

# A ALZHEIMER'S

## The Eyes Tell Whole Story Of Nightmare

By KIM PHELAN  
Globe-News Medical Writer

**M**axine Spiker only had to look into her husband's eyes to discover the frightening truth.

Bill Spiker didn't have to say a word — even if he could speak. The dull glaze of his eyes told the story.

Bill couldn't recognize his wife of 31 years. Maxine was a stranger to him. Soon the entire world would be a stranger to the 49-year-old Amarillo man whose brain is being consumed by Alzheimer's disease.

"There are days when I wonder if he knows who I am," Maxine, a paralegal, said as she sat cross-armed behind her desk at a local law firm. "We have gone through the phases where he has looked at me and said, 'Where is my wife?'"

"I knew the day was going to come, but it was still a jolt. Each time something different happens, it's a jolt in knowing that another level has come, that he has gotten one step worse."

As secretary of the Panhandle chapter of the Alzheimer's Disease and Related Disorders Association, Maxine is well-versed in the disease's fatal progression.

She knew that eventually Bill's brain would forget how to signal his larynx, and he would not remember how to talk. She knew that one day, he would not be able to remember the simplest sentences. But three weeks ago, when that day came, when Bill opened his mouth only to speak garbled sounds, Maxine was jolted again.

"I miss having someone to carry on an adult conversation with," the woman explained, leaning forward on her desk for emphasis. "Of course, I can talk to Bill, but he won't respond."

"Occasionally, not that often, but every now and then he will ask 'Where's my glasses?' or 'Where's my knife?'" she repeated in a tired mimic. "Most of the time they are on his face or in his pocket."

Bill is only one of 2.5 million Americans and as many as 160,000 Texans who suffer from this progressive, degenerative, neurological disease that attacks the brain and results in impaired memory, thinking and behavior, according to the Texas Department of Health.

And the numbers are growing with the aging of America.

The nation's fourth largest killer, Alzheimer's will affect about 10 percent of the popula-



Staff photo by Gaylon Wampler

Maxine Spiker gives her husband, Bill, a playful pinch, eliciting a small smile from the victim of Alzheimer's.

## Where The Mind Has Gone, The Body Is Sure To Follow

By KIM PHELAN  
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**T**he day the doctor told Bill Spiker he could never return to work, he was relieved. That same day, Maxine Spiker's nightmare began.

"He just kind of sat back and relaxed," his wife explained. "When you realize how hard they are working to maintain their status, how hard they are trying to hide their illness, you can begin to understand their frustration."

Bill, at the young age of 49, has Alzheimer's, a progressive neurological disease that will eat away his brain until he dies. Bill probably recognized he was sick a couple of years ago when, after working six years at Pantex, he had difficulty finding his way to work. So each morning, Bill would leave

■ Samantha Spiker and the father she never knew 3'  
■ Photographer Gaylon Wampler captures Alzheimer's effects 3'

his home in southeast Amarillo at 6 a.m. to assure that he would miss the traffic and the crowds that confused him, and arrive at work by 8 a.m.

"I think he knew something was wrong with him," Maxine explained. "But I don't think he ever understood what was happening and what ultimately will happen to him."

But Maxine does know what will ultimately happen to her husband of 31 years. He will die. What she doesn't know is when.

"It could last 20 years or he could die tomorrow," she said as she sat in her home with a photo album on her lap. She closed the picture book she composed for Bill last Christmas.

The photos, a trick often incorporated by families of Alzheimer's patients help Bill retain memories of his past and the identities of his family. They also remind Maxine of the man she once knew and the stranger she now lives with.

"I wish it would have ended a long time ago," she said softly looking down at her hands. "It's gotten to the point where we are only maintaining his body. If there were anything at all he could do, if he had any interest, it would be different."

"He won't even go to the kitchen and get a drink of water. So far as his

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tion over 70 years of age, 20 percent older than 80 and 30 percent over 90, said Dr. Harry Lipscomb, professor of medicine at Texas A&M University.

The risk is higher, however, if there is a genetic link in the family, he said. Those with the familial link at the age of 50 have a 10 percent chance of being affected by Alzheimer's, he said. And the risk increases 10 percent with each decade, ending with a 50 percent risk at the age of 90, he told the audience in the Amarillo Texas A&M building.

Lipscomb spearheaded a well-attended Alzheimer's workshop in Amarillo last month geared toward care givers - many of whom were family members searching for answers to the disease that is consuming their loved ones.

The onset of Alzheimer's takes about two to three years. Death often results an average of seven to eight years later, Lipscomb said, but can occur as long as 14 years later, according to the national office of the Alzheimer's Disease and Related Disorders Association.

There isn't a known cause. There isn't a known cure. And there isn't a definitive test that will positively identify the disorder.

Diagnosis is conducted by a process of elimination, Lipscomb said.

"It's a diagnosis of exclusion," he told the audience. "You have no right to call a living human an Alzheimer's patient. The most you can say is this person is a possible Alzheimer's patient. Right now the only way you can diagnose Alzheimer's is by an autopsy."

An autopsy will uncover the diseased, shrunken, two-pound brain

compared to a healthy three-pound brain, he said.

Discovered in 1906, Alzheimer's once was regarded as a mental disease, a product of aging sometimes called senility, sometimes called crazy, he said.

"It has a colorful and checkered past," he explained. "In fact, nobody has talked about it until the last few years. It has become the most popular thing next to AIDS.

"Alzheimer's is recognized as the most common cause of dementia. Dementia means not of mind or no mind. It doesn't mean crazy"

One family in every 10 has at least one elderly member who has some form of senile dementia, including Alzheimer's disease that accounts for nearly 80 percent of the dementia cases, according to the Texas Medical Association. The affected person slowly becomes increasingly confused, incapable of sensible conversation, unaware of surroundings and generally incapacitated, according to TMA.

"People will come to me and say 'I think I am losing my mind,'" Lipscomb said. "And, in a sense, they are. They are losing the neurons of their brain. The world of dementia is a lost world. The Alzheimer patient is a person who is forever seeking a world they have lost and will never regain.

"It's an endless searching, seeking, wandering. And, in a sense, not only have they lost their world, they are lost to us. They have annihilated us from their world, and they do not have the tools with which to rebuild their world."

# Where The Mind Goes, The Body Follows--

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being a productive person, he is past that point."

Maxine's sentiments aren't unique. Although Alzheimer's is killing Bill, the disease has a second, less-visible victim - the family caring for the patient. Looking after an Alzheimer's patient is a time-consuming, frustrating and often thankless task that can leave the family member fatigued, depressed, angry and alone.

The family member becomes the primary care-giver, jargon used in the health industry today that often is no more than a euphemism for unpaid female relative.

According to a 1985 study conducted by The Travelers Corporation, nearly seven of every 10 primary care-givers are female who spend an average of 16 hours a week providing care. Male primary care-givers devote only five hours a week, tending to do only those tasks that are necessary to "get the job done," according to the study.

Maxine cares for Bill during the early morning and late evening hours as well as 24 hours on the weekends. But the large portion of

the day, when Maxine works, her daughter-in-law, Denise, and son, Max, watch him.

Maxine hates to intrude on the young couple but realizes she cannot afford to hire a nurse who will give him individualized attention. And she doesn't want to send him to a day-care center where the multitude of clients will confuse and disorientate him.

So she keeps him at home. She realizes that some day she will have to relinquish her husband to a nursing home where trained professionals can provide Bill the necessary 24-hour care. But many obstacles stand in her way.

First, getting on a waiting list and into one of the coveted homes is often difficult, said Jane Rouk, secretary of the Panhandle ADRDA.

"This is one of our major, major problems in Amarillo," Rouk said. "There aren't enough nursing homes that have a staff that are trained to work with Alzheimer's patients."

Second, Maxine will have to relinquish her hold on her husband, a bitter-sweet task most care-givers are reluctant to do.

For Maxine, sending Bill to a nursing home would be admitting failure. Other care-givers fear that the professionals won't give the same attention they offer their loved ones. And still other care-givers fear society's hostility and their own disapproving guilt, said Dr. Harry Lipscomb, professor of medicine at Texas A&M University.

"The guilt is tremendous," he explained. "And the neighbors don't help. They don't understand why you sent her into the nursing home. They say, 'She's a strapping, healthy woman. Maybe a little looney, but she didn't need to be put in a nursing home.'"

"They don't understand that she wakes you up in the middle of the night, that she sets fire to the house, she puts her shoes in the freezer, and she wanders because she's lost her sense of time and place."

The time will come, Maxine said, when she will put away the guilt and the excuses, when her willpower and seemingly unending strength will dwindle to nothing. Then she will turn toward the nursing home - a move she realizes probably will bankrupt her and her family.

Although she isn't considered a wealthy woman, the little property she does own in the form of a home is enough to disqualify her and her husband from governmental financial assistance, she said.

"My choices are to ultimately surrender everything I've got and possibly all of my children's assets or to divorce him so he would be left as a single person without any property," she explained.

"I've discussed this with the children. It was a difficult discussion. But they didn't like the divorce aspect. I really think my children would rather lose everything, than have momma divorce daddy."

By the year 2000, an estimated 4 million Americans are expected to be stricken with Alzheimer's. Most will eventually require full-time institutional care at an annual cost ranging between \$17,000 and \$25,000, according to ADRDA.