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Keith Johnson

Concordia Seminary, St. Louis, ir_johnsonk@csl.edu

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THE SANDWICH GENERATION

Caring for Aging Parents

Keith L. Johnson

April 26, 1994

Concordia Seminary


Saint Louis, Missouri


Joseph Barbour
Advisor

April 19, 1994


Glenn Nielsen
Reader

April 19, 1994


Arthur Bacon
Director, Doctor of Ministry Program

20 September 1994

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Keith L. Johnson

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St. Louis, Missouri

Abstract:

The Sandwich Generation involves adult children, primarily women, responsible for the caring of aging parents. Adult children find themselves attempting to balance concern for their parents, their children, and their careers. With little or no understanding of elder care before it is thrust upon them, adult children need to learn about the physical, emotional and spiritual needs that accompany the aging process. This project revealed a wealth of information not readily recognized by caregivers. One way to provide this information is through a congregation sponsored workshop focusing on the above needs and on the needs of the caregivers.

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Major Applied Project

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INTRODUCTION

As a counselor of adult children, I have observed their struggles as they make difficult decisions with and for their aging parents. The emotions of adult children are torn between two important responsibilities, being "anchors" for their aging parents, while at the same time having concern or responsibility for their own children. I have witnessed the tension, guilt, concern, and frustration of these adult children as they desire to do the right thing for their aging parents. Many adult children feel they are in a generational sandwich. This situation for adult children is labeled "the sandwich generation." Many in this situation are women who are on the "daughter track," working, raising children, and helping aging parents.

There is little preparation or training for adult children that enables them to adjust to caring for aging parents. The problem of caring for aging parents comes at a time when adult children are helping their own youngsters gain independence, are brooding over an empty nest, and are struggling with menopause and other mid-life crises. As adult children they have gone through several relational cycles with their parents. After the honeymoon and the purchase of the first home, they entered a withdrawal stage. There was love for the parents, but they did not want the parents to interfere with their lives. When children arrived, the grandparents adored the grandchildren and offered to baby sit and help in other ways. They showed love and concern. Some-

times job advancements made it necessary to move great distances from their parents. Distance often complicated communication with parents. Suddenly, the adult children found themselves in a new cycle, one in which they were concerned about their parents' future and also the needs of their own family.

Pat Rushford describes the "generational sandwich" in this way:

One side of the bread is older, firm, but at times dry, brittle, and easily broken. Our parents who once saw to all our needs and took responsibility for us, now may have to look to us for help and support. We--the butter and meat--are sandwiched in the middle... you are the bologna--or the salami, or the liverwurst. More simply, we are the wage earners, the responsibility factor that holds the generational sandwich together.¹

I was a recent participant in a group of six professional workers in their fifty's who were dealing with the issues of aging and how it affected them.

These workers related their experiences of dealing with their aging parents.

This had the side effect of making them consider their own aging process. The following situations they described helped me to reflect on the timeliness of this project study.

Carl visited his parents in another state and noted the verbal abuse and critical comments by his retired father toward his mother. The brother who lived in the area chose chemical abuse rather than dealing with the problems of his aging parents. The father refused to become involved with volunteer service, even though this would have given him many resources to benefit others and

¹Patricia H. Rushford, The Help, Hope and Cope Book, (Old Tappan, NJ: Fleming H. Revell Company, 1985), 16.

occupy his time. The father harassed the mother rather than develop outside interests or a hobby.

George was frustrated with his father who exhibited depression over the death of his spouse. A stroke was surmised to affect his failing memory. The father spent money at the rate of about \$1000 per week on items which he could not remember ordering. The father leased a new car and drove more miles than the lease allowed. He proceeded to store that vehicle and lease a second new car to save mileage on the previous vehicle. The father gave several hundred dollars to neighbors who asked for assistance because of an emergency in their family. Closer evaluation resulted in expenditures totaling \$40,000 with only \$30,000 in assets. Fortunately, a psychologist reviewed the father's condition in a controlled setting. The diagnosis identified a chemical imbalance in the father's body which caused memory loss and the inability for rational thinking. George's brother lived with the father, but he did not assume responsibility for the aging father's deficiencies.

These two situations demonstrate the importance of adult children who need to be alert to the aging process in parents. There is no training period to learn to care for aging parents. Rather, adult children often become involved when emergencies arise with aging parents. Frequently, the adult children are not aware of the aging process. Adult children frequently approach their pastor in frustration over how they might care for their aging parents. The adult children have considered their parents to be anchors for their lives. When

situations arise which indicate that parents are unable to make decisions, care for their personal daily activities, or suffer from malnutrition, the adult children become aware of the aging process. Clergy can assist adult children with information on aging, be aware of community resources, and offer to lead support groups for adult children.

Goals of the Study

The purpose of this major project is to provide more effective pastoral care for the congregation. The goal is fourfold. The first goal is to assist adult children and clergy counseling with adult children to gain a deeper understanding of the needs of aging parents or relatives. A second goal is to assist adult children to understand the individual needs of aging parents and to uphold the family's integrity. A third goal is to assist adult children to develop a quality relationship and maintain open communication with their aging parents. The final goal is to develop guidelines for support groups for adult caregivers in which they will discuss concerns, vent frustrations, share feelings and exchange ideas for coping and dealing with aging parents.

Persons caught in the middle stage of life face many challenging dilemmas--mortgage payments, rebellious teenagers, and aging parents. Most middle-aged adults at some point must ask themselves the difficult question, "How can I enhance my parents' happiness and comfort while still encouraging

them to maintain their own individuality and integrity?"² While helping aging parents, adult children may often vacillate between a host of contradictory emotions, experiencing love with anger and respect with resentment.

Margaret Anderson describes the dilemma for adult children in the following way:

All things considered, however, you feel you are caught in a bind. Some of your children may still need financial assistance. You may be facing job complications. Your wife suffers from menopause difficulties. She may mourn an empty-nest. Suddenly you realize you aren't as young as you used to be. You contemplate retirement and your own mortality. Torn between your family's needs and those of your aging parents, you wonder how well you will handle this new filial role.³

Becoming caretakers for aging parents involves a new relationship. However, it is inaccurate to assume that this relationship involves a role reversal. The adult child can never exchange roles with the aging parent. Instead, one assumes a new child-parent interrelational role, identified as a "filial role." This role involves viewing parents with a different kind of understanding and love, perceiving them as individuals with their own rights, needs, limitations, skills and character traits.⁴

Becoming a caregiver for aging persons may involve the adult children, grandchildren, nieces, nephews, brothers, sisters, neighbors, and others. When

²Ibid., 11.

³Margaret J. Anderson, Your Aging Parents (St. Louis: Concordia Publishing House, 1979), 10.

⁴Ibid.

the aging person is not able to function with responsibility and alertness in his or her daily living activities, the caring person asks these questions: What am I going to do? Should I intervene? What are the alternatives? Where will the parent live? Will the parent be safe at home? How much care does the person need? Will it involve taking someone into my own home? Is nursing home care necessary?

It is not within the scope of this paper to consider all the alternatives for making arrangements for the aging parent. This paper will be limited to helping adult children understand the aging process, develop good relationships with their elderly parents, heal negative and hurtful feelings, and deal with some medical problems. Clergy can also be a resource to adult children by helping aged parents face life and death with hope and peace for eternal life through faith in Christ Jesus. And, through support groups, adult children will be encouraged to develop their abilities to cope with each other's burdens, pains, and pleasures.

CHAPTER 1

OLD HAS MANY FACES

Life expectancy has increased to the extent that it is not unusual that a sixty-nine-year-old daughter is caring for her ninety-five-year-old mother. I visited a ninety-one-year-old woman who lives alone in her apartment on the second floor and walks the stairs daily. There were five generations represented at one man's funeral. Besides the deceased, those present were his daughter from an earlier marriage who was born in 1891, a younger daughter born in 1912, this second woman's daughter born in 1944, and her daughter born in 1970. The morning news reports the "Walt Disney congratulations" to persons one hundred years of age and over. These are some situations demonstrating the aging of America.

In 1992, the Bureau of Census reported over thirty-one million people over sixty-five in America (12.5% of the population). The report also cited nearly forty-two million people over age sixty (16.7% of the population).⁵

"Old" is an individualized concept, which varies according to life-style and life experiences, as well as from the view of the beholder. Margaret Anderson suggests that older persons may be placed into five general classifications

⁵U.S. Bureau of Census, 1992, Statistical Abstract of U.S., 112th ed., Washington, D.C. Table 12, 14.

according to their individual character traits:

- 1) the mature--well-integrated persons who enjoy whatever they are doing at the moment;
- 2) the rocking-chair type--passive, dependent men and women who are glad to take it easy;
- 3) the self-protective--their motto:"I have to keep active or I will die";
- 4) the bitter--they adjust poorly to aging--blame others for their disappointments and lack of success;
- 5) the self-derogatory--depressed and gloomy, they adjust poorly, blame themselves for frustrations and failures. Each acts according to his own personality, no one else's.⁶

Not everyone ages at the same rate or in the same way, no matter what his or her chronological age. People vary according to the period of history in which they lived. People may vary according to their occupation, such as outdoor activity, operation of heavy equipment, pressure of office work, and meeting sales deadlines. Various illnesses, surgeries, chemical abuse and loss of limbs may affect their life expectancy. Their temperaments may also affect their approach to and view of life. Some persons appear to be "old" at age thirty and continue to age.

Despite the variation in the aging process, most older persons are resilient and self-reliant. Thus they have a distinct advantage for possessing wisdom, enjoying triumphs and coping with defeats. These life experiences qualify them to advise, instruct, encourage and console others.

Whatever the aging process has been, aging persons have the following five major desires: a) security--having enough funds to live a comfortable, independent life; b) association with other people--communication and a sense

⁶Ibid.

of belonging; c) respect for personal worth and recognition of their knowledge and skills; d) mental stimulation--providing them with new opportunities for learning; e) autonomy--the right to live alone and make their own decisions as long as they are able.⁷ Although not included in this list, another desire of many elderly Christians is the desire to retain and be supported by their religious values.

Younger persons can contribute to the fulfillment of some of these desires. I have discovered that younger children and adults have much in common, so much so that some child care centers are developing opportunities for the generations to mix. Here the young children can provide social contact, mental stimulation and respect for the knowledge and skills of the elderly. Feeling the need to respond, some elderly act as tutors in the school and serve as substitute grandparents. Others even go on to work in the church and community, participate in political procedures and engage in other volunteer activities.

The recognition of personal worth needs to be encouraged beyond the child care centers and the classroom. The elderly feel honored to share their life story with younger persons. Margaret Mead frequently asked her students to interview older people. One eighty-four-year old woman from my parish, encouraged by a niece to relate her life experiences, was honored to share her

⁷Ibid., 13-14 citing Vern L. Bengtson, The Social Psychology of Aging (Indianapolis, Indiana: Bobbs Merrill Co., 1973), 34.

life story in a printed book.⁸ Life stories are important because they establish continuity with the past that will enable generations to live more satisfactorily and fully in the future. Anderson suggests that this life history be designated as memoirs rather than biographies.⁹ Others have suggested that parents relate their stories by means of a cassette recorder. The tape might be edited later or placed in print by other members of the family.

Although adult children may not always be able to help aging parents achieve the five major desires, their first step toward understanding and helping them is to gain empathy for them. Old age is not shameful, nor is it a condition to be pitied. Yet in our youth-oriented society, growing old for many has become a nightmare. Rushford states: "In our culture, we value aged wine and antiques more than aging people."¹⁰

Johnson speaks of "ageism" as a very destructive prejudice that generates behavior that discriminates against older people simply because they are old. It comprises myths and stereotypes that are half-truths and unfounded assumptions.

We have this notion in our society which some sociologists have referred to as the YAVIS syndrome. The YAVIS syndrome states that all of us would rather deal with people who are young, attractive, verbal, intelligent, and successful. Anybody else somehow is not quite up to standard. Growing older certainly doesn't measure

⁸Anna Gresch Theurich Mueller, Just as I Am-The Story of My Life (Pickerel, Wisconsin: Chapmans' Impressions, December 1988).

⁹Anderson, Your Aging Parents (St. Louis: Concordia, 1979), 22.

¹⁰Rushford, The Help, Hope and Cope Book, 30.

up. To what degree is the YAVIS syndrome within us? We have to examine ourselves.¹¹

Some basic information about aging may affect contemporary attitudes about the aging process and provide assistance in caring for aging parents, thus counteracting some false myths and underscoring realities about aging. Rushford offers an "Aging Awareness Test" to alert younger persons in order to help their aging parents. Each statement is to be answered True or False. (See Appendix K for a copy of the test.)

Emotional Needs

Older persons have emotional needs which need to be considered by adult children. The emotional needs include psychological, social interaction, and spiritual needs. The older persons may have a renewed interest in a life review. However, this life review may result in a depression over how they valued life, the decisions made at various stages, and how they perceive their present status.

When emotional distress results from or is increased by a physical problem, understanding and treatment become more complex. I have been invited to assist a spouse and family make a decision for a sixty-eight-year-old wife and mother, whom I shall call Helen. Helen became depressed due to a chemical imbalance. She would drive a car to familiar places, such as a

¹¹Richard P. Johnson, Aging Parents - How to Understand and Help Them (Ligouri, MO: Ligouri Publications, 1987), 51.

shopping mall or a park, but pass by the homes of her married children. On one occasion, she purchased a revolver and drove to a park with the intention of taking her life. The spouse and family were able to rescue her prior to her completion of the act. The husband wanted to register Helen into a mental health center, but she needed to enter voluntarily. I was invited to assist the spouse to intervene and gain professional care for Helen. It took several months of treatment and support group activity before she could return home with her spouse and feel comfortable to welcome her children and grandchildren for a visit. This is but one example of how a life review resulted in an older person's being depressed over how she viewed her stage in life.

Johnson cites some of the frequently mentioned emotional needs of older persons so they can maintain healthy social interaction:

- *A sense of self-worth.* There is a sense that I am a human being and possess a dignity that deserves respect (a good self-image). An unhealthy view of life is exemplified by people who look at life and say: "My life has not been good . . . and it's MY fault." They have a lot of turned-in anger which may be the root cause of depression.
- *At least one close friend.* The healthiest older people have at least one close confidante.
- *To feel productive.* There is the internal feeling of being productive: "I have the capacity to do. I've done many worthwhile things in my life, overcome many difficulties. I can continue to do that now. I can keep going. I can run my own life." Or "If I can't run my life, I know where I can go realistically to get the help I need."
- *To feel useful.* There is the stimulus from outside affirmation: "There are other people out there who perceive me as a productive and useful member of society, and this perception is recognized and appreciated by me."

- *To be treated as a unique individual.* They dislike being lumped together with others in their age group.
- *To possess a meaningful sense of belonging.* They sense a feeling of belonging to a group, whether it is their immediate family or friends.
- *To overcome loneliness.* There is a need to interface with others to avoid loneliness or depression.¹²

Many older persons help to meet emotional needs by relying even more on their relationship with God. Additional time after following the routine of a busy work schedule permits an interest in reading devotional material. If they are not able to maintain active church attendance, the parish pastor or lay assistants can be called to make home visits. The pastor can provide the resources of large print devotional material, cassette tapes of worship services, and scheduled visits offering a devotion and holy communion. A caring pastor will discover these pastoral visits to be of mutual benefit to the older person and himself. Through such visits, older persons grow in their faith in Christ as Savior and prepare to meet Christ Jesus face-to-face.

Understanding the primary emotional needs of older persons can help family and friends form appropriate attitudes toward older persons. The pastor can assist families to be aware of community resources on aging, Senior Centers for social interaction, and local parish activities for the elderly.

¹²Richard P. Johnson, Aging Parents, 24-26.

Experiencing Loss

Losses are part of everyone's life, but to the elderly they may seem to occur more frequently. Several common losses experienced by older people are reported to have a devastating effect upon their life. The most difficult to endure is the death of a spouse or family member. I have personally ministered to families in which one spouse died and within four to six months the other partner also passed away. Within the past year I ministered to a husband who cared for his wife many years at his home. She passed away in August. The release from his caregiving role enabled him to return to church and feel free to enjoy shopping and recreation activities. One day in January he was going to the mailbox and died peacefully prior to entering his home. Although there may be no direct correlation, I suspect that he died of a broken heart.

The loss of physical mobility is another hardship experienced by older persons. They may not be able to walk to the corner store for their supplies, since they are exhausted from using a cane or walker. The loss of status in the community is related to their lack of physical mobility. Previous employment or community business enabled them to be affiliated with people in the community. The loss of physical strength and health hampers the amount of work they can complete in an hour or a day. Some days the older person can only care for physical needs.

Older persons may experience losing their self-determination and a feeling of losing control over their life. Frequently their decision-making ability

has been taken away by well-meaning caregivers. They may also lose their mental acuity rendering them incapable of making decisions for themselves. A diminished sense of self-determination causes them to express: "I'm no longer the master of my own life the way I used to be."¹³

The movement of children to various states causes the loss of family ties for the elderly person. The older person may experience the loss of financial resources to visit their children. The visits by children and grandchildren often are less frequent than desired by the elderly parent(s).

Adapting to the multiple losses of aging is an important developmental task facing older persons. Younger caregivers cannot prevent older adults from suffering these losses. The problems experienced by older persons are irrevocable. They cannot bring spouses back, restore mobility, or provide financial security. Concerned and loving caregivers can only deal with the reactions or the emotional responses that older persons give to these losses.

Defense Mechanisms

Older persons often use psychological devices, such as defense mechanisms, to adjust to losses that may leave them more vulnerable. Johnson states that a defense mechanism is an unconscious technique to prevent the ego's integrity from shattering under the pressure of intense, negative emotions. Johnson lists a number of common defense mechanisms used by older persons

¹³Ibid., 27-28.

some of which are the following:

1. *Denial*: "I'll act like this didn't happen." Sometimes older persons who lost their spouse still set the table for him or her, still keep the deceased spouse's clothes in the closet, or still keep the room as it was when the deceased spouse was alive.
2. *Total repression*: "It never did happen!" It's a kind of selective amnesia. The event is repressed so deeply into the subconscious that it simply doesn't exist anymore. An example would be a widow denying the fact of her husband's death by saying, "My husband is away on a business trip." Professional counseling is recommended for such a situation.
3. *Projection*: "Not me, but you." You are having trouble liking someone at a particular time, but you know you are expected to love that person (for example, your mother). To protect yourself, you project your ill feeling onto her and say, "I love this person, but that person doesn't love me!" Older persons frequently use projection to salve intensely negative feelings. An aging mother might be heard to say, "I don't know why my daughter doesn't care for me; what did I ever do to her?" There may be a hidden sense of jealousy because the mother envies her daughter's youth, vitality and productivity. There may be feelings of guilt because she wasn't the mother she wanted to be to her children.
4. *Fixation*: "I'm comfortably stuck." Some older persons refuse to act their age. They will dress as though they were fifteen years younger, modifying their appearance and their behavior to match the illusion. They are saying: "I don't want to get old and therefore I will refuse to act like I am old."
5. *Regression*: "It was better back then." Older persons using regression will try to live in the past, in the "good old days." Mentally and emotionally they are not living in the present. They find it easy to fantasize and focus on life as it was years ago.¹⁴

A working knowledge of these defense mechanisms can help a caregiver to understand the strange or confusing behavior, attitudes, or thinking which the aging parent may show from time to time. An appreciation for these defense mechanisms will also assist clergy or lay persons visiting older persons in the

¹⁴Ibid., 29-31.

parish. I remember visiting an older grandmother who wanted to change her will because one of the grand-daughters did not respond to the grandmother's desire to be taken to the hair-dresser. The next time I visited, the grandmother wanted to eliminate the other caregiving granddaughter because they had an argument.

Two "care principles" will prevent the adult child from falling into a trap of fostering an increasing dependence by the aging parent on the caregiver.

Johnson states: "The first care principle is to understand the real needs of your aging parent and to clearly separate these needs from all other desires or wants he or she may request Therefore boundaries must be established, limits must be set, a realistic accounting of the amount of care, time, money, etc., you can devote to your aging parent must be made."¹⁵ Johnson continues: "The second care principle is to build a quality rather than a quantity relationship with your aging parent You want a balanced, mature relationship with your aging parents."¹⁶

The adult caregiver (son/daughter or others) must determine how not to become involved in a continuous giving to the parent, which becomes increasingly destructive to his/her personal life and the lives of other members in the family. The "quantity relationship" would involve the adult children spending an enormous amount of time and energy "doing for" their aging parents. The

¹⁵Ibid., 31.

¹⁶Ibid., 32.

"quality relationship" involves the adult children in "being with" the parents and supporting them as they experience the effects of aging. A balanced, mature relationship will allow parents to tackle their own problems according to their ability, while at the same time supporting them as they respond to emergencies or reduced strength to handle the daily activities of living. Adult children may further attempt to develop a helping relationship. This helping does not mean imposing the will of the adult child upon the parent, but rather allowing him or her self-direction within his or her capabilities. An important goal for adult children dealing with aging parents is to love and honor them in action and words.

CHAPTER 2

HONOR YOUR FATHER AND MOTHER

The basic message coming to us as youngsters was to "honor your father and mother." This impression was instilled in us from the fourth commandment recorded in Exodus 20:12: "Honor your father and your mother, so that you may live long in the land the Lord your God is giving you." This commandment included a promise of longevity. To small children parents can be godlike. Our first love relationships, those with our parents, created in us an emotional center that in large measure determined the degree to which we would be open to others. We further placed our trust and faith in them, not only for our physical needs, but to care for our emotional selves.

Our parents, regardless of our age or their age, are still our parents. We are still their children. In practice, what are the implications of this for us as adults? Should we focus principally on 'obeying' the wishes of our parents? Johnson, utilizing the Interpreter's Bible, comments that the fourth commandment (Exodus 20:12) had the adult child in mind, noting how he or she would provide care for a parent feeling the ravages of time: "The commandment was principally a warning against the heathen practice of abandoning the aged when they could no longer support and care for themselves."¹⁷ In the Concordia

¹⁷Johnson, Aging Parents, 11.

Self-Study Commentary Walter Roehrs points out that "to honor father and mother" was a demand by God for His rulership to be recognized in those to whom He delegated His authority.¹⁸

Reverend George Rawlinson also explains that the honor children were to give parents came as a requirement from God.

They were to honour father and mother, not because father and mother said so, but because God said so. Plainly the honouring included both deep inward feeling and clear outward expression. The outward expression, important as it was, could only come from real and habitual feeling within. Outward expression by itself counted for nothing. Honouring with the lips while the heart was far removed from the parent would be reckoned a grievous sin against God. The child had to grow up esteeming and venerating the parental relation everywhere...¹⁹

Dr. Martin Luther's explanation to the Fourth Commandment in the Large Catechism states:

[God] "commands us not simply to love our parents but also to honor them. . . .Honor includes not only love but also reverence, humility, and modesty, directed (so to speak) toward a majesty hidden within them. It requires us not only to address them affectionately and reverently, but above all to show by our actions, both of heart and of body, that we respect them very highly and that next to God we give them the very highest place. . . ."20

Luther further comments concerning honor to parents: "You are also to

¹⁸Walter R. Roehrs and Martin H. Franzmann, Concordia Self-Study Commentary (St. Louis: Concordia Publishing House, 1979), 76.

¹⁹H.D.M. Spence and Joseph S. Exell, eds. The Pulpit Commentary, vol. 2, Exodus (New York: Funk and Wagnalls Company, New edition, no year cited), 150.

²⁰Theodore G. Tappert, ed. The Book of Concord (Philadelphia: Muhlenberg Press, 1959), Large Catechism, 379, 106.

honor them by your actions, serving them, helping them, and caring for them when they are old, sick, feeble, or poor; all this you should do not only cheerfully, but with humility and reverence, as in God's sight."²¹

But how do we show honor in a way that does not connote a blind obedience to their every whim? Two examples shared by Johnson may offer some insight.

Sue is a fifty-two-year-old mother of three girls, two of whom are now out of the home. She works full time and is a loving spouse to her husband, Harry. Her mother, Helen, now eighty years old, has lived alone in a housing unit since her husband (Sue's father) died ten years ago. Helen rarely goes outside except to go to the corner grocery store, a short distance she is quite capable of walking. Recently, however, Helen began to ask her daughter to do her grocery shopping for her. At first her request was for a few small items to "carry her over." Now she is asking Sue to do all her marketing for her. What should Sue do? Would it be more honorable to grant her mother's request, to refuse, or to take some middle ground between these two? How would Sue best honor her mother here?

Norman's eighty-five-year-old mother now lives with him after she fell and broke her hip three years ago. She had been quite helpful to Norman, himself a widower with grown children. She did the majority of the cooking and light housekeeping . . . at least until three months ago when she began to act strangely. Norman has found the gas range left on several times; her checkbook, which she formerly kept meticulously, is now in shambles; her personal hygiene has deteriorated, as has her attention to just about any detail. Norman wants his mother to see a doctor about these changes; she adamantly refuses. How is Norman to honor his mother in such a case?²²

If Sue or Norman were to give in to the unhealthy wishes of her or his

²¹Ibid., 380, 111.

²²Johnson, Aging Parents, 12.

parent, each would be exercising counterfeit honor. Johnson concludes that Sue and Norman would not be responding to the inevitable losses associated with aging. Yet if Sue and Norman do what is right for their parent, they will likely evoke some negative sentiments from their ailing parent.²³

Another reference to respect and responsibility for the elderly is recorded in Leviticus 19: "Rise in the presence of the aged, show respect for the elderly and revere your God. . . ." ²⁴ Showing respect to the elderly is acknowledged as a way to honor God. Proverbs 30 speaks of deserved punishment for those who mock and disobey their parents: "The eye that mocks a father, that scorns obedience to a mother, will be pecked out by the ravens of the valley, will be eaten by the vultures."²⁵ This passage indicates that severe punishment will be carried out to those who disobey their parents. In Genesis 47 Joseph displayed filial love in the care of his brothers and father: "So Joseph settled his father and his brothers in Egypt and gave them property in the best part of the land, the district of Rameses, as Pharaoh directed. Joseph also provided his father and his brothers and all his father's household with food, according to the number of their children."²⁶ Joseph's love and honor for his father enabled him to forgive his brothers so that a greater blessing and honor might be

²³Ibid.

²⁴Leviticus 19:32 NIV.

²⁵Proverbs 30:17 NIV.

²⁶Genesis 47:11-12 NIV.

offered to his father. Jesus gave the model for honor and respect for his mother, so that she might be cared for in her aging years. While on the cross, Jesus placed his mother in John's care: "When Jesus saw his mother there, and the disciple whom he loved standing nearby, he said to his mother, 'Dear woman, here is your son,' and to the disciple, 'Here is your mother.' From that time on, this disciple took her into his home."²⁷

Ecclesiastes 12 offers a clear picture of old age.²⁸ Psychologist G. Stanley Hall called this the most pessimistic description of old age ever written, even though it is realistic.²⁹ Days can be cloudy, strength fails, there is nothing to do, sight and hearing decline, fears increase, and there is a new realization of the nearness of death. In Titus we are told how "the elderly are to be

²⁷John 19:26-27 NIV.

²⁸Ecclesiastes 12:1-8. Remember your Creator in the days of your youth, before the days of trouble come and the years approach when you will say, "I find no pleasure in them" - before the sun and the light and the moon and the stars grow dark, and the clouds return after the rain; when the keepers of the house tremble, and the strong men stoop, when the grinders cease because they are few, and those looking through the windows grow dim; when the doors to the street are closed and the sounds of grinding fades; when men rise up at the sound of birds, but all their songs grow faint; when men are afraid of heights and of dangers in the streets; when the almond tree blossoms and the grasshopper drags himself along and desire no longer is stirred. Then man goes to his eternal home and mourners go about the streets. Remember him-before the silver cord is severed, or the golden bowl is broken; before the pitcher is shattered at the spring, or the wheel broken at the well, and the dust returns to the ground it came from, and the spirit returns to God who gave it. "Meaningless! Meaningless!" says the Teacher. "Everything is meaningless!" NIV.

²⁹Gary R. Collins, Christian Counseling (Waco, Texas: Word Publishing, 1988), 213, reported in C. Gilhuis, Conversations on Growing Older (Grand Rapids, Michigan: William B. Eerdmans, 1977), 19-21.

temperate, dignified, sensible, sound in faith, loving, and willing to persevere, teaching what is good, and not malicious gossips or excessive drinkers."³⁰

Gary Collins, a popular Christian counselor and a licensed psychologist, acknowledges that the Bible is realistic in its portrayal of old age, positive in its attitude toward the value of old age and specific on how to treat persons in old age. Older persons are to be respected, cared for, and loved as human beings.³¹ They have a positive contribution to make to the next generation with their wisdom and personal experiences.

The Bible affirms that aging is an inevitable, normal process--a part of God's plan for all of life. Birth and death are merely the two extremes of human existence, the bookends of life.³² The Bible relates stories about many aged persons who remained active into advanced years. Caleb at eighty-five years old asserted: "I am still as strong to this day as I was in the day that Moses sent me; my strength now is as my strength was then."³³ Moses at eighty, and Aaron at eighty-three, were called by Yahweh to convince the Pharaoh to release the Hebrew slaves. Moses and Aaron were requested to lead God's people toward the Promised Land. Simeon blessed the infant

³⁰Titus 2:2-3.

³¹Collins, Christian Counseling, 21.

³²Diana Hynson and Tammy Clark, eds. Honor Your Father and Mother (Nashville, TN: Graded Press, 1989), 6.

³³Joshua 14:11

Jesus, saying, "Lord, now lettest thou thy servant depart in peace."³⁴ Anna was an eighty-four year old widow whose faithfulness was marked by regularly worshiping in the temple.³⁵

The Bible is clear regarding the attitudes and relationships of younger people with older adults. Older persons are to be treated with honor and respect. "The command to honor father and mother must be understood holistically in the sense of taking care of, supporting, protecting, and respecting parents as long as they live."³⁶ Jesus admonished a rich young man to honor his parents.³⁷

The biblical story of Naomi and Ruth informs us that Ruth, the widow of Naomi's deceased son, was unwilling to see her mother-in-law, also widowed, return to her native home alone. Ruth was so concerned about Naomi's welfare and the sorrow she carried over from the deaths of her husband and two sons that she decided to go with Naomi rather than return to her own parents: "Entreat me not to leave you or to return from following you; for where you go I will go, and where you lodge I will lodge; your people shall be my people, and your God my God; where you die I will die, and there will I be

³⁴Luke 2:29.

³⁵Luke 2:36.

³⁶Hynson & Clark, Honor Your Father and Mother, 7.

³⁷Mark 10:19.

buried."³⁸ Ruth became a caregiver for Naomi by giving her respect and honor to the end of her days.

While concerned for the spiritual welfare of the elderly parent, the caregiver, who requires a large amount of love and patience, needs the support of his/her own personal relationship with God. God is the Creator who made each person a unique individual. God offered His Son as the sacrifice so that we might know life more abundantly. Knowing that every good and perfect gift comes from the Lord leads us to rejoice in the gifts of things and people. We therefore consider the elderly person a gift from God.

An important aspect of honor and respect for parents is awareness of their spiritual needs. Because the elderly experience many losses, they need the continued assurance of God's presence. The departing words of Jesus to his followers are a bold affirmation for people of all ages: "And surely I am with you always, to the very end of the age."³⁹ This assurance of God's presence in Christ is helpful for older adults as they review their spiritual journey which has taken them through wilderness, desert and storm. Sometimes they may have lost the sense of direction, taken a wrong turn, followed wrong advice, and found themselves where they did not intend to be. The nature of the pilgrimage may have involved uncharted paths and new horizons. The author of Hebrews reminds us that we should "run with perseverance the race that is set before

³⁸Ruth 1:16,17.

³⁹Matthew 28:20.

us, looking to Jesus the pioneer and perfecter of our faith."⁴⁰

Although all persons are involved in a threefold relationship - with others, self and God, for the faith-filled elderly this relationship, especially the relationship with God, is important. They view the meaning of love from the model of God's love for them in Christ Jesus. They know what it means to be merciful because they have received mercy. They know the meaning of forgiveness because they have been forgiven by God. Loving self and neighbor is the result of their relationship with God. Their sense of community with God informs, inspires and assists all other relationships. It is through the grace and forgiveness of God, often known through others, that they are made whole.

However, even the faith-filled elderly may experience a crisis of faith. The meaning of life may become a critical concern as they come to terms with both temporal and spiritual issues. Adult children need to be aware of resources that can help to meet the spiritual needs of those for whom they care.

A volunteer making a Meals-on-Wheels delivery said that one of the hardest things he had to do was to leave the food knowing that there was a hunger of the heart that went beyond meeting physical need. Feelings of not being needed, loneliness, isolation, and the desire to share love are prevalent among many older persons.⁴¹

Since the congregation offers a variety of spiritual resources to help older persons travel their spiritual journey, it may be the ideal place where caregivers

⁴⁰Hebrews 12:1-2.

⁴¹Hynson & Clark, Honor Your Father and Mother, 56.

and care-recipients can address these spiritual needs, the "hunger of the heart."

1. *The Bible.* The Bible offers a road map along the path and for the journey in this life unto eternal life.
2. *Other devotional literature.* Other devotional literature which is available in large print allows persons to identify with the spiritual struggles and victories of others and helps them to face life with renewed hope. The hymnal is another rich resource for devotional material. A book of prayers is a wonderful gift for an older parent or friend.
3. *Recognition of the elderly as "role models."* The exemplary lives of others serve as a model to chart the path of our pilgrimage. Many aging parents have become role models for their children, grandchildren, and friends. It is not unusual that adult sons and daughters mention a parent as the one person who has been most influential in their Christian life. Older adults are often recognized as mentors, counselors, and spiritual guides for their family and friends, and this recognition can significantly boost their morale.
4. *The Church.* The church with its ministry of Word and Sacrament, as well as the fellowship of Christian friends, is a strong influence in their spiritual formation and continued growth. When older persons are no longer able to attend the services of the church, then the church must go to them. Caring adult children should be alert to informing the pastor about the special needs of their adult parents. Many congregations make visits and make Holy Communion available to sick and shut-in persons. Tapes of the divine services could also be made available. Transportation to services might be provided for those who are unable to drive. Older members desire to feel they are still a vital part of the church.
5. *Life Review.* Life review is a way of affirming those things that have value in life. The sharing of memories enables older persons to assess the goals they pursued and perceive how God was involved in their personal history.
6. *Prayer.* Prayer is a key to loving God and to loving and serving others. God speaks through a person's mind, will, emotions and imagination. God speaks to us through our memory, enabling us to remember past grace and experiences. Prayer is not simply looking inward or talking to ourselves. Rather, it is presenting our lives and thoughts to a gracious God who responds to us in compassion and love. Prayer is a faithful communion with God who knows our minds and hearts with nothing

hidden.⁴²

Christian caregivers cannot think or act in love without applying I Corinthians 13: "Love is patient and kind" ⁴³ This Bible reference can arouse valid and real feelings of guilt by impatient children toward their parents. This response is so, because in our own strength we can never achieve this unconditional love described in I Corinthians 13. We nevertheless hold it up as a goal for our relationship with elderly parents because it underscores Christ's love for us.

The basic message of honoring parents should continue to affect the attitudes of adult children. Not only should honor and respect influence their attention to the physical and emotional needs of aging parents, but it should also make them aware of the need for spiritual support. Although the aging process may and often does involve physical and mental changes in parents, the adult children, motivated by love, should recognize all that their parents have sacrificed for them.

⁴²Hynson & Clark, Honor Your Father and Mother, 58.

⁴³I Corinthians 13:4-7.

CHAPTER 3

WHO HELPS THE ELDERLY?

Caregiving involves at least two-people, the person receiving assistance--the care-receiver--and the individual providing care--the caregiver. One study using the New York City Department for the Aging explained that the primary caregivers encompassed four types of informal supports: thirty-three percent were spouses, thirty-six percent children, nineteen percent other relatives, and twelve percent friends/neighbors.⁴⁴

If the family has both the capacity and the willingness to meet all the needs of the elderly person, then little would be needed in the way of formal services, except to encourage the family by providing back-up services. Elaine Brody, noted author on aged parents and aging children, states in many sources that the myth of isolation and abandonment by adult children cannot be substantiated. Families value the care for the elderly parent or relative as a way of showing honor and respect. Study after study emphasizes that "the family, not professional and the bureaucracy, is the main source of assistance to the disabled elderly; only a very small proportion of assistance is provided by

⁴⁴M. Cantor, "Strain Among Caregivers: A Study of Experience in the United States," The Gerontologist 23 (1983): 599.

the formal system."⁴⁵ The family provides eighty percent of the medically related services (such as bandage changing and injections) needed by older people living in the community.

Most of us know someone who is providing care at home for a loved one. That loved one may have been recently hospitalized and still needs some nursing care. He or she may be a disabled or frail person who has trouble dressing, bathing, or doing household chores. The loved one may be terminally ill, but has chosen to spend his or her last days at home. Many caregiving families are finding they need outside assistance to allow them some rest, and they contract with a homemaker or home-health-aide services on a part-time basis. The availability of such assistance often determines whether an individual can continue to live at home or must be placed in a nursing facility. Robert Maxwell favors a centralized source where one can determine the price and quality of home-care services: "Thousands of families across America could benefit if they knew how to find home-health-care and other in-home services, how to arrange for and pay for them, and how to evaluate the quality of service."⁴⁶ Home care can be a cost-effective alternative to institutionalization, as well as a help to older persons in maintaining their social ties and community involvement. Whether the caregiver is assisted by family members or an

⁴⁵Elaine M. Brody, Women in the Middle (New York: Springer Publishing Company, 1990), 32.

⁴⁶Robert B. Maxwell, "Now We Must Provide Quality Home-care," Modern Maturity, Feb-March 1991, 10-11.

outside service, the ultimate responsibility for caregiving usually belongs to one person.

Women in the Middle

A series of studies show that generally one person in the family is the main provider, an individual who is usually characterized as the principal or primary caregiver.⁴⁷ Elderly spouses are enormously loyal to one another. They provide the most comprehensive care, even when the other spouse is severely disabled. Despite the fact that spouses care for one another, in virtually every culture, the nurturing role belongs to women. Cohler and Grunnebaum point out that the sexes are socialized quite differently in early life.

Girls are encouraged to identify with and to be dependent on their mothers. As the ones who are taught to be the nurturers, nurses, homemakers, and "kinkeepers" in the family, they constantly receive signals that they should be like their mothers. Boys, on the other hand, are encouraged to be instrumental and active like their fathers; they learn early that work is their main role--to be the provider or "breadwinner."⁴⁸

The widespread, powerful social value that *families* are responsible for the care of the old really means that *daughters* are the ones held responsible.

Daughters provide more than three times as much help as sons to elderly caregivers with disabled spouses. The middle-generation women are the reliable "significant others" who shop, do household tasks, give personal

⁴⁷Brody, 80, citing B.J. Cohler and H.U. Grunnebaum from Mothers, Grandmothers, and Daughters: Personality and Childcare in Three-Generation Families (New York: John Wiley and Sons, Inc., 1981).

⁴⁸Ibid.

care, fill in when an arranged care program breaks down, and provide a home when necessary.

The process of educating women in the caregiving role begins when they are young.

I guess it falls on women because women have children. As an architect, I always considered myself a professional. Taking care of an old person was the furthest thing from my mind. But when you're growing up you see your mother doing stuff so you fall into that. Little boys learn from their dads. So that is how it happens.⁴⁹

The aging of America affects everyone, but no one feels it more than the person caring for an elderly parent. Research evidence indicates that more women are on the "Daughter Track" working, raising children and helping aging parents. Daughters are the largest group of such caregivers, sometimes described as women-in-the-middle.⁵⁰ The responsibility often falls to a woman who has finished raising her own family, claims Betty McCaulley, A University of Wisconsin Hospital and Clinic geriatric nurse practitioner.⁵¹ The "woman in the middle" is identified as being in her fifty's and deeply involved with her career. She has concern for her grown children, or is helping to raise grandchildren, and planning for retirement. She may also be involved with caring for one or both of her own or her husband's aging parents. Whether the care is

⁴⁹Ibid., 81.

⁵⁰Elaine M. Brody, Women in the Middle, 4, cites a study in the U.S. Department of Labor, 1986.

⁵¹"Caring for Aging Parents is Stressful." USA Today, May 1988, 11.

24-hour-custodial or a weekly visit, it can be stressful, even in the best of situations. McCaulley writes, "Everyone around the care-giver needs a part of her. The growing demand of the aging adult, accompanied by all the confusing feelings of sadness, frustration and helplessness, often result in what is known as 'care-giver stress.'"⁵²

The phrase "woman in the middle" is a metaphor that often involves all family members, including the adult children of the elderly, their sons and daughters, children-in-law, grandchildren, and, at times, even other relatives. The problems affecting one family member inevitably affect the others, and so the entire family is often caught in the middle.

Brody characterizes "women in the middle" in the following way:

- They are most often in their middle years, though they range in age from their twenties to their seventies.
- They are, in the main, a middle generation in three- or four-generation families.
- They are caught in the middle of the requirements of their various roles.
- Many are in the middle between conflicting values: the powerful, deeply rooted traditional value that care of older people in the family is 'their' responsibility, and the newer value that it is all right--even desirable--for women to work or to pursue other interests outside the home.
- Some are in the middle emotionally when the elderly people they are helping become rivals for their attention with their husbands and

⁵²Ibid.

children.⁵³

Women experience further pressure as they deal with the misconceptions of the modern family desiring to care for dependent older members. One misconception today is that adult children do not take care of their elderly parents the way they used to in the "good old days." Statistics do not support this evidence, even though the myth stubbornly refuses to be dismissed.

Cheryl Simon writes: "A recent congressional study reported that family caregivers provide between eighty and ninety percent of medically related care, personal care, household maintenance and assistance with transportation and shopping needed by older people."⁵⁴ The impact of demographic and socio-economic trends have converged to place parent-caring women in the middle. These trends have made "nowadays" very different from the so-called "good old days." The vast increase in the aging population and the falling birth rate have affected the number of women available for parent-caring. The large-scale entry of women into the work place has also affected the amount of time and energy available for parent care.

Although there is no question regarding the dominant role of women in parental care, the role of sons in the caregiving role cannot be overlooked. While sons do not feel comfortable with providing personal care, they are able

⁵³Brody, Women in the Middle, 3-4.

⁵⁴ Cheryl Simon. "The Myth of Abandonment." Psychology Today, April 1988: 47.

to provide emotional support, financial aid, visitation, and linkage services with the community. However, as men share more of the child-rearing duties, they will acquire more caregiving skills and be available to be a resource for an elderly parent.

Louis Fradkin, co-founder of the support group Children of Aging Parents (CAPS) states that "women feel they have to be superwomen and do it all themselves."⁵⁵ Many husbands are unable or unwilling to confront the emotional demands of elder care, even when the aged parents are their own. Horowitz concludes that "elderly parents who can depend only upon sons are, to a certain extent, at a disadvantage because they must do without the extra instrumental assistance that daughters provide."⁵⁶ Even grandchildren may be swept into the changing family dynamics. One mother, a divorced accounting supervisor, has cut down her work hours since her sixty-three year-old mother, an Alzheimer's victim, came to live with her. The daughter's thirteen-year-old daughter must be home by three-thirty each day to greet her grandmother who is coming home from an adult day-care center. This is one situation indicating how other family members can be drawn into caring for elderly relatives.

⁵⁵Melinda Beck and others. "Trading Places," Newsweek: 16 July 1990, 48.

⁵⁶A. Horowitz. "Sons and Daughters as Caregivers to Older Parents: Differences in Role Performance and Consequences." The Gerontologist 25 (1985): 616.

CHANGING RELATIONSHIP

Various psychological mechanisms encourage a lack of separateness between mother and daughter. The highly charged relationship that develops between a mother and daughter is characterized by the elderly mother's high expectations of her daughter. Cohler and Grunebaum, in writing about mother/daughter relationships, state that "the relationship between adult women and their own mothers is perhaps the most complex and emotionally charged of all the relationships within the family."⁵⁷

The "emotional charge" is intensified when the stage of life is reached when a mother is elderly and needs help from her daughter. At this time, it is the daughter rather than the mother who is the caregiver, and the two women have had no rehearsal for their performances in their changed roles. Some expect that "role reversal" will take place. Brody states that the phrase "role reversal" is a popular but incorrect psychodynamic cliché'.

As an explanation of the processes that occur when a parent becomes dependent on an adult child, it is a simplistic and superficial concept at best. Some elements of caring for another member of the family are similar no matter the relationship of caregiver to care-recipient--whether the dependent individual concerned be a child, a spouse, a parent, or a sibling. Certainly, some of the tasks the adult child may perform to help the parent are the same kinds of tasks that the parent had performed for the child when the latter was a baby--feeding, bathing, dressing, or changing the diaper, for example. But there the resemblance ends. Though the roles of both parent and adult child undergo *change*, such change cannot be equated with *reversal*.

⁵⁷Brody, Women in the Middle, 85.

A caregiver experiences very different inner meanings when her young child depends on her and when it is an elderly parent who is dependent. People caring for those who are at the opposite stages of life--that is, for a baby and for an old person--have very different reactions to things that are normal and will be dealt with in the normal course of development in the child, but are not normal in the elderly adult. A young mother's feelings about incontinence in her baby, for example, are not in any way similar to an adult child's feelings about incontinence in her elderly parent.⁵⁸

Some of the tasks the adult child may perform to help the parent are the same as caring for a child, spouse, or sibling, but the role of parent and adult child cannot be equated with *reversal*. However, the roles of both the parent and the adult child undergo a change in relationship.

Young parents bring a totally dependent being into the world; they expect the baby's need for total care. The future holds promise of a gradual reduction in the child's dependence. The goal is to help the child become more independent. There is a sharp contrast when an older person needs help. That situation is not expected or chosen by either the adult child or the elderly parent. Caring for the older person presumes increasing dependency, rather than increasing independence. Sadness rather than happiness accompanies each change when the trajectory of the parent's dependence is downward. Both the elderly parent and the adult child strive to avoid those changes. Daughter caregivers are aware of these differences:

I never think of it as a comparison of an older person becoming childish. It's not like having a child in the sense the older person is not getting more exciting or interesting and adventurous every-

⁵⁸Ibid.

day but going into the other direction. So it is a downer.

It burns me when anyone says this [caregiving to her elderly mother] is like raising a child. Children are malleable, curious, open to learning. They are selectively dependent, and it decreases. Old people do not become like children. Not in any positive ways. I watch my niece and nephew. They display all the positive things about children because they *are* children. Old people bring their own sadnesses with them.⁵⁹

Elderly parents realize they will not improve, nor can they regain their former agility. Yet they have wisdom and experience to share with children and grandchildren. Honor and respect for parents by children will allow them that privilege.

There can be no true role reversal due to the very nature of the parent/child relationship. No matter how much care an older person needs, he or she does not become, and cannot become, the child of the adult child and incorporate the feelings of either child or parent. Fifty years or more of a parent/child relationship cannot be dismissed. Although their roles are carried out differently in later life, parents cannot become children to their children and children cannot become parents to their parents. Love for a parent is a different love from the love one experiences for one's child.

Closely related to the concept of role reversal is the notion that the older person is in a "second childhood." Certainly there may be declining functional capacities and increasing dependency of disabled older persons, particularly those with Alzheimer's disease or related disorders. Brody states that the

⁵⁹Ibid., 86.

phrase "second childhood" does not take note of the very different physiological and psychological processes accounting for that behavior and functioning.

Reminiscence about early life experiences, failing memory, confusion, and disorientation do not mean that the old person has returned emotionally or psychologically to childhood. Eighty or more years of living cannot be erased. The fact that the individual may require services similar to those given to children (such as feeding, dressing, and other personal care) does not make that person a child physiologically.⁶⁰

Although there are an increasing number of options in caring for the elderly, the primary caregivers continues to be women. Often they struggle to balance the role of parent, significant person in the work place, and adult child whose relationship to aging parents is modified in the caregiving and care-receiving process. Because of this struggle, it becomes increasingly necessary for the caregivers to understand more about aging. This process involves not only the physical changes, but also the emotional changes resulting from the losses the elderly have experienced.

⁶⁰Ibid., 87.

CHAPTER 4

IMPACT OF ELDER CARE

Demographic Trends

The number of people sixty-five years of age and over has increased rapidly and steadily in proportion to the number who are under the age of sixty-five. Statistics indicate that by 1960 there were 16.6 million older people (9.2% of the population), but by 1985 there were 28.6 million. In 1987, there were more than 30 million older people (12.4% of the population).⁶¹

Another aspect of the demographic revolution affecting filial care is the result of hi-tech medicine and Medicare. The number of people seventy-five and over, particularly those eighty-five and over, has grown and will continue to grow rapidly. Men and women who reach the age of sixty-five can expect to live 14.6 and 18.6 more years, respectively.⁶² From the viewpoint of filial care, the very old are more likely to have adult children who also are old or are approaching old age.

Falling numbers in the birth rate have resulted in fewer adult children who can share the responsibilities of parent care. The pool of children on

⁶¹"Caring for Aging Parents is Stressful." USA Today, May 1988, 11.

⁶²Ibid., 7.

whom adult children can rely as co-caregivers is much smaller now. Fewer children means fewer daughters. Since many of these women are daughters-in-law as well as daughters, the chances of being called upon for parent or parent-in-law care, or both, increase greatly. Another dimension of this care is the growing proportion of births of women in their thirty's (U.S. Bureau of the Census, 1988). This fact means that more women in the future will be providing care while they still have young children at home.⁶³

In 1987, a national survey of caregivers was conducted for the American Association of Retired Persons (AARP) and the Travelers' Companies Foundation. A caregiver was defined in this research as someone who provides unpaid assistance to a second person, aged fifty or older, needing help with one activity of daily living, or two instrumental activities of daily living (IADL - grocery shopping, managing finances, housework, meal preparation, transportation, and administering medications). Using this definition, approximately 7.8 percent of all households contained a caregiver between December 1986 and December 1987. Almost seven million (6,979,000) United States households contained caregivers.⁶⁴

The survey by AARP identified the following characteristics of these caregivers:

⁶³U.S. Bureau of the Census, 1988.

⁶⁴American Association of Retired Persons, Health Advocacy Services, PF4855(1291).

- Seventy-five percent of caregivers are female.
- The average age is forty-six, with twenty-eight percent under thirty-five and fifteen percent over sixty-five.
- Sixty-six percent are married.
- Only thirty-seven percent share a household with the care recipient.

- Caregivers reported the additional responsibility of caring for children; thirty-one percent reported children in the household under twelve years of age and twenty-three percent reported living with children ages twelve through seventeen.
- Fifty-five percent of caregivers are employed; forty-two percent are employed full-time and thirteen percent are employed part-time.
- Thirty-three percent of full-time employees and thirty-seven percent of part-time workers have lost time from work due to caregiving responsibilities.
- Fifteen percent of those previously employed choose early retirement and twelve percent reported giving up work entirely while they were helping their older relative.

The survey also identified the following characteristics of care recipients:

- Care recipients are generally relatives of the caregiver (eighty-five percent), most likely a mother.
- Fifty percent live in their own home or apartment.
- Fifty-eight percent are housebound and twenty-eight percent of the housebound older persons are also bedridden, while twenty-four percent are wheelchair-bound.
- The average age is seventy-seven, with thirteen percent between fifty to sixty four years of age and twenty-four percent eighty-five years old and older.⁶⁵

⁶⁵Ibid.

Elder Care and the Workplace

More than fifty percent of the women who care for elderly relatives also work outside the home; nearly forty percent are still raising children of their own. While many women on the "Mommy Track" thought they could get back to their careers, some are finding themselves on an even longer "Daughter Track," with their parents, or their husband's parents growing frail. "The average American woman will spend seventeen years raising children and eighteen years helping aged parents, according to a 1988 U.S. House of Representatives report....because they delayed childbirth, more couples will find themselves 'sandwiched' between child care and elder care."⁶⁶

The aging of America is making "Elder Care" an important issue for employees and employers reports Sue Shellenbarger in the Wall Street Journal.⁶⁷ Sally Coberly, an aging specialist at the Washington Business Group on Health, states that "in the coming years, elder care will have a greater impact on the workplace than child care. . . .As the baby boom moves deeper into middle age, the need for elder-care services will explode."⁶⁸

A Boston consulting firm, Work/Family Directions Incorporated, expects about twenty-two percent of the work force will assume elder-care responsibility

⁶⁶Melinda Beck and others. "Trading Places," Newsweek: 16 July 1990, 48.

⁶⁷Sue Shellenbarger, "Geriatric Cases," The Wall Street Journal, 16 February 1994, A8.

⁶⁸Ibid.

over the next three to four years, compared to sixteen percent having the responsibility now. Andrew Scharlach, a University of California at Berkeley professor on aging, predicts that one in three employees will be providing elder care by 2020. Dr. Scharlach estimates productivity losses from elder care at \$2,500 per employed caregiver per year. Employees with elder-care tend to be "older, more experienced, more advanced in their careers and therefore more valuable to us," says Mr. McColl.⁶⁹ In spite of these assets, elder-care responsibilities may force an employee to give up work, pass over promotions, or be unavailable for transfers. Elder-care will continue to be an intense issue for employees and employers. Employees will be asking, "What can I reasonably ask my boss to do to help take some of the pressure off my double life as a worker and a caregiver?" Dr. Creedon, National Council on Aging Director of Corporate Programs, reports that employers will need to consider policies for varied family problems, including elder-care.⁷⁰

The Family and Medical Leave Act, effective August 5, 1993, provides for up to twelve weeks of unpaid, job-protected leave to eligible employees to "care for the employee's spouse, son or daughter, or parent, who has a serious health condition."⁷¹ Employees are eligible if they have worked for a covered

⁶⁹Ibid.

⁷⁰Michael A. Creedon, "Why are More and More Employers Taking Eldercare Needs to Heart?" in The Aging Workforce, National Council on Aging, ed. Marjorie Mezritz (Washington D.C.), 16.

⁷¹U.S. Department of Labor, Employment Standards Administration, June 1993.

employer for at least one year, and for 1,250 hours over the past twelve months, and if there are at least fifty employees within seventy-five miles. The employer must maintain the employee's health coverage under any group health plan, and restore the employee to the original or an equivalent position upon return with equivalent pay, benefits, and other employment terms.

Even with this limited and temporary advantage granted to some caregivers, the problems of caring for elderly parents will not diminish. Statistics indicate that many families contain at least two generations of older people, the old and the very old. "Of all people sixty-five or over, ten percent have at least one adult child who is also over the age of sixty-five. The U.S. Bureau of the Census, in making projections for the 21st century, points out that more people will find themselves caring for very old persons after they themselves have reached retirement age."⁷²

Brody describes the complexity of the situation: "Some parents in the parent-care years have both parents alive, and since many of those aging children are married, a roughly comparable proportion of their spouses would also have a surviving parent When there are two generations in the aging phase of life, adult grandchildren may find themselves helping both their parents and grandparents."⁷³

The effects of the aging of America are not limited to those sixty-five or

⁷²Ibid., 10.

⁷³Brody, Women in the Middle, 10.

older. Increasing numbers of dependent elderly and declining numbers of adult children to share the role of caregivers put a greater burden on fewer persons whose lives and careers may be affected by their new role. Younger married children may also have concern, not only for parents, but also grandparents and their own children. Additional tension for "the sandwich generation" will be evident because of the demographic mobility of family members scattered throughout the United States. The effects of elder care are long term and widespread.

CHAPTER 5

SCOPE OF PARENT CARE

Care for a parent may be interpreted as doing whatever is necessary to make the parent happy. Often the boundaries between expressive support and instrumental help are blurred in the perception of caregivers. Brody claims that these caregivers do not differentiate sharply between *caring about* and *caring for* the parent. "'Care,' is interpreted as doing whatever is necessary *for* the parent; if the caregiver does not do it all, she doesn't care enough *about* the parent."⁷⁴

The functional assistance provided by caregivers ranges from day-to-day care, to response and dependability in emergencies. This assistance may also be provided at times of temporary illness or special need, when convalescent or rehabilitative care is necessary. Horowitz conceptualizes family caregiving behavior as falling into four broad categories: ADL and IADL services, emotional support, mediation with formal organizations and providers (government and social and health agencies), and financial assistance.⁷⁵

An evaluation by social workers uses the labels ADL and IADL. ADL refers to "activities of daily living" (bathing, dressing, eating, toileting,

⁷⁴Brody, Women in the Middle, 83.

⁷⁵Ibid., 26.

transferring, and ambulatory). IADL identifies "instrumental activities of daily living" and refers to the ability to use a telephone, shopping, food preparation, housekeeping, laundry, transportation, medications, and the ability to handle finances.⁷⁶ The Statistical Handbook on Aging Americans in 1994 reports 27,538,000 persons sixty-five years of age and over needing some "assistance for daily living" (ADL). The following percentages share the reported needs of persons to remain in their homes: 1.1% need assistance with eating; 2.4 % for toileting; 4.4% with dressing; 6% help with bathing; 3.2% help with transferring (out of bed or into vehicles); 2.6% walking assistance; and 3.2% help for getting outside.⁷⁷ In addition, older people may require more technical health-related care such as bandage changing, injections, and tube-feeding.

Emotional support has been cited as the most universal form of family caregiving, the one most wanted by older people from their children, and the one the adult children themselves feel they can offer their disabled parent(s). Emotional support includes being the confidant, or the one with whom problems can be talked over, providing social contacts, such as phoning, visiting, or taking the elderly person out to family events, and assisting with decision making.⁷⁸ Providing emotional support may consume many hours a week and be stressful as well. Resolving interpersonal problems between parent and

⁷⁶Ibid., 24.

⁷⁷Statistical Handbook on Aging Americans (Phoenix, Arizona: Oryx Press, 1994), Frank L. Schick, ed. and compiled by Renee Schick, 114-115.

⁷⁸Brody, Women in the Middle, 27.

child may increase the amount of time spent with each other. Although most adult children want to visit and take the older person on outings, activities of this kind may be difficult to fit into an already busy schedule. The expectations of the older person and the caregiver may not coincide with the frequency of such contacts. This may place additional strain on the caregiver.

"Mediation with organizations" is a service that is now being called "service management" or "case management" when it is done by professionals. Frequently the real case managers are family members. Such mediation or management involves knowing what entitlements the older person has, for example, Social Security and Medicare benefits. It involves knowing what services are available in the community, such as homemaker, meals on wheels, and in-home nursing, to name just a few. It involves getting in touch with the particular organization, establishing eligibility, and following through to see that these services are actually received. The conditions and needs of older people and their families change over time. Services require rearrangement and access to new ones gained.⁷⁹

Financial assistance for day-to-day living expenses and paying the costs of medical care for those living at home have become less important issues today. Through Social Security (1935) and SSI (1974), it is generally accepted that securing an income floor for the elderly should be a government responsibility. Taking money from one's children is least wanted by the elderly. Their

⁷⁹Ibid., 28.

view is that they don't want to be a burden. Pensions, savings, and investments have helped give the elderly independence. Some adult children do help out with money management or by purchasing things needed by the parent. Brody cites recent census data that shows that approximately 900,000 older people received regular financial support from their adult children in 1985, with the average payment being approximately \$1,484 per year.⁸⁰

The scope of caregiving is wide ranging, so the caregiver must learn to be flexible enough to meet these often changing needs. These needs may include assistance for daily living activities, emotional support, emergency care, occasional financial assistance, and an awareness of community services.

⁸⁰Ibid., 29.

CHAPTER 6

UNDERSTANDING THE ROLE OF CAREGIVER

Families have reacted responsibly--even heroically--to the increased demand for parent and parent-in-law care. It is the women in the family--wives, daughters, and daughters-in-law--who provide the vast majority of services needed by dependent older people. The needs of disabled older people have exceeded the capacities of many caregiving women. In addition, societal values about women's roles have been changing so that the different values they hold may pull them in opposite directions.

The vast majority of women *want* to care for elderly parents and *do so willingly*. According to Brody, "they derive many positive benefits from parent care, such as satisfaction from fulfilling what they see as their responsibilities, adhering to religious and cultural values, expressing their feelings of affection, seeing to it that the parent is well cared for, reciprocating help the parent had given them in the past, and feeling that they are serving as a good model for their own children to follow."⁸¹

However, parent care often affects women's emotional well-being, physical health, life-style, and financial status. Brody and others report that emotional strains are by far the most pervasive and severe negative effects

⁸¹E. Brody, Women in the Middle, 41.

reported by caregivers. The litany of symptoms identified includes the following:

- Depression
- Anger
- Anxiety
- Frustration
- Guilt
- Sleeplessness
- Demoralization
- Feelings of helplessness
- Irritability
- Lowered morale
- Emotional exhaustion⁸²

Related to the effects mentioned above are restrictions on the caregiver's time and freedom, relationship problems, isolation from being confined to the home, conflict from the competing demands of various responsibilities, and difficulties in setting priorities. The scene is frequently complicated by constraints on life-style, such as interfering with social and recreational activities, disrupting the vocational life, and loss of privacy and space when the older person is introduced into the household.⁸³

The caregiver's immediate family is also affected by interference with their life-style, privacy, patterns of socializing with peers, vacation plans, and even future plans for retirement or moving away. The caregiver's time and energy may be diverted from family members to the older person. The older person's disabilities and decline are often a worry to those caring for him/her.

⁸²Ibid.

⁸³Ibid.

Discomfort, pain, and unhappiness are difficult to detect in the person for whom one cares. The thought may come to mind by the caregiver, "Will this happen to me?" Such a question is distressing when a parent suffers from Alzheimer's disease or a related disorder. Adult children have a double concern. Is the disease hereditary? How long will I be able to cope with the progressive stages of the disease?

It has been noted earlier that being a daughter rather than a son is associated with strain. Daughters who are the main caregivers frequently provide more help of the kind that requires hands-on care than do sons. Sons more likely than daughters involve their spouses, the daughters-in-law, in the caregiving situation and depend on them for help with parent care.

A study by Horowitz (1985b) comparing caregiving daughters and sons illuminates some of the differences between them that hold potential for daughters finding parent care more stressful. She confirmed the findings of others that the men tended to take on the role of main caregiver only in the absence of a female sibling and that daughters were more likely than sons to help with personal care, meal preparation, household chores, and transportation. The lesser commitment of the sons was also shown by the more limited time they devoted to parent care. Sons did talk with the parent regularly, however, and did not differ from daughters in the extent to which they helped to manage the older person's money provided actual financial help, assisted with dealing with bureaucratic organizations, and gave the parent emotional support.⁸⁴

Nearly every study of caregiving has found that the strains on the caregiver are much greater when the disabled older person lives in the caregiver's household. The vast majority of older people do not wish to live with their

⁸⁴Ibid., 46.

adult children and do so mainly because they become disabled and cannot live alone. Brody states that older people are approximately four times more likely to live with a daughter than with a son.⁸⁵

It should not be assumed that simply living under the same roof provides stress. Certainly, a shared household expands the arena for potential interpersonal conflicts when the enforced contact with various family members stands out in bold relief. Extra stress is noted when the older person is severely disabled and cannot manage independently. It may be the heavy care that produces strain, and problems may be aggravated if the home is small or ill-equipped for care, resulting in crowding or loss of privacy. Shared households clearly are more stressful if the household contains two or three generations.

When three different household configurations were compared to determine the differential strains on the caregivers, daughters whose elderly mothers lived in separate households . . . fared the best. Their elderly mothers were the most capable functionally and cognitively, and fewer of the daughters experienced caregiving strain, limitations on their privacy or life-style, or interference with time and relationships with their immediate families and friends."⁸⁶

When the "nests" of the caregivers and their husbands contained both their own children and the disabled elderly parent, the daughters reported significantly poorer mental health, more of the symptoms of depression, restlessness, feelings of isolation, and missing out on something. Such daughters

⁸⁵Ibid., 49.

⁸⁶Ibid., 49.

in three-generation households were more likely to view their mothers as critical of the sons-in-law and grandchildren, as well as more likely to complain. Multi-generational living can aggravate the role strain of the daughter or daughter-in-law in meeting the needs of husband, child(ren), and disabled parent, especially if the elderly parent complains and criticizes other family members.

Another factor causing a different kind of strain is living at a geographic distance from a disabled parent. No matter how concerned and responsible the child is, the day-to-day care cannot be provided when a parent is separated by a great distance. However, the strain of worry about the parent's decline is similar to that of the local children. The child at a distance may feel the need to make frequent trips to visit and display concern about not being close at hand for the parent.

The adult daughter who becomes the principal caregiver provides the bulk of help needed by the parent, with very little given by the other adult children or other family members. Assistance by other family members provides supplemental help, rather than reducing the helping activities of the caregiver. When the parent lives in the daughter's household, the shared services by other family members becomes even more unbalanced. Caregiving activities of siblings are important and may relieve the main caregiver's strains by helping her to feel that she has the emotional support of other family members. She knows she can depend on them at times of need.

Ideally, aging adults prefer to live independently as they grow older.

Adult children may have never considered having their parents or in-laws move in with them; however, health, financial, or other circumstances may change and they introduce the idea as a sensible choice. If the arrangement works out, it can provide balanced and sociable meals, companionship and security. On the other hand, one might find that constant tension and conflict create a very unpleasant situation for all concerned. The sale of property or the addition to the home to make room for aging parents may result in a greater burden than the adult child anticipated. Before having parents or in-laws move into the home, adult children might try this simple exercise. Each of the statements could be answered by a simple **yes** or **no** response.

1. Do you get along with your parents or in-laws?
2. Can you talk with your parents/in-laws about a variety of subjects without becoming upset or angry?
3. Does your spouse get along with your parents? OR Do you get along with your spouse's parents?
4. Could your parents/in-laws adjust to your way of life?
5. Would your parents/in-laws let you have some privacy and a life of your own? (Including will they be upset if you continue your present activities or leave for an evening, weekend or vacation?)
6. Could they and you maintain present friendship?
7. Will your parents/in-laws let you be "the boss" in your own home?
8. Will your parents/in-laws adapt to your new ways of cooking?
9. Will they try to lay a "guilt trip" on you if they feel they aren't getting enough attention? If so, do you think you can handle it?
10. If they are physically able, are you comfortable letting them do some

chores around the house?⁸⁷

The pastoral counselor working with adult children may assure them that there are no right or wrong answers to this exercise, but significant answers, positive or negative, may give an indication of a direction for them.

What Can A Caregiver Do Now?

1. Talk to the parents and spouse before a crisis occurs.
2. Gain knowledge about the aging process.
3. Clarify the relationship with parents now, as it exists, and compare it to what formerly existed in childhood.
4. Determine the availability of time and money.
5. Become familiar with community resources.
6. Learn how to ask for specific help. Instead of, "You don't help me enough," try "Will you take Father to the doctor at two o'clock on Tuesday?"
7. Become clear and direct in communication with parents.
8. Take a step back. The adult child cannot be the "happiness provider" for aging parents.⁸⁸

Making the Choice

The caregiving adult child must consider many factors, such as his or her

⁸⁷Seminar on "The Sandwich Generation" conducted by Lee A. Belmas, February 7,1993.

⁸⁸Ibid.

own spouse and children, a career that may be interrupted or forfeited for the caregiving responsibility, and a personal life that is separate from the personal life of the care recipient. In most cases in which an adult child becomes a caregiver for a parent or in-law, both parties have been living separate lives for many years. The adult child may have a picture of the parent who needs care as an individual who has few needs and who is basically independent. The adult child may be surprised to find that these parents who have always seemed strong and self-sufficient can be very tentative and/or demanding.

Deciding whether or not to become a caregiver, an adult child may have to deal with siblings whose interest in the situation ranges from no interest at all to a suffocating interest. Sibling rivalries and familial power plays will surface. Choosing a caregiver is a family affair. Everyone directly or indirectly involved needs the opportunity to have input, even if there are tears, angry outbursts, and other struggles.

How does one finally reach the decision to accept the role of primary caregiver for another adult? Jo Horne suggests that the caregiver ask the following questions, allowing for time and privacy to write down answers.

1. What is the relation of this person to you?
2. What physical and/or mental disabilities does this person have at this time, as far as you know?
3. How do you feel about the person's disabilities as you understand them? Are any of them repulsive to you?
4. Has the person's physician given you any idea of how quickly the person's health may decline?

5. Have you thought about the fact that the person's condition is likely to deteriorate? Have you thought about how much time it is likely to take to care for this person now and in the future when the condition worsens?
6. How long do you expect the caregiving to last? (Be specific.) What do you anticipate will happen to end it? (Be realistic.)
7. Where will the person live? Will anyone be required to move? From one town to another? Within the town? From one room to another?
8. Whether the person will live with you or in his or her own home, what do you anticipate will be inconveniences of the living arrangement?
9. Will the person you may be caring for have to make changes in his or her life that will mean moving away from familiar friends and places? Is the person likely to feel lonely or isolated?
10. What are the financial arrangements for caring for this person?
11. Will the person have special needs regarding such things as diet and clothing?
12. What is the person like? How well does he or she cope with stress? With change?
13. Whom do you think the person wants to have act as his or her caregiver? If that person is not you, why is it not possible for that other person to become the primary caregiver?
14. Have you and the person resolved any major differences you may have had with each other in the past? If so, how did you resolve them--by arguing, by giving in, or by not talking about them? How will you resolve problems in the future, especially if the two of you are to live together?
15. How do you feel about this person? Can you name three traits this person has that you like? That annoy you? Which three traits were easier to come up with?
16. How good are you at placing yourself in another person's shoes--at understanding another person's feelings?

17. How well do you cope with stress and change? Do you have a good sense of humor? How is your patience? Your flexibility?
18. What are your current responsibilities? Which of these cannot be changed? Which of these will have to be sacrificed?
19. Is your life enough in order to allow you to take on the responsibilities of caring for another adult?
20. Will caring for the person require a good deal of physical strength? Do you have that strength? (For example, if the person uses a wheelchair, will you have to lift the person into and out of the wheelchair?)
21. Why are you doing this--considering becoming someone's caregiver? (Try to write down every reason you have for taking on this responsibility.)
22. What are good reasons you have for *not* taking on this responsibility?⁸⁹

Before making the final decision to become another adult's primary caregiver, it is important to meet with other members of the family or household who will be involved in the caregiving process. Horne recommends that the following persons be involved in the family gathering:

Your spouse, children, siblings, and anyone else who will be a part of the relationship need to take part in this meeting. If you are single, living alone, and with no family, it would be wise to arrange a similar meeting with a trained counselor--your clergy person, the hospital social worker, or a family counselor--and perhaps a few close friends. At this stage you may not know yet the full extent of the caregiving role. At a later time you can meet again with these same secondary caregivers to assign specific caregiving tasks. For now you simply want to make sure everyone understands what becoming a primary (and secondary) caregiver will mean.

⁸⁹Jo Horne, Caregiving--Helping An Aging Loved One (Glenview, IL: Scott, Foresman--An AARP Book, 1985), 49-50.

A word here about the necessity of seeing that your own children, if they are in the home, have the opportunity to express their thoughts and reservations about caregiving if the care recipient will be living in their home. As a parent, spouse, and child who may be about to bring all three roles under one roof, you are part of a burgeoning new segment of the United States population--the so-called Sandwich Generation, or Women and Men in the Middle. Your children need to have a clear understanding that this new role of caregiving that you may assume will definitely cut into the time you will have for them just as a change in careers or a new baby would . . . Children are very perceptive, and you may be amazed at the insights they will offer through their questions and ideas.⁹⁰

Horne suggests it is probably a good idea that the person who needs care not be present at this meeting. A trained counselor may be helpful to offer objective insight. Horne offers the following points for discussion:

1. If you assume the role of primary caregiver, is everyone satisfied with that solution?
2. Does everyone agree that once the full range of caregiving tasks is known, there will be another meeting to divide those responsibilities fairly?
3. If the care recipient is to live in the caregiver's home, is there enough room for everyone? Are there enough bathrooms and bedrooms? Will there be enough privacy? If not, what compromises and changes need to be made?
4. In what ways do you each believe the care recipient will have to adjust to the new arrangement? In what ways will the primary caregiver and his or her family have to adjust?
5. Will everyone try to get along with everyone else if the person is to live in the same house? Can any differences be resolved before the move is made?
6. What are the financial and legal ramifications of the situation as it

⁹⁰Ibid., 51.

stands today? Who will pay for what? What extra burdens will caregiving place on the primary caregiver's budget?

7. What are the feelings of each person who attends the meeting and who is about to become a secondary caregiver about the new arrangement?
8. Does everyone at the meeting understand that if the caregiving role is accepted, that responsibility is likely to expand as time goes by?
9. What information does the primary caregiver need to gather before a division of duties can be outlined? Are any of the secondary caregivers willing to help collect that information?⁹¹

Many caregivers will not discover potential secondary caregivers from the family because there will be no one else willing to assist in the caregiving role. For others, the caregiving will be seen as a natural extension of the relationship to the care recipient as child or spouse. Assuming the role of caregiver and accepting the responsibilities takes a person with extraordinary qualities. This new role will alert the caregiver to discover his/her talents and strengths, as well as disabilities. There will be incredible demands made on every facet of life. Family members and friends and neighbors may criticize the way in which the task is being done. There may be major battles to obtain care for the person who is impaired or disabled. (In addition, professional services for the disabled are often complicated or nonexistent.) There will be inconceivable strains on time, physical and emotional resources, and the budget.

The more knowledge a caregiver has prior to assuming that role, the better prepared the person is for the role. Awareness of probable physical and

⁹¹Ibid., 51-52.

emotional stress and the possible effects on family life can enable the caregiver to cope more successfully with inevitable problems.

CHAPTER 7

FEELINGS OF A CAREGIVER

Trocchio maintains that providing care for an elderly person involves both challenge and discovery.

If you have decided to care for an elderly person in your home, you deserve enormous credit. The task is probably more difficult than you first imagined it to be. But at the same time, you are probably more capable than you ever thought yourself to be. You have a great deal of common sense and what you don't know, you can learn.⁹²

Certain aspects of the caregiving situation may become discouraging--no matter how much the caregiver wants to help, no matter how much satisfaction helping brings. A list of *common reactions* to being a caregiver are listed from TRIMS Gerontology Center:

- *Resentment* at having to give care, always attending to someone else's needs. "I thought I'd finally have some time to myself when Susan grew up. Instead, I have less time than ever since Mom's stroke."
- *Exhaustion* from the never-ending nature of the tasks. Personal care, cooking, and housework can feel like a treadmill--there are few places to stop and see what you have accomplished. "I work so hard, but there is always laundry waiting to be done, the next meal to fix."
- *Sadness* that the role your elder used to play in your life has changed. Whether you care for your spouse, parent, other relative, friend, or neighbor, chances are that this illness has affected your relationship. "I never expected to have to give my husband the kind of care I gave my

⁹²Julie Trocchio, Home Care for the Elderly (Boston, MA: CBI Publishing Company, 1981), copy unavailable.

children."

- *Frustration* that you do not have time for your own needs and pleasures. "When will it be my turn? And will I be healthy enough to enjoy it when it comes?"
- *Guilt* that you wish for more gratitude than your elder can express. "She could at least say 'thank you' when I bring in the meal."
- *Anger* that others do not offer more help. "Jean has always gotten lots of praise for being such a devoted daughter, but where is she now?"
- *Pain* at seeing the person you care for deteriorate, being less able than in former times. "She was such an independent, capable woman. It hurts to see her in that wheelchair."
- *Exasperation* at the social service system, which is difficult to pin down, often requires lengthy interviews and frequently cannot provide exactly what your elder needs.⁹³

All of these factors can create STRESS. Unrelieved stress may lead to a decline in the caregiver's health and emotional well-being, and it may affect other members of the family.

Some of the signs of stress are feeling irritable, being worried, pessimistic, preoccupied, having trouble sleeping, or being unpleasant to family and friends. The caregiver may experience negative feelings, such as pain, anger and resentment. These negative feelings may make the caregiver sick if they are not released. When the caregiver realizes that stress is mounting, the person can choose a variety of ways to relieve the stress.

⁹³Jane Corinne, *Aging, Living, and Caring: A Handbook for Elders, Families, and Friends* (Houston, TX: TRIMS Gerontology Center, 1985), 8-11.

What Can Help to Relieve Stress?

Getting adequate rest and good nutrition prepares the caregiver to face each day. If caring for an older adult prevents the primary caregiver from sleeping, perhaps another family member could come in one night a week to let the caregiver get a full night's sleep. Taking a good walk could help to relieve tension. If getting outside is difficult, the caregiver might exercise with one of the exercise shows or video.

The caregiver might get away to enjoy other activities, such as relaxing alone or with others. The caregiver might ask someone else to take over on a regular scheduled basis. Allowing others to help is a sign of strength, not weakness. Asking others to help the caregiver allows them the good feeling of being useful.

The caregiver might join a church or community support group to talk about his/her frustrations. Telling someone about the things that are bothering the caregiver may not change the situation but can make the person feel better. The person may discover that getting upset by feeling sad or angry doesn't improve the situation. These feelings are shared by others in a similar situation.

Milestones which are within reasonable achievement might be set by the caregiver. Planning to spend fifteen minutes a day for personal growth could be beneficial, regardless of the health or mood of the older person being cared for. The caregiver may reorganize work to make it easier for a change of pace.

Writing down personal feelings in a notebook "for your eyes only" can also help to relieve the stress of the caregiver role.⁹⁴

Some additional ways to release stress and negative feelings are the following:

- Breathe deep, with full breaths all the way down to the abdomen, then breathe out. Imagine the fresh air going through the mind, taking all tension and negative feelings out of the body while exhaling.
- Listen to music by taking a few minutes to sit down and concentrate only on the sound of relaxing music. Tape recordings of the ocean or mountain streams are available in large stores selling records or tapes.
- Relax the body by tightening the muscles in the face very tightly and then relaxing them. Additional muscle groups in the neck, shoulders, arms, abdomen, buttocks, legs, and feet could be relaxed. The caregiver might imagine the carereceiver with whom he/she is angry sitting across from him/her. Put the feelings into words, thereby letting out the feelings that have been withheld.⁹⁵

Because the role of caring for the elderly is a stressful one, it is important that the caregiver recognize distress signals and select ways to alleviate the problems before they become overwhelming. Meeting with other caregivers can counteract the individual caregiver's sense of isolation and reassure him/her that the feelings experienced are normal. This recognition can help the caregiver feel less alone. The last section presents a sample format for a support group and offers practical suggestions for dealing with aging parents, relatives or friends.

⁹⁴Ibid.

⁹⁵Ibid.

CHAPTER 8

SUPPORT GROUPS

The early Christians came together in small groups for teaching, fellowship, the breaking of bread, and prayer as described in Acts 2:42. Undoubtedly there was mutual support, encouragement, sharing, and burden-bearing. For Christians, this was the beginning of support groups. These gatherings were providing opportunity for the people to share their struggles, encourage one another, and develop feelings of closeness and solidarity.

A first step toward gaining respite and relief for the caregiver comes through a support group. Support groups provide caregivers an opportunity to learn coping skills that prepare them to make choices based on both the care recipient's need and their own. Most support groups meet on a regular basis at a time most convenient to the participants. Generally there is a facilitator or group leader, who may be a professional in the health care field. This person calls meetings, arranges for a meeting place, arranges for relief caregivers to keep the care recipients content during the time of the meeting, and schedules special programs and discussions at the request of the group.⁹⁶

The most successful support groups are those in which the members direct their own programs and choose their own topics for discussion. Groups

⁹⁶Jo Home, Care-giving: Helping An Aging Loved One, 270.

encourage sharing of experiences and techniques. They may even schedule an expert who can contribute to the education of the group. Most meetings last only a couple of hours, since caregivers often must exert tremendous efforts and considerable inconvenience to manage attendance. Caregivers will benefit from the emotional support they receive from the knowledge that caregiving is not an isolated experience. Caregivers gain new and useful insights into the feelings and needs of their relatives and learn of new options for caring. They receive encouragement and sympathy. They share laughter about circumstances which others might not see as funny. Caregivers find friends and receive positive reactions for the work they are doing.

Many support groups are organized by the local chapters of organizations for particular illnesses. Caregivers should call the local chapter for their relative's illness and ask for the support group nearest to them. Three national organizations may be able to advise a caregiver of a support group in the area:

National Support Center for Families of the Aging
PO Box 245
Swarthmore, PA 19081

Children of Aging Parents
2761 Trenton Road
Levittown, PA 19056

Family Caregivers Program
National Council on the Aging
600 Maryland Avenue, SW, West Wing 100
Washington, DC 20024

Sometimes a caregiver will say, "I don't have time to attend a meeting. I can barely get through the day now. Besides, why should I listen to others talk

about their problems?" Support groups are not crying sessions. They are opportunities--opportunities to learn more about giving care, to gain important information about services, and to socialize with people who understand and need no explanation.⁹⁷

⁹⁷Ibid., 271.

WORKSHOP⁹⁸

Caring for Aging Parents

I conducted a four-session workshop in January 1994 at my home congregation on the topic: "Caring for Aging Parents." This workshop was one of six "Winterim offerings" to be held on four Wednesday evenings beginning January 19 and continuing through February 9, 1994. The workshop was promoted through church publications and public announcements prior to weekend services. Advance enrollment was requested for the Winterim offerings.

This workshop was conducted in a 3,000 member suburban congregation which is located in a bedroom community of metro-Milwaukee, Wisconsin. The congregation operates a Child Care Center, Christian Day School and is a member of the Lutheran High School Association of Greater Milwaukee. One church membership profile demonstrates that persons from this congregation are arranged in lifestage groups ranging in age from eighteen to over ninety years of age.⁹⁹

⁹⁸The materials used in this chapter are adapted from Jane Goz Goodman, Aging Parents: Whose Responsibility? (Family Service Association of America, 1980).

⁹⁹Church Records of Hales Corners Lutheran Church, Hales Corners, Wisconsin, June 10, 1993.

AGE GROUP	NUMBER OF PERSONS	PERCENTAGE
18-24	35	3
25-34	260	24
35-44	302	28
45-54	164	15
55-64	142	13
65-74	103	9
75 +	82	8

Four persons were initially enrolled in the workshop to learn new ways of coping with and understanding their relationship to parents. The workshop was not intended to provide therapy. The emphasis was on learning new coping skills and understanding normative behavior and normative life crises. The group talked about where they were in the parental relationships, how they got there, and how they could make it better. They talked about what their parents could expect from them and what they could reasonably expect from their parents. The group discussed the feelings of anger, guilt, and fear. The workshop utilized discussions, mini-lectures, values clarification exercises, handouts, flip charts and role plays.

Ground rules included the following:

1. Members are expected to attend all scheduled sessions. If they are unable to attend, they should notify the leader in advance.
2. Material shared by group members is confidential.
3. For those who miss a session, a 'catch-up' session prior to the following session may be arranged by appointment.
4. If new members want to join the group by the second session, but no later than that, the group will make the decision about including them.

Session 1

I. INTRODUCTION--GETTING ACQUAINTED (20 minutes)

A. The leader introduced himself, setting the stage and making it easier for the members to talk about themselves. The leader spoke on two levels--professionally, and as an adult child who has coped with and counseled about various problems related to parental relationships.

B. Members of the group were asked to give their names and tell something about themselves and their parental situation. Five participants shared their current life situations with sick or healthy but demanding parents. Names have been changed to protect their identity and honor their confidentiality.

Gert's mother Rose, age eighty-four, has lived in Gert's home for sixteen years. Rose, and Gert and her husband, Duane, sold their homes to build a large home for Gert's family, including a separate area for Rose. Gert required corrective surgery on her knees. During the recovery, Rose was placed in a nursing home for about six weeks. When Rose returned to Gert and Duane's home, she was very critical of Gert. Rose would not speak to the family for several days, even though they had meals together. Rose had difficulty with diabetes, walking any distance, and sat in a wheelchair or soft chair many hours per day. Duane's mother, Irene, age eighty-two, also moved into the home following time spent in the hospital. Irene owns a home, but does not feel safe in her home for any extended period of time. The two aged mothers

compliment each other--Irene provides the legs, Rose the hearing and reading ability. Duane and Gert both expressed frustration over 24-hour care, for they were unable to take a vacation and could not share time with their grandchildren. Gert is the only living child of Rose.

Julianne and Bud are the primary caregivers for Julianne's parents. There are three daughters, but the mother confides in Julianne. The father has Alzheimer's disease. The mother would complain about not being able to handle her husband and say that something needed to be done. The mother did not want to make a decision, nor review potential care centers for the father. Julianne and Bud assisted the mother in locating a nursing home for the father. The mother is able to drive to the nursing home to visit the father but has guilt feelings about their separation.

Will and Denise are concerned about a severe depression and schizophrenic condition of Will's mother following the death of Will's father. Will reported that shock treatments have been ineffective. The mother maintains her own apartment. Will is a professional social worker who assists persons to link up with community resources for the aging. Even though he daily works with community agencies and has knowledge of their services, he says it is different when dealing with his own parent. Will and Denise have two children in elementary school.

This introductory sharing was an intense, emotionally laden, and tear-producing experience as group members shared their current life situations.

Members felt overwhelmed with feelings of guilt, anger, fear, and confusion.

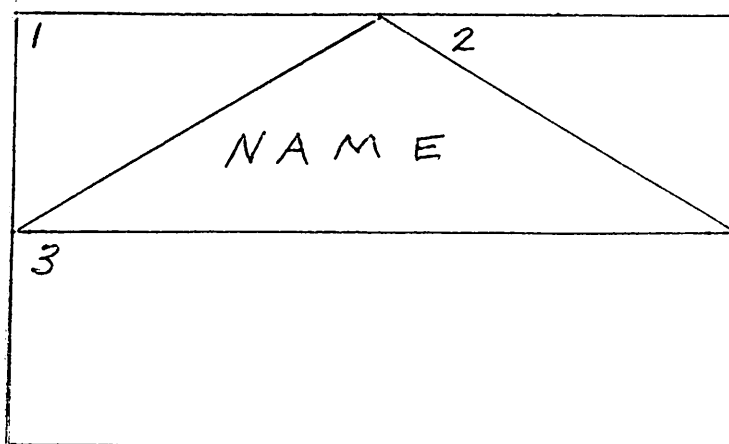
The leader observed the group developing a sense of cohesiveness based on the shared material. The members began to acknowledge a feeling of support from the group as well as a genuine concern for the others in the group.

Without exception, there was a shared feeling of relief as they expressed, "I didn't know anyone else was going through this."

C. Ground rules and overview of the workshop were expressed by the leader.

II. GOAL SETTING (20 minutes)

A. Extended Name Cards were completed on 8" x 5" index cards. A sample of the name card is shown below. The leader gave directions for preparing the name card.



1. In section 1, list in several brief phrases what you can reasonably expect of your parents and your responsibility to them.
2. In section 2, list in several brief phrases what your parents can reasonably expect from you as you care for them.
3. In section 3, list what you want to achieve from this workshop experience; what are your goals and needs?

4. On the back of the card list your wishes and fantasies for your activity and relationship with your parents.
5. Members leave their extended name cards with the leader at the close of the session to help the leader compile the list of goals for the next session.

III. VALUES CLARIFICATION EXERCISE (10 minutes)

A. **Exercise One** "Being old means. . ."

This exercise may be accomplished as a verbal go-round, as a written exercise, or the leader may write the responses on a flipchart or board. Some usual responses include: sick, unattractive, helpless, poor, senile, out of control, lonely, dependency, and impending death. The leader discussed the group members' responses. Our group added these items: experiencing losses, reduced strength, diminishing sight and hearing, and inability to accomplish many tasks in a day. The exercise was intended to help the group focus on some limitations experienced by older persons.

B. **Exercise Two** "Alternate Hand"

Instruct the group to write the following with the hand they do not normally use: their name, today's date, and their address. We discussed the reactions and feelings about the exercise. This exercise enabled the group members to experience the sense of a loss of vision, a steady hand for accomplishing small motor skills, and mental ability. My group shared their appreciation for the difficulties experienced by older persons.

IV. DETERMINING THE EXTENT OF YOUR RESPONSIBILITY TO YOUR PARENTS.

(NOTE: The following lecture was given by the leader after handing out a brief outline covering the six major points. See Appendix G.)

(Mini-lecture)¹⁰⁰ [15 minutes]

When we think about our parents and try to determine the extent of our responsibility for them, we are often in conflict over our struggle to meet our own needs, our immediate family's needs, and the needs of our parents. We may feel we are doing too little, which results in guilt feelings. The dilemma may be handled by doing too much (at the expense of our own and immediate family's needs), which results in expressed or unexpressed anger and resentment. The conflict may be so powerful that it immobilizes any action for assistance. In each of these three possible ways to handle parents' needs, ultimately no one's needs are fully being met. There is pain, confusion, anger, guilt, and resentment.

Before we can determine the extent of our responsibility toward our parents, we need to feel that we are okay, and that it is all right to meet our own needs. We need to have a relationship with our parents that permits us to relate to them out of love and care as an adult child to parent, not out of anger

¹⁰⁰Jane Goz Goodman, Aging Parents: Whose Responsibility (Family Service Association of America, 1980), 25-30. Material adapted from this resource for the workshop.

and fear. As you share your life situations, there is concern and care about your parents, but you are also frightened by the changes which you see taking place in your parents. Some of your parents are experiencing the beginning of the aging process with minimal change in function. Others are watching parents struggle with devastating, and perhaps life-threatening, illness and pain. Some have parents who are experiencing loss of memory, disordered thinking, and faulty reasoning. All of these conditions are painful to observe.

As young children with parents and grandparents, aunts and uncles, we had a sense, almost, of immortality, surrounded by so many strong, caring adults. Most children share a common fantasy that they will never die. As we mature and begin to experience losses, we are sobered by the reality that loved ones do die, and that perhaps we too will someday die. As parents age, become ill, perhaps die, we are pushed closer to the 'front line' and we experience uneasy feelings about our own mortality. Seeing our parents age, become ill, lose sensory faculties, and become dependent on others for care is frightening. This may even happen to us, we think.

This workshop is intended to work toward feeling better about ourselves, to become more understanding of our parents' struggles and problems, and to make some concrete decisions about how we can improve that relationship. Every advanced religious and ethical system demands that we honor the aged. We do have a responsibility toward our parents, but the extent of that responsibility is determined by you, your family, and your parents. Before you can work

out your own 'formula' for this, you must become aware of and recognize your own needs. It is acceptable to meet your own needs. If you give up meeting your own needs consistently, you will feel angry, guilty, helpless, or sick.

In determining the extent of your responsibility you must first determine with your parents (assuming this is possible) what needs to be done and what their preferences are. Then, meet with all of the members in your family to plan for and to share the responsibility. If you are an only child, or an only child in the area where your parents live, you'll need to involve surrogate family. Surrogates can be neighbors, friends, volunteers, professionals, or paid helpers. It is important to remember that parents' needs, as they see them, are taken into account in planning. Even if there are many adult children, the responsibility for caring for the parents falls on one adult child. It is time to begin thinking of ways to involve all family members (or surrogates) in sharing the responsibility for parents' care. If parents could live in their own home with the aid of a family or surrogate support system, make a list of exactly what will be required and then have a family meeting to work out the details. As we consider the variety of situations with your parents, how you resolve the total relationship to your parents is our task in this workshop. We cannot provide a magical formula for each situation, but we will consider the dynamics of the adult child-parent relationship and offer some suggestions for options, choices, better understanding, and alternate coping solutions.

The group did not have time to share comments on this presentation. |

was at the end of time for the session. I felt that the group was interested in the material. They responded very well to the values clarification exercises.

Session 2

I. WELCOME AND UPDATE

I invited the group to share comments or reactions to last week's session. I asked members to provide an "update" on their parental situation. The group provided strength and support for changes in situations and became like a surrogate family to each member. I personally invited three persons to attend this session who were not at Session 1. The persons from Session 1 briefly shared their personal caregiving situation with a parent(s). The parental situation of the new persons are shared below:

Caroline was the primary caregiver for her aging parents when they lived in a low-rent apartment. She did their shopping and responded to late evening emergency calls when her mother was taken to the hospital for a blood transfusion. A blood transfusion could be necessary several times in a month. The mother was placed in a nursing home and the father was placed in a group home with seven women. The mother died, leaving the father further depressed over another loss in his life. Caroline's sister assumed primary care for the father, since the group home was near the sister's home and business.

Caroline's husband Gerald retired and experienced difficulty with his legs. Gerald would take the father-in-law out one day per week for shopping or

fishing or bring the father-in-law to their home for a meal. This activity would take most of a day.

Caroline and Gerald's daughter-in-law developed a brain tumor. The daughter-in-law, age thirty-four, and mother of three children in elementary school, needed surgery. The surgery was followed by six weeks of recovery and therapy. During this time, Caroline and Gerald were caregivers for the grandchildren by providing transportation for them to school activities and maintaining some order in their lives.

Sarah attended one group meeting to share her concern over dealing with an aging mother having multiple complications and little desire to live. Her father was hospitalized in the past year, and is showing signs of reduced strength to care for his spouse and maintain the household. Sarah manages full-time employment, owns her home, and has a college-aged daughter living at home. She realizes that a great amount of time is required for parent care. She expressed: "I'm not ready for parent care!" Many questions were raised: "Should I sell my home? Quit my job? Move in with my parents to care for their daily needs? What about my daughter living at home?"

II. GOALS FLIPCHART

Reflect on items of concern and issues shared by the group from last week.

A. Sample Goals Chart

To learn how to cope with the guilt.

To overcome the anger associated with the responsibility toward my parents.
 To learn how to communicate, how to talk to my parents., say what I'm feeling without crying, screaming, or getting angry.
 To get help in learning to resolve conflicts, to forgive each other and not harbor deep intense resentment.
 To learn if my parents love me and approve of me.
 To learn how to cope with my own needs and my parents' needs and be fair in prioritizing these needs.
 To learn how to help my parents be as independent as possible.
 To be more patient and less short-tempered with my parents.
 To clarify the whole issue of responsibility--whose is it?
 To learn more about the process of aging.
 What are the community resources, particularly nursing homes, and how do I choose a good one?
 How can I have privacy when my parent lives with me?¹⁰¹

Our group shared the following goals for the workshop:

To gain an appreciation of other caregivers
 To learn more coping techniques
 To gain a better understanding of caregiving
 To have an objective overview to review caregiving and help me identify areas in which I am weak and possible ways to improve.
 Know that other people share and understand my feelings
 Knowing that I am not alone
 To give my wife support, her mother and sisters through all the pain
 That this might be the basis for a caregiver support group in the congregation
 Compare how others are meeting their parent's needs

B. Role Plays

This is an appropriate time to do some role playing based on input from members. Be sensitive to the discussion and test the group: "I wonder if it would help to role play what you're sharing?" Your group may accept

¹⁰¹Goodman, Ageing Parents: Whose Responsibility?, 43.

this method as a mode of problem solving and offer vignettes for the group to role play. A member who suggests the vignette gets actual practice in changing her or his behavior, and the others have an opportunity to hear and learn from it. Ask for volunteers to act in a person role which is different from their caregiver role. The leader may also serve as one of the characters in the vignette.

1. A woman is feeling overwhelmed, angry, and guilty because her parents always arrange their doctor's appointments at times that are inconvenient for the daughter who takes them to these appointments.

Ask for volunteers to play mother and daughter. Solutions offered usually include a recognition of the parents' feelings and needs as well as the adult child's needs and rights. The concept of "limit setting" is introduced. The daughter offered to take her parents to lunch prior to the doctor's appointment. The daughter set limits on days she was available and recognized her own right for personal activity.

2. An eighty-year-old woman lives with her daughter whose life had begun to revolve around physical care for her mother, including preparing meals, cutting food and providing a warm beverage at lunchtime. This routine prevented the adult child from leaving her home for a luncheon date or for other activities. The role play provided a solution: preparing a warm beverage and placing it in a

thermos and preparing food that required no cutting or was pre-cut.

3. An active and busy adult child, who enjoyed many activities, such as tennis, golf, organizational work, and meeting with friends, felt guilty. Her parents lived in their own home, were reasonably well physically, and had no financial problems. The adult child was feeling guilty and angry, however, because her mother called her early each morning to ask what she was doing that day, and then her mother would say that she was lonely and miserable and had no friends. The mother did not ask the daughter to do anything concrete, but the adult child felt guilty, miserable, and angry.

In the role play the adult child responded to the mother by saying:

"I'm really looking forward to my game of tennis today. The exercise is good for me and it's fun to be with my foursome." Another response was: "You sound lonely, Mom; would you like to have lunch and shop on Thursday?"

III. WHAT CAN I REASONABLY EXPECT OF MY PARENTS?

We discussed the items on the flipchart which were prepared from the group's extended name cards. Copies were provided for each group member.

The chart of comments prepared from name cards follows:

Understanding of my needs and responsibilities
 Help with the housework within her ability (for parent living with adult child)
 To love me and not be critical or disapproving of me and my family's lifestyle

To not make me feel guilty when I must say "no"
 To hear my problems and give me advice
 That they will let me know when they really need me in emergencies
 and not keep "secrets" from me regarding health problems or
 major concern while occasionally telling these "secrets" to others.
 Ask for help
 Love and friendship
 Unconditional love
 Not to manipulate me and my family
 To be friendly with my family and our life
 Consideration, respect, and acceptance
 To be courteous
 That they will be well-groomed and make a nice appearance
 Treat me with respect and dignity
 That they love me as much as my siblings and not show favoritism
 or play us against each other

The group discussed the common themes of showing love, respect and appreciation by the elderly parents toward their adult child. A handout; "Ten Commandments for Care-receivers," was shared with the group (See Sample in Appendix C). Several members of the group indicated that they were going to leave this handout in the presence of the elderly parent for their future reading.

B. Role Plays

1. The adult child and her widowed father who lived alone but maintained a key to his adult child's home: The father was using his key inappropriately, for instance, by coming in when no one was at home and opening the mail. In the role play the adult child asked her father to come over for coffee and discuss something that was bothering her. She stated that she wanted her father to have a key to her home, but she was feeling edgy when her father never called

prior to coming. She also requested that he not open the family's mail, since it was a breach of their privacy. The father in the role play got angry, and stated he didn't need to call prior to visiting his child's home. The daughter appreciated his feeling that way, but she was not just his "child," but a grown woman, wife, and mother, who had feelings and rights of her own. She stated that she loved her father but wanted them to be honest with each other and maintain a good relationship based on understanding and respect.

Some of the group members responded by saying that they often want to tell their parents how they feel, but they could not express their true feelings without fear of their parents' wrath. Efforts were made to help the adult child feel good about herself and thus reduce her defensiveness and anger. The solutions offered by the group included an acceptance of the father's need for contact with his daughter, his loneliness, and concerns about losing power and control over his adult child.

2. Parents are angry because the adult child did not invite a certain distant relative to a family gathering. This role play points up control issues and some limit setting. Played with love and respect for the parents, this role play emphasized the adult child's right to plan her own guest list even though it did not meet her parents' approval.

This role play could also assist the parents and adult child to process

the issues of approval, acceptance and validation.

3. The parent who has thought disorder or memory loss. This role play enabled the group members to deal with their pain and fear over the once strong, independent parent experiencing thought disorder or memory loss. The adult child was encouraged to respond lovingly without insisting on establishing his/her own identity as son or daughter.

IV. FILIAL MATURITY¹⁰² [Mini-lecture] (10 minutes)

The leader shared this mini-lecture with the group. Summary thoughts on "filial maturity" were handed out to the group after the presentation. A sample copy of this handout is included in Appendix H.

The term "filial" denotes the relationship of a child to its parent. The term "filial maturity" implies that we come finally to a relationship with our parents in which we relate, not as dependent child to parent, nor as parent to our parents, but as adult children to our parents. Very little is offered in literature to tell us about achieving and mastering the life task of filial maturity. We read and hear that adult children, faced with caring for their aging parents experience a "role reversal" in which the adult children become parents to their parents. This is not an accurate position. The dynamics of the child-parent relationship reversing roles may be fraught with temptations to 'get back' at or

¹⁰²Goodman, Aging Parents: Whose Responsibility?, 52-55. Material adapted from this resource.

retaliate against 'helpless' parents for what might be perceived as poor, deficient, or cruel parenting. All children feel frustrated occasionally as parents exert control over their lives, their destiny, and their wishes. The temptation as an adult child may be to vent angry or resentful feelings on a parent who is aging and deteriorating.

Many in the 'middle-age crunch' are still bearing responsibility not only for their own children but are also being faced with increasing responsibility for parents. Today's children often attend school for more years than their parents did but are still financially and emotionally dependent on them. The lifestyle of today sets adult children up to be sandwiched or 'crunched' between two sets of responsibilities.

Filial maturity is a life task in which adults learn to relate to their parents not as children, or as parents to their parents, but as adult children to their parents. Persons who have achieved filial maturity can hold their own, meet their own needs, set proper limits, and give real help to their parents without feeling overwhelmed or overpowered. Persons who have achieved filial maturity can finally forgive their parents, recognize their parents' needs, and accept their parents as adult human beings. The achievement of filial maturity requires effort, understanding, patience, trial and error, self-acceptance, and self-evaluation.

Session 3

I. WELCOME AND UPDATE (10 minutes)

I welcomed group members and inquired how things were going in their lives. They reported on their attempts to utilize some of the skills learned in the previous sessions. One couple reported that some tension had been lifted by the mother's decision to place her husband in a nursing home. Another couple reported that their situation had improved with the two mothers back in this couple's home.

II. WHAT CAN MY PARENTS REASONABLY EXPECT FROM ME?

I put up the flipchart which was prepared from the group's extended name cards. We discussed the list of comments supplied from the group's name cards.

A. Flip chart of group comments:

- Love and understanding
- Physical comforts and care
- Consideration
- Respect
- Cooperation
- Help with their problems
- That they will be included as part of our family
- Taking them to appointments, marketing, shopping
- To come to my home on a regular basis, and take part in family celebrations and holidays
- That I will be responsive to their emergencies
- That I will help them do the things they can no longer do for themselves
- To have fun with them, to listen and to see that they remain as independent as possible

That I will attempt to balance my lifestyle and my time so that I meet my needs and when I am with my parents I will not feel resentful, angry, and sullen

That I will express my appreciation to them when they are helpful
To be sensitive to their cues about how much help to offer and when to step in

To encourage my parents to communicate with me and not hold back out of a fear of intruding upon my life

As much care and love as I want from my children

B. Discussion and Role Play

Discussion centered on the interchange of the parental relationship.

Members related some old feelings about parents who continually interfere with their current relationships.

1. Role play suggestions to prompt group response.¹⁰³

For example, a woman, who worked full time, had a husband and grown children. She was the sibling designated by her family as responsible for the care of two very sick parents who lived in their own home. She was constantly berated and devalued by her mother, and the mother was supported in this role by the father. She was always the scapegoated child in the family, was always trying to win the approval of her mother, without success. Even now, she provided much of their cooked food, drove them to doctors' appointments, even though her father still does some limited driving. She has colitis and recalls that her daily phone conversations with her parents are hurtful when her mother still calls her 'messy, fat, and sloppy,' berates her efforts in general and is never appreciative of what she does.

A woman was struggling with feelings about her father's remarriage, following her mother's painful and protracted death. She was struggling to forgive her father for choosing another wife and in some ways regarded his remarriage as a personal rejection of both herself and her mother.

¹⁰³Goodman: Aging Parents: Whose Responsibility?, 69-72.

A man was concerned that his college-aged children did not want to visit their grandmother when they were in the city. He felt torn between understanding his children's needs to spend their time as they chose and in wanting them to accept some responsibility toward their grandmother.

Mother calls to tell you the night before you and your spouse are leaving for a long-planned vacation that she is sick and lonely and will miss you terribly and probably be in the hospital or dead when you return.

Parent calls you several times a day out of loneliness and boredom and wants to know where you were and what you were doing when you didn't answer, and what you're fixing for supper.

Mother tells you that she is very worried about your father who seems to be disoriented most of the time, is soiling himself and forgetful, and she wants you to help her decide what to do.

III. VALUES CLARIFICATION EXERCISES

A. Life Line Exercise

Supply the members with an 8-1/2" x 11" paper; draw a horizontal line lengthwise in the middle of the paper. Give the following instruction: At the left end put a dot and identify your birthdate. At the right end put a dot and "guesstimate" your deathdate. Between these two dots put a dot indicating today's date. Between your birthdate and today's date, choose significant events and dot and date them. Between today's date and your deathdate, place two dots, and date them, indicating two significant events that you want to happen between now and the time you die.

After all participants had completed the task, I asked them to

discuss their feelings about selecting a death-date. I said, "This is a good place to talk about death and fears of dying, relating it to how much more parents must think about dying. Death is a reality, we need to begin to accept as a fact, and talking about it is helpful." Several members of the group failed to indicate a death date. They reported: "I don't know when that will happen! All I can determine is what I know."

B. Basic Needs Exercise

I instructed the members to list their five basic needs on an index card. Then they ranked in order of importance their basic needs, with number one being most important. No direction was given as to the content of the basic needs.

I invited the group to read their lists. The most frequently given need in our session was to "feel loved." Other sample responses were:

- To feel wanted
- To be able to care for others who need me
- To like myself and feel good about myself, accept myself as I am
- To have privacy and time to be alone
- To be a good mother, wife, daughter, sister, daughter-in-law, sister-in-law, grandmother, friend, worker
- To keep myself busy, well-informed, and involved in life
- To do meaningful work
- To pursue my hobbies
- To continue the learning process

IV. HOW TO BE A HAPPY AND SUCCESSFUL ADULT CHILD TO PARENTS

A. Mini-lecture¹⁰⁴ (25 minutes)

(Leader presented this material to help the group focus on their needs.)

The exercises and discussions in this session helped us focus on you and your rights and needs. We attempted to move you toward a consideration of who you are and what you want. Many of you acknowledged that you had not given thought to what your rights or needs were, and that it was a new way of looking at yourself. There is a connection between the concept of self acceptance and the way you relate to your parents. The extent of your happiness and success as an adult child is based upon how you feel about yourself.

Let's go back and trace quickly how you learned to 'feel' about yourself and judge and evaluate yourself. As infants, we are totally dependent upon our parents or caretakers for our continued existence. We need to be fed, changed, bathed, housed, cuddled, and taught. This early period of being totally dependent on parents or caretakers is soon replaced by a period in which young children begin to gain mastery over themselves and their environment as they learn to turn over, crawl, walk, talk, and feed themselves.

As the child gains mastery, the parent must give up his total control and care and encourage the young child to separate from them. One of the most

¹⁰⁴Goodman, Aging Parents: Whose Responsibility?, 80-84. Material adapted for this workshop.

difficult tasks of parenthood is to recognize when to separate and begin to let go. Parents who are over-protective and watchful beyond what is reasonable may give messages to their children that they are incapable of caring for certain aspects of their life. This is failing to validate the young child. Parents who allow and encourage their children to do things themselves, and provide proper love and guidance are really validating their children--they are okay--and say "we respect and love you." Such children can usually feel good about themselves, accept themselves, and be helpful to others. Unvalidated children may become unvalidated adults. These adults may be sad, depressed, angry, or guilty in a vague way, feeling that they didn't quite measure up to their parents' expectations. When these adult children assume responsibility for their aging parents, it is difficult because they haven't worked out the earlier relationship and are still seeking their parents' approval and love.

What can you do if your parents have not validated you? First of all, your parents likely did the best job of parenting they could as a result of their previous experience. Secondly, you can validate yourself by coming to terms with who you are, and what you need, recognizing that you have to be yourself and that you are an acceptable human being. You must work toward accepting yourself unconditionally. If parts of you are unacceptable, you have the potential to change and modify them.

Now, how can we be happy and successful adult children to our parents? There is no magic formula. There are ways to relate to parents that can ease

difficult relationships and improve good relationships. One important way to help our parents as they become more dependent on us is to use good humor and grace. We may feel harassed, overburdened, and just plain angry. It helps to remember that we are going to be old some day and will want our children to treat us kindly.

Respect the dignity of your parents without undermining their independence. You may put your parents in touch with resources that they can use, but don't consider this as a substitute for yourself or what you personally can provide. Let your parents know that you love them, care for them, and that they can depend on you when they need you. Talk with them about their wishes, so when the time comes for you to be in charge or make decisions for them you have some knowledge about their desires. Relate to your parents in a loving spirit. Remember to smile, touch, stroke, hug, kiss, and embrace your parents. Like young children, older people have a need for physical contact.

Maintain regular contact, by telephone and in person, based on your lifestyle and preference. Include your parents in family and holiday celebrations. Invite them to your home and visit them where they live. Plan outings with your parents according to their health and interests.

When you buy gifts for your parents, be imaginative. Instead of bedroom slippers, dietetic candy, or a heating pad, what about a bird in a gilded cage, season's tickets to the theater or opera, a gift certificate for a new hairdo, facial, make-up session, manicure or pedicure, a dinner prepared by you for your

parents and their friends, a cassette recorder for precious reminiscences of early memories, or an easel and paints for creative hobbying?

Encourage your parents to take an active part in the community in which they live. Bring portions of the community to them: news of the outside, books, magazines, newspapers, photos, and people from the outside. Older persons need stimulation. I know of several persons in their eighty's and ninety's who enjoy working on word puzzles.

Finish any unfinished business with your parents. Don't wait until they've died to say "I'm sorry," or to help them say "I'm sorry" to you. Talk honestly about feelings and concerns. If your parents want to talk about their dying, you can be helpful, supportive, and reassuring by talking and listening.

Always treat your parents as adults. Respect their strengths and weaknesses. Forgive their past mistakes, and accept them as human beings won by the blood of the Lamb of God who happen to be your parents.

DISCUSSION: The lecture was designed to stimulate, encourage and give "permission" to these adult children to rethink and reconsider their old relationship with parents and move into a relationship of filial maturity. I invited the members to respond to concepts and suggestions and to put ideas into practice during the week. The group discovered new skills which they were willing to try during the next week. The matter of being validated captured their attention and they desired further discussion at a later date.

A handout summary of the mini-lecture was shared with the group to help them review the subject of validation, consideration of planning with parents for their care, and the importance of personal contact. A sample copy of this handout is included in Appendix I.

V. HOME ASSIGNMENT

Ask group members who do not wear glasses to bring either a pair of sunglasses, or someone else's glasses for next week's session. Do not explain why you want the glasses.

Session 4

I. WELCOME AND UPDATE

The group did an update on their own progress and shared reports on their parents. We heard positive and negative reports but noticed that the members had internalized a great deal of the workshop material. I noticed the group modifying some behavior and utilizing new approaches and new coping methods shared in the previous three sessions.

II. VALUES CLARIFICATION EXERCISES

A. Glasses and Earplugs

The leader may maintain an attitude of annoyance with the group, and speak so softly that he is not easily understood. As group members ask you to speak more loudly, do so by raising your voice

inappropriately and expressing your displeasure at being asked to repeat.

I chose to modify these instructions by ignoring the attitude of annoyance with the group. However, I did speak in a soft voice with the noise of a radio in the background. The group struggled with this exercise. This was an exercise to facilitate the process by giving the group a feeling of being unfairly treated. I utilized the following steps:

1. Collected the eyeglasses each member in the group was asked to bring. Smear the lenses with vaseline (a little goes a long way). Each group member must wear the glasses to do this exercise.
2. Distributed cotton balls and instructed the group to plug their ears.
3. Turned up the "noise" on the radio and spoke with a soft voice to increase the difficulty of being heard. Insisted that the group members wear the glasses so they would get the feeling of diminished visual acuity.
4. Speaking softly I asked them to write out the following on the paper provided:
 - a. Your social security number
 - b. Your automobile license number
 - c. Your grandmother's maiden name, date, and place of her birth
 - d. The names of your kindergarten and first grade teachers
 - e. The exact amount of money you have in your purse or wallet
 - f. The location of your birth certificate, marriage certificate, and insurance policies
 - g. Your blood type
5. Turned off the radio, smiled, and distributed some facial tissue (window cleaner works well) to clean the glasses and had the group remove their earplugs.

6. Discussion

I asked for reactions. Everyone wanted to answer simultaneously. The group shared these feelings about the exercise:

- Angry
- Frustrated
- Helpless
- Like crying or leaving
- Like refusing to do anything
- Wanted to be back at home where it was safe
- Out of control
- Defenseless

Discussion was lively as the group shared their feelings. I directed the discussion toward how it would be to feel this way permanently--without being able to wipe the "cataracts" away with a facial tissue or restore hearing by removing a cotton ball. The discussion focused on being sensitive to what it feels like to be treated harshly, unfairly, without kindness or empathy only because one is experiencing sensory deprivation not of one's choice!

B. Old People Are. . . .

I used two copies of the form "Old People Are. . . ." for each group member. (See printed copy in **Appendix J**.)

1. I distributed the form and asked the group to complete the phrases from their perspective. When they had completed the form, they turned it face side down.
2. I distributed a second copy of the same form. I instructed the group to imagine themselves to be eighty years old and to complete the form as they would respond at that age.

C. Discussion

The group was directed to empathize with what their parents were experiencing but without the leader moralizing, valuing, or being judgmental. The group noted that the "Old People Are. . ." forms filled out the first time were critical and negative, but that the forms filled out the second time were more positive and less harsh.

The following comments broadly summarized their responses:

1. Aging brings changes
2. Your parents are aging
3. You will age too
4. Planning for later years can be full, rich, and gratifying
5. As you are now, so you will be in later life, but more so!

III. THE AGING PROCESS: PHYSICAL AND EMOTIONAL ASPECTS¹⁰⁵

A. (Mini-lecture)

The leader shared this lecture to help the group focus on the irrevocable changes with the aging experience.

In this session you had an opportunity to glimpse for a fraction of a second a revocable experience in aging. You may have felt frustrated, helpless, angry, out of control, and you didn't like what was happening to you! You wanted the exercise to end. You wanted to be able to see, hear, and function as you normally do without being

¹⁰⁵Adapted from Goodman, Aging Parents: Whose Responsibility?, 103-109. Material adapted for this workshop.

harassed or hassled by anyone telling you what to do and how to do it, and, furthermore how ineffectively you were doing it.

Magnify this experience; imagine that it is not revocable, that it is not going to be reversed, and perhaps it may get worse. This may appear to be a negative picture, not because aging is negative, but what actually happens to many people as they grow older is negative and devastating. Aging brings changes in many ways. Aging can be an extremely rich period, a time for growth, maturation, renewal, and preparation for one's ending. We will be looking at the physical and emotional aspects of aging in a broad sense.

What are some of the physical changes in aging? Aging is a life-long process. Aging often brings some degree of sensory loss for most people. Some older people develop loss of sharp vision. It may mean an end to a lifelong pleasure in reading books, daily newspaper, an inability to continue valued correspondence with loved ones, and writing checks to pay bills. It may interfere with driving a car, using a bus, watching television, shopping, and getting around town. It may mean refusing to step outside the walls of a 'safe' apartment or home in which the elderly person can feel his/her way around the rooms with minimal risk of bumping into furniture or walls. Loss of visual acuity may mean a discontinuation of hobbies such as needlework, painting, cooking, playing cards, tennis and

golf.

Many elderly may also experience a loss in hearing. Most people beyond the age of fifty cannot hear high frequencies. This is not a major problem because the frequency of human speech is well below that level. Disease may result in even lower level frequencies being difficult to hear. People who do not hear well may become socially isolated, feel left-out, shunned, and embarrassed by their loss.

These losses are not the only physical changes the elderly experience. Digestion may become a problem because of the loss of teeth or poorly fitting dentures. Bones lose calcium and become brittle. Older bones are prone to fractures and less amenable to healing. If joints are inflamed, arthritis and rheumatism become painful problems for the elderly. They may become extremely cautious about climbing stairs and venturing out of doors in wet, snowy, or icy weather.

Aging also brings other changes. Strength is diminished. Skin may begin to wrinkle and sag. Muscles lose their elasticity and clothes may not fit as well. Voices may become thin and reedy, and hands become gnarled. Noses grow longer, and there is thinning of the hair and loss of hair, both on the head and on the body. Veins and pores enlarge and eyes may become rheumy. In men, the

prostate gland enlarges and creates a need for frequent urination. In women, voluptuous curves disappear, the breasts sag, the vaginal walls lose much of their lubricating secretions, and the problem of brittle bones, or osteoporosis occurs more frequently. Sexually, both men and women may remain active into their eighties and beyond, although there is less frequency.

Diseases which are not necessarily life-threatening represent a frightening change in lifestyle for the elderly. Diabetes, high blood pressure, and hiatal hernia are common. Sluggish circulation may cause pain for those who walk even short distances and may create heart problems and strokes. Sometimes memory may be faulty or thought processes may become disordered. Tempers may flare as insults (either real or imagined) are felt. Aging also brings changes in sleeping patterns. The elderly may have difficulty sleeping the night through, although they may experience an increased tendency to doze or nap during the day.

There is a higher incidence of accidents in the home for the elderly. Using the stove may be hazardous for those who do not see well or are not strong enough to lift heavy pots. Getting in and out of the bathtub may be a frightening experience. Many older women have difficulty washing their own hair or performing other simple routine activities.

Emotional aspects of aging must also be considered. Aging exaggerates earlier personality characteristics. If your parents were always cheerful and optimistic, they will probably continue to be so. If you parents were always sour and acerbic, they will probably continue to be so. Some emotional changes, however, may result from disease or neurological trauma.

In addition to physical and emotional problems, parents will at times face the loss of family members and lifetime friends. As they move into their eighties and nineties they will experience even more losses. Older people pay a great deal of attention to the obituary column and keep score of "who's left." As parents' contemporaries die, they are left with fewer people who knew them in their young, strong, capable, and attractive prime. They did not have to prove anything to those old friends. Making new friends and allowing them to know their full flavor may be difficult, if not impossible.

At any age losing a spouse is one of the most emotionally devastating experiences of life. As your parents age, lose a mate, or other family members and friends, they may feel increasingly lonely for someone who knew and loved them well. They also struggle with the problems of loss of independence, less income, decision-making of any consequence, and a sense of not being needed. For older people "moving" usually means the loss of the familiar when they

must give up many cherished possessions because they won't fit into a smaller home.

The elderly often become preoccupied with illness and death. Older persons have a realistic concern about the boundaries of pain to be tolerated in illness and fear loss of control and dignity. The elderly may become less flexible as they age, become less willing to try new things. They may be unreasonable and hard to talk to. They may be simply grieving, or frightened, or both. Older people are not always treated with kindness or consideration or respect.

One way for older adults to put their life in order is through a life review. The life review can occur in a mild form through nostalgia, regret, a tendency to reminisce, story-telling, and the like. The life review may cause a sense of regret, a feeling in which a person decides life was a total waste. Some of the positive results of reviewing one's life can be a righting of old wrongs, making up with enemies, coming to acceptance of mortal life, a sense of serenity, pride in accomplishment, and a feeling of having done one's best. The elderly may become more comfortable with the acceptance of the life cycle, the universe, and the generations. People may put together family albums and scrapbooks and study their genealogies. It is important for older people to reminisce about their life experiences. The life review is a healthy process.

Even if parents enjoy robust health, and are emotionally healthy, they will experience some slowing down and will suffer some losses. Aging parents will be needing all of the love and support and understanding which caregivers are able to provide as they face their old age, aging, and death. The pastor can provide assistance for adult children to help aging parents adjust to the aging process.

B. Discussion

The group members shared feelings of sadness for the "parent that was." They responded with statements of compassion and increasing empathy and sensitivity to a realization of what some of their parents were experiencing. Members talked about a new awareness of their parents' real loneliness and fears as family and friends die. They noted an appreciation of why the parent daily reads the obituary column in the newspaper. Some members spoke about parents who are "loners." They had an appreciation for parents who never did much socializing and how difficult it is now to begin going to community centers and senior citizen groups. I shared that this problem may become a sore spot between an anxious adult child and parent. Adult children sometimes become insistent that parents who have previously operated within a very limited social sphere now, deprived of a spouse, begin to seek out new friends, become active in "clubs," and volunteer in church work

or hospitals.

C. Evaluation of the workshop

This workshop could be expanded into additional sessions by inviting community resource persons, such as Interfaith or Agency on Aging, to share available community resources. Segments of the video series "For Those Who Care" would also provide excellent information on a variety of topics beneficial to caregivers dealing with disabled or handicapped aging persons.

The responses of the group were favorable to the workshop experience. Each came with a unique experience of frustration, concern, and anger experienced through being a caregiver for aging parents. Several expressed tension as the "sandwich generation." Each had a unique situation, but being a caregiver for aging parents and concern for the needs of children bonded the group.

Several persons realized an appreciation for the aging process as a result of the workshop. New skills for coping with their aging parents offered in the workshop were well received. The exchange of ideas and encouragement from group members strengthened their ability to be primary caregivers. Some of the group members were disappointed that the workshop did not meet their expectations with answers to specific needs or that they were not understood by some members of the group. One concern listed privately with me was

that one member of the group responded too candidly to her description of her situation by saying, "If things are bad now, they will get worse." The values clarification exercises had excellent participation by the group.

Chapter 9

SUMMARY

The information and data shared in this research project is offered as a resource for adult children and clergy to deal with the physical, emotional, and spiritual needs of a growing population of aging persons. They are people loved by God, persons deserving of dignity, and individuals who happen to be our parents, relatives or neighbors. Jesus said, "Whatever you did for one of the least of these brothers (sisters) of mine, you did for me" (Matthew 25:40). Followers of Jesus who pattern their lives after Him will seek ways to relieve suffering and promote wholeness as caregivers for aging parents. Caregivers need to understand that their personal needs for rest, relaxation, and time away from the care-receiver enable them to be better caregivers.

One goal anticipated with this project was to assist adult children and clergy to gain an understanding of the needs of aging parents or relatives. A aging awareness promotes a realization of the uniqueness of each individual, the relationship between child and parent, and the unique environment for providing care. This awareness assists adult children in upholding the family's integrity by planning with the parent(s) whenever possible, thereby honoring their role as parent. The parent/child role cannot be reversed.

Adult children dealing with aging parents should seek to love and honor

them in action and in words. The message "to honor your father and mother" is instilled in children at an early age and continues throughout their lives. The Bible offers many examples for parents and children to treat older persons with honor and respect.

Caring for aging parents involves more than just physical and emotional needs. Consideration for nurturing the spiritual needs of parents should be offered. Through faith in the promises of Scripture, elderly believers can look toward the peak of life's tall mountain and their heavenly home. The death and resurrection of Jesus is the touchstone for our faith and hope for this life even unto life everlasting. As they reflect on the blessings of God, the elderly need to be assured that as they travel the last treacherous cliff, God will transform the flickering light into a glorious eternity.

The primary caregiving role belongs to women. Adult children are frequently caught in the middle, thus the term "sandwich generation." They have caregiving concern for their children, and perhaps grandchildren, while often providing some care for the daily activities of living for aging parents. Caregiving affects the lifestyle of the whole family. There can be no "role reversal" on the part of the adult child and the aging parent, since fifty years of a parent/child relationship cannot be dismissed. Neither can the older person be considered as being in a "second childhood," even though their needs may often be of a regressive nature.

The development of hi-tech medicine is increasing the life expectancy of

aging parents and increasing the burden of parent care. The aging of America is also making "Elder Care" an important issue for employees and employers. Since more women are involved in the work force, there are fewer women able to provide twenty-four hour care for aging parents. Adult children often experience guilt regarding care for aging parents, but there is increasing evidence to demonstrate that adult children are providing care for more difficult problems and for longer periods than ever before.

There are a variety of effects on persons involved as caregivers. Parent care may affect emotional well-being, physical strength, life-style and financial status. Since the majority of caregiving activity is provided by daughters or daughter-in-laws, these caregiving daughters experience more strain than sons do. The majority of older people prefer their independent living and do not want to be a burden to their children, but extra stress occurs for parent and child when the aging parent lives in the same household with the adult child. Problems may be further aggravated when the older person is severely disabled. Another stress factor results when geographical distance from a disabled parent requires dependence upon others to care for the parent. Adult children need to consider possible stress and change of life-style prior to making decisions for living arrangements or assuming the role of primary caregiver for their aging parents. Being a caregiver for another person requires extraordinary qualities.

The feelings of a caregiver need to be monitored to prevent exhaustion

and stress. Unrelieved stress may result in a personal health decline and made the caregiver ineffective. To prevent these problems, the caregiver needs to have outlets which can relieve or reduce this stress. Support groups may offer practical suggestions to caregivers for dealing with aging parents, relatives or friends. There are organizations which can be a resource for support groups in the reader's area or location.

Demographic changes and mobility of families to other parts of the nation develop the need to utilize a variety of supplemental resources for parent-care. More women entering the labor force are reducing the supply of filial caregivers, while at the same time there are increasing pressures on women to care for several older people. Multiple caring responsibilities may also increase because older people who have no children will need to depend on neighbors, relatives, or community resources. The homes of some middle generation people are not only remaining filled with their offspring for longer periods of time, but are being refilled with young adults who return home. Some adult children of both genders help elderly caregiving spouses, and some care for both parents at the same time. Some younger adult children become primary caregivers when deaths in the middle generation leave a caregiving gap. Some grandchildren find themselves responsible for two generations of older people-- their parent(s) and grandparent(s). Even when not in primary caregiving roles, grandchildren and other members of the caregiver's extended families will be called upon as the invisible back-up system to offer assistance at times of

emergency or special need.

The workshop model for support groups provides an opportunity for adult caregivers to discuss concerns, share feelings, and exchange ideas on coping with aging parents. Adult children may be able to identify with being "the sandwich generation" as they meet the needs of their children, the needs of aging parents, and often pursue their own careers.

Although one workshop on caring for the aging is insufficient to test its value, favorable responses to the workshop experience indicate a need for a permanent support group. An increasing number of care-receivers calls for caregivers to have understanding of the aging process, appreciation for the inevitable changes in the elderly, and better preparation for their own role.

APPENDIX A**TEN COMMANDMENTS FOR CAREGIVERS¹⁰⁶**

1. Honor your mother. Love her with all your heart. She is the only one you will ever have.
2. Don't let your mother run your life. Be loving, gentle, but be in charge.
3. Don't be afraid of your mother. You're all grown up.
4. Be good to yourself so that you won't burn out.
5. Do not consider yourself mother to your mother. You are not and cannot be.
6. Don't patronize your mother or baby her. She has lost her youth, not her mind.
7. Do as little as possible for your mother as long as possible. She needs to do for herself.
8. Plan your mother's last years with her, not for her.
9. Do not be a martyr.
10. Accept your mother's aging and her death. You have no choice, and acceptance brings peace and understanding.

¹⁰⁶E. Jane Mall, Caregiving: How to Care For Your Elderly Mother and Stay Sane (New York: Ballantine Books, 1990), 210.

APPENDIX B

Dennis Saylor shared the following "Ten Commandments for Caregivers" at a National Conference on Pastoral Care:

1. Do the best you can. Leave the rest. Recognize when another can do a job better than you can. We all want to feel important.
2. Get peer support. Be with people who understand your needs and frustrations.
3. Accept your limitations. You can't have all the answers all of the time. We are only human.
4. Distinguish between reasonable and unreasonable responsibilities. You cannot be responsible for the actions of others and you cannot guarantee outcomes.
5. Do something for yourself each day. Nurture yourself in a way that is meaningful to you. Find personal space.
6. Accept second-best when necessary. Some may not want your ministry. No one person can do everything for everybody.
7. Learn to say "NO" to unreasonable demands without feeling guilty. Make good referrals. Set limits ahead of time.
8. Accept responsibility only for your own problems. You can't bail out everyone.
9. Do not make promises you cannot keep. Do not let yourself be manipulated.
10. Be patient. Very few problems develop quickly. So they won't be resolved quickly.

APPENDIX C**TEN COMMANDMENTS
FOR CARE RECEIVERS¹⁰⁷**

1. Honor your daughter/son. Love them as the loving adult daughter/son you are lucky to have.
2. Don't let your daughter/son run your life. Be loving, be firm, accept your growing dependence. Let them help you stay in charge of your life.
3. Don't be afraid of your daughter/son. You are still the mother. You are adults.
4. Be good to your daughter/son caregiver so they won't burn out.
5. Do as much for yourself as possible. Remember your daughter/son have other responsibilities and demands on their time.
6. Do not make your daughter/son feel guilty, but appreciated.
7. Give love freely and accept love graciously.
8. Keep your sense of humor. Make your daughter/son glad they are sharing this time with you.
9. Keep your daughter/son informed about what's happening to and within you. Know the difference between sharing this and complaining.
10. Your daughter/son do not know how to be old, how to die or accept your dying. Teach them.

¹⁰⁷Barbara Pittard Payne, Fort Worth, Texas, January 12, 1991. (Item received from a workshop attended at Catholic Social Services, Milwaukee, WI)

APPENDIX D
VIDEO SERIES
"FOR THOSE WHO CARE"

There are nine videos in this series that have been produced by Metropolitan Dade County, Florida, Department of Human Resources, Elderly Services Division. The series is also available from the Extension Services at North Dakota State University. Caregivers would discover this series a valuable assistance for "Taking Control of Health Care." The following list will help the viewer on the themes and topics covered in the series:

1. You're Only Old Once
2. Adding Life to Years
3. Taking Control of Health Care
4. Caregiving and the Law
5. Being the Best We Can Be
6. Benefits That Work for You
7. The Hardest Decision of All
8. The Art of Caring (Part I)
9. The Art of Caring (Part II)

I would offer the following summary on selected videos as an expansion on topics related to this paper.

Video # 3: "Taking Control of Health Care" involves a panel of physicians and pharmacists offering suggestions to health caregivers. There should be a bond between physician and caregiver at home. The caregiver should be tuned into changes in the physical condition of the carereceiver, what side-effects accompany certain medications and the accessibility of the physician. The visit to the

primary physician should offer answers to the following questions: Why did he/she come or call? What do you think is the problem? What are his/her fears? The caregiver should know the medications that are being taken, perhaps even take the bottles of medications along to the doctor's office. The caregiver should also be alert and ask questions from the physician, such as: What is the medicine for? What dosage? When should it be taken? Are there any foods or beverages to avoid? Are there any medications that should not be taken at the same time? Are there any special precautions?

The pharmacists offer the following suggestions:

1. Medications need to be individualized. Periodic evaluation is helpful.
2. Over the counter medications can be effective, but may also interact with other medications. Report multiple medications consumed.
3. Assemble all medications in one place in the home. Do not combine medications into one bottle. Store prescriptions in their own container.
4. Develop a "Medicines I Take" chart.
5. Arrange for a daily or weekly container system.
6. May instruct pharmacist to place medication in an easily opened bottle.
7. Dispose of all unused prescriptions down the stool, not in the trash.
8. Keep labels clean.
9. Never take medications in the dark.
10. Never take medications prescribed for others.

The panelists offer suggestions for information to be posted in the apartment or home for emergency reference:

1. Name and address of the individual with his/her age, birthdate and next of kinfolk or neighbors to contact.
2. Important identification numbers.
3. Names of doctors used.
4. List of medical condition.
5. List of any allergies and diet condition.
6. History of any substance abuse.

7. Health plan, address and phone number.
8. Health or social services being used.

Video # 5: "Being the Best We Can Be" with Raymond McPhee as Moderator, emphasizes the importance of exercise for both the caregiver and the care-receiver. The diet should contain a balance of the four major groups, but include more fiber and fluids. One may add variety to the foods offered but reduce the amount of salt in the diet. The caregiver should help the receiver to get involved in food preparation, as well as provide some input for decision-making about the food. The caregiver should realize that the rejection of food may not be rejection of the person preparing it.

The caregiver needs to care for himself or herself with exercise and good diet. The caregiver may have a job, concern for other family members, plus care for the older adult. Keeping all of these routines going may result in the caregiver's feeling tired, angry, and yet trying to tend to all three areas of concern. Many caregivers may have other relatives to care for the aging person, but they often get good feelings from doing the care themselves. The caregiver needs to take good care of himself or herself and learn to involve other family members. A caregiver may also discover a support group to be helpful for releasing tension and anger. Furthermore, the caregiver should maintain hobbies, hold outside interests, and stay in touch with friends.

Exercise is important for the aging adult. All have some range of mobility. A series of exercise activities may be used after breakfast and before

retiring. The video offers excellent examples of chair exercises involving stretching of hands, head rotation, hand to knee, and squeezing objects. If the care-receiver is confined to bed, there are also examples of exercises for rotation of wrist, raising arms, and rotation of ankle.

Video # 8 and # 9: "The Art of Caring" offers practical suggestions for transfer and ambulation within the home and into a vehicle for transportation. Floors need to provide a solid footing should a cane or walker be used. Grab bars may be installed at strategic locations in the bathroom to help with transfer.

Safety in the home is important to prevent accidents. Lighting may need to be improved. Non-skid mats or secure scatter rugs should be installed. Large print warning signs should be placed on appliances. Smoke detectors with fresh batteries and an emergency alert system should be installed. Dressing techniques, home care and cleaning, bed making, specialized dishes and silverware are further noted in this video.

APPENDIX E**VIDEO SERIES****"YOU AND YOUR AGING PARENTS"**

Another video, "You and Your Aging Parents" and an accompanying book entitled: Aging Parents-How to Understand and Help Them by Richard P. Johnson, will help the adult child deal with the frustrations of caring for an aging parent. The video and book will help him or her better understand the emotional and physical needs of the aging parent.

The goals of this video include the following:

- to help the adult child understand the physical and emotional needs of the aging parent.
- to help the adult child develop a quality relationship with the aging parent.
- to help the adult deal with his or her own feelings of frustration and anger.
- to help the adult child and the adult parent communicate.
- to show the adult child how to help his or her parent develop a more positive and meaningful attitude.

This video and book are also available through the North Wisconsin District Resource Library, Lutheran Church-Missouri Synod, 3103 Seymore Lane Wausau, WI 54401.

APPENDIX F

A Caregiver's Bill of Rights¹⁰⁸

I have the right:

To take care of myself. This is not an act of selfishness. It will give me the capability of taking better care of my relative.

To seek help from others even though my relative may object. I recognize the limits of my own endurance and strength.

To maintain facets of my own life that do not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things just for myself.

To get angry, be depressed, and express other difficult feelings occasionally.

To reject any attempt by my relative (either conscious or unconscious) to manipulate me through guilt, anger, or depression.

To receive consideration, affection, forgiveness, and acceptance for what I do from my loved one as long as I offer these qualities in return.

To take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my relative.

To protect my individuality and my right to make a life for myself that will sustain me in the time when my relative no longer needs my full-time help.

To expect and demand that as new strides are made in finding resources to aid physically and mentally impaired older persons in our country, similar strides will be made toward aiding and supporting caregivers.

To _____

Add your own statements of rights to the list. Read the list to yourself every day.

¹⁰⁸Jo Horne, Caregiving: Helping An Aging Loved One (Glenview, IL: Scott, Foresman and Company, 1985), 300.

APPENDIX G

Session 1

Key Points of the Mini-lecture (handout)

Determining the extent of your responsibility to your parents¹⁰⁹

1. We do indeed have a responsibility toward our parents, but a responsibility that is evolved and redefined by working through the old relationship which may have been painful and nonproductive, and arriving at a new relationship based on love, understanding, and self-acceptance.
2. Responsibility for parents is best met as a shared responsibility, either with other family members or with surrogate family: paid helpers, volunteers, neighbors, professionals, and community resources.
3. Parents' wishes and needs must be considered and be part of any planning on their behalf.
4. We need to be cognizant of our own needs and learn not to feel guilty when we take care of ourselves.
5. It is acceptable to meet our own needs.
6. If we give up meeting our needs consistently we will feel angry, guilty, helpless, or sick.

¹⁰⁹Goodman, Aging Parents: Whose Responsibility?, 35.

APPENDIX H

Session 2

FILIAL MATURITY¹¹⁰ [handout]

Filial maturity is a life task through which the adult child learns to relate to the parent not as a child to parent, nor as a parent to parent, but as an adult child to parent.

A person who has achieved this stage can hold her own, meet her own needs, set proper limits and give real help to her parents without feeling overwhelmed or over powered.

At the same time, a person who has achieved filial maturity can finally forgive her parents, recognize the needs of her parents and accept her parents as adult human beings.

As in mastery of other life tasks, the achievement of life task, the achievement of filial maturity requires effort, understanding, patience, trial and error, self-acceptance, and self-evaluation.

¹¹⁰Goodman, Aging Parents: Whose Responsibility?, 59.

APPENDIX I

Session 3

HOW TO BE A HAPPY AND SUCCESSFUL ADULT CHILD

TO YOUR PARENTS (Handout)¹¹¹

If you feel that your parent has not accepted you or loved you or validated you sufficiently, stop trying to make it happen, but begin to find new ways of accepting yourself, loving yourself and validating yourself as a human being.

Remember that your parents probably did the best possible job of parenting within their capacity. They were someone's children once, too!

Remember that your parents have needs and rights.

Help your parents as needed, with good humor and grace.

Help without undermining independence. Respect your parents' dignity. When you suggest available resources to your parents, do not consider this as a substitute for yourself or what you can do.

Do not plan for, but with your parents for their care, as long as they can reasonably be involved in the planning. Become aware of their wishes and desires now, so that you can respond accordingly if you should have to make decisions for them at a later time.

Let your parents know that you love them, that you admire and respect them (if you do) and let them know in a loving spirit that you will be there when they need you.

Be physically involved by smiling at, touching, stroking, hugging, kissing, and embracing (but not if it is completely alien to you) your parents.

Maintain regular phone and personal contact.

Invite your parents to your home, and visit your parents where they live.

¹¹¹Goodman, *Aging Parents: Whose Responsibility?*, 89.

Include your parents in family and holiday celebrations and plan outings appropriate to your parents' interests and health. Provide ample opportunity for your parents to be with you, your children, and your grandchildren.

Bring the outside world to your parent who is ill or debilitated. If your parent is physically isolated through illness, she or he needs as much stimulation as you can provide with books, magazines, conversations and friends' visits.

Be imaginative in the gifts you buy and do remember anniversary occasions.

Finish any unfinished business with your parents; say "I'm sorry" and help them to say "I'm sorry" to you.

If your parent wants to discuss death, either imminent or distant, listen and respond as honestly and realistically as possible. Assure your parent that you will carry out any wishes regarding funeral arrangements and so on.

Treat your parents as adults; accept them as human beings who happen to be your parents.

Maintain a sense of humor!

APPENDIX J**Session 4 Workshop****OLD PEOPLE ARE. . .¹¹²**

1. Old people should. . .
2. Old people always. . .
3. Old people look. . .
4. Spending time with old people is. . .
5. Old people need. . .
6. Old people have rights to . . .
7. As far as sex goes, old people. . .
8. Old people can expect. . .
9. Old people have power to. . .
10. Old people's small fixed incomes are. . .

¹¹²Goodman, Aging Parents: Whose Responsibility?, 117.

APPENDIX K**Aging Awareness Test¹¹³**

1. Senility or senile dementia is a normal part of body breakdown in the aging process.
2. Senile dementia is irreversible.
3. After the age of sixty-five the ability to learn is greatly diminished.
4. Creativity diminishes with age.
5. Most older people are physically weak and in poor health.
6. Over 50 percent of elderly people need nursing home or similar type care.
7. Vision loss or change is noted in over half of the people over sixty-five.
8. In the aging process, people's senses become less acute.
9. Only about one-third of the population over sixty suffer from hearing loss.
10. Retirement seems to bring about declining health.
11. Older people are unable to adjust to modern innovations.
12. The aging process causes people to become more self-absorbed and uninterested in community affairs.
13. Most elderly people have little or no interest in sexual activity.
14. Sexual capabilities diminish rapidly after sixty-five years of age.
15. Sixty-five percent of America's elderly are below poverty level or in economic straits.

¹¹³Rushford, The Help, Hope and Cope Book, 18-19. Only statements seven through nine are true. Seven or more correct answers gives you a passing score.

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VIDEO SERIES:

"For Those Who Care", Produced by Metropolitan Dade County, Florida, Department of Human Resources, Elderly Services Division. Available from NDSU Extension Service.

Johnson, Richard P. "You and Your Aging Parents" Produced by Liguori Publications, Box 060, Liguori, MO 63057.

ORGANIZATIONS:

Wisconsin Department of Health and Social Services, Division of Community Services, Bureau on Aging.

Alzheimer's Association offers local chapters information on the symptoms of Alzheimer's and the necessary diagnostic tests. Call the Association's toll-free number for the Chapter nearest you: 1-800-272-3900 (TDD: 312-335-8882).

American Association of Retired Persons, 601 E. Street, N.W., Washington, D.C. 20049

Eldercare Locator is a resource to help you find community services for seniors through a national toll-free number: 1/800/677-1116. The Locator gives you access to an extensive network of organizations serving older people at state and local community levels. These State and Area Agencies on Aging are funded in part by the U.S. Administration on Aging through the Older Americans Act.

Elder Link Information and Assistance for Older Adults, Milwaukee County Department on Aging may be reached at 414/289-6874. Offers a complete listing of available services and programs through community agencies to individuals 60 years and older.

Southeastern Wisconsin Area Agency on Aging is one of six regional area agencies in Wisconsin providing a link between the Wisconsin Bureau on Aging and the local County Aging Unit. The Agency coordinates, develops, supports

and monitors programs and services for older adults in Kenosha, Ozaukee, Racine, Walworth, Washington, and Waukesha counties.

The National Council on the Aging, Inc., 600 Maryland Avenue SW, West Wing 100, Washington, D.C. 20024 (Phone: 202/479-1200). NCOA publications are valuable to practitioners in health and social welfare settings, older persons, policy makers, students of gerontology, and the public at large.

NEWS MAGAZINES (Sample listing from one community)

50 Plus Southeastern Wisconsin Lifestyles, published in Hartland, Wisconsin.

The Senior Newspaper, Inc, The Newspaper for Southeastern Wisconsin's Older Adults, published in Milwaukee, Wisconsin.

BIBLE STUDY

Dear Lord, I'm Aging. St. Louis: Concordia Publishing House (Study Guide # 20-2093). A discussion-oriented course for adults of all ages. The six chapters focus on concerns of all people as they grow older. This large-print format enables individuals with impaired vision to participate more easily.