

Kathy Mattea:

he Girl Scouts may have helped prepare Grammy-winner Kathy Mattea for life as a country music and bluegrass star with 15 albums to her name. After all, it was at camp in her home

state of West Virginia that Kathy, now 50, first discovered her love of song and a talent for playing guitar. But although "Be Prepared" is every Scout's motto, Kathy was not ready to hear the diagnosis when her mother, Ruth, was told she had *Alzheimer's disease* (AD). "I was devastated," she recalls.

That's because Ruth Mattea had been healthy until her late 70s, when she developed an *arrhythmia* (an abnormal heart rhythm) and a thyroid condition. Complications followed that led Kathy and her father, John, to take Ruth to the Mayo Clinic, in Rochester, MN, in December 1999. "Mom had also been having some memory problems," Kathy says. "So we figured that while we were there, we'd also have those looked into." After extensive memory tests and neurological exams, the Matteas, including Kathy's two older brothers, were confronted with the worstcase scenario. Ruth was experiencing Alzheimer's disease, a *cognitive* (thought process) disorder that, among other things, impairs memory and strikes 13% of people over 65 and nearly 50% of those over 85 years of age.

Classic symptoms

Because her mother had the "classic symptoms" of the illness, including

How music helped a Grammy-winning country singer stay connected to a mom with Alzheimer's

Photographs by James Minchin

from dementia. Many people confuse dementia and Alzheimer's, but *dementia* is actually the umbrella term for several cognitive disorders that include AD and other disorders with similar symptoms. As it turned out, Ruth was also the second out of five sisters to be stricken with the disease in her 70s. And later, another sister was diagnosed and is currently in the final stages of Alzheimer's.

Doctors put Ruth on medication aimed at slowing the progression of the disease and stopping the plaque from forming in her brain. Taking the drug impacted Ruth psychologically for the better. Kathy notes, "My mom felt good taking action."

More than a memory disorder

But in February 2000, a second blow to the family would deeply affect Ruth. "My father was diagnosed with colon cancer that had spread to his liver," says Kathy. During his second round of chemo in April 2000, he stayed in the hospital for 10 days something that was very difficult for his wife to process. "She thought terminal illnesses. But Kathy had also enlisted medical aid from the moment her father was diagnosed. "We had lovely, caring people who were with us through my dad's illness," she says. "They then stayed on as my mom's illness progressed," she says. "We had a lot of support because her caregivers had so much experience with Alzheimer's. They knew what to expect in each stage, and they taught and guided us."

To cope with the range of emotions she was experiencing, Kathy also spoke to a counselor. "There was a great counselor at the hospital my dad was in," she states. "Seeing her helped a lot."

Music magic

After losing her father in 2003, Kathy watched her mother march backward through her life, down to the end, when Ruth became infant-like. "I'm so thankful I had my music to help me through those painful times," says Kathy.

But the music not only comforted Kathy—it also became an important way to communicate with her mom. "I remember that I was tuning a guitar and hit a chord. My mother—very

Labor of Love

memory loss, disorientation and a habit of consistently misplacing things, the Matteas were not completely surprised by the diagnosis. In fact, they had been dreading it. "That day, the doctors told us that Alzheimer's can't be 100% diagnosed without an autopsy to check for plaque that forms in the brain and short-circuits memory," she explains. "But it appeared that's what she had."

Hearing those words out loud from a medical professional was very tough on Kathy since her maternal grandmother had suffered my father was gone because he was having an affair," says Kathy, whose husband of 20 years, songwriter Jon Vezner, helped and supported her during these rough times. Kathy later learned her mother's uncharacteristic rage and jealousy are common symptoms of AD. "This common but lesser-known symptom is a part of the disease no one talks about. Alzheimer's is so much more than losing your memory."

It was extremely difficult to have both parents simultaneously battling

uncharacteristically—started singing one of my songs." In fact, her mother's response was so profound that one of the caregivers advised Kathy to play her greatest hits album to help her mom combat the confusion and agitation of "sundowners" (*see* "Understanding Sundowning"). Kathy did, and her mom suddenly started singing the opening line to the first song on the CD.

"That day, I sat and played every song in order, while mom and I sang," she *Continued on page 14*

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shares. "It was beautiful." The memory is especially poignant to Kathy because her mother never sang—she was tone deaf and very self-conscious of her voice. "That day was beautiful because it was the first time I ever sang with my mom," she states. "And she had the best time."

It was only about a year later that Ruth's illness progressed to the point where she was no longer able to recognize her daughter—or even speak. And in 2005, six years after her Alzheimer's diagnosis, Ruth passed away. Kathy notes, "Up until the end, she could still sing all the verses to 'You Are My Sunshine'.

"I am so glad to have a life wrapped up in music," says Kathy, "because music was the last connection my mom and I had." And her music still keeps her family connection strong.

Her latest album, *Coal* (Captain Potato Records, April 2008), pays tribute to the mining industry and her family. Kathy's grandfathers were miners, one of her brothers works in the coal industry and her mother worked for the United Mine Workers. "My music," she says, "is a labor of love." And the devotion she showed both parents was, too. **(**

-Gina Roberts-Grey

Kathy's Plan for the Future



G enetics play a role in the development of Alzheimer's disease (AD), especially in the early-onset variety (which develops between the ages of 30-60). Kathy Mattea's mom, Ruth, developed late-onset AD. The jury is still out on the genetics involved in this form of AD, but if one person in a family develops the disease, chances are higher that others will, too.

Kathy, however, refuses to live in fear that she may become the third generation of women in her family to develop Alzheimer's. To prepare for the future, and to make her life more worry-free in the present, she has established a long-term healthcare plan should she need it. "Since my husband, Jon, is several years older than me, and we never had children, I could wind up facing AD alone," she says. So she's found these planning tips bring her peace and comfort now.

Pick your place. If she someday requires it, Kathy plans to live at Abe's Garden, an Alzheimer's- and adultcare facility that's a few miles away from her Nashville-area home. Sign up. Both Kathy and her husband have written down their healthcare goals and wishes, and established long-term healthcare insurance policies.

Enlist help. Kathy has lined up a few close younger friends who have agreed to hold her power of attorney and assist in making healthcare decisions if needed.

Understanding "Sundowning"

Common in the moderate to severe stages of Alzheimer's disease (AD), sundowning describes the restlessness, confusion, disorientation, anxiety, agitation or delusions that often occur in people with AD. Usually beginning in the late afternoon and early-evening hours, these behaviors can get progressively worse through the evening, or "as the sun goes down."

While doctors are not sure what causes sundowning, they suspect it may be related to a number of factors, including fatigue from the day, sensory changes due to decreased light, shadows and a change in activity related to preparing dinner, for example.

Family members who live with people who have AD have found ways to cope with the phenomenon.

Here are a few tips:

- Sundowning is a part of the disease. Ride out this time of the day.
- Remain calm
- Make sure the environment is adequately lit and quiet.
- Encourage short afternoon naps.
- Prevent stimulus overload.

Most people feel tired toward the end of the day, but understand that this is magnified in persons with AD. Remember to call a doctor if the symptoms become too severe. Among other things, there are medications that can help.

What to Watch For

Alzheimer's occurs when proteins build up in the brain, developing into plaque deposits. These deposits prevent the cells in the brain from functioning normally, blocking the brain's normal "routine" and eventually interfering with memory, speech and behavior. The most common warning signs are: • Memory loss

- Difficulty performing familiar tasks
- Problems with language
- Disorientation to time and place
- Poor or decreased judgment
- Problems with abstract thinking
- Misplacing things
- Changes in mood, behavior or personality
- Loss of initiative

Source: Alzheimer's Association