could to maintain her mental abilities as long as possible.

"The main reason I had difficulty accepting the disease diagnosis was fear. I didn't know how to fix Alzheimer's or how to help my family with emotions caused by changes related to the disease. That scared me."

Over time, Grandma became uncooperative away from home. Even short trips to church or the doctor's office were increasingly challenging because of

her unwillingness to remain in spaces such as an exam room or the church Sanctuary. She wasn't combative but she refused to sit down. She wanted to wander from room to room and person to person. She looked inside rooms and stared at faces as if she were trying to recognize someone or some place. She appeared lost and a little anxious. It was painful for me to watch her at those times. I stopped going to church when I knew that she was to attend.

For five years before he died, Grandpa gave updates, "The doctor changed Sarah's memory medicine because it wasn't working." "I'm the cook in the house so we eat sandwiches and crackers." "Alzheimer's disease has got Sarah turned around!" "She gets out of bed at night. She was in the backyard one night last week. She became mad and tried to fight me when I brought her back inside the house."

The family was supportive. We cooked for them. My mother and aunts cleaned

Dementia And Alzheimer's: What's the Difference?

Dementia is a medical condition that involves a loss of short-term memory and other thinking abilities such as language and attention, impaired ability to carry out everyday tasks (like driving, finances, self-care), and a gradual shrinking of the brain caused by extensive loss of brain cells. Dementia can be caused by different types of brain diseases.

Alzheimer's is one type of brain disease that ultimately leads to dementia. A person can have Alzheimer's disease for several years before dementia develops. Like other diseases such as cancer, medical changes begin to occur long before symptoms become obvious to the doctor or to family and friends. Someone in the early stages may have a mild memory problem that goes unnoticed by most people. With time, as the disease progresses, this person may develop 'Alzheimer's dementia.'

the house and taught Grandpa to warm casseroles in the microwave. My uncle changed the exterior door locks so Grandma couldn't go out when Grandpa was asleep. We went with them to doctors' appointments. We even took turns staying with Grandma on Saturday afternoons so Grandpa could go fishing, visit his friends, get a haircut or just take a nap. He needed time for himself.

Then, one morning last June, Grandpa John died. By that time Grandma looked at us with no obvious signs of recognition. There was no reaction when she was told that her husband of fifty-seven years had passed away.


I'm a grown man but I cried like a baby that day. Grandpa was dead and Grandma undeniably had Alzheimer's disease. I mourned his loss and the fact that she would never talk, laugh or cry as she had in the past.

My mother and aunts cared for Grandma at home until swallowing became difficult for her. Her doctor explained that Alzheimer's disease affects the whole brain including parts that control swallowing and movement. By that time, she was also bedridden. The family agreed Grandma would have a feeding tube and go to a nursing facility. My mother became depressed and needed counseling from our pastor. Though she knew that the nursing facility was best for Grandma and she visited most days, my mother struggled with feelings that she had abandoned Grandma. Grandma lived at the nursing facility for three months.

Just over a year after we buried Grandpa John, we gathered again for

another funeral. Blessed Assurance, was sung. It was a favorite song for Grandpa John and Grandma Sarah. Grandma's coffin was draped with a quilt she had hand-sewn many years earlier when she remembered the names of her children. My family struggled with the impact of Grandma's Alzheimer's disease. We were unprepared for the emotions it provoked and unsure how best to help our Grandparents and each other. A few months after Grandma's funeral we decided as a family to seek help...to become better prepared in case another member of our family is diagnosed with Alzheimer's disease. We also wanted help for others struggling due to Alzheimer's disease. We searched the internet for organizations that provide Alzheimer's disease resources in our area. We met with our pastor to learn ways the church can support families trying to cope with this disease. The church agreed to serve as the site for an Alzheimer's disease workshop.

Community and church members attended with area resource providers. We were told about Alzheimer's including the usual course of the disease and mental and physical changes that tend to occur. It was a relief to hear information that reassured me the sadness I felt when Grandma no longer recognized me was a normal response to changes in the brain caused by advancing Alzheimer's disease. We received brochures that listed local, national and internet organizations that families and caregivers can contact for information or help with problems. Many church and community members



attended the meeting making the point that Alzheimer's disease is an important issue for lots of families. Now, a monthly Alzheimer's disease support group meets at our church. It's open to everyone (including non-church members).

My family's experience taught me that Alzheimer's disease can cause significant mental and physical changes for the person with the disease. Those changes can prove challenging for family members and caregivers but there is help in the form of support groups and local, national and even internet organizations that have useful information

What Cognitive Changes Are Normal As We Age?

It is normal to forget names more frequently.

It is normal to have more difficulty doing more than one thing at a time, referred to as multi-tasking.

It is normal to need more time and energy to learn new information. As we get older, we cannot learn as quickly as before.

It is normal to become a little more flustered or confused when doing too many things at once.

It is normal (and often frustrating) to have more difficulty recalling information exactly when it is needed (e.g. while having a conversation). Often this information is recalled much later, like in the middle of the night.

Charlene's Story

American Indians were the first farmers. The story of the Three Sisters is common place within all tribal communities. Corn, beans and squash planted together to help each other grow. The concept of companion planting, in which one plant helps the other, is the basic idea behind the Three Sisters. Farming goes back generations in many American Indian families; it was our means of supporting our families and also has a deep spiritual connection not only with the Earth but with our souls. Farming always brings us home...

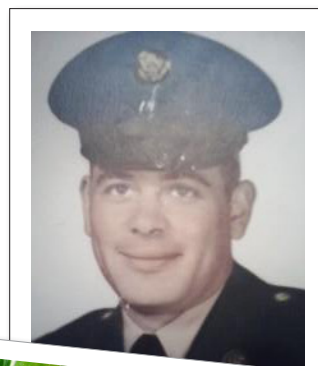
These roots run deep within my own Lumbee bloodline. My Great-Grandfather was a tobacco farmer, my grandfather and my Daddy, Charles, whom I am named after; followed in their footsteps. As a child, I can remember my feet loved being in the dirt and even though I am an adult I still get barefoot in my own garden. Thinking of the smell of tobacco as it hung curing in the "bacca" barn takes me right back to my childhood days. These memories provide good medicine for my mind, body and spirit... not just for me, but for many of my tribal people. The lessons the fields taught us at an early age are carried and passed down through the generations just like the storytelling of the Three Sisters.



Last year while being down home, I was in the garden with Daddy. He had a look in his eyes that shook me to my core. Daddy, are you ok? Daddy, do you know where you are? He was lost in his own garden. He was lost in this place that has been part of his life for years, the place that has given him joy and pride as he bragged about how big his tomato plants were. I could tell by looking at his expression that he did not know where he was. He was confused and lost and I could see this in his eyes. It was as if someone had briefly turned off his light. Slowly and with fear in his voice, he asked, "Where am I?" Hearing my Daddy ask that while we were standing in the middle of his own garden brought tears to my eyes and a sharp pain in my belly. Despite the unexpected raw emotion welling up in me, I knew to stay calm so that I did not alarm my father. I quickly grabbed his hand, looked him in his eyes, and said, "We are in your garden, Daddy."

In that moment, I was forever changed. Seeing my strong father, now 76 and hair full of white, was not only visibly aging but now it was painfully obvious that his mind had also started to slowly fade. As the sun set while standing there in the garden holding my Daddy's hand, I realized that my life was about to drastically change... and my mind drifted to the story of the Three Sisters. Standing there watching the sun's brilliance disappear made me think of his memories that were also starting to fade. What if he forgets me?

Since then, our family roles have changed. I spend more time visiting my father, and providing caregiving and support for my father – the man who helped make me who I am today. Now, I am the strong one – like the corn plant in the Three Sisters story – helping to hold my father up. I know that one day he will be too weak – in mind or body – to do this on his own.



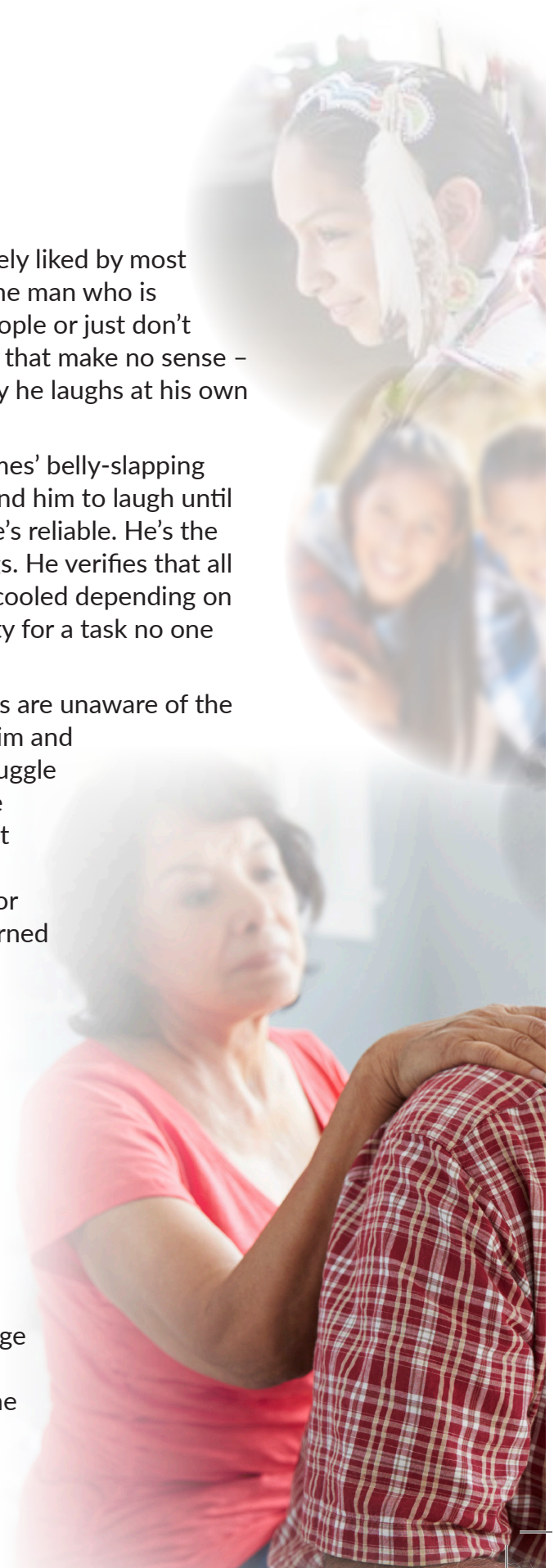
James' Story


James Everett Lambert is a man genuinely liked by most people. His wife Faye describes him as "...the man who is everybody's friend unless you don't like people or just don't want a friend." He's known for telling jokes that make no sense – but still make you laugh because of the way he laughs at his own jokes.

Honestly, the jokes aren't funny but James' belly-slapping and roaring laughter causes everyone around him to laugh until they cry! People also like James because he's reliable. He's the first to arrive at church on Sunday mornings. He verifies that all the classrooms are comfortably heated or cooled depending on the season. When he assumes responsibility for a task no one worries whether the job will be done.

However, most people who know James are unaware of the subtle changes in his memory that worry him and Faye. During the past year, he began to struggle to remember the punch line for his favorite jokes. Then, there was a Saturday night that he forgot to set his alarm clock. Faye tried to reason with him that everybody is late for church occasionally. Still, James was concerned because this was not the only thing he had forgotten lately.


He confessed to Faye that he lost his car keys at the Fall PowWow and secretly had a duplicate set made. She tried to make him feel better by telling him that a man in his 60's should expect a few memory lapses. He shook his head and told her about the memory lapses that most concerned him. He had forgotten an important tribal council meeting and missed the deadline for a tribal policy change because he didn't remember that he had committed to lead the writing efforts for the





This got Faye's attention and she started asking questions: Yes, he was working his job without complaints from his boss, No, there were no headaches or black-outs, and No, he had not lost his way home. After all of her questions were answered, Faye was concerned because she knew that telling jokes, writing policy changes for the tribe and serving the church were so important to James that forgetting something about them meant there was indeed a problem.

They made an appointment with the family doctor. The exam was normal. A week later the call came that all of James' blood tests results were normal. Three weeks later, James returned to the doctor because he was worried that he had forgotten another commitment to the tribal council. The doctor explained that there was no obvious physical problem but offered to complete a brain scan on him to check a little closer. A week later James received notice that the brain scan was also normal. Since James continued to be worried about his memory, his doctor referred him to a brain specialist who had experience caring for older adults with memory complaints.



James began to feel frustrated and worried. At work, he made lists to remind himself of things he needed to do. He figured out how to use his smartphone's alarm to wake himself early on Sunday mornings. Still, he was afraid that he would make mistakes at work and lose his job or let the church or tribal council down in some way. He stopped telling jokes partially because he forgot the punch line and largely because he was worried someone would realize

that his memory was a bit different from the past. His laughter was nearly gone. He felt afraid and uncertain of his future. Faye struggled to sleep because she worried that James had a brain tumor or maybe even Alzheimer's.

Faye started feeling sad and frequently felt like crying. When she lay awake at night, worrying, she frequently noticed that James was also awake. He would toss and turn and seemed to emotionally drift away from her. He didn't tell her that he was afraid but she knew him and realized that he worried. Faye felt that something new and unwanted had crept between herself and James... something that was interfering with James' memory and with their relationship.

Symptoms Of Alzheimer's Dementia

Forgets events that occurred in the last few minutes, hours or days.

Repeats parts of conversations with no recognition that the information was repeated.

Loss of interest in hobbies and other activities.

Feel confused on a regular basis (i.e., daily or weekly).

Difficulty managing everyday tasks such as cooking, gardening or other hobbies and finances.

Memory and other thinking abilities decline to a point where the change is noticed by others.

Dr. Frank Richardson

Frank Richardson and Mrs. Lynch's son, Tommy, were best friends growing up. Most Saturdays they fished in the pond behind Tommy's house or bow hunted in a wooded area between their family farms. Mrs. Lynch made a dessert each Saturday and often gave them a sample of her pie or cobbler made with sweet potatoes, pumpkins, apples or blueberries from the Lynch farm. On special occasions, she baked Frank's favorite, a thirteen layer chocolate cake.

After high school, Frank and Tommy chose different careers. Tommy learned to repair small engines and got a job in manufacturing in their community. Frank moved to Chapel Hill and got a biology degree and completed medical school there before returning home. Mrs. Lynch, Tommy, Tommy's wife and many tribal elders attended the Ribbon Cutting Ceremony for the opening of Richardson Family Practice. They were proud that one of their own tribal members had become a doctor and would provide care for his people.

Mrs. Lynch's first visit as Frank's patient was lengthy. She told him about Tommy's three girls. They lived next door to her and helped her bake cakes and pies. She knew their names but couldn't remember birth dates. Frank noticed that she repeated comments and he hoped it wasn't an indication of health complications. She was sixty-six years old. Her diabetes was uncontrolled, her blood pressure too high and she weighed at least seventy pounds above normal for a woman her height. She ate dessert every day. She admitted to occasionally forgetting her medicines.



Frank, now called Dr. Richardson, explained the dangers of uncontrolled diabetes, high blood pressure and obesity. He spoke firmly but respectfully about the increased risk of death, kidney damage, heart attacks and strokes, blindness, joint pain and loss of limbs. He suggested she not eat cake or pie daily. He warned that uncontrolled diabetes or high blood pressure can also decrease memory. He asked if she wanted resources to help her remember her medications. She nodded in agreement. The nurse gave her a pill planner with days of the week on it. She received sticky notes to place on the bathroom mirror and refrigerator as a reminder to take medicines. After taking her medicine, she would mark the day on the calendar the nurse gave her. An unmarked day was a sign to look at her pill planner to see if she had forgotten her medicine. She was also given notes that read, “Not Today”. She would place those on her cake pan.

The pill planner, calendar and sticky notes were helpful reminders. After a few weeks, Mrs. Lynch’s diabetes and blood pressure improved and her lab tests were good. However, it became apparent that she had ongoing memory issues. Dr. Richardson noticed she went to his office at unscheduled times and requested medicines that were recently refilled. She repeated questions and comments.

When Dr. Richardson realized Mrs. Lynch had dementia, he was sad. He felt connected to her as his patient and as an important person in his life. He knew the future could prove challenging for Mrs. Lynch and her loved ones. He did not want that to be true. He wanted her life to move forward without struggle



First Signs Of A Memory Problem (Before Dementia Develops)

More trouble remembering appointments and events.

May get confused a little more often than usual.

May feel 'overwhelmed' or 'stressed' more often than usual, even though there's no obvious reason for this change at home or at work.

May feel that 'something is not right' even though others fail to notice a change.

Mood may appear to be mildly different than what it used to be.

Other than these symptoms, which all appear to be mild, there are no other obvious problems with thinking or ability to carry out everyday tasks.

or further decrease of her memory. Still, he was her doctor and had to be realistic.

He wondered how much elevated blood pressure and blood sugar contributed into her memory loss. He thought about her quick agreement to take medications daily and use the pill planner and calendar. He began to wonder whether he could have done something earlier. He struggled with thoughts that he should have been a positive influence on her health while he was in medical school. He began to research Alzheimer's disease and dementia issues for American Indians. He wanted to know how best to help Mrs. Lynch and his other patients.

Dr. Richardson attended an American Indian health conference where he talked with a medical school friend. They recalled that medical school consumed their lives for years. They agreed to the joys and heartbreak of caring for people they knew outside the medical office. After the meeting, Dr. Richardson felt relieved. The talk reminded him there had been little time outside of medical school. He hadn't ignored Mrs. Lynch's needs. The conference supported much of what he had begun to suspect, American Indian elders and families need supportive, compassionate providers willing to discuss health conditions including Alzheimer's disease and dementia with words and examples that are culturally meaningful.

Dr. Richardson began to ask Mrs. Lynch to bring someone with her to her office visits. Still, she showed up alone and wouldn't tell him why. He assumed she didn't want her family's help. He had a dilemma. Should he call Tommy? Patient confidentiality was important but Mrs. Lynch had

dementia. He was concerned she would take medicines incorrectly which could be life-threatening. He also needed to learn more about her memory issues.

Fortunately, Tommy was also Dr. Richardson's patient. The office manager scheduled Tommy and Mrs. Lynch to be in the waiting room at the same time. Mrs. Lynch happily invited him to sit in on her visit with Dr. Richardson.

Tommy was aware of her forgetfulness and was concerned about Alzheimer's disease. Interestingly, Mrs. Lynch knew she forgot appointments. She also admitted to becoming confused, "...I get tangled up easy. I couldn't figure out how to get home from the tribal center last week and the staff person drove me home. She goes to our church but I can't remember her name." Tommy was shocked!

Dr. Richardson prescribed medicine for her dementia. He explained her dementia was likely due to Alzheimer's but that uncontrolled diabetes and high blood pressure might have been part of the cause. He told them the medicine would not cure or stop the disease but could help for a while. He explained the usual course of the disease and treatment then answered their questions with words that made sense to Mrs. Lynch and Tommy. They nodded agreement about the need to maintain blood pressure and blood sugar in a normal range. They discussed how to support Mrs. Lynch's care such as her signing permission for Tommy and his wife to know medical information. From that point onward, Mrs. Lynch was accompanied to doctor's visits by her son or daughter-in-law. She felt blessed that her only child and his wife loved her enough to be a vital part of caring for her. She admitted knowing for a long time that she needed Tommy's help but didn't want to interfere with his job or family time.

Mrs. Lynch taught Dr. Richardson two important lessons. Firstly, older patients may not ask for help. He now encourages older patients to invite family members to appointments. He explains the need to give a family member permission to know medical information. Also, family members are scheduled together in his waiting room to promote family support for older patients.

Secondly, Mrs. Lynch taught him the desperate need to protect the brain. He tells all patients that blood pressure and blood sugar must remain in a normal range to reduce the risk of dementia. Interestingly, Mrs. Lynch was an important person in Dr. Richardson's early life. Years later, her dementia diagnosis proved vitally important to his growth as a caring and compassionate health care provider.

Why Is Early Detection Important?

Early detection of memory loss and Alzheimer's disease is important for prevention. If the family waits until the symptoms are more severe and therefore quite noticeable to others before seeking help, it may be too late to slow or prevent the disease.

Early detection of memory loss and Alzheimer's disease is important to ensure that the family is adequately prepared to handle the challenges ahead and has ready access to appropriate support resources.

Resources

For Support Groups & Education:

National Alzheimer's Association
24 Hour Help Line: 1-800-272-3900
Website: www.alz.org

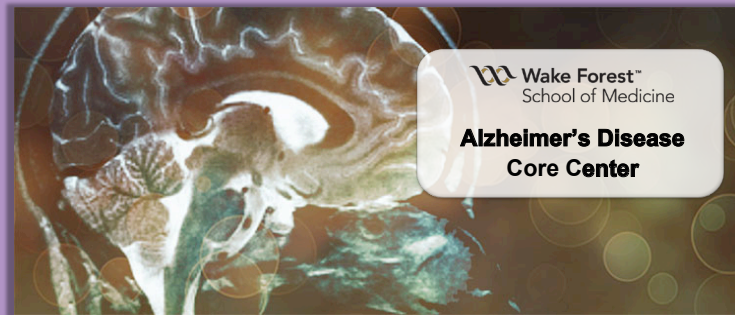
Western Carolina Chapter:

www.alz.org/northcarolina

Eastern Carolina Chapter: alz.org/nc

For Clinical Trials & Education:

Wake Forest Alzheimer's Disease Core Center,
Winston Salem, NC
Phone: 855-381-MIND (6463)
Website: wakehealth.edu/alzheimers



Wake Forest[®]
School of Medicine

**Alzheimer's Disease
Core Center**

