

“Cast Me Not Off in the Time of Old Age”

Nell Folkman

When they can't run their lives any more, they get angry. People think they're just being difficult, but it's because they've lost their identity; they've been *someone* all their lives, and now they're nobody.

Growing old in the last part of the twentieth century is unlike anything that has gone before. The population of older people in the United States has increased dramatically, rising from 18 million in 1965 to more than 29 million in 1987 (U.S. Bureau of the Census 1988, 15). By the year 2020, those over sixty-five will comprise 20 percent of the population (Holden 1987, 272). Those over eighty make up the fastest growing group, and the number of 100-year-olds will triple by the turn of the century (Maxwell 1987, 710).

Although the Church does not keep comparable statistics, we might expect, due to the higher-than-average birthrate for LDS families, that the percentage of aged in the Church (in the United States) would be less than for the country as a whole, even though Mormon health practices tend to increase longevity. Census data for Utah seems to support this; 8.2 percent of Utah's population is over sixty-five compared to 12 percent for the United States (U.S. Bureau of the Census 1988, 15, 73).

For the first time in history, we have two groups of old people. The “young-old” are in their sixties and seventies, healthy, vigorous, financially secure, integrated into the lives of their families and communities, politically active, and, in the Church, going on missions. The “old-old” are those in need of special care.

In spite of all the talk of parents being abandoned to nursing homes, family care for the old-old is still the rule for LDS families as well as most other Americans. Almost all of this care is given by wives, daughters, and daughters-in-law. Because they live longer, many women will also care for ailing spouses.

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Nearly 80 percent of primary caregivers are women (Hagestad 1986, 151; Garland, King, and Weiner 1987, 60). Work excuses sons from giving care; women must formulate work schedules around care of elderly parents. When sons do help, they usually take on only such traditionally acceptable responsibilities as making home repairs or managing finances (Wood 1987, 30).

Caring for the elderly today is different than it was in earlier periods because, for the first time, young-old women are caring for old-old parents. A study by the National Center for Health Services Research showed that the average age of caregivers was fifty-seven with one-third of them over sixty-five (Wood 1987, 29). Women who have looked forward to the time of life when it would be "their turn" and children's needs would no longer be their first priority now find that they must again put others' needs before their own.

Taking in aged parents, or extending care to them in their own homes, always dramatically increases the work load for sometimes already overburdened women. It is especially difficult for the growing number of single women who must work outside the home to support themselves and their children. Even in traditional families many women find it necessary to work to meet family expenses. The high cost of missionary service and college for large families forces many LDS mothers back into the workplace as their children become older. Increased illness among young-old women can often be traced to stress created when the care of older parents is added to an already full life (Hagestad 1986, 149).

While this "graying of America" has become a matter of great concern for the medical and mental health professions and the government, the Church seems to have taken little official notice. In 1983 Paul H. Dunn spoke in general conference about "those who have been privileged [to have had the] experience of having aging parents and grandparents with them" and "the countless ways the elderly bless our lives" — the only talk I can recall in recent years about the elderly.

As the voice of the Church, the *Ensign* contains a multitude of articles suggesting ways to deal with many of life's problems: how to teach our children, reach a straying family member, improve sagging marital relations, and even keep ourselves financially solvent. Except for occasional touching stories about the blessings of caring for aging parents, however, the old have been largely ignored. True, the June 1987 issue has several articles about older people going on missions and working in genealogical libraries, name extraction programs, and temples. It also contains a thoughtful, helpful personal essay on coping with a husband who has Alzheimer's disease (Walters 1987, 62).

Many of us have wonderful memories of the grandparents who lived with us when we were children or, as adults, have experienced the joy of serving our aged parents. But these memories should not blind us to the difficulties that may arise.

A Relief Society presidency in which I served became aware that many sisters in our ward were struggling with the care of their elderly parents. In an attempt to address these needs, we replaced our outlined fifth Sunday Relief Society lesson with one on aging. During this class time, many sisters shared

the frustration and real hardship they were facing trying to give their parents the kind of care they felt they deserved.

Problems seemed to center around two areas: the overwhelming demands placed on women, and decisions about how and where care was to be given. The stories that follow were shared in this Relief Society meeting or in subsequent interviews with Relief Society members in several wards. One sister has permitted me to include excerpts from a journal she kept while caring for her mother. I hope that sharing these stories will increase our dialogue and understanding of the problems as well as the joys of caring for our parents.

In the past, people who reached old age could count on several children living nearby to care for them and could stay in their own homes surrounded by their family and lifelong friends. Now families are often scattered, and other arrangements must be made.

My mother was only sixty-two and I had been married little more than three years when I had to face the kind of problems that arise when parents need help and there are no children living close by. My husband had just finished graduate school, and we were getting established in a new job and new home. We had one child and were expecting our second. Even though we had been to visit my parents five months earlier, I felt a strong prompting to return. With my husband's blessing, I took our small daughter and made the trip from Arkansas to southern Utah where they lived.

Mother's health had always been fragile, but as the burdens of caring for small children eased, her weak heart had actually become stronger, and the shadow of death which had lurked just around the corner during our childhood began to fade. Therefore, when I arrived at her home that January, I was not prepared for the extent to which her health had deteriorated. She was never one to stay in bed. Even after a heart attack she'd be up in a day or two managing the family's activities. Now it was obvious that she would have to remain in bed permanently. With her damaged heart nearly worn out, her body was swollen with edema, and other vital functions were failing as well.

As the eldest daughter, I had always taken over when mother was ill. When I left home to attend the University of Utah, I still returned back as often as I could. During these visits I spent most of my time doing the things Mother wanted done that my father didn't see the importance of doing. Now, I stepped easily back into my familiar role. I felt a special joy and closeness to Mother as I took care of her medical and personal needs, bathed her, brushed and fixed her hair, and made sure her bed was neat and comfortable and the house the way she liked it. Yet, as my two-weeks' visit stretched longer and longer, I felt inexplicably close to tears, resentful, and almost angry. I longed for my husband. Our daughter needed her father. He needed us both. He had urged me to stay as long as I felt it was necessary. But what if that turned out to be months or even a year?

It would have been less painful to split myself in two than to choose. Where did I belong? "Honor thy father and thy mother," the scriptures say, and "Cast me not off in the time of old age; forsake me not when my strength faileth" (Psalms 71:9). And yet, I recalled just as clearly Genesis 2:24:

“Therefore shall [a woman] leave [her] father and mother, and shall cleave unto [her husband].”

My feelings could not be entirely attributed to the separation from my husband. When some visiting neighbors asked Dad what plans he’d made to take care of Mother when I returned home, he answered, “I’ve always expected Nell to stay and do it.” But he hadn’t asked me. My help was just *expected*. Nobody had asked me what I wanted to do; I had not even asked myself. I was just an obedient child again, not an adult used to being consulted with and making my own decisions.

Conflicting needs, feelings of resentment and guilt, and the physical strain of caring for Mother, even with my father’s help, took their toll. I began having problems with my pregnancy. I consulted Mother’s doctor, who told me she might live six months or longer. He recommended a practical nurse for Mother so that I could go home. “It will be easier for her to get used to a stranger caring for her now while she’s still in control of her faculties than later on,” he advised.

When I discussed it with my husband, he said, “I miss you as much as you miss me, but you’re there and see how things are. You’ll know how to make the right decision.” As I continued to search for answers within myself and to pray, I began to understand and accept my own feelings. Only then could I talk to my mother about how I felt. She shared with me the feelings of resentment she’d had when her widowed mother insisted she leave a teaching job she loved and come back home to live. She understood why I needed to go back to my own home.

When I told Dad I’d decided to leave, he responded with bewilderment and incredulity. “I’d always counted on you being here when your mother needed you,” he lamented. Even though I felt my decision was right and knew that Mother understood, I still felt enormous guilt. Visitors made me feel worse when they wondered, “How could you do this to your own mother?” But with a little more time to think about it, Dad realized that it would be best for me not to stay, and my pregnancy became a convenient scapegoat to deflect some of the continuing criticism from others.

We interviewed several practical nurses in spite of Dad’s insistence that he could surely care for Mother himself. Over the years he’d always done a lot to help, but I didn’t see how he’d be able to cope with the intimate personal care she needed day after day. Finally, we hired a nurse for a few hours each day. At last I felt comfortable with my decision to leave, and my prayers confirmed my feelings. My parents understood, and I had come to understand myself.

Mother died the morning I was scheduled to leave. I was not surprised. A patriarchal blessing, given to her by her father when she was very young, promised her that she would “live as long as she so desired.” She often spoke of it. I am convinced that her faith alone had kept her alive to raise four children and bury two others. Now life was no longer worth the effort. It was time for her to enjoy a sweet reunion with her parents and her two children who had died so young.

If we live close enough to parents to help them as they get older, they may be able to stay in their own homes much longer than would otherwise be pos-

sible. This was the case of Leona, a single mother who still had two children at home when her parents began to need help. Although she worked full-time, she assumed responsibility for their care, driving fifteen miles from her home to theirs several times a week to help with housework, laundry, and shopping. Her sisters lived too far away to help regularly, and her brother, who lived nearby, did not see their care as his responsibility.

Caring for her parents took most of her after-work time, especially after her mother became ill. She says, "I was always spending too much time with my folks and didn't have time for my kids. Dad couldn't do things the way Mother wanted. It was easier for me to do it than see how bad Dad felt when she scolded him. She scolded me too, but it didn't bother me as much."

As her parents' need for help increased, she was forced to change from a full-time to a part-time job. She never had quite enough money to make ends meet although her father helped her financially from time to time with such big items as taxes or car repair.

When her travel time mushroomed because of added traffic congestion, Leona simply didn't have time for everything. With the help of her brother and sisters, she convinced her parents to move closer to her. This was easier on Leona, but her parents never adjusted to their new home. Her mother had an especially difficult time. "Her family had been her life, and when they were gone, her home and her set way of doing things became her security. It provided the only continuity in the events of her life. She was too set in her ways to accept changes."

Her parents' needs continued to increase until Leona was needed almost full-time. She quit her job when her father decided to pay her for her help. "I needed a job, and they needed a helper. I was fortunate my dad could afford to pay me. Many parents couldn't. But the pay was never enough. I couldn't say to my dad 'I need more — this just doesn't make it.' He would never understand because it was more money than he'd ever spent when he had children."

Leona's help enabled her parents to remain in their own home for several years, but after surgery her mother had to be moved to a skilled nursing facility. Leona hated the indignities her mother endured and wished she could take her mother home again. "The worst part of a nursing home is they don't have time or patience to consider the individual. They have their routine that *must* be followed regardless of how the person feels about anything. One day, when my father and I went to visit Mother, we had a hard time finding her in the day room. They had her hair pulled back tight with a bun on top of her head and had literally slopped makeup on her — totally unlike anything she was used to. There she sat with a cup of coffee in front of her, completely disoriented and not knowing what to do. No wonder we didn't recognize her; she didn't recognize herself.

"After Mother died, Dad lived only fifteen months. He did pretty well living alone at first. I continued to help him every morning and, in the evening, I'd go back and fix dinner. Sometimes I'd stay and eat with him. He needed that, but I still had a son at home. I didn't spend enough time with him.

There's a kid who could have gone wrong! He was left alone too much. I'll have undying gratitude that he didn't. And he knows it!"

Leona was fortunate to be able to get a home health aide to relieve her part of the time when her father began to need care around the clock. Even so, he fell several times, and Leona and the aide were unable to lift him. Leona called her brother from work several times to help them. A move to a nursing home became inevitable.

The change was extremely hard on him. He didn't like all those strangers touching him and calling him by his first name, and he was often angry and belligerent with the nursing home staff. Leona gives us insight into what it can be like for an elderly person under these circumstances.

"What they didn't understand was that this man had always been given titles of respect: President, Mister, or at least Brother. No one other than his wife and family ever called him anything else. This perceived familiarity was more than he could tolerate.

"My dad was a man who was admired and looked up to. He'd passed the California Bar before he even went to law school. He'd been a stake president and a counselor before that. He was a counselor in the mission presidency. He'd had people come to him for advice and counsel all his adult life, and suddenly he couldn't even make a decision about what shirt to put on or what he'd like for dinner. It was not only the absence of status that made life unbearable for him, but also his total dependence on someone else. He was angry, not only because he'd lost some of his capability, but also because he really didn't know what he wanted. Mother would always know what he wanted and take care of it. Others couldn't do that. He just couldn't adjust to her not being there to do that for him."

Leona, now nearly sixty, does not regret the sacrifice she made for her parents. She works in two low-paying, part-time jobs and gets a little money from some family property. She has no retirement or health insurance and has not been able to accumulate savings. In fact, she's still trying to pay off the debt she accumulated over the years just providing necessities for her children.

"Dad just didn't pay me enough, and I didn't really expect him to. But it was hard." She feels her brothers and sisters had little understanding of how close to the edge, financially, she lived for so many years.

We might expect that large, close families in the Church would make it easier for Church members than for the general population to share the workload and financial burdens of caring for failing parents. However, when I asked Leona why nearly the whole burden of her parents' care fell on her, she answered, "My brothers and sisters did what they could. But even when we were little and my dad would say, 'Now your mom needs help,' I was always the one who'd do it. My sisters just weren't inclined that way." My observations lead me to believe that this unconscious choosing of one family member to be the "helping one" is rather common.

When they can no longer manage in their own homes, moving aged parents into an adult child's home can often be a rewarding solution for everyone. However, this is not always the case. Some aging parents find little to stimulate

and interest them in the homes of their children. One such ninety-year-old father, whose daughter wanted him to escape the cold Utah winter by coming to her comfortable California home, put it this way: "They think they're doing me a favor, but I hate it. They're gone in the morning as soon as I get up. Everyone is busy with work or school or church; I hardly have a chance to see them. I can't drive here like I do at home. I feel trapped. I'm not coming back again!"

Sometimes what starts as a rewarding experience can become a real nightmare. Martha's mother, Elsie, had lived in a retirement center since moving from New York to California to be nearer her daughter. Having her mother close by, with their nearly daily visits, was a great joy for Martha. They enjoyed each other's company and the chance to be close again after many years' separation.

In time, however, Elsie began to deteriorate both physically and mentally. When she fell, panicked, and couldn't find the emergency button, Martha decided to move her mother in with her and her husband.

It was easy at first. Martha wrote in her journal, "Home health aides come three times a week to watch mother so I can continue my job [teaching special students part-time]. I hope I don't have to give that up. Tom and I can get out to a concert or see friends once in a while."

Within a few months, however, Elsie's physical and mental condition had further deteriorated. Martha lamented in her journal: "I feel like I'm trying to walk a tightrope. Mother often wants 110 percent of my time, energy, and attention. By the time I take care of her, spend a little time with my family, and meet other commitments, I have no time to renew myself. I pray so hard to make good decisions."

The doctor instructed Martha to keep her mother as mobile and independent as possible by using a wheelchair and helping her with physical therapy several times a week. Elsie fought this all the way, resisted the wheelchair, and would have nothing to do with the exercises. "It's my body and I'll do what I want with it," she snapped. "Leave me alone. You can't make me do it."

Constantly having to lift her mother into the wheelchair and onto the bedside commode strained Martha's back. "My back has been so bad I've had to go in for physical therapy too. I must try to remember to do my own exercises. When I find time, it's usually so late I scarcely have energy to wash my face and brush my teeth before falling asleep exhausted."

Elsie's bizarre behavior became increasingly difficult for Martha and Tom to deal with. "She demands to go to bed, then accuses me of locking her up. She thinks people are stealing her things. She accused Tom of trying to poison her. Mother never used profanity, now I'm ashamed to write down what she says. She curses me and says 'I have no children.' The next minute she wants to be hugged and kissed. I try to understand the brain damage that causes her to do these things, but it still hurts."

Home health aides quit almost as fast as they were hired, unable to cope with the abuse. Although her husband tried to help when he was there, Elsie

usually wouldn't let him. The burden fell more and more on Martha. Medication to reduce Elsie's paranoia had little effect.

Martha became chronically exhausted. "It was bad enough being up half a dozen times a night, but now nights have become a real nightmare. Mother screams, tears off the bedclothes, bangs the commode seat, demands to be fed, wants to get up in the wheelchair and then back into bed. I'm up four or five times every hour all night. I can't keep on much longer.

"Mom always begged me never to send her to a rest home, and I promised her I'd take care of her as long as I could, but I've reached a point where I'm afraid I'll be the one to break down and end up in the hospital. I've spent hours looking at nursing homes. Mostly I get, 'No room.' 'Long waiting lists.' They all seem like warehouses and the smells are terrible."

Desperate, Martha finally chose a nursing home that seemed to offer the best care, but no bed was immediately available. "It's been two months since I applied at the nursing home. I call the doctor and tell him I can't go on much longer. I tell him he's got to get her in."

Even so, Martha was filled with remorse when, a month later, a bed became available and Elsie was finally moved to the nursing home. Martha wrote, "What have I done putting my mother in this place? She deserves better than this. I stay with her most of the day, but she still begs to come home. I feel so guilty! I have reread my journal a dozen times to remind myself why she has to be there. But I still hate it!"

Elsie's physical condition continued to deteriorate, and Martha had to learn how to cope with the slow process of dying. "Now Mother's leg is full of gangrene. It's agony for her to have the dressings changed. The doctor says it should be amputated; in the next breath he says that no surgeon in his right mind would operate on someone so old and frail. Why does God let her go on like this? How much more must she take?"

Martha found some solace in the scriptures. Alma 38:5 was particularly helpful: "I would that ye should remember, that as much as ye shall put your trust in God even so much ye shall be delivered out of your trials, and your troubles, and your afflictions, and ye shall be lifted up at the last day."

"I try to put my trust in God and ask him to sustain me. But I still ask, 'Why does Mother have to suffer so much?' I pray constantly that she will be relieved of her tribulations soon."

When the doctors decided they had no choice but to operate, Martha gave her consent. "I have prayed to know that this is the right decision and feel impressed that we should go ahead." After surgery, Martha sat by her mother's bed day after day. "She's not really conscious, but it seems to comfort her if I sit and hold her hand. She talks about going on a long trip. 'Do we have all the baggage? Why can't I leave now?' I tell her, 'I've taken care of everything. It's all right for you to go now.' I think we're all ready for her to leave." Still, she lived nearly three weeks longer.

What can we learn from these stories? Leftover emotional baggage, which may surface during times of stress, must be dealt with before we can make realistic decisions regarding our parents' care. Sometimes we can do this by

ourselves; sometimes we need counseling to help with self-understanding. It helps to recognize that seeking counseling is not a sign of weakness or lack of faith. Martha learned from a community support group that sharing ideas and giving support to one another made coping easier.

Having support and counseling within an LDS framework is important for most Church members. However, Martha found that the counselor she saw several times from LDS Social Services seemed better trained to deal with marriage and family than with geriatric problems. Discouraged, she finally turned to a counselor outside the Church who specialized in geriatrics.

Caring for our parents does not mean that we physically have to do everything for them. Our own well-being and the welfare of our families must be considered along with the needs of our parents. When demands on time and energy for elderly parents' care become so great that family relationships break down, when our loved one's condition continues to worsen despite our best efforts and we no longer have any time or place for respite and renewal, we need to make other arrangements. As John Wood points out, you must have help "when there are no more happy times, loving and caring have given way to exhaustion and resentment, and you no longer feel good about yourself or take pride in what you're doing" (1987, 31).

As Martha discovered, keeping a journal can put things in perspective. Rereading her journal reminded her why her mother had to be in the nursing home.

If we care for the elderly in our homes, we should make it as easy on ourselves as possible. Some hospitals conduct workshops on aging and the area Agency on Aging has useful information and advice. A hospital bed, bedside commode, and wheelchair make home care easier. Geriatric medical consultation is a must, as is a continuation of some outside interest. Martha wrote, "My teaching job is the main thing that keeps me sane. As I concentrate on the needs of those children, I can forget for a short time the difficulties I have at home."

Men need to reassess their role in care giving and accept their share of the responsibility and work. On the other hand, women need to examine the way they may exclude men from this role. Leona's father was capable of doing many of the things she did for her mother, but because his help did not meet his wife's standards, it was rejected. In my case, I assumed that my father could not do bathing, toileting, and other personal care chores. Now I wonder what blessings I deprived him of by making this assumption.

Leona summed up what she learned this way: "You can't feel guilty. Just accept that you're doing the best you can. You've never been down the road before. You have to forgive yourself for what you don't know and can't do. You must pray a lot. One thing that was most important to me was to know that my Heavenly Father knew what I was doing and approved of it and that I had both the mental and physical strength to do it. Without that, I couldn't have made it."

Should there be an institutional role for the Church? In our community, other churches offer programs for the elderly: classes, exercise programs,

organized craft activities, telephone care networks, and special day care for Alzheimer's patients. Most of these programs are open to anyone. Some are free; some have a small fee.

While the Relief Society provides some activities for women, older women often don't relate well to the usual homemaking classes, and there are few things especially designed for them. There is almost nothing for men. For some older people, serving in the temple provides companionship and a feeling of worth and belonging. Still, many feel lonely and isolated and need more interaction with their peers.

Good home teachers and visiting teachers can offer real service. Leona asserted, "My father's home teacher was tremendous, and Mother's visiting teachers continued to call on him after Mother died. That meant a lot. People were kind to greet my father when he came to church with me; even the little boys would hurry to open the door for us. It would lift him for days."

She also wished there could be Church-sponsored nursing homes. "Nursing homes here don't understand the difference between LDS standards and the standards of others. My parents would have been happier 'with their own kind.' Maybe this is better in Utah. Here in California it's hard to find a nursing home with other LDS patients."

Even though we have a tremendous network of support among Church members, there are gaps through which people may fall, and often the support they receive isn't sustained. Undoubtedly, as the aged population in the Church increases, it will be a drain on the family, on the Church, and indeed, on the economics of everyone. We need to start now to think about how to meet the needs of these older members.

As part of our own personal preparedness program, parents and children need to discuss these future decisions with each other. Much of the guilt described by these sisters could have been reduced if decisions regarding parents' care had been made before the help became necessary and while parents were competent to make rational decisions. Older people need to let their children know where and how they want to be cared for, their feelings about life-prolonging mechanical devices, and the state of their financial affairs. Parents also need to understand their children's family and financial situations. Insurance to cover costs of long-term care should be considered. The way things stand now, a family must spend itself into poverty before government help is available.

When children promise, "I'll never put you in a nursing home" or parents extract such a promise from their children, it can only lead to more pain and guilt for caregivers. When my father's Alzheimer's disease necessitated twenty-four-hour care, my decision for nursing home placement was easier because he had, long before he became ill, let me know that his worst dread was not a nursing home, but becoming a burden to his family.

No one likes growing old, but unfortunately there is only one alternative, and most of us try to avoid it as long as possible. If we start making plans early, not only for how we will manage to care for our parents when they are old, but also how our children will care for us, we can increase the joys of

this service and lessen the pain and guilt many people experience as they make decisions regarding their parents' care.

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