

Lewy Body Journal:
Our Family's Experience with Lewy Body Disease

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Journal Introduction

This journal is an account of our family's experience after our mother became ill with Lewy body disease. It was written by two of Mother's children, with input from the other two. (For purposes of clarity, the son who accompanied Mother and Dad on doctor visits is referred to as Son.)

Documenting our mother's decline has not been an easy task. Plus, we want to maintain our family's privacy. Nevertheless, we thought that writing this journal was important. Knowledge is invaluable. As hard as it might be, reading this journal can help families learn what to expect when a loved one is diagnosed with Lewy body disease and how to care for that person, particularly if you choose to care for the person at home. Our family has gone through many of the challenges you will face. We hope you can learn from what we went through.

A second goal of this journal is simply to make Lewy body disease better known. Everyone knows about Alzheimer's disease, but most people haven't even heard of Lewy body disease, despite the fact that it's the second most common form of dementia. We hope this journal will help make people (including health professionals) more aware of the disease.

Mother passed away in May 2006. This journal chronicles our experiences from early in her illness (1997-98) until then.

1. Who Mother Was

Mother was born in 1927 and grew up in the Bronx, New York. Mother's immediate family consisted only of her parents and a younger brother who died in childhood, but she had a large extended family of many cousins, aunts, and uncles with whom she was very close. Family was always important to her. Her own mother suffered from a form of dementia (although we don't know the specific type — back then, these things weren't diagnosed as well as today) and died in her late seventies. We are unaware of any other family member suffering from dementia.

Mother attended the New York City public schools then went to college, where she earned a bachelor's degree. An excellent student, she subsequently earned a master's degree in education. While in her forties, Mother returned to school for a second master's degree in learning disabilities education.

"An excellent student, Mother earned two master's degrees"

Mother married Dad in the early 1950s. Eventually, they moved to a suburb of New York City, where they raised their four children.

Mother was a teacher. First, she taught in the New York City public school system. After moving to the suburbs and while her children were young, Mother taught business education classes at the adult school, which offered continuing education classes at night at the local high school. Because of Mother, many women who had taken time off to raise their children learned the skills they needed to return to the workforce. When her children were older and in school, Mother taught elementary school children who had learning disabilities. After she retired from teaching, Mother volunteered at the town library and soon afterward became a staff member there.

Mother was also very active in the community. She was president of the local and county chapters of the League of Women Voters, chairperson of the town planning board which approved all new building construction, treasurer of the friends of the library, and treasurer of the town museum. She participated in other community activities as well.

"Mother led a full, active, and healthy life"

Mother had diverse interests. She loved to read books on many different subjects, and she particularly enjoyed mysteries. She followed politics closely. Mother was adept at many needlecrafts including intricate bobbin lace and knitting. She loved spending time outdoors, be it hiking or sitting in the backyard watching the squirrels and the birds. She had many friends and acquaintances. She never hesitated to visit someone who was ill or to offer her assistance. In sum, she led a full, active, and healthy life.

2. First Hints of Trouble

The first hints that Mother was ill were subtle and easy to dismiss, even by professionals (indeed, they were dismissed). That they were signs of illness became apparent only in retrospect. We took Mother to a neurologist for the first time after she exhibited a troubling, albeit temporary, problem. This was in late 1997 or early 1998 when she was 70 years old.

The incident that precipitated the first visit to a neurologist occurred at the weekly book lunch held at the library, where the attendees swap book recommendations. Mother, who was a

great reader, was leading the session. She was reading a passage of a book out loud to the assembled group when all of a sudden the words on the page looked funny. She continued reading without apparently knowing there were any other problems, until she looked up and saw the expression on the faces of the others in the group. It turned out that what she was saying was gibberish. In a few minutes she was fine and drove herself home. Mother's family doctor sent her to a hospital for an MRI brain scan and an ultrasound of the arteries in her neck and arranged for her to be seen by a neurologist.

"While reading a passage out loud, the words on the page looked funny"

It was on this occasion that Dad told us for the first time that he already thought there was something wrong with Mother, that her behavior was "off" in some ways. Suspecting that she might be developing Alzheimer's disease, he hoped that the neurologist would test Mother's memory. The neurologist, however, did not do so. In retrospect, the neurologist may not have been very good. It was also the case that, despite Dad's concerns, Son, who accompanied Mother to the neurologist, didn't ask the doctor to test her memory. On his visits home he'd never seen any problems, and frankly, he didn't know how to bring up the issue in front of Mother. The neurologist determined that Mother's MRI was normal for someone of her age, and he performed a rudimentary physical exam, which found no problems. His diagnosis was that Mother had had a TIA (transient ischemic attack), a temporary neurological problem that was not necessarily a harbinger of future problems. He agreed with the family doctor's prescribing of Plavix, a mild blood thinner. We let it go at that, and Mother was obviously greatly relieved, since the incident at the library was so disturbing for her. Mother remained anxious about reading aloud in public and practiced occasionally for us. A couple of months later, she was happy to report that she had read aloud at a book meeting and everything went well.

Was the TIA an early sign of Lewy body disease? We don't know, but it seems likely that it wasn't directly related, because the disease later manifested itself so differently. On the other hand, it could have been a hint that not everything was right.

Mother's next visit to a neurologist (a different one) came in the fall of 1998. This time the visit was precipitated by concerns Dad had about Mother. He still

"Dad was concerned about Mother's uncustomary forgetfulness"

thought her behavior was "off," and he had some anecdotes about uncustomary forgetfulness. For example, one day when the two of them were going to a lunch meeting, Mother prepared them a bag lunch of cheese sandwiches. When it came time to eat, they discovered that Mother had included slices of bread, but no cheese. He also remarked that Mother had abandoned her needlework hobbies. At this point we children hadn't seen any signs of problems. The only possible change was that when we came to visit for the day or for the weekend, Mother was unusually "clingy," that is, she wanted to be around us all the time.

The neurologist did a physical examination and administered the Mini Mental Status Exam, a short test of memory, language, and thinking. Mother made no errors. Consequently, it was easy for the neurologist to disregard Dad's anecdotes as minor incidents of normal aging. As subsequent events showed, Dad was in the best position to notice that something was awry, and he was right.

3. The Signs Become More Pronounced

By late 1998 or early 1999, like Dad, we began to notice during our visits that Mother's behavior was "off." One early problem was that Mother's perception of time seemed to be off-kilter. For example, she would start to prepare dinner at 2:30 p.m. When we told her it was too early, she would stop while saying that it takes time for the food to cook. Half an hour later, she'd be back in the kitchen starting dinner again. Dad also reported that she would sometimes wake up in the middle of the night and begin to dress for the day.

For Thanksgiving, 1998, for the first time Mother announced that she would no longer prepare the big dinner.

"Now Mother took short, slow, guarded steps"

When asked why, she said, "I've been doing it all these years and now it's time to pass the baton." This was reminiscent of her reason for retiring from her part-time job at the library ("I've been working all my life and now it's time to retire.") or for forgoing household chores she'd done previously ("I'm retired now."). By early 1999, we started noticing that Dad was the one who was mainly preparing their meals with Mother's assistance, instead of the other way around.

At about this time, Mother tripped on a staircase at home. While bruised, fortunately she wasn't seriously injured. Dad suggested that she use a quad cane he had. Mother liked the idea, but she had trouble learning the procedure for using it on steps. We also noticed that Mother's walking had changed. She had always been a strong walker, but now she took short, slow, guarded steps.

Furthermore, Mother had lost her ability to do math, something at which she had previously excelled. Mother was responsible for maintaining the checking account, but she could no longer balance the checkbook.

"Mother lost her ability to do math"

While we noticed these problems with Mother and saw that she was having some difficulties, we didn't want to believe it. After all, she had just been to a neurologist a few months earlier and she'd done so well on his tests.

In retrospect, there were other, even earlier signs. We believe that Mother suspected that something was wrong for some time before we had noticed anything, but she kept any concerns to herself. Later, it became evident that Mother had decided to retire from her job at the library the previous year because she realized that she was no longer capable of doing it. Her responsibilities there had included paying invoices and operating a computer.

There was also an incident a year before when Mother lost her balance in front of the post office and fell breaking her nose when she struck the ground. At the time, we thought nothing of it, but looking back, that fall (plus two others we remembered later)

may well have been one of the first signs of the physical effects of Lewy body disease — problems with balance, stiffness of limbs, and difficulty walking.

In the years following Mother's diagnosis with Lewy body disease, we couldn't help but look back at some prior incidents and wonder whether they were early hints of a problem. Human behavior is so variable that it's impossible to know. With regard to Mother's falls, she was seen by doctors after each one and none brought up the possibility of a neurological problem.

4. Back to the Neurologist

In late winter or early spring of 1999, Mother went back to the neurologist accompanied by Dad and Son, who described to the doctor Mother's problems including her walking. Once again, the doctor administered the Mini Mental Status Exam, but this time Mother made two or three mistakes, which still wasn't bad but worse than a few months earlier when she made no errors. We privately expressed surprise at her good performance on the test, because her problems at home had become obvious.

The neurologist didn't overtly diagnose Mother with Lewy body disease, or Alzheimer's disease, or any kind of dementia for that matter. (On a later visit, he showed us his records in which he had

written his diagnosis of Lewy body disease.) Perhaps, he feared that talking about dementia would upset the family. He only said that Mother had some cognitive problems along with aspects of Parkinson's disease. He prescribed Aricept, which was then the primary treatment for Alzheimer's disease. Upon hearing that Aricept had been prescribed, our family just assumed that the diagnosis was Alzheimer's.

"Our family assumed the diagnosis was Alzheimer's disease"

5. Aricept and Mother's Quick Decline

Mother started taking a 5-mg dose of Aricept on a Friday, with the expectation that after a while the dose would be increased to 10 mg. By Sunday, however, we were distressed at her condition. She was extremely agitated and forgetful. Just two days before, she had made two or three errors on the neurologist's exam, but now it didn't seem like she could remember anything.

Mother's agitation was obvious too. That day, a friend was picking her up to take her to a party. Mother was greatly concerned that her friend might not drive her home afterward, stranding her at the party. Continual reassurance from us wouldn't suffice, and Dad had to call the friend to ask explicitly if she would drive Mother home. Mother went to the party and had a good time, but we knew we had to call the neurologist to find out what we should do.

"Mother started taking Aricept and became extremely agitated and forgetful"

The neurologist's secretary relayed messages between us and him, and his response was to stay on the Aricept. We did, but we decided that we needed to get a second opinion. Our immediate problem was the effect the Aricept was having on Mother. A second concern was that we get the right diagnosis. We knew that Alzheimer's disease was usually diagnosed only after ruling out everything else, but this neurologist hadn't done a lot of testing.

Dad contacted a family friend who is a neurologist at Columbia Presbyterian Hospital in New York City. He referred us to a behavioral neurologist, and we made an appointment. During the couple of

"Her agitation subsided, but the sudden decline in memory remained"

months between seeing the old neurologist and the one at Columbia Presbyterian, Mother kept taking the Aricept at the 5-mg dose. Her agitation subsided, but the sudden decline in her memory remained. We have heard that Aricept seems to have helped many people with Alzheimer's and Lewy body disease, but we think it had a negative effect on Mother. Sure, her disease would have caused a decline anyway, but the Aricept seemed to speed up the process. Possibly, it was no more than a coincidence that her decline came just when she started taking Aricept, but as we describe later (10. Things Get a Bit Worse), we have further reason for suspecting the Aricept. This is a sore point for us. It sure would have been nice to have had a neurologist who would have talked to us directly on the phone in a timely manner. Fortunately, doctors now have other medications available in cases where Aricept doesn't agree with the patient.

6. Columbia Presbyterian Hospital

Mother's appointment at Columbia Presbyterian was scheduled, and she was anxious about it. She knew her abilities had declined, but she was eager to do well on the tests she would be given. From her experience with neurologists, she knew that they were going to ask her certain questions, and for some reason she fixated on one of them in particular: she was determined to get the answer right when they asked her the date. A few days before her appointment, she wrote the date of her doctor visit on a slip of paper and put it in her pocket. Continually over the next few days, she'd pull out that paper to check the date, put the paper away, and then forget the date. It was very sad to watch.

By the time of her appointment, Mother was also becoming lost in her own home. Initially, this happened only at night when she moved around the house with the

"Mother was becoming lost in her own home"

lights off. After getting up in the middle of night to use the bathroom, Mother sometimes ended up returning to a bed in one of her children's old bedrooms. On another occasion, instead of going to the bathroom, she wandered downstairs and urinated on a kitchen chair. Later on, she became confused even when the lights were on and during the daytime. For example, one evening while watching television with Dad, she went down to the kitchen for a bite, became confused, and phoned Son for help. She told him that she seemed to be alone in the house, which made him concerned that something might have happened to Dad. He had her hang up the phone and told her not to answer when he called back until the phone had rung six times. Fortunately, after a few rings Dad picked up and went down to rescue Mother. On another occasion Mother became disoriented in the afternoon and phoned the police for help.

At Columbia Presbyterian Mother went through a battery of exams and tests that took several days to administer. On her first visit, after taking her history, the neurologist recommended stopping the Aricept because of the problems we had associated with it. (Over the next two months while she was off the Aricept, she did not seem to change for the better — or for the worse.) The neurologist saw her anxiety about not doing well on his memory tests and asked if she'd be more comfortable if her relatives waited outside. She said she would be, so we don't know how well she did, but by this time our expectations were low. In addition to the neurological exam, Mother had to have a battery of tests: extensive blood work, another MRI brain scan, a SPECT brain scan (to examine blood flow in the brain), and neuropsychological testing (a series of tests of cognitive functions, including memory, thinking, language, and visuospatial ability). The neuropsych testing was particularly trying for Mother, because it lasted for several hours and her poor performance made her feel bad.

After the doctors had examined all the data, they told us that Mother had Lewy body disease. They told us that it was a degenerative dementia with no cure. We had never heard of it before and were

"They told us Mother had Lewy body disease, and it had no cure"

surprised because we had assumed she had Alzheimer's disease. We had some hope that the presumed Alzheimer's diagnosis was wrong and that Mother had a curable disease. Instead, the Alzheimer's diagnosis was replaced by the diagnosis of another, less well-known, incurable dementia. Mother's reaction to the diagnosis was interesting. She knew about all of the intensive research that had been going into Alzheimer's disease, so she said, "It's almost too bad it's not Alzheimer's disease, because they're learning so much about it."

The neurologist prescribed Aricept again, the medication for Alzheimer's disease, because that was the best they had to offer, although it was unclear how well it had been tested on people with Lewy body disease. He also prescribed a medication to treat the hallucinations and delusions Mother was beginning to experience. He prescribed Seroquel, but later on, another neurologist thought that drug would worsen Mother's motor problems. He recommended Zyprexa instead.

Being a research institution, Columbia Presbyterian also gave us a form describing an investigation they were conducting. The form asked if we'd donate Mother's brain post-mortem for analysis. Research is good, but this was a bit disturbing and Mother mentioned it a few times over the next week. One helpful piece of advice was to plan ahead, because this is a progressive disease, and to seek help when needed.

7. Dr. Jekyll and Mrs. Hyde

People with Lewy body disease often have hallucinations about inanimate objects moving or seeing things that aren't there. Mother had these problems too, in a relatively mild way. Usually, these problems occurred only in the late afternoon or evening. This "sundown effect," in which symptoms worsen in the late afternoon and evening, is fairly common among people with Alzheimer's disease and apparently for those with Lewy body disease as well. As noted, these problems were relatively mild, but sundown also brought a delusion that caused a lot of difficulty and grief in our family: Mother began to think that she wasn't in her own home and that Dad wasn't her husband.

Mother would be fine in the morning, but the delusion often appeared by late afternoon, when Mother felt an urgent need to go home. To get a ride home, she would usually call one of her two children who live locally and express her dire circumstances. They started to dread getting a phone call. If Mother called and said, "Hello, this is Mother," they'd know she was all right; if she said, "Hello, this is B— [her first name]," then they knew they were going to be asked to take her home. Mother could really make us feel guilty saying, "I'm relying on you," "You promised you'd help me," "My parents are waiting for me and don't know where I am," among other things. When told that she was already in her home and that Dad was her husband, she'd say, "Yes, this is my home, but it's not my home" or "There are two identical houses and two identical Dads and I'm with the wrong ones."

"Mother began to think that she wasn't in her own home and that Dad wasn't her husband"

These delusions hit Dad particularly hard, since Mother could become quite agitated and adamant that she had to go home. Although he knew it was all due to the illness, it was hard for him to deal with her agitation and hard for him not to take it personally, since Mother seemed to be saying that she didn't want to be with him. He would tell Mother that she's staying there and she'd be sleeping in the bed with him, the bed they'd shared for nearly 50 years. From Mother's perspective this was horrifying, because she didn't want to share a bed with someone who wasn't her husband. If Mother could be calmed down and did go to bed, the next day she was fine — until the afternoon. Dad started saying she was like Dr. Jekyll and Mrs. Hyde.

On several occasions Mother wandered out of the house in the afternoon to try to find what in her delusion she thought was her real home. One time, Dad found her on the corner of the street. Another time, she went to the home of a neighbor, who took her in and fed her. Both times, it was only after extensive persuasion that Dad could coax Mother to return home.

"Mother wandered out of the house to find her real home"

When Mother's pleading was strong or Dad was desperate for help, one of us would drive over to calm the situation. Often, it was enough for someone else to be there

until Mother became too tired to stay up. If that didn't work, the most effective treatment would be to take Mother out for a drive in the car. After spending 10 or 15 minutes in the car, she was so happy to be home that she would give Dad a big hug and ask if he'd missed her. In her mind she'd been away at an identical house somewhere far away.

The medication (Zyprexa) prescribed for the hallucinations did calm Mother down, but mainly because it tended to knock her out. After taking the medication, she became very sleepy, which didn't seem to be much of a solution either. It was mainly because of the delusions and the difficulty we had in dealing with them that we knew Mother and Dad needed a full-time, live-in aide.

8. Living Arrangements and Daycare

When Mother had started doing less around the house (even before a neurologist had noted any problems), Dad took up the slack. He said he was up to the task, although it was not easy for him. He was then in his early eighties and he had health issues of his own. Nevertheless, it worked out all right for a while. To ease the cooking issue, they regularly drove to the senior center for lunch. Soon, however, it became clear that assistance would be helpful.

In addition to doing the many household chores, someone had to help Mother with her personal needs. Mother's walking had become impaired. Soon, muscle stiffness affected the flexibility of

"Muscle stiffness affected the flexibility of her arms and legs"

her arms too. Although she knew how to dress and undress herself, it became hard for her to do it herself simply because the range of movement of her arms and legs became restricted. For the same reason, bathing became difficult. Our parents already had a shower bench, but now our sister came over to help Mother bathe. Another problem was that Mother had started using the bathroom very frequently. She felt the urge to urinate from one to three times an hour. She was taking Detrol to try to control this, but it didn't help. We suspected that she might have been afraid she would wet herself and was visiting the bathroom frequently as a precaution. In any case, she could go to the bathroom by herself, but it meant going up and down a half flight of stairs and her stair walking was shaky.

At first, we got an aide who came over three times a week, for a few hours each time. She assisted Mother, did housework, and prepared a meal. We had found her through an agency used by an acquaintance whose mother had had Alzheimer's disease. It quickly became clear that this wasn't enough assistance.

In looking for more assistance, Dad called a friend of Mother's who worked in social services. She recommended that Mother might benefit from going to senior daycare. This seemed reasonable. By this time, Mother had lost interest in many of her usual activities, so it would keep her occupied and it would give Dad a break from Mother, since the two of them were now together constantly. We visited a daycare center, and Mother agreed to give it a try. A week later, Mother went for her first day in daycare, she was introduced into the group, and we went to another room to give her a chance to become acclimated. After a few minutes, she wanted to go home. They tried to distract her, but to no avail. She insisted that she didn't fit in because, she said, all the other people there were so old. The director of the center thought that Mother was still thinking of herself as she was before she became ill. Altogether, Mother spent no more than half an hour in daycare.

Another issue raised by Dad was that it might become too difficult for Mother to live in their house. It was a split-level, which meant that the bedroom and bathroom were on one floor, the kitchen and living room on another level, and the outside was on still another level, and Mother was having trouble with stairs. One idea we investigated was assisted living. We visited three assisted living complexes. All seemed very nice, had a good range of activities and facilities, and the food looked good. All were quite costly, however, and not all were set up to provide sufficient assistance. One assisted living complex told us right away that it wasn't an appropriate place for Mother, and this was when her condition wasn't too bad. Another had different levels of assistance, each with its own cost structure, plus you could hire your own aide for more help. While the cost was discouraging, one other factor worked strongly against these places: Mother's condition was progressive, and there would come a point when no assisted living residence could provide adequate care for her. One facility had an adjoining nursing home if things came to that, while a second had an Alzheimer's ward. (An Alzheimer's ward would not necessarily be appropriate for people with Lewy body disease, who lack the mobility that people with Alzheimer's generally retain.) Dad strongly felt that Mother should not go into a nursing home, because he didn't think she would receive the proper care and attention there, but if they sold their house to move into assisted living, when Mother's condition deteriorated, what choice would they have?

"If they moved into assisted living, when Mother's condition deteriorated, they'd have no choice but a nursing home"

Apart from assisted living, another idea Dad entertained was moving into an apartment. Again, cost was a factor because they could live at less expense if they remained in their own home, which was fully paid for. An additional consideration was the limited space that would be available in an apartment. Still another concern we had was that Mother's confusion might worsen if she changed environment.

As it turned out, staying in the house had its benefits because it provided space for a live-in aide and for everyone to be able to have some breathing room.

9. We Need Aides

Living at home brought the issue back to finding an aide who could work more hours than the one we then had. The daycare center had given us a list of aides and agencies they were familiar with. One aide, who was highly recommended, already cared for a man with Alzheimer's disease, but only in the afternoon. She could work mornings for us, and she had a friend who could take the afternoon shift. They were very nice and did a great job of cleaning the house. They did a little cooking too and helped Mother go to the bathroom. This was important because she was shaky on the stairs and she started to become confused in the bathroom. First, she sometimes forgot exactly how to use the toilet paper and where to dispose of it. Then, she sometimes wasn't sure where to sit in the bathroom. It soon became clear that Mother needed help getting ready for bed, which was after the aides stopped working, and then there were the hard-to-deal-with delusions, frequent in the evenings and not stopping for the weekends when the aides didn't work.

Starting with the daycare's list, as well as other agencies we knew of, our sister made many calls to find full-time aides. Some people on the list were just individuals without any special training, while others had experience working in nursing homes. One, who was expensive, was a nurse who moonlighted as an aide. There were also several agencies. Some seemed to specialize in getting aides from certain countries, like the "Polish girls" and the "Slovakian girls." Some agencies required families to pay for special visits from supervisors. We also found that there are companies specializing in eldercare case management. While pricey, some of these may take care of most aspects of finding and managing aides.

The first full-time aide we hired was a Jamaican woman. Initially, we thought that if we had a full-time aide during the week, our sister and Dad could care for Mother on the weekends. But as Mother

"The job soon took its toll on our first aide, and she suddenly had a family crisis"

required more assistance, we hired another aide to work on the weekends. Our sister was in charge of finding, interviewing, and hiring the aides. The first full-time aide was shy and not as experienced as the aides we would later hire as Mother's condition worsened. When we hired this aide, none of us fully realized how much work her job would entail. Soon the job took its toll on her. Mother was waking up constantly at night to use the bathroom, and the aide wasn't getting any sleep. Mother's ability to walk up and down stairs was increasingly difficult, and because of the arrangement of the house, she had to navigate the stairs many times throughout the day. Then, of course, there were the delusions. After several months, the aide unexpectedly announced that she had a family crisis and had to go to Jamaica immediately.

Mother's circumstance being what it was, we had to replace the aide as soon as possible. Thus began a procession of aides — weekday aides, weekend aides, and vacation fill-in aides. Some aides stayed for several months, while others lasted for only a few weeks. Typically, they left due to a situation in their own family or to take another job. Our sister began to keep a list of standby aides we could call if an aide announced an

unexpected vacation or quit. Instead of using an agency, we had the most luck finding aides by word of mouth. Many friends or acquaintances have had an elderly relative who was cared for by an aide, and either that aide was now available or knew of another aide who was. Still, we always have to scramble when we need to find a new aide.

We are fortunate that our current primary aide has been with us for over two years. She has had a lot of experience caring for elderly patients. Our weekend aide is not as experienced, although she cared for an elderly woman before coming to us.

Live-in aides are a mixed blessing. They generally provide excellent care for Mother; without them, it would be impossible for her to live at home. The tradeoff is that there is a loss of privacy

for Dad and they have their own way of doing certain things. For example, they insist on washing the dishes by hand, rather than using the dishwasher. Furthermore, there have been personality differences that we've had to overcome. Although most of the aides have been agreeable, one of our best aides has a strong personality and doesn't like to be told how to do things. On the one hand, this leads to her managing Mother's care and the household quite well (she's industrious and doesn't have to be told to do things). On the other hand, if Dad or another family member doesn't like something, well, voices can be raised on both sides. Of course, we are reluctant to offend an aide for fear that she might quit and leave us stranded at the last minute. When an aide bumps Mother's wheelchair into a table, it's often best to bite your tongue.

"Live-in aides provide excellent care but are a mixed blessing"

10. Things Get a Bit Worse

Mother was still walking with assistance. She was friendly and liked to call friends and relatives on the phone (although eventually she needed someone to dial the numbers for her). At this point, she didn't do a lot around the house. She stopped reading and wasn't interested in the books on tape that a friend gave her. (She also had great difficulty remembering how to use the stereo's tape player.) She watched television with Dad, who likes news programs, and Mother seemed to retain a lot of the news. We were sometimes impressed by her knowledge of current events, while her memory of other things wasn't so good. Some things from the distant past were remembered, others weren't; some recent things were remembered, others weren't.

There were a couple of incidents of nighttime incontinence, but physical problems were really the next big concern. Mother's walking was a problem, and her arms had a lot of muscle tension. If you

"L-dopa helped with Mother's extreme muscle tension for a while"

held her hand, she would crush your fingers. We sought assistance by returning to the local neurologist, the one who had been reticent to talk about dementia. We informed him that Mother had had a full work-up at Columbia Presbyterian, and they concluded that she had Lewy body disease. He was very interested in hearing about the tests that had been done and produced his notes, which showed that Lewy body disease had been his diagnosis too. He had a couple of ideas for dealing with Mother's mental and physical problems. He noted that Mother was taking 5 mg of Aricept a day, so he suggested increasing the dose to 10 mg. We followed that suggestion briefly, because right away Mother became very agitated, just as she had when she first started taking Aricept, and we weren't going to go through that again. On our own, we went back to the original dosage and her agitation subsided. This is another reason why we think the Aricept was not a good drug for Mother.

To help Mother with the muscle tension, the neurologist prescribed L-dopa (levodopa/carbidopa or Sinemet), which is commonly given for Parkinson's disease (and was the "miracle" drug in the movie *Awakenings*, based on the book by Oliver Sacks). One big concern was that L-dopa could make Mother's hallucinations worse, which meant there was a tradeoff between improving her physical symptoms and worsening her hallucinations. A small dose of L-dopa did seem to improve Mother's flexibility for a while. As things got worse again, the doctor bumped up the dosage, which again improved things for a while.

Another thing the doctor did was to prescribe a round of physical therapy. The physical therapist was based in a local hospital but made house calls. Medicare covered a limited number of visits. The therapist told us that she had two other patients with Lewy body disease, but it was a relatively new disease for her too.

The physical therapist was good. She took Mother through a series of exercises and got her up and moving around. The best thing, though, was that she knew that the house had to be set up for improved safety and to prepare for future deterioration of Mother's condition. Until that point, Mother was still sleeping in her bedroom upstairs, the same level the bathroom was on, but she needed to go downstairs to eat and sit in the living room. The aide assisted her on the stairs, in using the bathroom, in getting dressed, and with her daily hygiene. Mother could no longer rise from a chair by herself, so the aide would pull her up by her arms and assist her in walking from room to room. The physical therapist didn't approve of Mother's using the stairs, and she knew what equipment we could get through Medicare. Immediately, she ordered a walker, a wheelchair with a gel seat pad, a hospital bed, and a commode. When these arrived, the dining room was converted into Mother's bedroom. The commode went behind a screen in the corner. Now, the aide brought basins of water for Mother to wash with. Getting this equipment was the greatest service provided by the physical therapist. (Only the walker turned out to be inessential, since Mother couldn't use it — she was too unstable. The commode was useful for about a year, until the incontinence increased.) Any physical improvement from the therapy was short-lived, however. In fact, about six months later, the neurologist again prescribed physical therapy, but the therapist said that she could no longer help Mother.

"The physical therapist ordered a walker, a wheelchair, a hospital bed, and a commode"

Later on, the neurologist also thought it might be helpful for Mother to visit a rehabilitation doctor. That doctor thought Mother might benefit from being in a rehab facility for a while. Although Mother was amenable to the idea, it seemed totally unrealistic to the rest of us, since Mother's condition was progressive and it wasn't clear that the rehab center was prepared to give Mother the level of care she now needed. Instead, we opted for more physical therapy at home, but as noted, the therapist thought it wouldn't help.

Shortly before going to the rehab doctor, Mother developed a visual problem. She had trouble seeing things in the left side of her field of vision. For example, if a glass of water was to the left of her plate, she wouldn't notice it. In the living room, Dad usually sat in a chair to the left of Mother's wheelchair, so she sometimes didn't know he was there. The rehab doctor confirmed the presence of the visual problem, but there was nothing she could do about it.

11. The Wheelchair Ramp

With the new equipment at home, we were better prepared for Mother's physical needs. Taking her out of the house was a problem, though. The procedure was to wheel Mother close to the front door, hoist her from the wheelchair, and assist her in walking to and getting into the car. Then we'd fold up the wheelchair, carry it to the car, and put it in the trunk. Unfortunately, the wheelchair covered by Medicare wasn't the latest or lightest model. We later got a spare, more lightweight wheelchair through the local ambulance corps (which lends out wheelchairs, walkers, and canes donated to it) and that simplified matters.

Things became much easier when Dad decided to have a wheelchair ramp built by a local carpenter. Springtime was coming and Dad wanted Mother to be able to spend time outdoors so she could enjoy

the warmer weather. One thing we hadn't counted on was how long the ramp had to be. In order to ascend the five feet or so from ground level to the front door at a reasonable angle, we ended up with a large structure that covered a lot of the front lawn. Nevertheless, it was worth it. Mother could go out and enjoy the weather and it was easier to take her to the doctor. It became even easier when we started using the town's wheelchair van to take Mother to the doctor.

"Dad decided to have a wheelchair ramp built by a local carpenter"

12. "I Want to Die"

Mother had periods of confusion and periods of relative lucidity. Once or twice, during a lucid period, she would tell one of us that she wanted to die. Having your mother say this to you is hard. She said this to each of us on at least one occasion. Here is roughly how such a conversation went:

Mother: "I want to die."

Us: "Why?"

Mother: "I don't want to be a burden on anyone."

Us: "Don't worry about that. We'll take care of you."

Mother: "I want to kill myself."

Us: "It can be hard to kill yourself."

Mother: "That's why you have to help me."

At that point it would have been impossible for Mother to have killed herself, simply because of her physical incapacity. Also, her lucid moments were fleeting, and this sentiment probably wouldn't have occurred to her during a nonlucid moment. During her lucid moments, when she could have been aware of her condition and where she was headed, her sentiment is understandable. But life is precious, and at that point she was still able to have some enjoyment of life from time to time. Later, it became less clear whether Mother had moments of enjoyment. Of course, none of us could help our Mother die at any time.

"Mother: 'I don't want to be a burden on anyone'"

13. Hygiene and Dental Care

Due to her limited range of movement and declining cognitive capacity, Mother wasn't able to wash herself. The aides washed her as she sat up in bed or, later on, as she lay in bed. We regularly bought supplies of liquid body wash, baby wipes, and disposable gloves.

Mother was never the type who liked to have people fuss over her, and that attitude continued after she became ill. Fussing over Mother's appearance, sometimes an aide would suddenly brush her hair or wipe her mouth, and Mother would complain. She also took to "protesting" nonverbally. For a few months, when an aide tended to her in the wheelchair, she would try to punch the aide. Due to her limited arm movements, this never became a serious problem, but we know the aides found it annoying. At other times, when the aide was holding Mother upright with one arm while tending to her with the other, Mother would try to bite the aide's shoulder. Perhaps, Mother's biggest protest was over the wheelchair's seat belt. The aides and Dad liked to have the belt buckled to make sure Mother didn't fall out of the chair. But, for some reason, Mother resisted by complaining about the seat belt or, on occasion, unbuckling it herself. After a few months, this behavior subsided.

Mother had always taken good care of her teeth, but now the aides had to brush them for her. Brushing another's person's teeth isn't easy. The aides clearly differed in how well they did it and how well they even tried. Some would make a good effort, while one in particular thought it was adequate to make two or three quick swipes with the toothbrush. Needless to say, Mother's teeth suffered. She had to have several large cavities filled and two teeth extracted.

"The aides had to brush Mother's teeth and her dental hygiene suffered"

To alleviate the situation, we got an electric toothbrush. A dental hygienist taught our primary aide how to do a better job, and Mother goes to the hygienist for a professional cleaning periodically.

The state of Mother's teeth is far from her worst problem. But after a lifetime of caring well for her teeth, it was indicative of how things had changed for her. She was completely dependent on the care of others.

14. Slow Decline Continues

Gradually over the past couple of years (from 2001 to 2003), Mother's condition has declined both mentally and physically. Soon after she began taking all the new medications, she would get sleepy early in the evening. Now, she goes to bed at about 7 p.m. and wakes up at about 9 a.m. The aide puts her to bed in the afternoon for about an hour too, but that's partly to take some of the weight off her rear so she doesn't get a bedsore. During the day, she is often inalert and sleeping, sometimes with her eyes partly open.

Mother's ability to interact with people has declined as well. She was always friendly, but at first some inappropriateness would slip into her

speech, as when she referred to Dad as her father. Things always got worse in the late afternoon and evening. For a while, at that time of day, she would recite a bunch of numbers; possibly she was counting something she alone saw. Even after going to bed, she would wake up and recite numbers. Later on, she tended to stop talking spontaneously. If you asked her a question, she'd usually answer, though, and sometimes she'd add a remark to a conversation going on around her. Her answers and remarks became less and less meaningful over time. Now, she'll answer a question from time to time, but she's largely silent.

"Mother's ability to interact with people has declined"

As Mother's condition declined, the delusions subsided, with only an occasional reappearance. Once in a while, when we were saying goodbye, she'd ask where we were going. When we said, "Home," she'd say, "Take me home too." When we told her she was home, she would immediately acquiesce. After a while, no signs of the delusions remained.

Physically, Mother became unable to walk even with assistance, but she was still able to support her weight on her legs for a while. The aide could pull her up and, while Mother stood with the aide's support, help her dress. After a while, Mother's legs would just crumple under her. To get Mother from bed to wheelchair, we ended up getting a lift, paid for by Medicare.

A problem with sitting all day is that Mother has become susceptible to bedsores and blood clots. One day, her leg swelled up and she was diagnosed with deep vein thrombosis, a blood clot in the leg. (This also can happen to airline passengers and has been called "economy class syndrome" in the press.) Mother had to spend almost a week in the hospital while getting Heparin, a blood thinner, intravenously. When she got home, she had to take the Coumadin blood thinner orally for a while. Keeping her legs elevated seems to help.

Mother now has so much muscle tension in her arms that they are always crossed in front of her and very restricted in their range of movement. Her hands are always balled tightly into fists.

Sometimes, she would get a rash on her palm or her fingers would bruise her palm. Putting a sock or washcloth in each hand helped with that. Still, Mother continued to damage herself. Recently, a wound doctor took a look and found that the tendon going to her thumb was exposed because Mother's fingers were digging into that area. The doctor had Mother visit the rehab department of a local hospital, where they built special hand splints for her. The splints keep her hands open a bit and should prevent that kind of damage in the future.

"Mother now has so much muscle tension that her arms are always crossed in front of her"

Mother has lost control of her bladder, which means a lot of adult diapers, bed pads, and laundry washing. Possibly due to her sedentary life, constipation is a problem. At first, prune juice, Metamucil, and senna helped. Now, periodic enemas are a necessity.

Because of her physical problems, Mother lost her ability to use silverware or pick up a glass, so she has to be fed. For a while, she could pick up some kinds of food with her hand, but now even lifting her hand to her mouth would be difficult. A more recent problem is that Mother is having some trouble eating. The aide gives her soft food or uses a food processor to break her food into small pieces. The aide sometimes has to tell her to open her mouth, chew, and swallow. Her swallowing isn't good.

15. Living Will

Before she became ill, Mother had signed a living will and executed a power of attorney. The power of attorney allows us to manage her financial affairs without getting the authorization of a court. The living will is a more sensitive matter. It states that Mother doesn't want to receive extraordinary care that would extend her life. This is going to pose issues for us down the road as Mother's health worsens and we have to make decisions about her treatment. Of course, any decisions of this kind are to be made in consultation with Mother's doctor. But it raises the issue for us of what constitutes extraordinary care for a person suffering from Lewy body disease where the inevitable result is a vegetative state and a slow death.

Recently, a lump was discovered in Mother's breast. It proved to be non-cancerous and not serious. However, in the days before we knew this, we had to consider whether we would want to subject Mother to chemotherapy and

radiation and whatever other treatments there are for cancer. The treatments would cause Mother pain and suffering. And, considering her quality of life, for what result? When we expressed these concerns to the doctor, she was sympathetic. If it was cancer, Mother would take an oral medication and no more. Fortunately, the lump wasn't cancerous, but it did give us pause, and we re-read Mother's living will with a fine-tooth comb.

"The living will states that Mother doesn't want to receive extraordinary care that would extend her life"

A second concern raised similar issues. Mother is having trouble swallowing. On the two occasions that Dad has mentioned this to her doctor, he said that in the future Mother might have to have a feeding tube inserted. But the living will gives the feeding tube as an example of the kind of extraordinary care that is not authorized. As a result, we made sure that Mother's doctor had a copy of the living will and understood that Son, not Dad, was Mother's authorized healthcare representative. This was significant because it seemed that Dad's first priority was to make sure Mother always has the best treatment and we were concerned he might take actions that would prolong Mother's life at any expense. As it turned out, when we discussed the matter with him, we found that his attitude had changed and he agreed that life-prolonging treatment wouldn't make sense. We think this is because, when Mother was first diagnosed and for several years afterwards, Dad clung to the hope that there would be a cure or at least some drug that would stop the disease from worsening. As Mother's quality of life deteriorated, Dad seemed to recognize that Mother will eventually succumb to this disease. In fact, he recounted the futility of measures taken by his mother to prolong his father's life.

16. Coping

Dad deserves a lot of credit, because he's the one who has observed firsthand Mother's decline and has put up with the aides. His world has been turned upside down, but he has seen to it that Mother is cared for well. If anyone has done his best to uphold the traditional marriage vow of "in sickness and in health," it's him. When someone who didn't know Mother before the onset of the disease comes to the house, Dad feels compelled to describe to them what Mother was like when she was healthy so that they can possibly glimpse the woman he knew — the smart, vibrant, active woman she used to be.

Living with someone who is declining with dementia can't be easy. With some diseases you take a pill and you're all better; with others you can't be cured but your symptoms can be treated. Lewy body disease is completely different. Mother started taking Aricept and all the other medications, but with little effect. Dad would say with disappointment, "Your mother isn't getting better." When we got up the courage, we'd tell him that she won't be. He knew that, of course, but he didn't want to believe it or give up hope for improvement.

"Dad would say with disappointment, 'Your mother isn't getting better'"

For Dad, Mother's decreasing responsiveness seemed to be a particularly salient indication of her decline. Every morning, he would say "Good morning" to her, and she would reply, "Good morning." Sometimes, he would ask, "How are you feeling?" She would usually say, "Fine," which consoled him, since she wasn't in pain despite her problems. As the weeks passed, however, on some days Mother didn't respond. That bothered Dad. Still later, she stopped responding altogether. That was a hard blow for him.

Early on, we investigated support groups. There are none for Lewy body disease, but there are many nearby support groups for Alzheimer's. We encouraged Dad to attend, because we thought it might help him if he could speak to others about what he was going through. However, he was disinclined to attend. He subscribes to an Internet e-mail list for caregivers. In general, though, he doesn't have the patience to read all the comments and finds that many of the people cared for are mildly afflicted or are in a nursing home. He reads some of the comments, but they don't give him solace.

Dad is bitter that most of Mother's friends and acquaintances have stopped visiting. When they first heard about Mother's illness, a number of her friends made efforts to visit. After Mother's situation deteriorated significantly, these friends stopped visiting. It was understandably difficult for them because Mother didn't interact much with others, and later on, it became unclear whether she knew they were there. But we think that friends abandoned her too soon, at a

"Mother's friends abandoned her when she still would have enjoyed their company"

time when she still would have enjoyed their company and welcomed the diversion. Of course, Dad would still enjoy their company.

As for Dad, for us children this is a sad situation. Each of us visits regularly, but we have our own lives, so we're not constantly faced with Mother's illness and can put it out of our minds for a while. It's certainly hard to share our experience with friends. Talking about it can be hard. Friends who haven't had a parent with dementia cannot comprehend what we are going through. Everyone is quick to say the correct catchphrases ("I'm so sorry"), and some friends ask occasionally how things are going, but it's apparent that many others would rather not know.

17. Future Concerns

Mother's doctor continues to report that her heart and lungs are healthy. Until the onset of Lewy body disease, Mother had few health problems. It's now 2003, four years since Mother was diagnosed with Lewy body disease and over two years since she was able to walk. She is inattentive but occasionally responds when given a rousing "Hello, Mother." Sometimes, she replies with a plain "Hello," other times with a "Hello, Father" (regardless of who she's responding to). Recently, she responded with "Hello, Donald." (We don't have any relatives with that name.) On occasion, a stereotyped question such as, "I'm back, Mother; did you miss me?" will elicit a response of "Yes, of course." To other questions, she might nod her head or say a word or two. She is often inalert, so frequently no reply is made.

Mother is dependent on others for all aspects of her care. The major concern continues to be her ability to swallow food. She is still able to be fed by hand, but her food often has to be chopped into small pieces. Her eating has to be rated as her biggest problem.

"Mother is dependent on others for all aspects of her care"

Aside from our concerns about Mother, we have concerns about our own future. Will we contract this disease when we get older? Did we inherit a gene for it? No one knows what causes Lewy body disease, but it's hard to avoid having a fatalistic view.

We wonder whether Mother harbored thoughts like these herself. In old age her own mother had become ill with dementia. Back in those days, doctors didn't diagnose the kind of dementia like they do today, but Mother saw her mother decline. In the back of her mind, could she have had questions about her own future? If she did, she clearly didn't let them prevent her from leading a productive life. In that way, she provides a good example for us to follow.

"Any thoughts Mother may have had about her own future health clearly did not prevent her from leading a productive life"

All we can do is follow news reports about progress being made in understanding and treating Alzheimer's disease. We continue to hope that more attention will be given to Lewy body disease.

18. The Wound Doctor (April 2003)

Over the past few months, Mother developed some additional physical problems, but there was also a glimmer of good news.

On most days Mother spent many hours sitting in a wheelchair. Since she went to bed early and got up late, about half her day was spent in bed. Also, during the day she would be put to bed for a couple of hours, mainly to relieve the pressure on her back side and prevent bedsores. It turned out that this wasn't good enough. From sitting in the wheelchair so much, Mother started to develop many sores on her back and behind. Now, she spends most of the day in bed, and the aide shifts her position now and then. Because she is spending so much time in bed, she now seems more isolated.

A second problem is that Mother developed a red rash on the upper half of her body. The source of the rash is a mystery. Several months ago, a doctor started coming over every week or two, originally to examine Mother's hand

wound. He seems to think the rash might be an allergic reaction. But Mother never had allergies and the rash affects only her upper body. In any case Mother now takes an allergy medicine, which seems to be having some effect.

"From sitting in the wheelchair so much, Mother started to develop many sores"

This particular doctor started making house calls to examine wounds that had developed on Mother's hands. Mother had so much muscle tension that her hands were always clenched into fists and her fingertips were digging into her flesh. Her left hand was a particular problem, since her thumb was usually trapped inside the fist. Until the doctor came over, the aide tried to put a rolled-up washcloth inside each fist. The doctor, who specializes in wounds and bedsores and often sees patients in nursing homes, found that Mother's fingers had damaged the tendon of her left thumb. He sent her to a local hospital, where they built splints to hold her fingers apart somewhat. Use of Duoderm, a fabric impregnated with medicine, helped the wound heal. Although the splints seemed to work, the damage to the tendon was done and Mother's left thumb is permanently damaged. Additionally, the splints irritated the rash Mother had developed, so the aide can't use them for now. That means it's back to using the less effective rolled-up washcloths. The only thing that has prevented this from being a bigger problem is that Mother's muscle tension has decreased somewhat due to a new drug treatment.

The wound doctor consulted with a neurologist about how to deal with Mother's extreme muscle tension. The neurologist recommended a drug called Requip. This drug is sometimes used by people with Parkinson's disease. Apparently, it can enhance the effect of L-dopa, which Mother was already taking for muscle tension. A major side effect of Requip is somnolence. In fact, Mother had tried Requip over a year ago, but she was always so sleepy that we had it stopped. This time around, the Requip has had a more positive effect.

The doctor started Mother on a small dose of Requip, and the aide reported that her flexibility increased. To us, a second effect was more striking:

Mother became more vocal and seemed more alert. Before the Requip, Mother was almost always silent, but now she started talking again. She responded to questions and spoke up during the conversations she heard going on around her or to words she heard on television. Admittedly, a lot of what she said wasn't coherent. Still, it seemed to be a positive development. Over the next few weeks, the doctor increased the dosage. Unfortunately, that had the effect of inhibiting Mother's speech.

"A small dose of Requip made Mother more vocal and alert"

We liked it when Mother was more alert and more vocal on the lower dose of Requip. The aides, on the other hand, like the higher dose, because Mother seems to be more flexible. Our first reaction was to go back to the lower dose, especially since our goal isn't to make life easier for the aides. Rather, we want what is best for Mother, which is an almost impossible judgment at this point. Does greater alertness increase the quality of Mother's life, or does it just make the family feel a little better? It turned out that the proper course to take became clear. The aides told us that Mother is better able to eat and swallow with the higher dose. The higher dose it was.

The weather is warming up and Mother has been able to spend some time outdoors. We hope she can enjoy it.

19. Various Problems (August 2003)

The effect of the Requip was short-lived. In our April 2003 update, we reported that a medication called Requip made Mother more alert and vocal. Unfortunately, the effect was only temporary. After a few weeks, Mother became largely silent and unresponsive again.

The reversal of the Requip wasn't our only setback.

Dad has been taking Mother to a dentist every three months for a professional cleaning. With the aide using an electric toothbrush, she hadn't had a

major dental problem in about a year. In her last visit, however, the dentist found problems with three of her teeth. He said that two teeth had such big cavities that they should have root canal procedures and a third tooth had sheared off completely. We decided that we didn't want to subject Mother to invasive, prolonged procedures to fix these problems. She doesn't seem to have any discomfort, although it can be hard to tell.

"The reversal of the Requip wasn't our only setback"

Bedsore have continued to be a problem. Because of the bedsore, Mother is mainly confined to bed, with the aide shifting her position throughout the day. The beginning of summer was particularly cool and rainy this year, but even when the weather has been decent, Mother hasn't been outside for long because sitting in the wheelchair inflames the sores. One thing that has perhaps improved the situation has been the air mattress. Paid for by Medicare, we now have an air mattress that replaced Mother's traditional bed mattress. The air mattress has an electric pump, which keeps it inflated to the right pressure.

In addition to the bedsore, Mother continues to have a problem with constipation, and for a while her general appearance was not good. (Also, she seems to chew her lower lip sometimes.) Dad decided that it would be good to have a doctor make an occasional house call. Until this time, he had periodically taken Mother via wheelchair van to their regular doctor. Their regular doctor didn't make house calls, but by calling a referral service at a local hospital, he found one that did. The new doctor came over and, although she hadn't heard of Lewy body disease, Dad was pleased with the exam she gave. A week later, she called Dad with a new recommendation she had. She told him that Mother might benefit from a feeding tube, since that could help hydrate her body.

Dad called us about the doctor's advice. We had previously dealt with the issue of the feeding tube (15. Living Will) when it had been raised by Mother's regular doctor. Now, this second doctor

brought the issue back to the fore. After much discussion, Son called the doctor and advised her of Mother's living will, which explicitly cites the feeding tube as a procedure she doesn't want. Mother had signed the living will many years before, when she was in

"The doctor understood that the goal wasn't life extension"

good health and showed no signs of dementia. Son also told the doctor that Mother had expressed a desire to die some two years earlier (12. "I Want to Die"), so her sentiments hadn't changed after she became ill. The doctor accepted all of this amicably. She said that she now understood that the goal wasn't life extension. Son said that we wanted Mother to be comfortable. (See the Information section of LewyBodyJournal.org for more about feeding tubes.)

Mother now lies in bed almost all the time. She is still able to eat as long as her food is chopped into small pieces. When we talk to her, she seldom responds. Sometimes, she'll nod her head slightly, often with her eyes closed. Once in a while, usually in the evening, she'll vocalize a little. When we gently stroke her arm, sometimes it seems to disturb her, as her breathing speeds up and becomes more forceful. Because of her unresponsiveness, it's sad to say that she has become more marginalized. We think that everyone spends less time trying to interact with her. Dad has begun to think about where he might want to live after Mother is gone. A couple of Mother and Dad's friends have called, and Dad has described Mother as like "the living dead." That may sound harsh, but we can't say that it's not reality.

20. Stasis (May 2004)

From week to week, it's hard to notice changes in Mother's condition, and that's made it difficult for us to write a journal update. But now when we look back, the operative word is stasis. In the April 2003 and August 2003 updates, things weren't looking good, mainly because Mother had eating problems and bedsores. Now, Mother is eating fairly well and her bedsores have healed.

As Mother's eating problem worsened, the aides cut her food into smaller and smaller pieces. Now, they use a food processor to chop solid food up. When they put food into Mother's mouth, she chews and swallows. Occasionally, she'll swallow wrong, but her eating doesn't seem like the serious problem it did before.

"The operative word is stasis ... Mother is eating fairly well and her bedsores have healed"

Careful attention to Mother's bedsores fixed that problem. Mother sleeps on an air mattress, and the aides shift her position periodically. One aide also gives her a gentle massage once in a while to get the blood flowing. It seems like the only wound Mother gets is one on her ear from lying on her side, but even that is infrequent.

Mother had had a constipation problem, but that was resolved as well. One of the aides has a friend who works in a nursing home. The friend gives her portions of a prune concentrate to feed to Mother. A regular dose of that really does the job. Mother used to need a couple of enemas a week. No longer. We believe the product is Fruit-Eze (www.fruit-eze.com). When it isn't available, the aide has stewed prunes in prune juice. This is practically the same thing and seems to work as well.

Phlegm has become an occasional problem. It collects in Mother's throat and she seems to be too weak to cough it up. Mother regularly takes cough medicine to help break it up. In addition, two or three times a week the aide uses a strange toothbrush to reach in and pull out gobs of phlegm. The toothbrush is a piece of foam on a thin plastic dowel. A neighbor who is a nurse gave us a few. Apparently, this kind of toothbrush is used in hospitals and nursing homes.

Mother's extreme rigidity continues. Her hands are always balled into fists and her arms are crossed in front of her. Touching her arm reveals how tense her muscles are. When touched, she usually flexes her arm even more. This winter, Dad had a doctor come over to give Mother a flu shot. He wanted to take her blood pressure, but he was afraid he'd break her arm if he tried to straighten it. Her legs don't seem as tense, but they can't be straightened fully either. Now that the weather is warmer, the aides are trying to get Mother outside for some fresh air. The problem is that she can no longer bend enough to sit properly in the wheelchair. The aides have to be very careful to make sure she doesn't slide off the chair.

"Mother's extreme rigidity continues"

We had written before about the splints that were constructed to keep Mother's hands open to prevent her fingernails from digging into her palms. The splints were used until Mother's palms healed. Now, because of the extreme muscle tension, it's not possible for the aides to put the splints on Mother. Instead, they put rolls of gauze in her hands and that has sufficed. Mother's fists are so tightly closed that fresh air can't reach her palms, and her hands can get smelly. The aides solved this problem by cleaning her palms with vinegar, which we're told is an old folk remedy.

A strange thing has happened for a year or two that we haven't written about. Mother sometimes perspires profusely for no apparent reason. A few years ago, we had noticed that her face would sometimes become flushed and she would breathe heavily for a few minutes, then she would be back to normal. About a year or two ago, she started to perspire heavily every afternoon for an hour or two, regardless of the season or indoor temperature. This continues today. To try to keep Mother comfortable, we have a small fan aimed in her direction, which the aides turn on when the perspiring begins.

Mother's mental condition remains poor. She spends all day in bed and is very inattentive. She still sleeps most of the day and usually has her eyes closed. We've found that having her eyes open or closed is not necessarily a good indication of whether she's asleep. When her eyes are open, you might touch her or speak to her and she'll be startled, possibly because she'd really been asleep. When her eyes are closed and you say something, she might nod her head slightly.

There's little evidence that Mother can understand what we say. She seldom responds. Once in a while, when asked a question, she'll nod her head; more rarely, she'll say, "Yes." We don't think that

means she understands us. Rather, she might be responding to our voice intonation. When people are talking nearby, Mother sometimes makes a word-like utterance or two. Her reaction to touch varies a lot, from no response to startle. At times, she winces, especially when touched around the head or face. When touched on the arm, as noted, the arm usually flexes, but there's usually no response from touching her leg. Otherwise, she seems largely unaware of what's going on around her.

"There's little evidence that Mother can understand what we say"

We continue to rent all of our medical equipment, despite the fact that we have rented long enough to take possession of all the items. This way, when anything needs to be repaired, the equipment company is responsible. Medicare may be changing its reimbursement policy for the wheelchair, since we've had it so long, so we might take ownership of that. Mother rarely uses it, so repairs won't be a big factor. A couple of items that did need repairs lately were the hospital bed and the air mattress. With the air mattress, the problem was that a section of it wasn't retaining the air. The equipment company sent someone over to examine it, and he determined that it should be replaced. Someone else then came over with a new mattress, installed it, and left. The training for these guys couldn't be very good, since the new mattress didn't hold the air. Calls to the

company simply provided the obvious advice to make sure the valve was closed. Finally, by unzipping the mattress cover, deep inside we found a second valve that had never been closed. What a mess that was for a couple of hours.

It's clear that the aides who care for Mother are very good. Both our regular aide and the weekend substitute have now been with us for more than three years. If not for them, it's doubtful that Mother would have survived until now. Would Mother have wanted this? We don't know.

21. Little Change (May 2005)

Mother's condition remains poor. Her body is tense and inflexible, with her hands in fists and her elbows and knees always bent. She has her eyes closed much of the time, and when they are open, she stares blankly. When touched on the upper body, Mother often flinches. (Our sister thinks this may be a reaction to being "handled" — washed, rolled over — by the aides. Or maybe it's just a surprise response.) Touching her legs doesn't seem to elicit a response. She is largely silent, but on occasion she utters some syllables and, rarely, a recognizable word. Our sister thinks she shows some response to the sound of familiar voices, but we're not so sure. In any case, when the aides put food in her mouth, she chews and swallows.

Mother eats food that doesn't require a lot of chewing, such as crushed pineapple, lentil soup, and tuna. The aides sometimes use a food processor to make the food into a consistency she can handle. Mother didn't have a problem with liquids until this year, when she would sometimes gag while drinking. To help with that problem, the aides thicken her liquids with Thick-It or Thicken-Up. These products mainly consist of cornstarch, with another ingredient or two to prevent lumps. We've read that plain cornstarch might work as well if you use a small wire whisk to combine the cornstarch and the liquid.

"Mother's condition remains poor ... but when food is put in her mouth, she chews and swallows"

To prevent bedsores, Mother's bed has an air mattress, and the aides shift her position regularly. Since she is always in bed, she does get sores and the aides tend to them regularly. So far, they have been successful in preventing them from becoming a problem. The latest device they've been using is an inflatable rubber doughnut. While being fed, Mother has to spend a certain amount of time on her back, and her back would get red. The doughnut is placed under her and keeps pressure off the affected body parts.

Constipation continues to be a problem, but the aides haven't had to resort to enemas. The combination of senna, prunes, and prune juice seems to be working.

We wrote before (20. Stasis, May 2004) that phlegm had become a problem. At that time, the aides dealt with it by giving Mother cough medicine to break the phlegm up. They also pulled phlegm out using a special toothbrush (a piece of foam on the end of a thin plastic dowel). After a while, this wasn't sufficient, as Mother would choke on the phlegm. It was really horrible to hear. To take care of the problem, the doctor wrote an order for a suction machine, which we rent from a medical supply company. Now, the aides suction Mother's mouth and throat as needed, which has become a few times a day. Hearing Mother choke on the phlegm was unbearable, but hearing her being suctioned isn't pleasant either.

"Mother would choke on the phlegm, so the doctor wrote an order for a suction machine"

Part of Mother's phlegm problem may have been due to a cold. Her gagging became so frequent that an aide called a doctor who makes house calls. According to the aide, the doctor wanted Mother to go to a hospital and be hooked up to some kind of machine for the delivery of medicine. This was the doctor's opinion without first examining Mother. When we heard about the plan, we thought it sounded like it would violate Mother's living will. When the doctor came over to examine Mother, our sister was sure to be present. She made it clear to the doctor that the treatment should be for comfort, not for life extension. The doctor thought part of Mother's phlegm problem could have been due to a cold. She prescribed a decongestant that came in a liquid form. She also prescribed albuterol, a medicine that is often used to treat the wheezing and breathing problems in diseases such as asthma and bronchitis. In Mother's case, the albuterol is given through a nebulizer. This is a small machine that vaporizes the drug and delivers it through a facemask. Mother just breathes it in. The treatment has helped. Mother's coughing and gagging have diminished, but she still has problems, which is why the suction machine is used.

We know that all of this sounds bleak and it is, but being in our parents' house isn't as depressing as you might think. That's partly because this has been going on for so long that everyone has become accustomed to things — to the extent that we can. The amount of time visitors spend with Mother varies a lot. Some people take only a quick look. When we visit, we talk to Mother for a while, but it can be hard to spend a lot of time with her. No one wants to be present when an aide is caring for her (feeding, cleaning, or changing her). Every morning, Dad says hello and touches Mother's face, and he looks so sad. Other than that, he keeps his distance.

"All of this sounds bleak and it is, but being in our parents' house isn't as depressing as you might think"

We are now renting a lot of medical equipment, and we have had problems with the suppliers. The hospital bed and air mattress seem to break down fairly regularly. The medical supply company often sends over someone who can't fix the problem, so nothing gets done until the second or third visit. The bed we have is electrically powered, but the company says that it made a mistake in giving us this bed. They say that Medicare is only supposed to cover manually adjustable beds. Whenever our sister calls about getting the bed repaired, the company always offers to take it away and replace it with a mechanical bed, which we don't want. Dad also became quite annoyed about Mother's wheelchair. He had wanted to stop renting it and take possession of it, but he couldn't. The wheelchair provided by the supply company was old and worn. Over the years, though, we had the company replace practically every part of it. Renting still made sense, since the company would be responsible for repairs. Now that Mother is rarely in the chair and most of the parts haven't been replaced, Dad thought we could save Medicare money by taking possession of it. The medical supply company informed us that it was too late for that. We could have taken possession a couple of years ago, but we didn't, so now the wheelchair can only be rented. Dad was quite annoyed, since the government has probably paid for that old wheelchair several times over.

Dad has cut out ads from the newspaper about hospices, and he's had us call the insurance company to find out about hospice coverage. We don't know when we'll need it, but it can't hurt to be ready.

Over the past few months, the case of Terri Schiavo was a major news story. Doctors said she was in a persistent vegetative state, so her husband wanted to remove her feeding tube and let her die, while her parents opposed that action. This story resonated with our situation with Mother. She was diagnosed with Lewy body disease about six years ago, and her situation has been bad for the past few years. From the news coverage, we learned a few new things about persistent vegetative states and living wills. We're glad that Mother had the foresight to make out a living will to guide us in making decisions on her behalf.

22. The New Doctor (March 2006)

It's now 2006 and our family is beginning another year of living with Lewy body disease. Mother remains about the same. The one noticeable difference is that she no longer speaks at all. Until a few months ago, she would sometimes utter a recognizable word. Now, except for an occasional sound when clearing her throat, she's silent.

The only significant event that occurred during the second half of 2005 was Mother's need for dental work. A front tooth was loose and became

positioned in a way that interfered with the aides' feeding her. The tooth beside it was loose as well. Our dentist didn't know anyone who made house calls, so we called a local nursing home to find out who they use. Their dentist was pretty expensive, but before we called him, Dad saw an ad in the newspaper for another dentist and arranged for him to come over. Mother's aide told us later that she thought she should move Mother into the wheelchair for the dental exam, but Mother kept sliding out because her body is so rigid. The dentist gave a local anesthetic and ended up removing three loose teeth. He looked around and said there wasn't any sign of infection. That surprised us, because the last time Mother had been to a dentist a few years ago, we were told that she had some big cavities and a tooth had sheared off (19. Various Problems, August 2003). We didn't treat those problems. Anyway, when the dentist wrote up the bill, he was even more expensive than the dentist from the nursing home. The funny part was that, after totaling the exorbitant charges, he deducted 10% as a senior citizen discount. Thank you very much. At least, he seemed to do a good job and even called a couple of times to make sure everything was all right.

"Our family is beginning another year of living with Lewy body disease"

As the new year began, a few things were on our mind: We know that Mother wouldn't want to live like this. The situation is hard on all of us, especially Dad. Another year of this. We also had some questions: Are the aides caring for Mother properly? Does Mother really need all the medications she is taking? Hospice care is appropriate only when a person is within six months of death, but how do we know when that point arrives? We decided that we should find a good doctor.

Before Mother got Lewy body disease, she visited a doctor regularly. Afterward, we continued to take her while she was able to sit in a wheelchair. Then she became too stiff to sit in a chair and bedridden. Since her regular doctor didn't

make house calls, she was seen by a different doctor but only a few times in the past few years. We found the doctor through the referral service of a local hospital. She had no special knowledge of dementia or end of life issues, but she made house calls. After her first visit with Mother, she recommended a feeding tube, which we disagreed with and is ruled out by Mother's living will (19. Various Problems, August 2003). Last year, when Mother was gagging a lot, the doctor prescribed albuterol administered through a

"As the new year began, a few things were on our mind ... We decided we should find a good doctor"

nebulizer and a facemask (21. Little Change, May 2005). That seemed appropriate at the time, when Mother may have had a cold. But we learned only near the end of 2005 that the doctor had prescribed the albuterol again after Mother's aide called her, and the aide was using it every two or three hours. Was that appropriate now that she no longer had a cold?

Mother has one primary aide, plus a weekend substitute. The primary aide is very diligent and we've generally left Mother's day-to-day care to her. We were surprised that she had the doctor prescribe the albuterol for such frequent use when we thought it was a temporary measure. We were also aware that the aide was suctioning Mother's mouth and throat continually throughout the day. It seemed that whenever Mother coughed a little, the aide would rush over and suction. Mother shows little reaction to anything, but she does react negatively to the suctioning. This concerned us too. (A Web site we looked at suggested that suctioning might even cause the production of more phlegm.)

We were thinking about all these things, and we wondered when hospice care would be appropriate. We decided to find out more. From the National Hospice and Palliative Care Organization

"We got a doctor recommendation from the nurse at the hospice"

(www.nhpc.org), we learned that all of the local hospitals have hospice programs. Son called one and spoke to the intake nurse about hospice and about Mother. The nurse said that because Mother is still eating, she could live quite a bit longer. She also said that it's not necessary to suction every time a person gurgles. Before the call was over, Son got a doctor recommendation.

We told Dad about our plan to call a new doctor and mentioned that Mother wouldn't want to live like this. He agreed and said that the situation was very hard on him too. We then told the aide that a new doctor would be visiting. Right away, she became agitated and wanted to know why we didn't get the doctor who had been there before. We explained that the new doctor was recommended by the hospice and knows about end of life issues. We didn't think Mother was ready for hospice, but we wanted to establish a relationship with a knowledgeable doctor. She calmed down, but prior to the doctor's visit, Dad said she became agitated again. Our sister had to talk to her and reassure her that she's doing a good job, which she is. She's not a nurse or a trained medical professional, but she's been good.

Before her visit, we wanted to advise the doctor about Mother's condition and some of the issues we wanted to discuss. Son faxed her this letter:

January 18, 2006

Dear Dr. I:

Tomorrow, you will be examining my mother. Before your exam, I wanted to fill you in on my mother's condition and what we would like to get from you.

My mother was diagnosed with Lewy body disease about 7 years ago. Since then, her condition has declined significantly. Today, she is completely incapacitated and completely unaware. She is cared for at home by a live-in aide. My mother has a living will and I am her health care representative. We know that our mother would not want to live this way. Therefore, the goal of any medical treatment is to provide comfort, not to prolong life.

My mother's primary doctor had been Dr. W, but since he does not make house calls, he has not seen her in a few years. Another doctor has visited, but her advice was too aggressive for my mother's situation. For example, she recommended a feeding tube. The hospice at the local hospital referred us to you. Since you were referred by the hospice, we trust that you are knowledgeable about end of life issues.

Examination Since my mother is still eating, she probably is not within the 6-month window required for hospice care, but we would like to get your opinion.

Medication My mother is still taking all of the medications she had been prescribed before her condition declined. We would like to know whether these drugs are still necessary. The drugs are:

- Aricept 5mg, one per day
- Carb/Levo 25-100mg, three per day
- Requip 0.5mg, four per day
- Norvasc 5mg, two per day
- Plavix 75mg, one per day
- Potassium chloride 10meq er, one per day
- Hydrochlorothiazide 25mg, one per day

Suctioning My mother's aide is very conscientious, but we find that she is suctioning my mother's mouth and throat continually. The suctioning seems to be unpleasant to my mother, so we need your opinion about its necessity. The aide has also been using a nebulizer to administer albuterol, which had been prescribed long ago by another doctor when my mother had a cold. The aide is still using it. Is that necessary?

We look forward to meeting you tomorrow.

The doctor came over and gave Mother a short exam. She listened to her heart and lungs, which were fine. Because Mother's arm can't be straightened, the doctor could get only the first number of her blood pressure: a healthy 115. The aide explained how she treats Mother's sores with various creams and sometimes with Duoderm (a fabric impregnated with medicine), and the doctor was impressed. Afterward, the doctor sat down with us to get Mother's history. We also learned more about the doctor, including the fact that she used to work in a veterans' nursing home. She doesn't have in-depth

knowledge of Lewy body disease, but at this point that doesn't seem necessary. In response to the letter we had faxed her, she agreed that a feeding tube would not be appropriate. We also informed her that, in line with Mother's living will, we would not treat infections like pneumonia. She said that was all right, that some families would treat infections while others would not. She generally recommends aggressive treatment only for younger patients and those who can improve.

We reviewed all of Mother's medications and the doctor thought several of them were no longer necessary. Aricept is for mild to moderate dementia and Mother is well past that. There didn't seem to be any reason to continue the potassium supplement or the hydrochlorothiazide. We also took her off Plavix, a mild blood thinner, but we had some qualms about that (what if she got a blood clot in her leg again? — see 14. Slow Decline Continues). After our long discussion, we had the aide come back and the doctor spoke to her about suctioning. The doctor recommended not suctioning for every little thing. If Mother coughs, don't suction right away. Wait half an hour and then see if she still needs it. That turned out to be great advice, and the aide is now suctioning much less frequently.

Before leaving, the doctor said she would like to return every month. We agreed because that way she could monitor Mother's condition and know when hospice would be appropriate. She could also look at the effect of having removed the medications. There's also the possibility that she would reduce other medications.

We were pleased with the doctor, but the aide was not. She told Dad a couple of times that we were trying to kill Mother, which was untrue, of course. He had to tell her not to say that again. When our sister talked to the aide, one of the things that bothered her was the elimination of the Aricept, but that is clearly unnecessary for Mother's present condition. The aide also seemed concerned about not being able to use the albuterol nebulizer so frequently. Mother does wheeze on occasion, but it doesn't seem to bother her. In looking at the aide's reaction (before the doctor came and afterward), there might be more to it than just the medications. The aide really likes living at our parents' house and might want to continue living there as long as possible. She's also a fairly religious person and has told Dad that she is against Oregon's assisted suicide law and similar things. It's also true that she is very conscientious, and it could be that she wants to do more, rather than less. We're really not certain why the aide was hostile to the doctor and the changes to Mother's treatment.

"We were pleased with the doctor, but the aide was not"

After the supply of albuterol ran out, the aide complained to our sister about it, because she thought it was so important. Son called the doctor's office to have it prescribed again, if the doctor approved. (During the doctor's visit, she had told us that she didn't think it was doing much.) The doctor's assistant said she would call the pharmacy to renew the prescription. Fortunately, our sister called the pharmacy, because the doctor's assistant had simply renewed the prescription as written by the previous doctor — which called for using the nebulizer four times a day and giving five refills.

Our sister told the pharmacist not to fill the prescription until we saw that it was really necessary. The next day, she went over and found that Mother wheezed a bit, but otherwise seemed all right. We didn't fill the prescription.

The new doctor was supposed to visit again in a month, but we asked her to come back sooner as the aide again started telling Dad and a neighbor that we were trying to kill Mother. Dad got particularly upset when the aide waited until he was within earshot and told Mother, "They're trying to kill you" and "You'll be in a better place soon." The irony was that the aide was saying this when Mother was under the regular care of a doctor for the first time in years. Before Mother's doctor returned, Son took Dad for a visit to his doctor, the same doctor who used to treat Mother. That doctor said that it was good that we found a doctor to come over regularly, and he agreed about dropping medications. In fact, he said he probably would have dropped all the medications. He thought the aide was afraid of losing her job after Mother was gone.

Before the doctor came for her second visit, Son faxed her this letter:

February 7, 2006

Dear Dr. I:

It's been three weeks since you examined our mother, so I would like to schedule your monthly appointment. For the reasons I go into below, I would like to schedule the appointment sooner rather than later.

Last week, I called your office because we were out of albuterol. Your assistant called the pharmacy and renewed the prescription. My sister, who you met, called the pharmacy to check on it and found that the pharmacist was duplicating the prescription that had been written previously by another doctor. That prescription called for administering the albuterol four times a day and gave five refills. Since we thought our aide was using the albuterol too frequently, it seemed that that prescription would give her license to continue overusing it. When we visited our mother, we found that she wheezed sometimes but it didn't seem serious. Therefore, we did not fill the prescription.

Our most serious problem right now is with the attitude of the aide toward the changes in our mother's treatment. For reasons that are not clear to us, she was not happy about having you come over and she remained unhappy after your visit. In fact, she has been telling people (our father, neighbors) that we are "trying to kill" our mother. My sister has spoken to her and she seems concerned about dropping the Aricept and about not being permitted to give the albuterol continually. Even though you found that our mother's lungs are clear, she seems to be concerned about fluid buildup, because she now spends a lot of time tapping our mother's back.

Please understand that all the members of our family agree with your treatment. At the same time, it is important for us to keep the aide happy, since our mother depends on her and she can make life miserable for our father. Being sensitive to the aide's feelings may amount to no more than including her in our discussions, reassuring her about our mother's condition, and explaining why certain medicines and treatments are not necessary. I want to make it clear that, however the aide may feel about things, we do not want treatment that will prolong our mother's life — our mother would not want that. All treatment is for comfort only.

Please let me know when you will be returning.

The doctor came over shortly after receiving the fax. Her exam found Mother to be the same as before. When we sat down to discuss things, we asked the aide to join us, but instead she left the room. The doctor heard Mother wheezing a bit, so she recommended using the albuterol again as needed. We called the aide back so that the doctor could instruct her. The doctor also explained that wheezing and phlegm would not cause fluid to build up in the lungs; fluid in the lungs is caused by congestive heart failure (weak pumping of the heart), which Mother doesn't have. The albuterol would provide some comfort and not extend life. While the aide was there, we asked if dropping medications had a negative effect on Mother. The doctor said it didn't and started to explain that Aricept is not for advanced dementia. In the middle of her explanation, the aide asked for the doctor's permission to leave and there was no choice but to grant it.

After the aide was gone, the doctor wanted to know more about why the aide was unhappy. The doctor assumed that the aide was used to being in charge and now she had to follow a doctor's orders. That may be. We really don't know. Whatever the case, all the members of the family agree that it is good that we have a doctor visiting regularly. If we'd found the doctor earlier, we don't think that would have affected Mother's treatment or the progression of the disease, but we are finding it reassuring now. Mother is a very sick person and should be under a doctor's care. We should have done this a long time ago.

"It is good that a doctor is visiting regularly ... We should have found a doctor a long time ago"

23. Final Days (May 2006)

On Thursday, April 20, Son came over to our parents' house with the groceries for the week. As he brought the bags into the kitchen, he heard a strange, regularly repeating sound. Upon investigating, it was Mother — it was the sound of her rapidly gasping for breath. The aide had her sitting up in bed; her skin had a bloodless pallor, her lips were a dark brown; her mouth was drawn back in a grimace. The aide said she had been like that since the previous evening, but despite her obvious distress, the aide hadn't said anything because "when she said things before, she got into trouble." This seemed to be related to the poor attitude the aide had adopted because of her dislike of Mother's new doctor (see 22. The New Doctor, March 2006). The aide hadn't called us or attempted to suction or use the nebulizer, although the doctor had clearly told her that she should do both as needed, which seemed to be the case now.

Son called the doctor, who also thought initially that Mother's distress could have been due to a buildup of phlegm. However, suctioning and administering the nebulizer now had no effect. (Having Mother lie flatter did

"Mother's lungs were filled with fluid ... She had developed congestive heart failure"

improve her color.) Later that afternoon, the doctor came over and found that Mother's lungs were filled with fluid. She thought that Mother had developed congestive heart failure, which allowed her lungs to fill up due to weak pumping of the heart. It was not something that could be fixed with a suction machine and a nebulizer. For all these years, Mother's heart was strong and her lungs were clear, but now the doctor said she was in very bad shape and would probably not live through the weekend. The doctor called the hospice but it was too late for them to come over. The doctor urged them to come early the next day.

The doctor prescribed the two drugs used by the hospice and had us fill the prescriptions right away. The drugs (morphine sulphate and hyoscyamine) were supposed to relieve the shortness of breath and any pain and help dry out the secretions. Both come in a liquid form and were to be squirted into Mother's mouth periodically throughout the day and night. (The local pharmacy had the hyoscyamine in pill form only. This turned out to be hard to administer. Since Mother was breathing rapidly through her mouth, there wasn't much saliva to dissolve the pill, so we squirted in a little water with an eyedropper. The next day, the hospice nurse made sure we got the liquid form of hyoscyamine.) The doctor also filled out a DNR (do not resuscitate) form to keep near Mother's bed. That evening, Son and Daughter called our other siblings to tell them of the serious turn that Mother had taken.

Son was going to stay and give the drugs until 11 p.m. that night and then Daughter was going to tend to Mother for the remainder of the night. But Mother's breathing continued to be rapid with a loud gurgling and, even more disturbing, her mouth sometimes filled up with foam. After Daughter arrived, Son stayed on because he

thought Mother was going to die that night and didn't want Daughter to be there alone. Mother's breathing remained rapid, gurgling, and somewhat erratic throughout the night.

Mother survived the night and the foaming stopped. The next morning, the doctor called and explained that foaming is typically an end of life sign. Soon after, a nurse and a social worker arrived from the hospice. They had already talked to the doctor that morning and were aware of the

"The hospice nurse said that someone in Mother's condition survives anywhere from a few hours to a few days"

situation. The nurse said that Mother's condition was very poor and usually someone in that state survives anywhere from a few hours to a few days, but definitely not for weeks. She said that, although Mother's breathing was painful for us to hear, she wasn't in pain. She suctioned and repositioned Mother, which made her breathing less loud. It was still rapid, however, and Mother's upper body moved with each breath. The nurse had an oxygen machine delivered to make her more comfortable. Mother could no longer eat or drink, but we could put a chip of ice in her mouth or swab her mouth with some water.

Dad wasn't aware of how much distress Mother was in, but he knew something was up since all of his children were around and the doctor had visited. When the hospice people were there, we had him come down and told him how dire things were. He had previously said that he didn't want Mother dying at home. That was mainly because he thought she would stop eating at some point and he couldn't bear the thought of her wasting away over a long period of time and possibly being in pain. The social worker spoke with him and addressed these issues. Mother wasn't in pain and it seemed that her death was imminent. After treating Mother at home for all these years, it only made sense to see it through to the end. Dad agreed.

The hospice service was based in a local hospital. It provided us with regular visits by nurses, who were always very nice but, after the first visit, stayed relatively briefly. In addition, a social worker came the first day; an aide was scheduled for three times a week to give our regular aide a break; and a pastoral counselor visited that first week and would be available for 13 months after Mother's passing. The hospice had all medications and any supplies we needed delivered to us. They gave us a telephone number that we could call around the clock if we had questions or needed assistance.

From the beginning, we four siblings took turns sleeping over and giving Mother the drugs through the night. The aide did it during the day and seemed to do her job all right. By Saturday

"We took turns sleeping over and giving Mother morphine through the night"

morning, Mother's breathing had slowed and quieted down, but the nurse who visited that day said that Mother's lungs were still very congested. She'd been on call the previous night and had been told to expect a call from us because it was likely that Mother would pass away Friday night. That's why it was a surprise when, the next day, the Sunday nurse said that Mother's lungs were not too congested.

The nurse who visited originally came back on Monday. She remarked that it was extraordinary how much Mother's lungs had cleared up. We asked whether it might be possible for her to eat or drink. This would require reducing the morphine she was getting, which, although a relatively small dosage, would make it difficult to swallow. However, the nurse was concerned that Mother would aspirate food (i.e., the food would go into her lungs resulting in pneumonia and other problems). She discouraged us from doing this. She thought it was possible that Mother had already been aspirating food and liquid before being in hospice care.

The hospice nurses suggested that the aide administer an enema to remove any waste and prevent a blockage that can sometimes be uncomfortable. When the enema was unsuccessful, a nurse provided suppositories, which were also ineffective. The nurses decided that any waste was probably minimal and so chose not to perform a more intrusive procedure that could have been uncomfortable for Mother.

On Tuesday, all of Mother's medical equipment was exchanged to satisfy Medicare's requirements. Hospice is covered 100% by Medicare and while a person is in hospice all of her treatment must be under hospice. Mother had a hospital bed, air mattress, lift, wheelchair, nebulizer, and suction machine, which were covered mainly by Medicare, but the medical supply company that provided these items was not the one used by the hospice. Therefore, the hospice nurse had to call the company they use and arrange to have them deliver new equipment and she had to call the company we had used and have them pick up the old stuff. It seemed kind of silly, but that's what happened.

During that whole week, Mother's condition remained about the same. Her breathing was regular with only a little gurgling. Sometimes, she would cough a bit, but shifting her position seemed to help. Dad came to see her every day and remarked that she seemed peaceful and serene. In addition to visits from the hospice nurse, the pastoral counselor came over. (Previously, the leader of our parents' own religious congregation had visited.) She was a nurse who had continued on in counseling. She spoke to Dad and us for a good while and said a nonsectarian prayer over Mother and later with Dad. She said that people who aren't eating or drinking usually survive about a week.

There was little change until the morning of Sunday, April 30, when Mother started taking short, rapid breaths. Daughter had been on duty that night, and she paged the hospice nurse. The nurse reported that Mother's lungs were congested again and she had a fever. Although her breathing didn't seem quite as bad as it had been a week before, the nurse said that things were worse because Mother was now much weaker.

A neighbor who is a nurse was over several times on Sunday, trying to keep Mother comfortable by suctioning a bit and helping to shift her position. She did not think things looked good. That

"At 1 a.m., Mother was still hot and breathing rapidly. At 2 a.m. on May 1, Mother had passed away"

night, it was Son's turn to stay over. At midnight, Mother was still taking short, rapid breaths and was feverish. As Son held his hand to Mother's forehead, her breathing stopped for a few seconds then it started again. This happened a couple more times. At 1 a.m., Mother was still hot and breathing rapidly. At 2 a.m. on May 1, Mother had passed away. Her forehead was still warm, though not hot like before. There was the sound of air rustling, but it was coming from the oxygen machine until it was switched off. Mother's arms and hands, which had been stiff and tense, were loose for the first time in years. At times, we had worried that the person who was there when Mother died would be devastated. It didn't turn out to be that painful because it had been so hard to see Mother's decline in those last 12 days. Needless to say, despite the number of years she had been ill, her death was still a blow to us.

Son called Daughter, who lives nearby, and she came over quickly. He also called the hospice, which paged the on-call nurse. The nurse returned the call quickly and came over too. She was the nurse who had visited the first Saturday Mother was in hospice, the nurse who hadn't expected Mother to survive the day, let alone over a week. She said that Mother seemed peaceful. She filled out the death certificate and called the funeral home. She suggested that we tell Dad and our other siblings so that they could have the option of seeing Mother. We woke Dad and told him about Mother's passing. He immediately got dressed, but at first he said he didn't want to see her. He then changed his mind, came down, and said a prayer over Mother. The funeral took place soon after.

24. In Memoriam (May 2006)

Mother's funeral was in the first week of May 2006. Daughter's eulogy follows.

My mother was a remarkable woman. It's impossible to summarize my mother's 79 years in just a few minutes. Her life was devoted to her family and to her community. As a child, I remember going with Mother to League of Women

Voters meetings, attending candidates nights organized by her, helping out at book sales for the Friends of the Library, and weeding the plants by the railroad tracks with the town beautification committee — just a few of the organizations that my mother belonged to.

"Mother's life was devoted to her family and to her community ... Mother's life touched so many people"

My mother's life touched so many people. For many years, Mother taught children with learning disabilities. She didn't just educate the kids; she befriended them, gave them confidence, and advised them. At night, Mother taught business education classes at the adult school. She was instrumental in helping many women acquire the skills they needed to return to the workforce. And when Mother finally retired, rather than stay home, she got what she referred to as her retirement job, working at the public library. She loved being active and interacting with people.

Mother's life was devoted to public service. She literally made a difference in our world. For many years, she chaired the town planning board and safeguarded our town from overdevelopment. She was the president of the town League of Women Voters and later the county chapter. She helped end racial steering in housing in our county, made sure that our town didn't sell off its parks, sponsored numerous local candidates nights, did voter registration, and worked at the polls on election day. Mother also volunteered with many other organizations and was the treasurer of the Friends of the Library and the museum society. She organized fundraising trips, helped out at book sales and tag sales, and performed numerous tasks for these organizations.

Mother was interested in local history and was part of the committee that advised an historian on his book about our town. In fact, Chapter 7 of the book begins by describing my parents' decision to move to our town in 1956 from the cramped one-bedroom apartment they had been living in with three kids in New York City.

Mother had an immense love of learning. She was always reading and was a regular attendee at the library's Friday books and lunch. When she was in her mid-40's and had four children, Mother went back to school and earned her second master's degree in education. Mother earned degrees from Hunter College, NYU, and Fairleigh Dickinson University.

Mother had a strength about her. If you were nervous, Mother always had the right words to calm you. She was willing to take a stand on issues. A number of years ago, a local clergyman suggested providing sanctuary to Central American refugees, and

Mother was ready to do it even though it might result in her going to jail. She was a feminist who believed strongly in women's equality and rights, and she imparted that belief to her daughters.

Mother was vibrant and active. She took us hiking. She loved crafts; she knit us afghans and sweaters, made lace, did needlepoint, and took classes on tai chi, automotive repair, furniture caning, even golf (at least until she became pregnant with her first child). With my father, she attended Elderhostel classes in Hungary, Massachusetts, and Pennsylvania.

She loved the arts. From when I was about 6 years old, every year we went to see a Gilbert & Sullivan operetta. She took me to see my first Shakespeare play. We went on trips to museums and historic homes. And Mother and Dad were always going to the movies.

Most of all, Mother was fun to be with. Because Mother was a teacher, she always had the summer off. Every summer, we would read a book together. My love for Sherlock Holmes comes from the summer we read *The Hound of the Baskervilles*. Each week, we would go to the Palace Theater for the Disney double feature, we would try new restaurants, and jump barefoot in the puddles after a summer shower. My favorite part of the summer was sitting with my parents in the backyard, looking up at the trees, watching the squirrels, listening to the birds, and Mother trying to whistle like a cardinal.

Mother loved her children and grandchildren. She always encouraged us and was interested in what we were doing. She taught us to climb the apple tree in our front yard. She kept her children's diplomas on the wall of the den. She read all of her son's papers that appeared in psychology journals and was probably the only one in the family (other than her son) who understood them. She was a regular correspondent and while at camp or in college, we would frequently receive her typewritten letters telling us of her activities, including a forsythia clipping from the shrub next to the house or containing one of our favorite recipes. As adults, on our birthdays, our parents would telephone us and sing "Happy Birthday." I loved sitting with Mother in the kitchen as she prepared dinner talking about everything and anything, telling me about her day at work, the book she was reading, and the family stories.

"Mother loved her children and grandchildren ... Family was central to my mother's life"

Family was central to my mother's life. She grew up not only with her parents and brother, but also with a large extended family of grandparents, aunts, uncles, and cousins. She never hesitated to help a relative and remained close to them throughout their lives.

My parents were married in 1951. I never heard them argue. I often heard them laugh. They took care of each other and loved each other. And for the last several years, as my mother succumbed to Lewy body disease, my father took care of my mother. Even as the disease took its toll, you could still see the love that existed between them.

The memories of my mother's joy in life and her love for us will always be with us. We were each so fortunate to have known this wonderful woman and have her in our lives for so long. She was one of the best people whom I will ever know. On behalf of my family, thank you for coming today and celebrating with us our mother's life.