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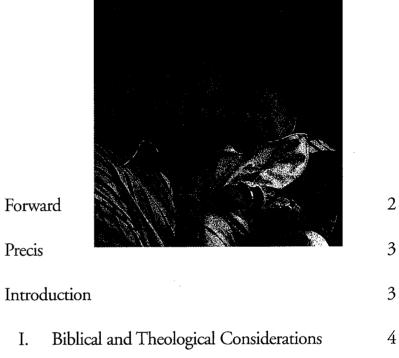
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Trends Related to an

III. Challenges to Caregiving

Recommendations

Aging Society and Caregiving

#### Forward

The Advisory Committee on Social Witness Policy (ACSWP), in consultation with the General Assembly Council's Office on Older Adult Ministry, was asked by the 210th General Assembly (1998) to study and develop a resolution on the ministry of caregiving. The Assembly called upon the ACSWP "to explore what the ministry of caregiving means as the population rapidly ages, and especially, for those with debilitating and/or fatal illnesses" (*Minutes*, 210th General Assembly (1998), Part I, pp. 80, 474).

In adopting the Resolution on the Ministry of Caregiving in Relation to Older Adults, the 213th General Assembly (2001) offers the church an urgent call to care for its members-in fact as well as in faith. The urgency of the call is made explicit at this time as the post-World War II baby boomers experience a lengthening of the average life span and are becoming the fastest growing age group in the older population. Those in our congregations and in the surrounding communities that our congregations serve will increasingly need caregiving. To take our faith seriously, we must begin now to develop ways to meet the needs of those who are elderly and have debilitating and/or fatal illnesses. The resolution which follows offers biblical and theological resources to assist churches to reflect on their caregiving responsibilities. Trends related to an aging society and caregiving are explored. The challenges to caregiving presented by changing family patterns and contemporary values are presented in brief form.

People of faith and the congregations in which they serve must assess the needs of the aging population in their community and seek ways to support and sustain family caregivers. The church can play a vital role in developing models that provide caregiving to all who are in need.

A small resolution team, appointed by the ACSWP and chaired by Jananne Sharpless, met together as a group for study and the development of the resolution for the committee. Along with its chair, the group included the following: William Arnold, Mary Jane Patterson, Marty Richards, Karen Meier Robinson, Miriam Dunson, Bernellyn Carey. Belinda M. Curry served as staff from the ACSWP.

This brochure includes the recommendations in bold print as well as the full rationale from the resolution.

Peter A. Sulyok Coordinator Advisory Committee on Social Witness Policy

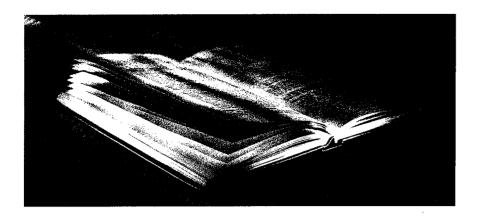
#### Precis

This report and recommendations are in response to the following referral: 1998 Referral: 25.0358. III. Reports and Resolutions. C. Resolution on the International Year of Older Persons. Recommendation j. That the Advisory Committee on Social Witness Policy, in Consultation with the General Assembly Council's Office on Older Adult Ministry, Study and Develop a Resolution on the Ministry of Caregiving and Report No Later Than the 213th General Assembly (2001)-From the Advisory Committee on Social Witness Policy (*Minutes*, 1998, Part I, pp. 80, 47475).

### Introduction

This resolution, written at the direction of the 210th General Assembly (1998) to explore what the ministry of caregiving means as an aging population rapidly increases and especially, for those who are elderly and have debilitating and/or fatal illnesses, calls the attention of the whole church to the increasing number of elderly people in the population, emphasizes the need for caregiving, and makes the following recommendations for action to various entities of the Presbyterian Church (U.S.A.). The resolution further recognizes that the locus of ministry to older persons is at the congregational and middle governing body levels and that the General Assembly should provide resources and raise the awareness of the church and society to the needs of older adults.





## 1. Biblical and Theological Considerations

The ministry of caregiving is so fundamental to the life of Christian faith that it is often taken for granted. However, in particular situations, such as the growing need for caregiving in a society in which the percentage and number of elderly people is rapidly increasing, it is well for the church to remember some of the theological underpinnings that shape and guide its responsibilities in this regard. To neglect these basic commitments may result in a parallel neglect of the human beings who both need care and are still able, in sometimes amazing ways, to care for others.

At the very foundation of the church's understanding of what it means to be human is the belief that life is a gift from God. We are made aware of this in the opening chapters of Genesis, and re-affirmations are woven throughout the biblical witness. God created us out of God's own free choice. Knowledge of the source of this gift of life brings an accompanying responsibility to respect and care for ourselves. Furthermore, we are to know that not only is our life a gift, but the life of our neighbor is a gift.

In addition to life being a gift from God, the biblical writers proclaim that human beings are made in God's image. Indeed, when we look into the face of our neighbor, we are, in a very real sense, looking into the face of God. However, it is not merely in looking that the image of God becomes visible, it is also in the relationship that develops. No one human being can reflect the image of God fully. We are finite creatures; we are limited. Our doctrine of the trinity reminds us that God is far more that we can be. Indeed, God is a relationship. No one person can be a relationship, but when we enter into relationship with one another, we step further into the experience of reflecting the image of God. To initiate and maintain caring relationships is a part of being faithful to our Creator. To turn away from caring relationships, is to turn away from God, to be unfaithful.

Out of these beliefs, regularly reinforced in Scripture and in the ongoing theology of the church, the responsibility that we carry, as creatures made in the image of God, to care for each other are evident. The history of the church, from the genealogies of the Hebrew Scriptures to our continuing records of generations of people of faith, is a testimony to the importance of caring for and about those who preceded us and will follow us. Caregiving is an intergenerational, familial obligation for people of Christian faith.

Within the tradition of caring, there are many forms. Most traditional histories of pastoral care in the church describe four forms of caring: healing, sustaining, guiding, and reconciling. Each of these forms offered selectively in different circumstances has evolved as greater awareness has dawned upon humans of the variety of ways in which caring is needed, received and offered.

Caregiving is both an individual and a corporate responsibility. Individuals offer care, but no one person can provide all the care that is needed by another. Nor can any one person receive all the care that is needed from only one other. One parent is not enough; a spouse is not enough; a pastor is not enough; one good friend is not enough. The experience of caring relationships teaches us of both our individual need and our individual inability to meet the demands of the task of caring alone.

In partial response to that reality, God created the church . . . the community of faith whose faithfulness is demonstrated by the willingness and the commitment of care for one another within "the family," as well as for those in the larger community. Individually and corporately, by the very nature of our creation, we are called to be caregivers-for ourselves, as reflections of the image of God, and for others, who also are created in the image of God. This knowledge and this responsibility elevate some of the very basic constituents of our call to stewardship and service.



# 2. Trends Related to an Aging Society and Caregiving

The past century has witnessed a remarkable lengthening of the average life span in the U.S. from 47 years in 1900 to more than 75 years in the mid-1990s. And as life expectancy continues to increase, trends for birthrates are declining. The combination of these trends is creating a shift in our society's age distribution where the percentage of older individuals comprising the U.S. population is gaining proportionally. In 1997, 13 percent of the population was 65 years and over. By 2030 it is estimated that 20 percent of Americans will be 65 years and older with the fastest-growing group being 85 years and older.

In looking at trends in aging, gender does make a difference. On average women currently live longer than men. According to the National Center on Women and Aging, "women represent 59 percent of Americans over the age of 65 and 71 percent of those older than age 85."

The living arrangements of older persons vary significantly by age, sex, race and marital status. According to a government survey, in 1997 a majority of persons 65 years and older lived with family members, while nearly one third lived alone. Women in every age category were more likely than men to live alone. The number of residents living in nursing home rises sharply with age with persons 65 to 75 years comprising 1 percent and persons 85 years and older comprising 20 percent. As far as gender is concerned, in 1997 women had higher rates of nursing home residency than men.

While many more people are realizing longer lives, the aging process has made the elderly much more prone to chronic diseases. Heart disease, cancer, stroke, and chronic pulmonary diseases are the leading causes of death among the older population. According to the U.S Department of Health and Human Service, Health and Aging Chart Book (1999), "In 1995 among the non-institutionalized persons 70 years of age and over, 79 percent reported having at least one of the seven chronic conditions common among the elderly." In addition, the majority of those persons reported experiencing arthritis, a third hypertension and 11 percent diabetes. While included in that statistical group, women specifically are more likely to suffer from osteoporosis, diabetes, hypertension, incontinence and arthritis than men.

of didwide some 29 million people suffer from dementia of which Alzheimer disease is common form. Predictions indicate there will be a profound increase in the disease as a population continues to grow older. Their mental and neurological disorders can produce a relatively minor effect to the incurable and life threatening. But in many affect conditions are severely debilitating. The population over 85 years of age is a spirit (isk. Evan et al. (1990) reported that 47 percent of the population in that agost had some form of dementia.

the changes in health care financing and delivery have intensified family caregiving appoints bilities and presented a paradox. More medical procedures performed on an outpatient basis, shorter hospital stays and more complex equipment in the home leave some caregivers overwhelmed. The majority of caregivers are women attempting to balance daily family caregiving (which often includes caring for their children and caring for their parents) with outside employment. They often must make adjustments in their work schedules such as working shorter days, taking leaves of absence, or giving up outside employment altogether. On the other hand while many of these situations may be daunting, those giving care, i.e. spouses, adult children, relatives and friends, have also found rewards in spending quality time with their loved ones and in providing situations of familiarity, comfort and dignity for persons receiving care.

In 1995, 70 percent of the caregivers were women and 73 percent were unpaid or informal helpers (U.S. Department of Health and Human Service, 1999.) An emerging social trend, however, seems to be toward greater parity in



caregiving between men and women. A recent study by the National Family Caregivers Association estimates that men represent 44 percent of the 54 million people who are caring for a family member at home.

Family caregiving studies indicate that the burdens of the family caregiving experience have negative consequences on the physical and mental health of caregivers. Caregivers commonly suffer stress, depression, anxiety and fatigue. Research has also linked chronic stress of caregiving to breakdowns in the cardiovascular and immune system over time. In addition to the physical strain, the accelerating costs of health care often leaves the financial resources of caregivers depleted before they can access any type of state or federal assistance.

According to a 1999 U.S. Government survey, among informal and unpaid caregivers, 91 percent were family members and 51 percent lived in the same household as the recipient of the help. One fourth of the caregivers were spouses and slightly more than one half were children. With the shift in age distribution, smaller families and lack of connectedness between generations, fewer able family members may be available for caregiving in the future. This trend is being met with an already existing shortage of professional caregivers. Under today's conditions, this problem is likely to continue particularly in the geriatric setting where professional caregivers are provided lower wages and status in their professional life.

One unknown and possibly offsetting trend is the change in employment patterns and early retirement. This change has significant implications on how society will function, i.e. the amount and use of discretionary time and voluntary services, and what it might mean in terms having a potential pool of able and experienced people available to meet the growing needs of providing care.



## 3. Challenges to Caregiving

Changing family patterns and contemporary values have put additional pressure on a caregiving system that has been relying on family members as caregivers. In a mobile, competitive, fast-paced modern existence, the



value of maintaining family connectedness and kinship solidarity is eroding. In its place, being independent, self-reliant and "not a burden" has become the number one national sign of worthiness or wholeness. Consequently, older family members functioning independently in daily life can continue to feel good about their place in society and feel worthwhile in their contributions. Unfortunately, as soon as one becomes frail or disabled, dependency increases, attitudes change, and the individual is perceived as a problem. Self-sufficiency as a singular mark of worth contradicts the theology highlighted above and counters the needs of people with diminished autonomy because of chronic, debilitating, and terminal illness or diminished mental capacity. It is too often the case that family members, protective of their own autonomy, look for a solution that will not "interfere" with the busyness of their ongoing lives. In addition, a cultural view of "pity" for caregivers reduces the perceived worth of the caregivers themselves. Those who are paid to be caregivers are generally at the lower end of the compensation scales, which further contributes to a low view of the value of quality caregivers.

Along with the change in family patterns is the challenge posed by the change in societal patterns where neighborhoods, housing patterns, social programs and activities emphasize "age-separation." This condition supports differences and isolation versus the important connective web between generations that capitalize on the gifts of each and responds to the interdependency of each generation to one another. Being a caregiver and responding to the needs of the elderly are as much an intergenerational issue as the care and nurturing of our children.

Another challenge is the failure to recognize the variety of meanings of "care" itself. Such variety in forms of caregiving is an expression of diversity among human beings from racial/ethnic considerations to gender differences, to family traditions. Individual human beings are raised in different families and circumstances. Within those families and circumstances there are experiences of nurture, or lack of nurture, that shape each person. A sensitive expression of care is dependent on a number of variables, including: the relationship between the caregiver and the recipient of care; the family and friends of the recipient; knowledgeable professionals; cultural background and traditions of the

recipient; and the nature of the relationship of the recipient and the caregiver to the church. All of these people must join together on their recognition of the importance of care and their desire to insure its provision in the best possible way in each circumstance.

Given the diverse culture of a people who share a variety of backgrounds and traditions, no one model of caregiving can adequately respond to such multiplicity of caregiving situations. However, rather than an obstacle to response, diversity can provide a richness of human experience from which all can learn, adapt and profit.

Failure of the church to address the caregiving challenges results in a number of losses. Of course, the ones in need suffer the major loss. Rather than care, which reflects a perception of them as made in the image of God, the recipients are treated as objects without value because they do not fulfill the cultural requirements of productivity and self-sufficiency. This may even mean that the values and wishes of the recipient are not respected even to the point of their desires being disregarded in the distribution of their possessions and in the content of their memorial services when death comes.

There is also the loss to the family and friends of the ones in need of care. The provision of care characterized by the witness of the Christian faith results in richness not only for the recipient but also for those who provide the care. This is not to say the caring is always a pleasant or regularly fulfilling endeavor. However, caring provided within the context of a belief in the integral worth of all human beings results in a meaningful experience for all concerned.

Finally, there is the loss to the extended family, the church, and society as a whole. As esteem diminishes for those in need of care, and for those who give care, the result is conscious or unconscious fear that our own time of being "disregarded" lies ahead. Such a perception, results in a diminution of the human spirit and a life lived without the "abundance" God intended: a life lived in the knowledge that we all are created in the image of God and are, therefore, deserving recipients of care.

Despite the difficulties and challenges, many of today's caregivers report rewards received from caregiving experiences. Many caregivers find strength to cope with the situation by turning to their religious practices, rituals, and beliefs. This increased reliance on faith traditions and spiritual perspectives is a positive aspect of caregiving that needs to be reinforced and nurtured. As individuals face the increasing demands both as caregivers and care recipients, more and more faith traditions will be important in providing the meaning for this life experience.

For all these reasons, people of faith and their congregations are vitally needed to support and sustain family caregivers. The leadership of the church needs to create models related to the ministry of caregiving.

The Advisory Committee on Social Witness Policy (ACSWP) reminds the church that its existence as a caregiving community carries certain obligations and recommends that the 213th General Assembly (2001) of the Presbyterian Church (U.S.A.) approve the Resolution on the Ministry of Caregiving in Relation to Older Adults and call upon the assembly to approve the following actions:

- 1. Encourage the church to be diligent in being faithful to its covenantal responsibility to care for all its members, in fact as well as in faith, especially older adults, those with debilitating and/or fatal illnesses, and their caregivers.
- 2.Direct the General Assembly Council, Office on Older Adult Ministry, to make available resources that enable congregations to celebrate caregiving through conducting ceremonies and in the use of symbols, such as in healing services, liturgies, banners, stories, etc., in order to support the spiritual nurture of caregivers.
- Affirm the Parish Nursing model for the ministry of caregiving, and encourage local congregations to contact the Office of Health Ministries (USA) for resources on Parish Nursing.
- 4. Establish or strengthen the Parish Nursing model by partnering with community hospitals/other health care agencies to provide and/or strengthen the ministry of caregiving.
- Commend the Board of Pensions for their Employees Assistance Response
  Program, which provides counseling and support for church employees and
  their eligible dependents on a variety of life issues, including caregiving.
- 6. Encourage the Mission Responsibility Through Investment (MRTI) committee, in its conversations with corporate employers, to lift up the impact of caregiving on worker productivity and the importance of caregiving in the design of benefit packages, employee assistance programs, and pension levels.
- 7. Affirm that the ministry of paid caregiving is an important vocation. Direct the Presbyterian Washington Office to advocate for just and fair pay for caregivers, in consultation with the General Assembly Council, Office of Health Ministries (USA), Advocacy Committee for Racial Ethnic Concerns (ACREC), and Advocacy Committee for Women's Concerns(ACWC).

- 8. Urge the Presbytery Committee on Ministry and Committee on Preparation for Ministry to note the continuing studies on clergy stress and burnout and to design programs to assist pastors in coping with the demands of parish life (including caregiving responsibilities), finding resources for continuing education and consultation on, and care of self.
- 9. Urge the Presbytery Committee on Ministry to design programs for retired and retiring pastors, giving specific attention to the implications of their frequently being disconnected from their most recent communities and the accompanying loss of potential caregiving resources for themselves.
- 10. Encourage middle governing bodies to take action to create special programs at the local level to meet the identified needs by connecting to local community resources, and hospitals to implement the needed programs (e.g., support groups, care teams, adult daycare, home delivered meals, and cooperative ventures with senior centers).
- 11. Encourage congregations and middle governing bodies to offer education/training that is held during regular adult education classes or during Sunday School. These events might include general education regarding aging/caregiving issues; education for special needs populations (e.g., dementia); and end-of-life decisions.
- 12. Encourage congregations to observe Older Adult Week and consider ongoing ceremonies to make caregiving visible in their ministry.
- 13. Encourage congregations to build support groups for caregiving, including emotional and spiritual support for long distance caregivers.
- 14. Remind local congregations that they, too, are employers and should view the impact of caregiving issues on worker productivity, as well as the importance of considering caregiving issues in the design of benefit packages, employee assistance programs, and pension levels.
- 15. Encourage congregations to train their deacons or others responsible for visitation ministry for spiritual enrichment visiting in nursing homes, such as reading Bibles, taking hymn books, reviewing church bulletins and church newsletters so that the visit becomes an extension of the caregiving ministry of the church.

- 16. Encourage each congregation to acknowledge the strengths and diversities of each racial ethnic group and be willing to be open to learn new ideas and ways of caregiving.
- 17. Encourage congregations to become agents of change to enable all people to value caregiving and thus to break down traditional gender role stereotypes so that all people can become nurturers and caregivers.
- 18. Encourage congregations to find intergenerational opportunities to use the talents/abilities of their older adult members to provide nurture/care to younger people of faith.





