

EDUCATIONAL/GROWTH GROUP INTERVENTION
FOR ADULT CHILDREN WHO ARE PROVIDING
CARE FOR THEIR DEPENDENT PARENT

by

© Jerry Floom

Report of a Practicum

Presented to

The Faculty of Graduate Studies

In Partial Fulfillment

of the Requirements for the Degree of
Master of Social Work

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BY

JERRY FLOOM

A practicum submitted to the Faculty of Graduate Studies
of the University of Manitoba in partial fulfillment of the
requirements of the degree of

MASTER OF SOCIAL WORK

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Introduction

Rationale and Objectives

Demographically, there has been a dramatic change in the population of North American society. There has been a geometric increase in the elderly population over eighty (Davis, 1983; Gillaspy, 1979; Statistics Canada, 1975, 1980, 1981). With the current increase in the numbers of the elderly and particularly the old-old, (over 80 group), the care of the elderly becomes an ever more pressing problem. This fact will have major implications for relatives of the elderly. With survival to old age comes greater vulnerability and dependence on others. Though most old people wish to be independent of their families, it is primarily children to whom they turn when in need of general assistance and, particularly, in times of crisis (Robinson and Thurnher, 1979; Shanas, 1979; Sheldon, 1982).

There is an increasing emphasis in the health care system toward a community approach to care. Rapidly rising health costs, the current trend toward earlier discharge from acute hospitals and with the shortages of nursing home beds, there has and will continue to be an increase in home care. All these factors have resulted in more adult children becoming involved in caring for physically dependent parents (Robinson and Thurnher, 1979).

The relatives of the aged are expected to provide care. They are considered to be the primary support system. When the relatives are placed in this situation, they are not always prepared to handle the stresses and burdens associated with their new role (Cohen, 1983; Glosser and Wexler, 1983; Hartford and Parsons, 1982; Hausman, 1979; Robinson and Thurnher, 1979; Sanford, 1980).

There is increased recognition that caregiving relatives require assistance. The need is not only for emotional support, but for gaining greater understanding of the processes of aging, for help in planning and direction for future action, for locating resources, for understanding roles and relationships, and for acquiring behavior appropriate in the particular situations (Cohen, 1983; Hartford and Parsons, 1982; Hausman, 1979; Silverman, Brahce, Zielinski, 1981).

A group work approach has demonstrated suitability for meeting the emotional and educational support needs of caregiving relatives on the issues of aging and their role as caregivers. Support groups have been shown to counteract isolation. Groups help members to realize that they are not alone with their problems. In this type of group, participants experience psychological relief by sharing common difficulties, engaging in mutual problem-solving, and receiving recognition and support from other group members. The presence of others gives members a chance to receive feedback that can assist them in their change efforts. Members are able to express fears about their own aging as they encounter mental

and physical deterioration in aging parents. Support groups offer an acceptable outlet for the anger, the frustration, and the guilt felt by caregivers who are confronted with their relatives' increasing dependence and the necessity of altered plans (Cohen, 1983; Hartford and Parsons, 1982; Hausman, 1979; Sanford, 1980; Toseland and Rivas, 1984; Yalom, 1970).

Support groups are also a source of instrumental aid to the caregivers. Members can learn to evaluate their own capacity to care for a disabled relative as well as to recognize and to accept realistic goals for themselves and the dependent family member. Support groups serve as a means of learning new modes of communication (Hartford and Parsons, 1982; Hausman, 1979).

An overall objective of this practicum is to provide an effective group intervention for individuals who are coping with the problems of caring for a dependent older relative. Some specific goals are:

- 1) To provide information and to develop an understanding of the aging process;
- 2) To assess and begin to work on some ways of coping with the tensions, feelings, and responsibilities of the caregiving relatives toward their older parent;
- 3) To provide mutual support for the members by developing a social network that will permit and support expressions of ambivalence and resentful feelings about current conditions, responses, and

- relationships, and to offer empathic responses;
- 4) To help group members develop a greater awareness of their responses to their aged parent;
 - 5) To help them adjust to role changes and other areas of stress;
 - 6) To increase their understanding of emotional reactions of older people for the purpose of initiating group problem-solving to cope more effectively with their own and their parents' concerns;
 - 7) To provide an atmosphere where problem-solving and information-sharing can take place in order to provide assistance in the planning for the older parent.

There are educational benefits from the development of this practicum. One is to gain skill and knowledge relevant to the development and leadership of a support group. A second is to gain an understanding of the needs and concerns of the caregivers.

The following chapters will deal with issues and content related to A Group for Adult Children Caregivers Who are Providing Care for their Dependent Older Parent. Chapter I will present a literature review of the "Sandwich Generation". Chapter II will present social work practice and the "Sandwich Generation".

Chapter III will outline the Practicum in regards to setting, clients, referrals, structure, and evaluation. Chapter IV will review the results from the Practicum. Chapter V will present an analysis of the Group Work Approach used in this intervention. In addition, this chapter will present the differences in the group processes

between the two groups. Chapter VI will be the conclusions and recommendations for the further development and implementation of this intervention.

Chapter I

Literature Review

The Sandwich Generation

In today's society there is a special generation, one which is caught in the middle, men and women pulled in three directions, trying to rear their children, live their own lives, and help their aging parents, all at the same time (Brody, 1981; Masciocchi, Thomas, Moeller, 1984; Neugarten, 1979; Silverman, Brahce, Zielinski, 1981; Silverstone and Hyman, 1976). This is the "Sandwich Generation". This generation is confronted with issues and problems that are fairly new in contemporary society. They are caught in the middle in a developmental and generational sense. They are confronted with issues of their own aging and, in many cases, attempting to resolve problems related to an aging parent.

There is a recognition that the elderly who are living into their 70's, 80's, and 90's require more support from their families. In a report, the United States Federal Council on Aging indicated that meeting the future long-term care needs of the elderly will require an even greater utilization of the resources of "significant others", such as family and friends (Reece, Walz, Hageloeck, 1983).

During the last one hundred years, the population has experienced a major shift in age distribution, moving from a relatively

young population with a high birth rate to a relatively old population with a low birth rate (Gillaspy, 1979). The proportion of the elderly persons over the age 85 is increasing geometrically. Statistics and population projections indicate numbers of elderly in the population will increase (Statistics Canada, 1975, 1980, 1981). In 1976, the elderly aged 65 and older comprised 8.7% of the Canadian population and 10.4% of the Manitoba population. In 1981, this increased to 9.7% and 11.8% respectively (Statistics Canada, 1982).

As life expectancy increases, particularly with regard to what we formally called the later years of life, we are approaching the four and even five-generation family. Three and four-generation families are not uncommon and the number of five-generation families is on the increase (Neugarten, 1979; Seelbach, 1984).

Demographic changes have reshaped the contours of the parent-child relationship, considerably increasing the span of years in which children and their parents meet and interact as adults. In contrast to previous generations, when children often experienced the death of a parent during their formative or young adult years, contemporary men and women in mid-life and beyond are having to re-define and re-negotiate what it means to be a son or daughter when one has children, or even grandchildren, of one's own.

Increased survivorship to later maturity has generated tensions, conflicts of interests, and related difficulties for the "Sandwich Generation", the population approximately 40-60 years of

age (Schwartz, 1979). Pressures on the "Middle or Sandwich Generation" can be great as adult children are torn between the feelings of responsibility and need to care for their children, spouses, parents, or other relatives, and at the same time, attempting to recognize their own personal needs, which include adjusting to their own aging processes.

In North American society the concept of a three or four-generation family is a relatively recent phenomenon (Townsend, 1968). Since this is a relatively new concept, adult children have very few role models to follow. Therefore, they have no real means by which to measure their behavior or to know exactly what to do when certain situations arise.

Families go through periods of transitions. With each transition, both family structure and relationships require varying degrees of modification (Steinman, 1979). Adult children dealing with aged parents is a transition in the family cycle. This transition can lead to conflicts between the generations. Conflicts can be a result of life-long differences between the generations in lifestyles, morals, and values.

The middle generation is an important group because they are the ones that are most responsible for the care of their elderly parents. The social myth that in contemporary North American Society old people are alienated from their families and children, is not an accurate portrayal (Lee, 1985; Neugarten, 1979; Shanas, 1979).

The family is an important source of support and help for older adults, particularly as friends are lost and dependency increases. The past decade has seen the emergence of considerable research validating the role of the family and other informal supports in the care of frail and chronically ill elderly (Brody, 1981; Cantor, 1975; Chappell, 1983; Jette and Branch, 1983; Monk, 1979; Morris and Sherwood, 1985; Reece, Walz, and Hageloeck, 1983; Robinson and Thurnher, 1979; Schwartz, 1979; Shanas, 1979; U.S. National Centre for Health Statistics, 1984; York and Caslyn, 1979). Robinson and Thurnher (1979) found that 47% of their respondents saw their parents weekly or daily, 13% saw them at least once a month, and 40% saw them less than once a month. All but two of the 23 respondents with parents living in the same city saw them at least once a week.

A survey of 42,000 U.S. households by the U.S. National Centre for Health Statistics found that 88% of elderly people living on their own had visits or telephone chats with family and friends during the two weeks prior to the interview (Saskatoon, Saskatchewan, Star-Phoenix).

Chappell (1983) formulated data on a random sample of 400 elderly individuals (aged 65 and over), living in Winnipeg, Manitoba. The data revealed that few elderly (8 or 2%) were isolated in terms of available social supports.

York and Caslyn (1979) have shown that families do not separate themselves from their older relatives. A large proportion of families in their study helped their older relative on a variety of tasks,

from shopping to physical care. In addition, 30% of the families took the older relative into their home before placement and nearly all of the families maintained frequent telephone contact.

Shanas (1979) found that in 1975, 53% of persons with children, including those with a child in the same household, saw one of their children the day they were interviewed or the day before that. The proportion of older parents who saw at least one child during the week before they were interviewed has remained stable over roughly 20 years: 83% in 1957, 77% in 1975.

Elaine Brody (1981) in her research reinforces the findings that adult children do not dump old parents into institutions. She states that placing an elderly relative is the last, rather than the first resort of families. In general, they exhaust all other alternatives, endure severe personal, social, and economic stress in the process, and make the final decision with the utmost reluctance.

Jette and Branch (1983) made a study on the use of formal and informal sources of long-term care. Eight hundred and twenty-five non-institutionalized survivors of the Massachusetts Elders Panel Study reported on their use of long-term care assistance. Almost 10% used help to bath; close to 15% used grooming assistance. Substantially more elders used personal assistance to perform instrumental activities. Almost two-thirds used assistance for transportation activities; close to half used help in housekeeping and

grocery shopping; approximately one-third used assistance in meal preparation and small business affairs. The overwhelming majority of elders who used assistance used the informal support network.

Cantor (1975) in a study of the Inner City Elderly of New York found that the level of involvement of children with parents was 87%. At least two-thirds of the parents received help from their children in the case of illness. It has been estimated that presently families already provide as much as 75-85% of all long-term care for older adults (Monk, 1979; Reece, Walz and Hageloeck, 1983; Schwartz, 1979).

Morris and Sherwood analyzed interview data obtained from approximately 700 "vulnerable" elderly persons. Most of the older persons lived alone, so spouses were not available as helpers. Ninety percent of these older persons identified at least one person as an informal source of assistance, and 86% identified two or more such persons. Very few relied solely (3%, or primarily 5%), on formal sources of assistance. Approximately 87% of the vulnerable elderly in this study receive one-half of their assistance they needed from informal sources, most of whom were either children or other relatives (Lee, 1985).

Reece, Walz, and Hageloeck (1983) developed a study to examine intergenerational caregiving provided by children and grandchildren. They found the overall levels of caregiving was high. Shopping and transportation were the most commonly provided services. However,

46% of the sample also provided personal care such as bathing and dressing, and 36% provided home health care such as administering medications and changing dressings.

When impairment does occur, irrespective of the availability of formal services, which ebb and flow, it is the family who provides the bulk of home care services to the impaired aged (Masciocchi, Thomas, Moeller, 1985). Manitoba has a Home Care Program established to provide care for elderly in the community. The Manitoba Home Care Program views the family as the primary care provider. It is the objective of the Program to expect the provision of services by family members where realistic and then to provide periodic services, as appropriate, to relieve family members to prevent deterioration of family support. Home Care Services are not provided to meet care needs for which the individual has appropriate resources within his/her own family (Department of Manitoba Health, Office of Continuing Care, 1983).

Despite the devolution of caregiving to kin, families are not socialized to assume the role of caregiver and are ill equipped to manage the emotional and physical requirements of such a role. Adult caregivers of elderly family members are not equipped with the knowledge, resources, or skills necessary to provide them with continuing, optimum support. As a consequence, family relationships, as well as the ability of adults to assist their elderly parents or relatives, may be less than satisfactory. The problem in many cases

is not that family members are unwilling to give support, so much as that they lack the necessary skills and know-how (Kahn and Silverman, 1976; Sanford, 1980).

The period in the family life cycle in which elders are unable to maintain an independent existence may present a crisis as they adapt to new roles and expectations. Whether care is provided in the household or from a separate residence, redefinition of roles for the elderly, for the primary caregiver, and for other family members, is necessary. Adult children, who may be in the process of lessening their parenting role, must relinquish their more independent position to render a caregiving situation. Siblings of the caretaker and extended family members may be called upon to support the caregiving family. These changes may disrupt the balance of the family and challenge the system to modify itself. During these periods of transition, families often face crises as they adapt to new roles and expectations.

Family aid to the elderly may range from periodic financial assistance to living arrangements that include an older person too ill or otherwise incapable of residing alone. The extent of dependence primarily determined by functional disability, dictates the type of aid. The burden assumed by the caregiver generally becomes greater as the impaired aged family member grows older and the dependency becomes multidimensional (Masciocchi, Thomas, Moeller, 1984).

The middle generation does encounter special problems.

Dilemmas and problems facing the middle generation can be viewed as developmental tasks which occur as a normal part of the life cycle (Silverstone, 1979). Some of these tasks may include mourning our lost youth, years in which one confronts his or her own mortality and advancing old age, years in which one's own children are approaching maturity and moving out, and with concerns in regards to their relationship with their parents, who have become very old and may be in need of support and help.

In terms of adjustment, adult children who provide care for their parent may experience a circumscribed lifestyle. They may experience restrictions on their own leisure activities, personal wants and freedom of choice about time expenditure. Stanford measured the tolerance of caregiving toward problems encountered in giving care to mentally impaired older people. Caregivers found the lack of time for themselves and sleep disturbances the most difficult to tolerate (Masciocchi, Thomas, Moeller, 1984). Zarit, Reeve, Bach-Peterson (1980) developed an interview to assess the level of burden experienced by caregivers. Their study consisted of 29 older people with senile dementia and their 29 primary caregivers. They found that a burden for the caregivers was lack of time for oneself.

Cantor (1983) found that children and other relatives suffered less from physical strain, and their level of financial strain was

even lower and decreased progressively with decreasing centrality of the relationship. It was in the sphere of personal desires, individuality, and socialization that the greatest deprivation occurred. The greatest strain experienced by the caregivers of dependent elderly was in the emotional area.

In a generationally-linked family, the role of the caregiver will usually fall upon the middle generation woman, the adult daughters, who may then be in a "squeezed" position of providing support to both younger and older kin. A number of studies have found that the daughters or daughters-in-law of the impaired aged family member provide the bulk of support (Brody, 1981; Horowitz, 1985; Reece, Walz, Hageloeck, 1983; Rosenthal, 1986; Sanford, 1980).

Brody (1981) describes a phenomenon in which middle-aged women are in the middle (from a generational position) and are required to meet demands of older and younger generations. These women are also caught in the middle between two values, one traditional and one contemporary, in which care of the elderly as a family responsibility competes with a desire to be free to work outside the home and to establish autonomy. This, in part, is a result of demographic and social changes which may result in stress of being pulled in many directions at the same time. Role overload is almost inevitable as the caregiver attempts to balance the responsibilities of caregiving with demands from other family

members and the caregiver's own personal needs, which may include an occupational role.

Rosenthal (1986) found that kinkeeping is primarily a female activity and the position persists over time, frequently passing from mother to daughter. Daughters assumed the burden of caring for elderly mothers, and visiting their parents more often than sons, and played the central part in orchestrating family gatherings (Winnipeg Free Press).

A concern for the adult caregiver is the conflictual interaction that may be a consequence of their new role with their parent. Conflict can occur when an older parent appeals to someone who will understand and help to alleviate circumstances brought on by aging. The request for help itself does not necessarily create a strain between the generations (Quinn, 1984). The life situation of parent or child, or the history and development of the relationship, such as the movement toward the challenging of the parent's authority by the child, may be present at the time of such a plea (Quinn, 1984). Thus, the consequence of the parent's request for help is influenced by timing, forces presently acting upon the individual within the relationship.

Robinson and Thurnher (1979) found that many of their respondents in their study perceived the responsibilities for care of their aged parent to occur at an inopportune time. Some women had looked forward to freedom from worries and to the pursuit of favored

activities after their children were established. Some men and women were planning for retirement and looking forward to travel. There was the general awareness that the time to make up for missed gratifications was limited and that enjoyment should not be delayed. Under these circumstances, any unanticipated constraints on one's preferred or hoped-for lifestyle were bound to evoke frustrations, sometimes accompanied by unwilling resentment.

Frequently, adult children are sought as confidants and supports during stressful periods experienced by aged parents. These adult children sometimes find it difficult or are uncertain about the way to respond and to provide support while meeting responsibilities in their own immediate families. Watson contends that taking on filial care can be to the detriment of meeting other personal and family responsibilities (Quinn, 1984). Cicirelli states that the situation for these children often results in fatigue and frustration not necessarily because of other stresses or responsibilities not fulfilled, but simply because of the disappointments or agonizing moments arising from a sense of failure in meeting the requests or needs of one's parents. The expectations of the adult child and their sense of loyalty towards their parent can play a significant part in their satisfaction as a caregiver. Furthermore, these expectations can also threaten the relationships, regardless of external demands in the life of the child (Quinn, 1984).

A stressful situation that children who are providing care feel, is that they understand and treat the person for whom they care for better than they were treated in return. Among children the normal strains of caring for an ill older person seem to be compounded by intergenerational differences. Cantor (1983) found that only 48% of the children in their study felt that they understood their sick parent well, and only 28% felt that they were understood in return. Only 20% of the children felt that they shared similar views on life with their parents. Reece, Walz, and Hageloeck (1983) also state that relatives who feel that older persons do not appreciate their efforts, are more likely to report a higher level of negative import.

Silverstone and Hyman (1976) state that in establishing their life's priorities, adult children, if they are not able to assign first or even second or third place to their parents, they may never forgive themselves. But, if they try to shoulder their parents' burdens as well as their own, they may feel continually resentful and put-upon, wondering when is there going to be time for their own lives.

Conflicts which may develop between the adult child and the parent may have been the result of life-long differences between the two generations. Conflict may also occur concerning issues which never before required family attention (Steinman, 1979). The result of a parent moving into the home of her child can lead to a number of conflicts which were not previously present. The

death of one parent can lead to new conflict. If an older woman was very dependent upon her husband for many years, she may at this point turn her dependency needs towards her children.

Issues of independence and dependence can lead to conflict between the two generations. The parents may struggle over how dependent they wish to be upon their now adult children, and the children may struggle over how dependent they wish their parents to be upon them (Steinman, 1979).

Adult children have reactions to these intergenerational conflicts. The adult child might become enmeshed in the conflicts to the point of feeling overwhelmed, anxious, resentful, and helpless. Guilt often accompanies interactions with the parents, and over-helpful children may feel manipulated and as if their parents are attempting to "guiltify" them. The adult children, despite these feelings, continue to do whatever is asked of them, and more, and frequently attempt to take care of everyone else before themselves (Steinman, 1979).

Adult children share a range of feelings toward elderly parents but are usually reluctant to voice them, especially if they feel these feelings are negative. Many of the feelings adult children have about their parents in later years are the same old ones they always had about them. They were formed in childhood and a pattern was established to be carried through life. The intensity and immediacy of these feelings may change with adulthood (Silverman and Hyman, 1976).

Old feelings from the past can disturb adult children when their parents get older, feeble, or sicker, and are in need of help. Adult children can no longer retain an emotional distance even when physically separated, and too easily fall back into old patterns, both the pleasant and the unpleasant ones (Silverman and Hyman, 1976).

Adult children may experience uncomfortable feelings such as sadness, anger, hostility, burden, shame, hopelessness, fear, entrapment, and guilt. As adult children see their parents decline, they may see themselves as next in line, and feel more vulnerable. As well as feeling sad, they may also begin to feel angry because of their own vulnerability or because they feel a sense of abandonment. Besides anger, adult children may feel hostility or resentment. Sometimes the helplessness and disabilities of their aged parents will rekindle or evoke past feelings of anger and resentment. Children many years later can still be angry and resentful about their parents' failures in the past. The fact that they are now old and frail may not diminish these feelings, particularly if they continue to behave in the infuriating manner they have disliked for so long. Sometimes they feel angry because they think there is nothing they can do to help.

For adult children of elderly parents, shame can sometimes be an ever-present feeling. The most common form of shame comes when children feel they do not do enough for their parents.

Guilt is a pervasive emotion expressed by adult children.

The middle generation has difficulty in coping with and resolving feelings of guilt in conjunction with feelings of responsibility. Guilt feelings with regard to aging parents may derive from a number of sources: 1) the feeling that they have not lived up to some code of ethics or morals, 2) they have not lived up to their parents' expectations of them, 3) they have not lived up to their own expectations, or 4) they are caught between competing responsibilities requiring that priorities be set (Silverman, Brahce, Zielinski, 1981; Silverstone, 1979). Guilt feelings may derive from any one or combination of these things.

Steuer and Clark (1982) found that families who were providing care for an Alzheimer-type dementia relative encountered feelings of isolation, hopelessness, frustration, entrapment, burden, anger, directed towards both the parents, other family members and health professionals, guilt at negative feelings, and fear - fear of further deterioration, fear of parent aggressiveness and fear, especially among adult children, of heretability, both for themselves and for their children.

Adult children must deal with facing the decline of their parents, not only physically but mentally. Children must learn to accept the reality of their parents' problems. They must accept the "lost umbrella" (Silverstone and Hyman, 1976). Children must learn to deal with the concept of filial responsibility.

The concept of filial responsibility is important for the intergenerational relationship. The concept of filial responsibility

refers to an adult child's sense of obligation in meeting the needs of parents. Blenker defines filial maturity as a newly found recognition of and commitment, in middle age, to being depended upon (Seelbach, 1979).

Adult children when confronted with filial responsibility may have a tendency to over-react and implement the phenomenon of role-reversal. The adult child not only takes over the role of caretaker but also becomes the sole decision-maker. Both the old parent who has extreme difficulty being dependent and the one who is overly dependent may hamper efforts of the adult child to become filially mature. If the adult child must acquire the capacity to be depended on, the elderly parent must have the capacity to be appropriately dependent and as a result to permit such growth.

The middle generation must face up to their feelings of old age in general, and their own old age and their own mortality. The behavior of children toward their elderly parents can be profoundly affected by these feelings. The feelings adult children have about their own old age often have a direct bearing on how effectively they can help their parents during their old age (Silverstone, 1979).

Adult children who have a generally positive attitude toward old age in general, including their own, are more likely to be able to reach out to their elderly parents with constructive support (Silverstone, 1979). If old age appears as a time to be dreaded, then a parent's decline may seem very threatening.

Adult children have difficulty in setting boundaries on their responsibilities to their parents. Adult children have difficulty in recognizing that their aged parents are adults, and that they need and should have input into the decisions that directly affect their lives. There is a strong emphasis by the children to create a psychological dependency. This dependency in many cases is established because of the negative norms attached to old age. Dependency is a pervasive norm that encourages the concept of role reversal. The trap adult children easily fall into is the assumption that as people get older they become less capable of fending for themselves or making rational decisions about the conduct and quality of their lives (Dangott and Kalish, 1979; Schwartz, 1979).

The relocation of parents may be a major concern for their children. This may occur when the parent becomes too frail or dependent to remain in their original residence alone or too deteriorated to live unprotected in the community. The result may be for the adult child to consider having the parent move to their home or the possibility of nursing home placement.

The self-centeredness of older parents may be an issue for their adult children. Adult children in the caregiving role may view their parent as selfish, demanding, inconsiderate, and uninterested in the activities and accomplishments of their own children and grandchildren, who were formerly the main focus of their interest.

Communication with parents, other relatives, and professionals, is another major problem. When needs change and dependence increases, many older people cannot ask for the help they need because of their belief in independence, their dread of being a bother to someone, their fear of being taken over and stripped of their autonomy if they ask for assistance (Hartford and Parsons, 1982). Many families establish indirect ways of communicating with their relatives that can lead to misunderstandings.

It has been indicated that adult children do not abdicate their role as caregivers as their parents age and require support. Adult children do encounter problems and dilemmas in their role as caregivers and in their intergenerational relationships with their parents. Despite this fact, much of the focus of family interventionist strategies have been aimed at the needs of the elderly. Consideration of the needs of the families of the elderly is of vital importance. Haveghuet (1948) described the last developmental task of middle age as one of adjustment to aging parents. He stated that the task included meeting parental needs in a manner that is satisfactory to both generations. Such a definition underscores the needs of the family members as well as those of the aging parents (Robinson and Thurnher, 1979).

In dealing with aging families in many cases a redefining of who the client is must take place. It often becomes apparent that the child rather than the aged parent becomes the client.

This review of theoretical and research literature has identified that stress accompanies the role of being a caregiver. Many community-based programs developed to complement the informal support of the family have largely been designed to assist with the personal care and homemaking tasks. While these programs improve care for the elderly and lessen the burden of the caregiver, there are other needs of the "Sandwich Generation" which have to be addressed.

As outlined in this chapter, an important need of the "Sandwich Generation" is to set priorities for themselves. They must establish a balance between the time they devote to caregiving for their parents, the time they give to their family, and the time they allow for themselves. In their role as caregivers, members of the middle generation experience a variety of feelings, such as guilt, anger, and frustration. In order to cope more effectively in their roles as caregivers, they must have an opportunity to express these uncomfortable feelings. The "Sandwich Generation" must also deal with feelings related to their own aging, and aging in general. In view of these needs of the "Sandwich Generation", it becomes apparent that support and educational groups, centred on the broader issues of aging and caregiving, are a necessary component in the delivery of care for the elderly.

Chapter II

Social Group Work Practice and The Sandwich Generation

Social Group Work Practice provides a dynamic mode of intervention to assist in meeting the needs of the Sandwich Generation. The use of a small professionally-led group should be aimed at providing education and growth experiences. It is to help the member, primarily, and provide an opportunity for each member to make gains for himself by participating with others while contributing to a collective experience which helps others in and through the group. The individual member may experience support, growth, or change.

A major consideration in using a group approach as a method of intervention for adult children caregivers is the simple pragmatics of the situation. Considering the increased need for the support of caregivers, the reasonableness of groups as an intervention becomes apparent. More individuals can be treated at any one time.

The group approach appears to be the more effective means of intervention when considering the needs of the adult caregivers. There are special properties of groups that are not found in dyads. Some of these properties are essential in meeting the needs of the adult children caregivers: the capacity of the group to develop cohesiveness or a sense of belonging; the capacity to define reality

for the individual; the capacity to induce and release powerful feelings; and the capacity to provide a contrast for social comparison and feedback (Lieberman, 1980).

The dual premise underlying this group is that relatives require both information and affective support (Clark and Rakowski, 1983; Cohen, 1983; Getzel, 1983; Glosser and Wexler, 1983; Hartford and Parsons, 1982; Hausman, 1979; Lazarus, Stafford, Cooper, Cohler, and Dysken, 1981; Sanford, 1980; Silverman, Brahce, Zielinski, 1981; Steuer and Clark, 1982). The group approach interweaves both modalities into a combined approach. Throughout all sessions, it is hoped, that members will share their feelings, support one another emotionally, explore options and alternatives, and participate in mutual problem-solving. These objectives are prominent in the groups that were developed for relatives that are caregivers for their dependent parents (Cohen, 1983; Glosser and Wexler, 1983; Hartford and Parsons, 1982; Hausman, 1979; Lazarus, Stafford, Cooper, Cohler, and Dysken, 1981; Sanford, 1980; Silverman, Brahce, Zielinski, 1981; Steuer and Clark, 1982).

Direct therapy is not the primary mode of intervention, rather therapeutic effects should be facilitated indirectly by the group process. This approach should be more of the supportive, current functioning, reality orientation-type, with a didactic educational approach to understanding the normal and pathological changes in aging, with an emphasis on helping members cope with and master their current situations (Hartford and Parsons, 1982; Hausman, 1979; Silverman, Brahce, Zielinski, 1981).

Considerable apprehension and concern about aging relatives can be overcome when adults receive accurate information. The education or learning component is provided through direct didactic or content material. The information is structured around what seems to be universal needs: information about aging as distinct from disease, physical/social/emotional aspects of the aging process; information about how to deal with the community support system; problem-solving techniques (Cohen, 1983; Getzel, 1983; Hartford and Parsons, 1982; Hausman, 1979; Silverman, Brahce, Zielinski, 1981).

Members frequently display strong and conflicting feelings in responding to their relatives' demands for help and attention. The group allows members to ventilate and deal with their feelings of anger, guilt, hopelessness, entrapment, and frustration (Clark and Rakowski, 1983; Cohen, 1983; Getzel, 1983; Glosser and Wexler, 1983; Hartford and Parsons, 1982; Hausman, 1979; Lazarus, Stafford, Cooper, Cohler, Dysken, 1981; Sanford, 1980; Silverman, Brahce, Zielinski, 1981; Steuer And Clark, 1982).

The benefits of providing information and allowing members to ventilate their feelings include the following: 1) helps them cope with their emotions; 2) allows them to be more effective caregivers; 3) instills in them a more positive attitude towards aging, their parents, and caregiving; 4) allows them to feel more satisfied with themselves; and 5) allows them to learn about successful aging.

Caregivers have a sense of being alone and unique in their situation. The group allows members to discover that they are not

alone and that others encounter similar difficulties, burdens, and emotions. The development of a sense of universality is one of the most important benefits of the group (Clark and Rakowski, 1983; Cohen, 1983; Hartford and Parsons, 1982; Hausman, 1979; Sanford, 1980; Silverman, Brahce, Zielinski, 1981; Steuer and Clark, 1982; Yalom, 1970). Many caregivers feel that they are in a unique situation. They feel isolated and alone. The knowledge that there are others experiencing the same situation can be a relief (Yalom, 1970).

Yalom (1970) lists a number of curative factors that can operate in every type of treatment group. The curative factors assume a differential importance depending on the goals and compositions of the specific group. A number of curative factors gained from group participation are an instillation of hope, imparting of information, interpersonal learning, a sense of universality, and group cohesiveness. The preceding is a partial listing from Yalom (1970) which seems appropriate to a group focused on support for relatives that are careproviders for dependent older adults.

Didactic instruction is used in the group. It is used to transfer information, to explain the process of aging, and to structure the group. Often it functions as the initial binding force in the group until other curative factors become operative. The explanation of a phenomenon may be the first step toward control of the phenomenon (Yalom, 1970).

Cohesiveness may be described as the attractiveness of a group for its members (Hartford, 1970). Evidence of cohesion appears when members begin to refer to themselves, each other, and the group, as we, and when they take hold of an idea or problem and work together on it. Members who show high mutual understanding and acceptance are, by definition, cohesive (Hartford, 1970).

Cartwright states that the individual member's attraction to a group will depend upon four major factors: 1) the incentive nature of the group, its goals, program, size, type of organization, and position in the community, 2) the motivation of the person, his needs for affiliation, recognition, security, and other things he can get from the group, 3) the attractiveness of other persons in the group, and 4) if the group serves as a means for satisfying needs outside the group, that is, helps the person to achieve alone (Hartford, 1970). These are all factors that must be taken into account when developing a group for caregivers. The adult caregivers have needs that can be shared best in a group environment. They share similar needs with other caregivers in the Sandwich Generation. They receive positive benefits from relating their situations and problems to others in the same situation. Cohesiveness develops, which is vital for the development of the group (Hartford, 1970; Toseland and Rivas, 1984; Yalom, 1970).

Cohesion is more than the addition of each member's individual attraction. Cohesion is a group phenomenon, the product of the interaction and the achievement of group factors (Yalom, 1970).

Research has shown in a variety of situations that as group cohesion increases, the power of the group over the membership also increases (Douglas, 1979; Hartford, 1970; Northern, 1969). Motivation of members to take part in a group is influenced by cohesion. Members of a cohesive group tend to show less anxiety (Hartford, 1970).

Caregivers with the commonality of shared experiences with their afflicted relatives fostered cohesion. Group cohesiveness resulted in better group attendance, greater participation of members, and greater influenceability of the members. The literature of various authors has shown that cohesion is a vital factor in facilitating education and growth among members (Douglas, 1979; Hartford, 1970; Hausman, 1979; Toseland and Rivas, 1984).

Education and support groups have been shown to work well with adult children who are providing care for their dependent older adults (Cohen, 1983; Glosser and Wexler, 1983; Lazarus, Stafford, Cooper, Cohler, and Dysken, 1981; Hartford and Parsons, 1982; Hausman, 1979; Sanford, 1980; Silverman, Brahce, and Zielinski, 1981; Zarit and Zarit, 1982). In general, the use of this educational/support group modality has shown to increase coping skills, facilitate understanding, relieve stress, and provide mutual support for the family members of dependent elderly parents (Clark and Rakowski, 1983; Davis, 1983; Masciocchi, Thomas, and Moeller, 1984; Zarit and Zarit, 1982).

Cohen (1983) found that a group approach was an effective and cost-efficient treatment tool for adults who were responsible

for aging family members. The group process encouraged and facilitated information-sharing, giving and receiving support, and working through some of the emotional and practical problems associated with care of the elderly. Group members reported feeling better emotionally, and reported utilizing ideas and suggestions of others in the group. Sharing, recognizing the universal nature of the problem and hearing others' solutions to it, gaining information, and having many others to talk to during and after the group sessions were highly therapeutic to the members.

Glosser and Wexler (1983) ran educational/support groups for relatives of patients with Alzheimer's Disease and other dementias. Overall, the group meetings were positively evaluated by members. Despite the formal structure of the group meetings which emphasized education and didactic presentations about dementia, members found the contact with other family members and the opportunity to share feelings, receive support, and learn from each other to be some of the most beneficial aspects of the group.

Lazarus, Stafford, Cooper, Cohler, and Dysken (1981) ran a group for relatives with Alzheimer's Disease. Members became more knowledgeable about the illness and more accepting of their ambivalence toward their afflicted relative. The group facilitated the sharing of common experiences and feelings, thus helping to relieve some of the isolation and loneliness that relatives experience.

Hartford and Parsons (1982) developed small groups for

care-taking relatives of dependent older adults. The decision to offer the group was based on the requests by people who were seeking assistance in dealing with an older relative. Frequently, the request for assistance or understanding was not for the older relative who was becoming increasingly dependent, or deteriorating, but for the concerned or care-taking relative. While each request was unique, there were common or similar themes in each family. Previous life patterns and psychological condition of the dependent relative, made each situation unique but there were enough similarities in the feelings and the experiences of the concerned relative, that a group modality appeared to be useful. All participants seemed to need the kinds of assistance which a group could offer.

Members of the groups gave support to each other and gained some insight by talking with peers who had similar problems and by looking at content that gave some cognitive understanding of the aging processes being experienced by their relatives. Several common themes emerged from the groups: interpersonal relationships change as relatives become more dependent, ways to deal with the attitudes and emotions of the care-taking relative, and learning "parent-caring" skills.

Hausman (1979) ran groups for caregivers of dependent older parents. Results indicated that this informal, supportive modality was effective in helping adult children make decisions and act upon them. Some common issues were: independence, fear of one's own aging, and communication.

Sanford (1980) developed an educational and supportive program for families of the mentally-impaired aged. Sanford found that common to all groups was the sense of anguish as members helplessly watched the physical and mental deterioration of their kin. Finding others who shared this problem was one of the most important benefits of the program.

Silverman, Brahce, Zielinski (1981) developed another education/support program for adult caregivers of dependent older parents. They found that the sharing of feelings and increasing knowledge of aging were most beneficial for the caregivers.

Zarit and Zarit (1982) found that a helpful treatment modality for families caring for a dependent family member with senile dementia was support groups. The intervention included education about the disease, problem-solving, and support. The support groups were professionally-led. They found that an important advantage of the groups was that they allowed caregivers to make suggestions to one another based on their own experiences of what had been successful. Caregivers also modelled after one another, learning new strategies of responding to the dementia relative by observing what the other members did, particularly in areas where they had previously had trouble making changes.

Zarit and Zarit's support groups allowed caregivers to share information with one another, and helped them understand their own experiences better. They stated that members of their groups

felt they were going crazy, until they learned that other caregivers experienced the same frustrations as they. The two groups were time-limited, ran for 6 - 10 sessions once a week and lasted for 1 - 2½ hours for each session. The groups consisted of 8 - 17 members and were all leader-led. All group members had common situations which enhanced cohesion and universality.

Model Implemented

The model primarily used for this group was developed by Toseland and Rivas. They conceptualize group work as a series of generic skills and activities carried out by the worker over the life of the group (Toseland and Rivas, 1984).

Every group with its unique membership undergoes a highly individualized development. Considering the complexity of human interaction, the course of a group will be to a great degree, unpredictable. Nevertheless, there are forces operating in all groups which broadly influence their course of development and which provide workers with a useful sequence of developmental phases (Garland, Jones, and Kolodny, 1965; Gavin, 1981; Hartford, 1970; Henry, 1981; Northern, 1969; Schwartz, 1971; Toseland and Rivas, 1984; Yalom, 1970).

There appears to be a basic consistency regarding the basic stages of group development. The various stages can be divided into four stages: planning, beginning, middle, and end (Toseland and Rivas, 1984).

During the planning phase, the worker assesses the need for a group, considers potential membership and sponsorship, and identifies the group's purpose. Additionally, the worker composes the group, recruits and orientates members, and prepares for the first meeting by locating a suitable room and making other necessary arrangements (Hartford, 1970; Toseland and Rivas, 1984).

The need exists for a group for adult children caregivers who are providing support for their dependent parent. The caregivers are the "Sandwich Generation" and can benefit from the support that a group can provide. Their role as a careprovider is stressful and they are in need of assistance in dealing with their emotions in regards to their caregiving role.

The beginning phase occurs during the first few meetings of the group. As members begin face-to-face interaction, the worker helps to build relationships by clarifying the group's purpose.

Establishing the group's purpose is one of the most important aspects of the group. The purpose for which any group has been formed influences all that follows (Levine, 1967). A clear statement of group purpose should be provided by the worker (Northern, 1969; Schwartz, 1971). This assists in answering the question, "What are we doing here together?" It can help prevent a lack of direction that can be frustrating for the group. A brief statement of the group's purpose generally includes information on why the group is meeting, how the group might conduct its work, and what the range of individual goals or tasks might be in the group (Toseland and Rivas, 1984). The two main group purposes for the adult children caregivers are education and growth.

Clarity of purpose provides a base for the group members to develop a bond and a means for attaining their common goals. Without regard to purpose in the establishment of groups, there is increased

danger of the groups being weakened by basic interpersonal conflict that may weaken energies from goal achievement. The principles centering on clarity of purpose in group-work treatment are designed to facilitate the development of combined and directed energies toward the attainment of group goals (Levine, 1967).

During the beginning phase, the worker helps members to get to know each other (Toseland and Rivas, 1984). During this initial stage, the group will go through a period of orientation, characterized by a search for structure and goals (Hartford, 1970; Henry, 1981; Northern, 1969; Toseland and Rivas, 1984). Yalom (1970) states that during this stage there is a great dependency on the leader and a concern about the group boundaries.

In the middle phase, the worker helps members to achieve their individual goals and helps the group accomplish its tasks. The worker helps structure the group's work and helps to build group dynamics that are conducive to achieving the expressive and instrumental goals of the group (Hartford, 1970; Henry, 1981; Toseland and Rivas, 1984).

Workers during this phase are expected to perform four activities. These activities are: 1) preparing for group meetings; 2) structuring the group's work; 3) helping members achieve their goals; 4) monitoring and evaluating the group's progress (Toseland and Rivas, 1984).

There are a variety of tasks associated with ending the group. Workers help the members acknowledge that the group is actually ending and to help members with their feelings about the end. The worker also helps in evaluating the work of the group and maintaining and generalizing change efforts (Hartford, 1970; Toseland and Rivas, 1984).

Hartford (1970) provides a differentiation between an aggregate of people and a group. The group may be distinguished from an aggregate of people by the development of a consciousness of self as a unique collective with shared purposes, direction, and goals; the emergence of norms and culture; patterns of collective behavior; and a mutuality of influence that results from the interactions of the participants.

Toseland and Rivas (1984) define group work as a goal-directed activity with small groups of people aimed at meeting socio-emotional needs and accomplishing tasks. This activity is directed to individual members of a group and to a group as a whole within a system of service delivery.

The term treatment group will be used to define the type of group used for adult children caregivers. The term treatment group is used to signify a group whose major purpose is to meet members' socio-emotional needs (Toseland and Rivas, 1984). The purposes for forming treatment groups include meeting members' needs for education, growth, behavior change, or socialization (Toseland and Rivas, 1984).

In classifying a group as being treatment orientated, it is important to consider certain basic characteristics. Members of treatment groups are bonded together by their common needs and their common situations. Roles are not set before the group forms, but develop through interaction among members. Communication patterns are open. Members are encouraged to interact with one another. Treatment groups usually have somewhat flexible procedures for meetings, such as a warm-up period, a period for working on member concerns, and a period for summarizing the group's work. Treatment groups are composed so that members have common concerns, problems, or abilities. Members are expected to disclose their own concerns and problems. Self-disclosures often occur regarding emotionally-charged, personal concerns. Proceedings of the sessions are usually kept confidential. Treatment groups are successful to the extent that they help members meet their individual treatment goals (Toseland and Rivas, 1984).

In the group for adult children who provide care for their dependent older parents, one of the purposes is to provide ways of coping with their role. The group is classified as a treatment group because it is convened to meet the personal needs of its members. The members are bonded together by its common purpose and the common needs and concerns of its members. All members of the group are finding their role as being a caregiver to their dependent parents as being stressful and difficult to cope with (Cohen, 1983; Glosser and Wexler, 1983; Hartford and Parsons, 1982; Hausman, 1979; Sanford,

1980). All members are caught in a squeeze position of having to meet three different needs, their own family needs, their own needs, and their parent's needs (Brody, 1981; Schwartz, 1979; Silverstone and Hyman, 1976).

In the group, members are expected to act as resources in helping each other in their adjustment to their role as caregivers. Members will be asked to help each other problem-solve. The group will foster a high level of self-disclosure because of the similar characteristics of the members and the problems they face. Members will discover that they are not unique in their situation. They will discover that other members have the same emotions about being caregivers to their parents.

Roles will develop based on how members assist in accomplishing the purpose of the group and how members meet each other's needs.

The adult caregivers' group was composed around the similarity of adult caregivers' concerns. The concerns centered around adult caregivers' ability to set priorities for themselves, to deal with their feelings toward their role and their parents, and to set long-range plans.

Patterns of communication focused on the needs of members, such as adjusting to being caregivers and becoming effective caregivers. Communication was also centered around member-to-member interactions.

In the evaluation of the success of the group, the worker

focused on members' satisfaction with the group experience and whether or not the group had met their needs.

Toseland and Rivas (1984) list four primary purposes for treatment groups: education, growth, remediation, and socialization. Toseland and Rivas (1984) did not add support and mutual aid because these purposes are basic to all types of treatment groups (Hartford, 1970; Shulman, 1985).

Groups for adult children who are providing care for a dependent older adult can be classified as having educational and growth goals. Groups with educational goals are aimed at increasing members' information or skills. For adult children caregivers, the educational approach can be used to understand the normal and pathological changes in aging and what is at stake for the older person. This includes the emotional response to bodily changes and feelings of loss. Acquiring basic knowledge of the aging process and refuting stereotypes and misinformation are basic to the group.

Members are also supplied with some skills and information in managing the bureaucracy, problem-solving, and guilt. The leader introduces information and knowledge but also includes opportunities for group discussion to foster learning. The leader concentrates on the individual and on the group as a whole, as a medium for learning, reinforcement, and discussion.

A growth orientation in group work implies opportunities for members to become aware of, to expand, and to change their thoughts,

feelings, and behaviors regarding self and others (Toseland and Rivas, 1984). In groups for adult children caregivers, the members are brought to the awareness of their needs relevant to the pressures they feel about their parents and in their role as the "Middle Generation". The members are then asked to assess the ways of coping with tensions, feelings, and responsibilities.

The focus of a group should be for support, belonging, mutual aid, and strength, which the members can carry outside of the group, plus practical help in carrying the family-support role. This can help build cohesion and problem-solving (Hartford and Parsons, 1982).

Schwartz conceptualized social work groups as enterprises in mutual aid (Shulman, 1985/86). William Schwartz views a group as an enterprise in mutual aid, an alliance of individuals who need each other, in varying degrees, to work on certain common problems. The important fact is that this is a helping system in which the clients need each other as well as the worker. This need to use each other, to court not one but many helping relationships, is a vital ingredient of the group process and constitutes a common need (Schwartz, 1971; Shulman, 1985/86).

This conceptualization of the group as a mutual aid system has implications for the role of the leader. Rather than seeing one's sole role as providing help to clients within a group context, the worker also concentrates on the tasks involved in strengthening the members' ability to help each other. The worker, in this view, is but one source of help to clients (Shulman, 1985/86).

Mutual aid may involve the help members can give each other in discussing a taboo subject. Group members may not be in touch with their own feelings if they believe these to be inappropriate. As members hear others speak of these emotions, it may cause them to experience openly the same emotions (Shulman, 1985/86).

The mutual experiencing of ideas and emotions may lead to the "all in the same boat" phenomenon. This is the healing process which occurs when one realizes that one is not alone and that others share the problems, the feelings, and the doubts (Shulman, 1985/86).

A mutual aid process can be observed in the way in which group members provide support for each other. When a group member is in difficulty, or is revealing painful feelings which have been long repressed, there may be direct and indirect efforts on the part of individual group members and the group as a whole, to provide empathic support. Carrying a burden is often easier if others express their understanding (Shulman, 1985/86).

Consequently, a treatment group approach was used for adult children who were providing care for their dependent parents. The group had two primary purposes, education and growth. The intervention chosen in this Practicum assumed that the needs of the adult children caregivers would best be met by the social work approach designed by Toseland and Rivas. It assumed that adult children caregivers required an atmosphere that would foster mutual aid and provide the opportunity to interject some relevant informational content.

Chapter III

The Practicum

In the following sections, the main components of the Practicum will be outlined. The setting for the group will be described and the clients and the method of referrals will be examined. Furthermore, an analysis of the structure of the Practicum will be made and the methods of evaluation will be discussed.

The Setting

All group sessions took place at the Misericordia Hospital during the period from November, 1985, to May, 1986. The hospital location was chosen for two basic reasons. One was that it is centrally located and easy to reach. The second reason was because I felt it would be available and supportive of the program. I felt that referrals would be provided through the hospital. The indication I received from the Social Services Department at the hospital was that there was a need for this type of group. A written proposal was approved by the administration of the hospital. (Refer to appendix A - Proposal).

Clients

There were fifteen members in the two groups, six in the first and nine in the second. All group members were adult children who were providing care for their dependent older parent. The ages of the members ranged from 30-65, with a mean age of 48. The predominate sex was female. There were thirteen females and two males. This ratio of women to men was expected. The literature validates the premise that the role of caregiver will usually fall upon the middle-generation woman (Brody, 1981; Horowitz, 1985; Reece, Walz, Hageloeck, 1983; Sanford, 1980). The members of the group could be classified as being the "Sandwich or Middle Generation". They were trying to meet their own families' needs, their own needs, and the needs of their parents.

When composing the group, it was important to consider the level and the source of member motivation. A pre-group interview was conducted with the group members to determine their desire to attend and deal with their problems. All group members expressed a desire to work on their problems or concerns. All group members were caught in the position of trying to meet their parents' needs as well as their own and finding their role as a caregiver very stressful to maintain. All members expressed a desire to gain some knowledge and support that would help them in coping with the stress of being caregivers. Members expressed an internal motivation to grow, change, and to deal with their problems.

Referrals

All referrals were originally contacted by telephone. If they indicated a desire to attend the group, then a personal interview was conducted.

One of the referrals who attended the group came from the Home Care Department at the hospital. The rest of the referrals who attended the group came from the Home Care Department in the community. Originally, the referrals were to exclusively come from three departments in the hospital: Social Services, Home Care, and Emergency. It was originally thought that there would be a ready supply of referrals from the hospital. This was based on the belief that since the hospital was discharging the elderly into the community, the relatives who were to assume a caregiving role could benefit from a supportive group. The referrals did not come from the Home Care Department in the hospital because they had little interaction with the families.

Referrals were made from the Social Services Department. None of the referrals were interested in attending the group. The primary consideration in not attending the group was that their parent was in the hospital and not in the community. The hospital had now assumed the role as primary caregiver and they did not see the need or urgency to attend.

Referrals from the Home Care Department in the community came primarily through the author's caseload and from other case co-ordinators. To be able to use the clients from Home Care, an outline of the group was submitted to the Regional Director of the Program. Once approved, I distributed the outline to other case co-ordinators. (Refer to appendix B for Outline).

Structure

The Practicum consisted of two separate groups. Each group consisted of six sessions. The six sessions were set with anticipation of the amount of time necessary for the group to go through the phases of group development and the content that would need to be covered. Originally, the groups were to meet for eight sessions but it was felt that this would be too much of a commitment for caregivers. The time-limited approach also gave an opening for escape for those members who were uneasy about the group approach, but could accept a limited number of sessions. It was felt that once the groups began, then recontracting could take place in regards to extending the sessions. Both groups met on Thursday evenings for 1½ hours from 7-8:30 p.m. The first group met from November to December. The second group met from March to May.

A closed group was chosen because cohesion was an important facet of the intervention. Members of closed groups may form a greater sense of cohesion because they have all attended the group

since its beginning (Hartford, 1970; Toseland and Rivas, 1984; Yalom, 1970). There is often a greater stability of roles and norms in closed groups. The benefits associated with a stable membership include higher group moral, more predictability of role behavior, and an increased sense of co-operation among members. Planning for group sessions can also be easier because of the stability of membership (Hartford, 1970; Toseland and Rivas, 1984).

The pre-group stage of the group included establishing the group's purpose; assessing the potential membership; recruiting members; composing the group; orientating members to the group; preparing the group's environment.

The process of assessing potential members and orientating them to the group was done by a pre-group interview. The interview assessed potential members' desire and capacity for group memberships, initially clarified the stated purposes for the group, and determined the suitability of the member for that purpose, discussed the potential member's objectives and goals with respect to the stated group purposes, and represented the basic procedures and methods to be used in the group. The pre-group interview also provided an opportunity to administer two tests to the members. Both of these tests required pre-and post-scoring so as to determine if there had been any changes in the members as a result of the group.

Six members attended the first group and nine members attended the second group. Attendance throughout all sessions

of both groups was high. Attendance at the first group was vital because of the small size. Attendance at the first group was difficult because of the severe weather conditions.

All group sessions were video taped. The taping was done for educational purposes. The student advisor reviewed the tapes and offered suggestions on how the group was developing and analyzed the intervention and the effectiveness of my role as a leader.

The structure of the group was of an educational/growth type. The group was structured in a manner that would encompass a dual interventional modality. The structure of the group encouraged the formation of a mutual support network among the members. It also incorporated the use of didactic material in dealing with the issue of aging.

In structuring the groups, the beginning of each session was used to encourage members to express concerns or problems that may have developed since the last meeting. The end of each session was used to summarize, conclude interactions, and get feedback on how the members felt, rather than to begin new agenda items. The feedback from the members helped in the structuring of session material.

Setting session agendas was the most important way of structuring the group's time. The format of the sessions and the material to be covered were basically set by the leader. (Refer to appendix C for Outline of Agendas). Before the groups were

convened, agendas were set out. The agendas were fairly structured but the intervention was of a lesser structural manner. The worker for most sessions acted as a facilitator of group discussions in which members were encouraged to share their mutual concerns and their diverse effects at being caregivers for their dependent older parent. Such a structure encouraged the formation of a mutual support network among the adult caregivers.

The agendas for the group sessions focused on several issues that were derived from literature on adult children and their parents. Members were encouraged to discuss their feelings toward their role as caregivers and toward their parents. Members were encouraged to establish the range of feelings they had towards their parents, whether they be positive or negative. Members were encouraged to find a balance between responsibility to one's self, one's nuclear family, and one's parents. Members were encouraged to set priorities and to realize that there is a limit to their ability to give of themselves. Members were asked to look at their own individual situations and determine if they were establishing a balance for themselves.

The intervention that was used to deal with these issues aimed at helping the group members to problem-solve and discuss their own situations with each other. The leader would introduce the concepts but the group would problem-solve among themselves. The leader in many cases would introduce open-ended questions that would stimulate interaction among group members.

The educational and practical information was provided in two ways. One was to be presented in a formal manner where the leader took a directive approach. This approach was used in dealing with the issue of aging, resolving guilt, providing some information on problem-solving, and how to deal with the bureaucracy. (Refer to appendix D for further information).

In dealing with the issue of aging, the leader dealt with some of the stereotypes and myths. The format presented aging not as a disease but as a natural transition. It tried to dispel the negative images of aging. Despite the fact that it was presented in a formal manner, the group members were encouraged to look at their own feelings of aging. A questionnaire was applied to the members as well as open-ended questions.

The members were also provided with information to help them understand that change is inevitable and that losses occur with age. They were provided with information to help them understand that emotional reaction to change or loss is common and that people in later life can make adjustments and cope.

The second approach to dealing with the educational and practical information was to provide group members with hand-out material. (Refer to appendix E). This would give members more detailed information to review in depth at a later time and would help the group in not getting caught up in educational information. Members appeared to want short answers to specific questions.

Experiential exercises were used in the group. They were primarily used to develop member-to-member linkages. A variation of the round-robin method of introducing members to each other was used in both groups. In order to increase member interaction, the members were asked to divide into pairs. One member of each pair interviewed a partner for five minutes, asking details specified by the leader. With these groups, the members were asked to discover each others' situation, relationship, concerns, and needs with regards to their aged parent. They were also asked to find out what they hoped to gain from the group experience or why they decided to attend. After five minutes, members of the pair reversed roles. When the group reconvened, the partner of the member who was first interviewed, introduced that member to the group by recalling the facts learned during their conversation. The process was repeated with each member introducing the partners whom they interviewed.

Role-playing was used in the group. Role-reversal was used to help clarify situations and it increased member self-awareness.

Evaluation

Three tests were used to evaluate the process and the outcome of the group. The group experience was used with the recognition that changes in members' knowledge, feelings, approaches to problems, and ways of dealing with their relatives may occur. At the final meeting, each member was given a questionnaire with a series of subjective evaluative questions relating to the value of the experience, strengths and weaknesses of the group, qualities of leadership, and possible improvements. (Refer to appendix F for Questionnaire).

An existing instrument, The Ontario Opinions about People - Form A, that has been determined to be valid and reliable was used as an evaluative measure (Hartford and Parsons, 1982). The Ontario Test on Attitudes toward Older People, developed by the Ontario Department of Aging and the Toronto, Ontario, Welfare Board was administered before members attended the group sessions and after they had completed the six sessions.

The Ontario Opinions about People - Form A is designed mainly to assess the attitudes of adults of all ages toward the aging process. The instrument identifies seven attitude dimensions: realistic toughness toward aging, denial of the effects of aging, anxiety about aging, social distance to elders, family responsibility for aged parents and relatives, public responsibility for

the rights and well-being of the aged, and unfavorable stereotypes of older persons (Hartford and Parsons, 1982). (Refer to appendix G for Test).

Each member of the group was also given a Burden Interview test before the group met and after the last session. The Burden Interview was designed by Zarit and Zarit (1983) to reflect the stresses experienced by caregivers. (Refer to appendix H for Test).

Monitoring was used to evaluate the group process. A video tape was used to obtain information about the group. A summary recording was also used by the worker. Summary recording focused on the critical incidents that occurred in the group. They were used to monitor the group's progress after each group session.

Chapter IV

Group Intervention Outcomes

This chapter will provide an analysis of the three tests used to evaluate the process and the outcome of the group. The attitudes test examines various attitudes of the caregivers towards aging while the burden test measures the degree of burden experienced by caregivers. Finally, a subjective questionnaire was administered to assess the level of satisfaction gained by members in the group.

The Attitudes Test

The Ontario Opinions about People - Form A was given to nine members from both groups. Refer to Tables I - VII for the Pre-test and Post-test scores, and Differences. The attitudes measure the following seven dimensions: Realistic toughness toward aging; Denial of the effects of aging; Anxiety about aging; Social distance to the old; Family responsibility toward aged parents; Public responsibility for the rights and well-being of the aged versus unconcern for the aged as a group; Unfavourable stereotype of the old versus acceptance of the old as equals. Refer to Table VIII for Mean Scores and Differences.

Table IRealistic Toughness Toward Aging

Pre-Test	Post-Test	Differences
83	61	- 22
55	76	+ 21
78	85	+ 7
93	99	+ 6
77	72	- 5
77	86	+ 9
133	123	- 10
102	105	+ 3
61	62	- 1

Table IIDenial Of The Effects of Aging

Pre-Test	Post-Test	Differences
9	21	+ 12
21	11	- 10
8	8	-
19	13	- 6
20	14	- 6
19	19	-
13	15	+ 2
13	19	+ 6
12	15	+ 3

Table IIIDegree To Which Members Equate Old Age With Problems

Pre-Test	Post-Test	Differences
52	37	- 15
52	60	+ 8
61	55	- 6
97	111	+ 14
77	80	+ 3
84	90	+ 6
85	64	- 21
29	67	+ 38
60	58	- 2

Table IVSocial Distance To The Older Persons

Pre-Test	Post-Test	Differences
86	75	- 11
121	102	- 19
106	90	- 16
148	137	- 11
127	146	+ 19
86	112	+ 26
122	111	- 11
74	108	+ 34
119	84	- 35

Table VFamily Responsibilities

Pre-Test	Post-Test	Differences
137	67	- 70
74	101	+ 27
134	101	- 33
116	102	- 14
103	99	- 4
44	109	+ 65
141	106	- 55
78	92	+ 14
108	89	- 19

Table VI

Public Responsibilites For The Rights and Well-Being Of
The Aged Versus Unconcern For The Aged As A Group.

Pre-Test	Post-Test	Differences
68	40	- 28
57	65	+ 9
29	27	- 2
54	61	+ 7
57	41	- 16
37	47	+ 10
59	56	- 3
40	46	+ 6
49	46	- 3

Table VIIUnfavorable Stereotypes Versus Acceptance Of Older Persons

Pre-Test	Post-Test	Differences
63	61	- 2
58	37	- 21
43	35	- 8
58	63	+ 5
47	61	+ 14
13	27	+ 14
66	54	- 12
57	57	-
58	44	- 14

Table VIIIMean And Differences For Attitude Scores

	Pre-Test	Post-Test	Differences
Attitude I	84	84	-
II	15	15	-
III	66	69	+ 3
IV	109	106	- 3
V	104	96	- 8
VI	50	47	- 3
VII	51	49	- 2

For each attitude dimension there is an attitude scale, a possible range of scores. An intermediary position on each scale may be fixed - it is that score that denotes uncertainty.

Each of the seven attitude dimensions has its own scoring scheme, with weights assigned to particular items. Because of this, the range of scores is different for each attitude dimension; and a score on one attitude dimension cannot and should not be compared with a score on another dimension.

To interpret any attitude dimension score, it must be considered in terms of its position in the appropriate attitude scale. For all seven attitude dimensions, the lower the score, the more so, that is, the stronger the feeling.

The first dimension, realistic toughness toward aging, measures the degree to which respondents believe that older people need to rely on themselves. (Refer to Table I, page 57). To hold a tough, almost cynical, attitude towards aging (as indicated by the low scores), a person would strongly believe that old people cannot depend on anyone but themselves to face old age and that financial independence is the best protection from hardship. A person having this attitude would tend to resent an older person who cannot look after him or herself.

On both the pre-test and post-test, the group mean indicated that the members were in the little range, that is, they tended to want to be more helpful and responsible for the older relatives.

One member's attitude change illustrates the impact of the group process on this dimension. This member had assumed the responsibility for many of her parent's needs and appeared to be manipulated by her father. With the use of problem-solving, questions, and the support of the group, she began to set priorities for herself and set limits on what she was going to do for her father. This member's score, a difference of 22, showed the most change in the dimension of becoming more "tough" toward aging or the belief that older people can do more for themselves.

The second dimension, denial of the effects of aging, measures the degree to which respondents admit that physical changes take place in aging. (Refer to Table II, page 57). Persons who deny strongly the effects of aging (as indicated by a low score) may tend to have too high expectations of older people and expect them to act beyond their capabilities.

On both the pre-test and post-test, the group mean was in the uncertain range, indicating lack of knowledge of the effects of aging. When one looks at the individual scores, four group members recorded an increase in their post-test scores. This would indicate an increasing acceptance of their parents' aging.

The third dimension, measures the degree to which members equate old age with problems. (Refer to Table III, page 58).

This attitude about aging (as indicated by a low score) leads to the belief that most people are institutionalized as they grow old.

Both pre-test and post-test means of members showed little anxiety about aging, although the post-test mean showed a slight decrease in anxiety.

One member's attitude change illustrates the impact of the group process on this dimension. This member could not understand or accept her feelings towards her mother. She could not understand the reasons for her becoming angry at her mother and could not understand the reactions and behaviors of her mother. There was also the concern that she would become as confused as her mother. The opportunity to express her feelings and to accept them, helped to relieve her anxiety level. The fact that she realized that her feelings and emotions were normal also helped to relieve anxiety. The illustration that aging and disease are not related helped her as well. She had mainly negative feelings about the aging process. The information on the positive aspects of aging and the reality that aging is not a prerequisite to illness helped her to feel less anxious in the presence of her mother. This member's score, a difference of 38, showed the most change in the dimension of becoming less anxious about aging.

The fourth dimension, social distance to the older persons, measures the degree to which members believe that there is a gulf between young and older persons. (Refer to Table IV, page 58). Much social distance (as indicated by a low score) can be seen as an

inability to communicate and may lead to dislike and distrust.

The group means of the pre-test and post-test stayed in the little social distance as reflected in the attitudes of the members, although the post-test group means showed a little movement toward greater social distance. This movement could be interpreted to demonstrate a more realistic perspective of some of the real distances between the generations.

One member's attitude change illustrates the impact of the group intervention on this dimension. This member's score showed a decrease from the pre-test to the post-test of 35. This score indicated a sense of greater social distance between himself and his mother. This member had assumed complete responsibility for the care of his mother. Her care needs had reached the point where he was considering quitting his job so that he could devote more of his time to her. The group, as a whole, reacted strongly to this approach considered by the caregiver to quit his job. They expressed strong objection to his quitting his position. They felt that he would be sacrificing his life for his mother. They felt he would regret it later in his life.

The group member, through the intervention of the group, became more aware of his sacrifice to his mother and how inappropriate his reactions were to her care needs. This realization tended to increase his social distance from his mother which could be interpreted in a positive manner.

Another member's score showed an increase from the pre-test to the post-test of plus 34. This indicated a decrease in social distance. This individual had observed a great change in her mother in the past few years. Her mother had become very confused and disorientated. She began to view aging as a disease and really could not understand what was occurring to her mother. She had always had a good relationship with her mother but now she tended to dislike her.

The group allowed the group member to express her concerns and feelings about her relationship with her mother. The group provided the member with support in the way of mutual aid and information that would provide her with a more accurate appraisal of her mother's illness. This helped to reduce the social distance between the group member and her mother. This appeared to reduce the tension in the household and the guilt of the group member if she had to consider nursing home placement for her mother.

The fifth dimension, family responsibility, measures the degree to which members believe that the primary responsibility for old adults rests with the family. (Refer to Table V, page 59). The pre-test and post-test group mean scores showed that members were for family responsibility toward aged parents. The post-test score showed a slight increased belief in family responsibility.

The individual scores showed primarily an increase for family responsibility toward their parents. Six members of the group had an increase in their scores from the pre-test to the post-test. All group members showed a desire to keep their parent in the community

and perceived nursing home placement as a final resort.

One group member's score showed an increase of plus 65. This indicated a decrease in family responsibility toward her parent. This member was caring for her mother who had been diagnosed as having Alzheimer's Disease. She had moved from British Columbia to Winnipeg so she could provide some support for her mother. When she entered the group, she was feeling overwhelmed by the care needs presented by her mother. The group helped her to accept the limitations of her role as a careprovider. They helped her accept the fact that she had her own needs to be met and that boundaries had to be set in the amount of care she could provide.

The sixth dimension is public responsibility for the rights and well-being of the aged versus unconcern for the aged as a group. (Refer to Table VI, page 59). To be strongly for public responsibility (as indicated by a low score) is to recognize that services should be available for the aged should they require them. The group pre-test and post-test mean scores indicated that the members strongly believed in public services and responsibility. The post-test group showed a slight increase in the belief for public responsibility.

The seventh dimension, unfavorable stereotypes versus acceptance of older persons, measures the degree to which a respondent accepts old people with individual qualities. (Refer to Table VII, page 60). Acceptance of the old (as indicated by a higher score)

means to accept old people as individuals and to recognize there are differences among the old as among the young. The pre-test and post-test mean scores of the group reflected little stereotyping of older persons. It could be assumed that people who are living every day with older people who have realistic problems have very little room for stereotyping.

Burden Interview Test

The Burden Interview was given to nine members of the two groups. The caregivers were asked to respond to a series of twenty-two questions about the impact of the relative's disabilities on their life. For each item, caregivers indicated how often they felt that way: never, rarely, sometimes, quite frequently, or nearly always.

The Burden Interview was scored by summing the responses of the individual items. Higher scores indicated greater caregiver distress: 0-20 Little or No Burden; 21-40 Mild to Moderate Burden; 41-60 Moderate to Severe Burden; 61-88 Severe Burden.

The results of the Burden Interview indicated that two scores increased, three stayed the same and four decreased. (Refer to Table IX, page 68).

Table IXBurden Interview Scores

Pre-Test	Post-Test	Differences
30	44	+ 14
39	60	+ 21
43	43	-
40	40	-
36	36	-
63	48	- 15
68	48	- 20
62	45	- 17
48	37	- 15

The mean scores were 47 for the pre-test and 44 for the post-test. The post-test indicated a slight decrease in the level of stress for the group members.

One member's burden level increased from moderate to severe. Part of this increase can be related to a crisis that developed with her mother. This placed the group member in a highly stressful situation.

Three group members' burden level decreased from severe to moderate. This does indicate that the group did provide a means for stress management. Members were able to gain support from other group members who were experiencing the same problems and concerns. Members saw that they were not alone with their problems and this was helpful in reducing their stress. The fact that they were able to express

their feelings about their role as caregivers and their attitudes to their parents was burden-reducing.

Subjective Questionnaire

A feedback questionnaire was distributed at the last meeting of both groups, to be filled in anonymously, if so wished by the individual member. Members were asked eight questions:

- 1) What were your initial expectations of the group?; 2) Were your expectations met?; 3) Was the information presented about aging helpful to you in understanding the aging process?; 4) Rate the effectiveness of the leader; 5) What did you find most helpful about the group?; 6) What did you find least helpful about the group?; 7) Overall, rate your satisfaction with the group; 8) I would recommend this type of group to people in a similar situation.

Most members stated that they had joined the group for the chance to share their concerns, to acquire new knowledge and information related to aging and how to cope more effectively with their role, or to deal with their feelings of anger, frustration, and guilt. Some comments from group members were: "Discussing aging parents and their care"; "To gain knowledge re my situation with hopes of understanding my parents better - due to her condition, and my responsibility"; "To learn how to cope with the stress and guilt feelings brought on by being the only caregiver"; "To learn more about aging and the options available for the aged as they reach

the different levels". Some members stated they really did not know what to expect.

All members from the second group felt that their expectations had been well met. Some comments were: "Yes! I really felt the group helped me deal with a lot of my feelings of depression and guilt"; "Yes - I must learn to accept my limitations as the situation won't change"; "Yes, especially when it came to dealing with feelings about being a caregiver". A number of members simply answered with a "yes" statement.

Two members in the first group felt that not all their expectations were met. Some comments were: "For the most part - yes. I would have liked to see more time spent directly on stress management"; "Only on the last session where one had a chance to reflect on previous sessions and come to certain realizations that - yes "That is the situation I am in after all".

When asked to write what they found most helpful about the group, the three most frequently chosen were: support, sharing of similar problems, and that they were not alone. Some examples of responses were: "Support and sharing of similar problems"; "Support of others in the same situation was most helpful"; "I found that just being able to talk about my problems with people in the same position as myself helped me in coping with my situation"; "The openness and honesty of the people and I felt very comfortable with each and every one of them"; "That others share so many similar

problems in their role as caretaker. (Everyone was very open re their problems)"; "Hearing that I was not the only one having a difficult situation and hearing about how they (the group) were dealing with their problems".

When members were asked what they found least helpful about the group, the most common response was - nothing. One member mentioned the video camera. One member from the first group felt she did not belong because her mother had Alzheimer's Disease. Another member from the first group felt that stress management was least helpful.

Out of fourteen members who answered the questionnaire, eleven found the information presented about aging very helpful in understanding the aging process, two found it somewhat helpful, and one found it a little helpful.

In rating the effectiveness of the leader, eleven found him very helpful and three found him somewhat helpful. The three who found the leader somewhat helpful all came from the first group.

In rating members' overall satisfaction with the group, ten were very satisfied and four were satisfied. Out of the four, three came from the first group.

When asked if they would recommend this type of group to people in a similar situation, ten strongly agreed and three agreed.

Additional results became apparent at the conclusion of the group sessions. In both groups, members developed a feeling of universality. Most members who began the group, felt that they were alone and unique in their role as a caregiver for their parent. Members felt that they were alone in having a difficult time dealing with the problems of being caregivers. Members received comfort in the knowledge that they were not alone in their situations. As stated earlier, Yalom (1970) describes a sense of universality as a curative factor.

The mutual experiencing of ideas and emotions led to the "all in the same boat" phenomenon. Again, this is the healing process which occurs when one realizes that one is not alone and that others share the problems, the feelings, and the doubts.

Members of both groups were provided with a positive outlook on aging. Members were encouraged to separate their conceptions of being old from being ill. It was stressed that disease and aging are totally separate. This was done to reduce the threat in their role as a caregiver.

A great deal of ambivalence was expressed about health professionals and the Home Care Program. Many members expressed disappointment, anger, and frustration in trying to deal with their Home Care Co-ordinator and the Program. In some cases, services were being implemented but not to the satisfaction of the family. One member of the second group stated that the homemaker who was to provide services for her parents was reading her biology text. The group member stated that she was not totally aware of what the

homemaker was to do and did not know where to turn to deal with this situation.

The group members helped in dealing with this situation by providing examples of how they dealt with the bureaucracy. Members were able to give each other a means to deal with their individual problems. One member stated that you had to be firm and articulate when expressing your concerns and needs to a professional.

There was another situation expressed by another group member. She stated that her mother was a stroke victim and was being discharged from the hospital. She was totally dependent on others for all of her needs. The group member stated that the Home Care Department had put in a Home Care Attendant to assist her mother with her needs. The member stated that the Home Care Attendant did not know how to transfer her mother and put her at risk. She phoned and begged for help. This did not work and she became angry. The response she received from her Home Care Co-ordinator was that if she did not like the service, she could hire someone private. A few members stated that they were hesitant to complain to their health professional because they were concerned that their services would then be withdrawn.

In the first group, there was a considerable amount of anger and frustration directed at doctors. They felt that their parents' doctors tended to ignore the elderly and did not provide an adequate service.

The situations indicated to the group members that they were not alone in having problems with the health care field. The group members were able to support each other through the use of mutual aid. Members were able to share similar problems.

The implication of this to the health field is that family members have a difficult time dealing with the bureaucracy and other health professions. On the one hand, there appears to be a lack of communication between professionals in the health field, and on the other hand, an inability of family members to relate properly to the bureaucracy.

Professionals should understand that family members, in many cases, are dependent on the health field for support in caring for their parents and that they feel vulnerable. Family members should be included in the care plan for their parents. They should be aware of what is planned for their parents and how it is to be implemented.

Family members should be given some guidelines in how to best confront the bureaucracy. Family members are in many cases, very anxious and apprehensive in dealing with the bureaucracy, and they may feel overwhelmed. When confronting the bureaucracy, family members should be specific, it helps to know exactly what one is looking for. They should be polite but firm. They should not apologize when asking for help. They should get names, be prepared and assertive. They should also check all options (Silverman, Brahce, and Zielinski, 1981).

Members from both groups were able to ventilate feelings and as a result, deal with their emotions towards their role as caregivers and their feelings towards their parents. In being able to express these feelings openly, members learned to accept them, put them into perspective, and come to a better understanding of their own emotional needs.

Members from the two groups expressed similar feelings towards their dependent elderly parents. This re-enforced the findings of others, that adult children share a range of similar feelings toward their elderly parents (Cohen, 1983; Hartford and Parsons, 1982; Hausman, 1979; Silverman, Brahce, and Zielinski, 1981; Silverstone and Hyman, 1976).

Members expressed feelings of helplessness, frustration, anger, fear, sorrow, and guilt. One member stated that she felt sorrow for her mother because she remembered how independent she once was and now how dependent she was on her. One member stated that she was always fearful that her mother would wander off. She would stay up at nights listening for noises. Another member stated that she became frustrated with her mother because she continually repeated herself. A member stated that she became angry with her mother because of her confusion. There was also anger because of selfishness of their parents. Members felt that their parents showed little concern for their needs. One member stated that when she told her mother she could not do the shopping

because she was ill, her mother's response was, how could you get sick, I need someone to do my shopping. All members expressed the feeling that no matter what they did was never enough.

The group members had a difficult time in associating any positive feelings toward their role as a caregiver. They tended to view their roles in negative terms. The group was structured to look at the problems that members encountered in their role as caregivers for their dependent older parents.

The major significant findings in this chapter have been outlined. Members of the group as caregivers had the attitude that their parents could rely on them for support. They wanted to be helpful and responsible for their parents. The group as a whole saw themselves as primary careproviders and felt that this was their responsibility as family members. The members of the group did find their caregiving role to be stressful. Almost all members felt that their parents were nearly always dependent upon them and that they quite frequently felt strained when they were around them. The members of the group found the most satisfaction from the support offered by the group members and the sharing of similar problems. They also received satisfaction from the knowledge that they were not alone.

Chapter V

Common Elements of Group Process

Both groups employed a dual interventional foci. The dual premises underlying the groups were that relatives require both information and affective support. The method of intervention was an interweaving of both foci into a combined approach.

The use of the experiential technique in the first sessions of the two groups was very effective. Members were able to get acquainted and at the same time, share common concerns and issues with one another. This technique helped members to feel at ease with one another. It also helped in developing group cohesion and demonstrated that members were not alone with their problems. One other advantage of the exercise was that it helped to develop member-to-member linkages.

The use of role playing was an effective technique for the group members. Role reversal was the technique used in the groups. This technique helped to clarify situations and it increased members' self-awareness. In the two cases that this technique was used, members became aware that their reactions to their parents' demands re-enforced their parents' behavior. The members also became aware that their parent can be manipulative and that giving in is not always the answer.

The pre-group interview was an important facet of the planning process for the two groups. It helped in assessing the potential members and orientating them to the group. It made their transition to the group easier. They were given information before the group met and the anxiety about coming to the first meeting was reduced because they had met the worker and, therefore, knew a group member. The interview also determined suitability.

The method of intervention took place at basically two levels, the group member and the group as a whole. In dealing with intrapersonal interventions, members were helped in accurately identifying thoughts, feelings, and behaviors and learning to discriminate among them. Some members had a difficult time in putting their subjective thoughts and feelings into words.

Members of the groups had a difficult time in describing some of their feelings. They had a tendency to answer a question about what they were feeling with a description of a behavior or a thought. Some members had a difficult time in putting their uncomfortable feelings about their parents and their role as caregivers into words. One member stated that it bothered her that her mother continually repeated things. It took her time to realize that she had feelings of anger and frustration. Another member stated that her parents seemed to not care about her needs. The member stated that her parents' demands took up a great deal of her time and she was not able to meet her own or her husband's

needs. The member realized after some discussion among the group that she had feelings of anger and resentment. It took the support from other group members for her to be able to express these feelings. Another member stated that she felt nothing. In actual fact, she felt helpless and angry.

Through the group process, the members began to recognize that there is an association between thoughts, feelings, and behaviors. This was done through the group discussion. In some cases, the discussion revealed that specific thoughts were exacerbating or maintaining unwanted-feeling states and behavior patterns. A number of group members found that their thoughts were focused on their inability to never do enough for their parents and thoughts that consequently their parents would be at risk. This also made it very difficult to establish their life priorities. Adult children, if they were not able to assign first or even second in their place to their parents, they could never forgive themselves. As their thoughts were discussed in the group, it became clear that these led to their fears and their anxiety about their role as caregivers.

The members were helped in analyzing the rationality of their thoughts and beliefs. This pertained particularly to their feelings of guilt. Members became aware that they had a tendency to take too much responsibility for events that were beyond their control. They also became aware that they were not perfect and

were encouraged not to use such statements. Members had a tendency to believe that in order to consider themselves good and worthwhile children, they must be able to assist their parents with all their needs. In those instances where their performance fell short of their unrealistically high standards, they felt guilty.

The group provided mutual aid and support in dealing with guilt. They were able to share similar situations and problem-solve as a group. The group helped the members to come to the realization that there were limits to their ability to provide care for their parents. They must be able to set limits in order to be effective in their role as a caregiver.

In some cases, corrective information and feedback were sufficient to change thoughts and beliefs based on incomplete or incorrect information. Some members expressed concern about dementia and Alzheimer's Disease. They felt that since their parents were exhibiting dementia, the same would happen to them. It was pointed out that this was not necessarily the case. Accurate information about Alzheimer's Disease helped to alleviate some of their concerns. The group itself helped members to express their fears of Alzheimer's Disease and corrected any misinformation.

The techniques for changing thoughts, beliefs, and feelings were in the forms of cognitive restructuring and cognitive self-instruction. Members were asked to examine some of their assumptions on which their thoughts and beliefs were based. Members were also encouraged to generate alternative assumptions. Members received

feedback from other group members about the logic of their assumptions.

The use of the closed group helped to develop group cohesiveness which was important to the process of the group. The time-limited approach made members aware that they had only so much time to deal with issues and as a result they were more focused.

The use of a formal presentation of material should be kept to a minimum. The major focus is the group process. A certain amount of information is important but the leader should not get caught up in only answering direct questions.

The formal presentation on aging was appropriate but it did not have to consume as much time as it did in the group. The formal presentation of material must be used carefully because it may interrupt the development of group cohesion and problem-solving. When presenting information, it is important to make it as stimulating and relevant as possible. I tried to involve the group members in the presentation on aging. I used a true and false questionnaire. The group appeared to respond to it and it made them think about their attitudes to aging. I felt that the one thing that needed to be discussed was that aging did not mean disease.

Feedback was used as a technique of intervention. Feedback was a way of checking how the members felt about the group. At the conclusion of each session, members were given the opportunity to discuss their feelings of what went on during the session. It was also a

way of checking to ensure that the meanings of the messages that were communicated were understood correctly.

Mutual aid presented itself in helping members to discuss uncomfortable feelings. Members were able to relate feelings such as anger, frustration, guilt, helplessness, and shame. Members were also able to relate comfortable feelings such as love, compassion, and generosity. They were able to share ideas, facts, beliefs, and resources, which they found helpful in coping with similar problems. Members of the group related how they dealt with the bureaucracy. They realized that they were all in the same boat which offered relief. Members also provided emotional support and mutual demand.

Mutual aid was a technique used in the group. Members were encouraged to interact with each other. The groups developed in a way that members needed each other as well as the leader. The resolutions to many of the problems were directed to the group members. This was more evident in the second group.

Members of the groups did provide empathic support. Carrying a burden is often easier if others express their understanding. As group members supported a member with their feelings, they were also helping themselves with their own similar feelings.

The term mutual demand was evident in the group by the fact that members were willing to confront each other. There was a number of cases where this presented itself in the group. There was

one member who was thinking of quitting work so he could provide more care for his mother. The group as a whole confronted the member and let him know that they felt that this was not an appropriate approach to take.

Differences Between The Two Groups

There were differences between the two groups. The differences were related to group dynamics and group process. I found the second group to be more effective in meeting the needs of the members and the objectives of the group. I felt that the fact of learning from the first group helped in the development of the second group.

The first group's interaction pattern tended to be more focused on the leader than the second group. In some cases with the first group, there tended to be leader-to-member or member-to-leader communication patterns only. There also appeared to be occasions where there were extended back and forth exchanges between the leader and a member as others watched. I felt that this occurred because I failed to redirect their attention to the group as a whole. Members during the initial stages were eager to interact with each other but I had a tendency to present myself as the expert.

The second group's interaction patterns were more of the free-floating type. All members of the group took responsibility

for communicating. There were some instances where the leader became the central figure and the communication pattern was from leader to member or from member to member.

In both groups, I tried to maintain and facilitate the development of the group-centred rather than leader-centred interaction pattern. The second group tended to have freer interaction with each other and the channels between the members were open. Members in both groups wanted to express their situations to other group members. In the two groups, members had little hesitation in relating their problems to others.

Group attraction or cohesion developed quickly in both groups. With the introductory experiential exercise, members realized that they had common problems. Cohesion also developed quickly because members had common needs they wanted dealt with in the group. The desire and the need to attend the meetings were evident in most members.

The cohesion in the first group had a tendency to dissipate in the later sessions. This was partly due to the structuring of the group. The agenda was formulated by the leader and there was little deviation. In some cases, the needs of the members were replaced by the needs of the leader.

The agenda for the first group sessions were set before the group met. As the leader of the group, I had a tendency to ignore

some of the needs of the group members and push forward with my timetable and agenda.

The second group's cohesion grew with each session. I felt that part of this was due to the fact that I was more aware of the needs of the clients. I had gained the knowledge from the first group that the structure and agenda must relate to the needs of the group members and that they should have some determination on what would be dealt with.

In the second group, I listened to the needs of the members and structured the group agenda around their needs. I was aware that trying to fit in my content in each session was not the overriding concern. In the second group, the second session dealt with unresolved issues from the first session. Members in the group appeared to want to discuss alternate living arrangements. This was included in the second group meeting.

I felt that the size of the groups affected the cohesiveness. I felt that the first group was too small. If one member failed to attend, it affected the group as a whole. It really took away from group cohesion. There appeared to be a real letdown by other group members. The fact that the group was closed, caused some anxiety from the leader. The need for complete attendance put pressure on the leader.

The second group had a larger number of members. This number appeared to be optimum in developing cohesion and providing group interaction. The more members increased the problem-solving

ability of the group. Members were able to receive more suggestions on how to deal with their situations.

Informational content was used more effectively in the second group. It was interjected to provide necessary information on particular problems. In the first group, it was provided on the basis of the leader's agenda.

Members of the second group presented problems related to alternate living arrangements for their parents during the first session. During the second session, the leader provided the group with some informational content that would help them cope more effectively with this problem. This was done in a concise manner.

In both groups, it was evident that members had to make difficult decisions for themselves as well as their parents. During the second group, problem-solving techniques were offered to the members. This was not done in the first group because it was not part of the agenda set out by the leader before the group met.

The two groups employed a dual interventional modality that was effective in meeting the needs of the group members. It was important that the groups developed an atmosphere where mutual aid and problem-solving were encouraged and fostered. The educational component should try and supplement the growth aspect of the group. The presentation of material should be kept at a minimum and only implemented at specific times for specific problems. The agenda

of the group should be flexible and suited to meet the needs of the group members. The use of two groups for the Practicum helped in developing the skills of the leader in relation to group process and group material.

Chapter VI

Conclusions

An Educational/Growth Group is an effective intervention for adult children who are coping with the problems of caring for a dependent parent. There is an increasing need for adult children who have a caregiving role for their parents to receive assistance with handling their feelings, realistic planning, understanding of aging, and support for their day-to-day responsibilities and frustrations.

The literature review for this Practicum helped guide and predict the needs of the "Sandwich Generation". There are feelings that are pervasive. Guilt is one feeling that was evident for all group members. The knowledge that adult children caregivers had common feelings helped in developing the agenda of the group.

A mutual aid system is vital for the group to be effective. Mutual aid facilitates the sharing of common experiences and feelings, thus helping to relieve some of the isolation and loneliness that adult children often experience.

This Practicum led to a further awareness of the extensive and urgent needs of adult children caregivers. These caregivers are caught in the middle of trying to meet their own needs, their

families' needs, and their parents' needs. They are caught in a squeeze position. They are in many cases, placed in the position of having to make difficult decisions that greatly affect their parents' lives.

Group members should be encouraged to look at the comfortable and positive feelings that are associated with their role. The acknowledgement of comfortable feelings help members to perceive their role in a more positive fashion. It helps to balance out some of the uncomfortable feelings and may also reduce their burden level. Feelings of love, generosity, concern, and devotion were some of the positive feelings expressed by the group members.

The Attitude Dimensions showed that the members of the groups who took the test wanted to be helpful and responsible for their older relatives. Group members believed that primarily, responsibility for care lies with the family but that support should come from the public sector. The scores also indicated that members were uncertain in regards to knowledge and of the effects of aging.

The Burden Interview indicated that members of the group experienced stress in their role as caregivers to their parents. Most of the members felt stressed between caring for their parents and trying to meet other responsibilities.

The Subjective Questionnaire indicated that group members found three elements of the group most helpful: support, sharing of similar problems, and that they were not alone.

The closed and time-limited format of the group is an appropriate format for adult children caregivers. Six 1½-hour sessions appeared adequate for the majority of members but the flexibility to extend the number of sessions should be provided to the group.

An ideal size for the group would be 8 - 10 members. This number of members provides a greater opportunity for common experiences and feelings to be shared and for the providing of alternate solutions.

The Educational/Growth Group offered participants relief in sharing common difficulties, engaging in mutual problem-solving, and receiving recognition and support from other group members. The presence of others, gave members a chance to receive feedback that assisted them in their change efforts.

The response of adult children caregivers whose parents are receiving care from the Home Care Department, indicates a need for an Education/Growth Group. Adult children are considered primary supports for their older relatives but are being overwhelmed by their needs. They are finding it extremely difficult to carry on with their lives while trying to support the many needs of their older relatives. Their needs may vary from actual hands-on-care to providing emotional support and decision-making, which may dramatically alter their lives. Consequently, the Home Care Department in the community may consider incorporating an Educational/Growth Group in their Program.

APPENDIX A

PREPARED PROGRAM

- NAME:** Support and information group for relatives of dependent older adults.
- PURPOSE:** To provide emotional support and practical information to family members who are care-givers for dependent older adults.
- TARGET POPULATION:** Families of elderly patients who have come to the attention of the Misericordia Hospital through emergency or admission during the months of July, August, and September, 1985. The family members will be the children or other relatives of the patient.
- REFERRAL PROCESS:** Attendance is strictly voluntary. The referrals will come from the Misericordia Hospital. All referrals will receive an interview before admission to the group.
- STRUCTURE:** The group will be a closed one. The membership will be between 7-13. The group will meet once a week for approximately 8 sessions of one and one half hour duration, during the months of October and November, 1985. The group will be directed by Jerry Truon, B.A., Certification of Education, B.S.W., a student in the M.S.W. Program, and a Home Care Coordinator for the Manitoba Department of Health. This group is a requirement of the Masters' degree and is conducted in conjunction with the Department of Social Work, Misericordia Hospital.

PROGRAM CONTENT

SESSION 1. Introduction.

- Objectives:
1. To share expectations.
 2. To allow each participant the opportunity of sharing their concerns and needs.
 3. To establish an atmosphere where group cohesiveness will develop.

continued...

SESSION 2. *The Aging Process and the Psychological Aspects of Aging.*

- Objectives:
1. *To better understand the physical and emotional factors that affect the aging process.*
 2. *To understand their feelings about their relatives' aging, as well as their own aging.*

SESSION 3. *Understanding the Stresses That Confront the Care-giver.*

- Objectives:
1. *To better understand the needs and concerns of the middle generation.*
 2. *To explore the responsibilities of adult children to their parents or relatives.*

SESSIONS 4 & 5: *Confronting Their Range of Feelings Towards Being Caregivers and Their Family Members.*

SESSION 6. *Providing Practical Information on How to Problem-Solve and the Management of Stress.*

SESSION 7: *The Availability and Utilization of Community Resources.*

SESSION 8: *Conclusion - What to do With One's Older Dependent Adult.*

EVALUATION: *A pre-test and post-test will be provided to group members. A feed-back questionnaire will also be completed by the members of the group.*

APPENDIX B

Support Group for Relatives who are Providing Care for Dependent Older Adults.

Objective: The group will provide a helpful service to family members who are coping with the problems of caring for a dependent older relative.

- Goals:
- 1) To provide information and to develop an understanding of the aging processes.
 - 2) To assess and begin to work on some ways of coping with the tensions, feelings, and responsibilities of the caregiving relatives toward their older relatives.
 - 3) To help them adjust with role changes and other areas of stress.
 - 4) To provide an atmosphere where problem-solving and information-sharing can take place.
 - 5) To provide assistance in the planning for the older relative in light of their changing condition.
 - 6) To provide mutual support for the members by developing a social network that will permit and support expressions of ambivalence and resentful feelings about current conditions, responses, and relationships, and to offer empathetic responses.

Method of Intervention:

The dual premise underlying this group is that relatives require both information and affective support. Therefore, the group approach is an interweaving of both modalities into a combined approach. Throughout all sessions, members share their feelings, support one another emotionally, explore options and alternatives, and participate in mutual problem-solving. An eclectic group approach will be used, which will be derived from various theoretical orientations as it seems appropriate for the needs of the members. Direct therapy does not take place, rather therapeutic effects are facilitated indirectly by the group process. This approach will be more of the supportive, current functioning, reality-orientation type, with a didactic educational approach to understanding the normal and pathological changes in aging, with an emphasis on helping members cope with and master their current situations.

Clients for Referral:

Relatives who are providing care for a dependent older adult. Primary emphasis is toward adult children. Spouses are not appropriate referrals for this group.

Setting: The Misericordia Hospital.

Referral Process:

Attendance is strictly voluntary. The referrals will come from the Misericordia Hospital and community Home Care. All referrals will receive an interview before admission to the group. All referrals are to be directed to Jerry Floom - 945-7323.

Structure:

Group will consist of 10 - 13 members. The group will meet once a week on Thursdays for approximately 6 sessions of 1½ hours duration, during the months of March and April, 1986.

Appendix C

Outline of Agendas

- The First Group
- Objectives of Sessions

Session I

- a) Presented guidelines of the group.
- b) Established a common bond between group members.
- c) Began process of establishing cohesiveness.
- d) Began to establish the range of feelings adult children have toward their parents.
- e) Established concept of universality.
- f) Established the group's purpose.
 - Techniques.
 - Opening exercise.
 - Round robin.
 - Established linkage from leader-to member to member-to-member links.

Session II

Objectives

- a) Understand the needs and concerns of the Middle Generation.
- b) Explored the responsibilities of adult children to their aged parents.
- c) Established that the range of feelings adult children have toward their parents are appropriate and serve a purpose.
- d) Strengthened the cohesiveness and communication between the members.

Session III

Objectives

- a) Developed some positive feelings about caregiving and their parents.
- b) Began to explore their feelings about their own aging.

Session IV

Objectives

- a) Understand the physical and emotional factors that affect the aging process.
- b) Developed an understanding of the aging process, their own and their relatives.
- c) Clarified misconceptions about aging -
 - Used charts.
 - True and false questionnaire.

Session V

Objectives

- a) Re-establish member-to-member links -
 - Exercise.
- b) Developed problem-solving methods.

Session VI

Objectives

- a) Dealt with ways of defeating guilt.
- b) Encouraged members to relate their feelings about the group.
- c) Integrated the material presented and discussed in the previous five sessions.

Second Group

Session I

Objectives

- a) Set down guidelines of the group.
- b) Developed feeling of universality.
- c) Developed member-to-member linkages.
 - Exercise.
 - Round robin.
- d) Established the group's purpose.

Session II

Objectives

- a) Dealt with uncomfortable feelings group members have in regard to their role as a caregiver.
- b) Dealt with the issue of alternate living arrangements for their parents.
- c) Dealt with some issues of being in the "Sandwich Generation".
 - Used flow chart.

Session III

Objectives

- a) Dealt with members uncomfortable feelings towards their role as caregivers and their parents.
- b) Dealt with feelings of guilt -
 - Didactic information.
 - Ways of defeating guilt.
- c) Provided a means for stress management.
 - Dealt with burden.
 - Realize stress.
 - Pulled in many directions.
 - Priorities must be set for themselves.
 - Dealt with some positive feelings of being a care-provider.

Session IV

Objectives

- a) Dealt with the issue of aging -
 - Dispelled some stereotypes and myths.
 - Didactic.
 - True and false questionnaire.
- b) Understand the relationship between aging and disease.
- c) Further dealt with positive feelings of caregiving.

Session V

Objectives

- a) Maintain sense of cohesiveness.
- b) Dealt with problems as a group -
 - Use of problem-solving techniques.
 - Use of role-playing.
- c) Provided some didactic information on aging and dealing with professionals.

Session VI

Objectives

- a) Understand that change is inevitable and that losses occur with age.
- b) Understand that emotional reactions to change or loss are common.
- c) Understand the ways that persons in later life can make adjustments and cope.
- d) Encouraged members to relate their feelings about the group.
- e) Integrated the material presented and discussed in the previous five sessions.

* This and the following reference materials not cited by author have been compiled from numerous sources. See Bibliography.

Issue of Aging

Appendix D

Being old has been depicted as a tragedy. We are provided with a lengthy list of how needy the elderly are, how poorly they are treated, and how much must be done for them. As obviously true as these needs are, it seems that the picture can become distorted. Aging is often defined entirely in terms of the sick and needy. By emphasizing the horrors of aging, we have looked only at ways of alleviating these horrors. As a result, the benefits of being older, the potential for growth in the later years, the possibilities for pleasure and satisfaction are all ignored.

Few would relate aging to the transition from infant to toddler, from child to adolescent, from teen to adult. In short, aging is popularly linked to the elderly and to negative implications.

What is your image of the aging process? The old concept of aging was a downhill path, beginning at 60 or 50 or even 40 or 30, it implied slow deterioration, accelerating with time. Aging can be seen as an opportunity for personal growth. The popular misconception is that to be old is to be sick. This does not

necessarily have to be the case. The elderly today are healthier than in the past.

Successful aging may depend as much on your expectations as it does on your health. Can you imagine what your life will be like when you are old? No one, of course, has a crystal ball, but we do have projections, anticipations of our wishes and anxieties. In recognizing our expectations, fears, and image about aging, we are in a position to influence positively what will happen.

Explore your thoughts about some of the following questions:

1. What personality qualities do you most like to see in old people?
2. What do you most fear about growing older? What is the worst thing that can happen to you in old age?
3. Would you like to retire? At what Age? Will you have a choice? How do you feel about retirement? What do you picture your economic situation to be?
4. What kind of housing would you like? What kind of neighborhood do you want? What kind of community?
5. How will you like to spend your leisure time? What kind of activities do you expect to find pleasurable?
6. What changes do you expect in your sexuality?
7. What will be the quality of your friendships? Will you make new friends easily?
8. What do you imagine your health will be like when you are old? What health problems do you anticipate?

9. What advantages do you see in being old? What kinds of pleasures are more possible in your later years than in your youth?

How old are you? As old as you look? As old as you act? Actually, most people, when asked that question would reply by giving a number - their age in years.

Some might think of their age in years but not want to say it, for that magic number, if it is thought to be "too high", brings up negative connotations of old age, and they would rather not be judged by an unfair standard. Using chronological age as an indicate for an individual can be highly misleading. Any changes occurring in an individual occur at a pace unique to him, and the pace may change and vary.

What do you fear most about aging? For most people, self-sufficiency and independence are extremely important qualities of life. What people say they also fear about old age are the possibilities of being helpless, poor, sick, dependent, and unable to care for self. Poor health is something we all dread and for some people it represents a condition worse than death. But in the absence of chronic poor health, why should growing older be an ordeal?

Too often we adopt stereotypes of aging from the sick and the needy, rather than from the healthy and successful. Many people associate old age with the expectation that they will be incapacitated.

Aging is not an inevitable circumstance that happens to us as passive recipients. It is a style of living that we create. We actively choose from a number of options that determine our health. We must all age, however, we need not grow "old" in the contemporary derogatory sense.

What are your suppositions about older people? Do you presuppose a certain type of personality, or a different kind of intelligence? How do you react when you meet someone who appears to be old? Many of us try to avoid older persons because we feel uncomfortable with them; we are also likely to feel impatient because we anticipate that the older person will move slowly or understand poorly. Does that describe you at all? The next time you meet a "senior citizen" try to observe what happens; increase your awareness of what "oldness" means to you.

A 70-year old woman was asked in an interview "What do you encounter as the stereotypes of old age?" "Oh, there are so many", she replied, and older people believe them, and younger people are taught to expect them. Old people drool. They take laxatives all the time. Their sex organs are dried up. They cannot understand youthful progress and are stuck in the past. Senility is judged an inevitable part of age. How would you describe old age?

Stereotypes make your thinking rigid and over-simplified. References to "the elderly" imply common characteristics for a group of people based on their age. In reality, elderly individuals are no more alike than people of any age.

How would you complete these sentences:

- 1) In general, old people need
- 2) One of the greatest fears of many old people is
- 3) Old people resent
- 4) One of the greatest pleasures of old people is

Some results:

- 1) Younger people often named assistance.

Older people cited wanting to be liked and valued by others.

- 2) Younger people said that death and dying were great fears.

Older people stressed lack of money and financial security.

- 3) Younger people felt that older people resented younger people.

Older people most resented rejection.

- 4) Younger people felt that the greatest pleasure was family.

In older people it was companionship and love.

Our stereotypes of old age are negative. Unless people are in poor health, rarely do they judge themselves as "old". "Old" usually refers to the way in which we see others. You may have heard your 84-year old aunt refer to her somewhat younger friends in a nursing home as "those old people".

Facts about Aging:

1. Intelligence is relatively stable throughout life unless the person is suffering from a health condition affecting her or his cognitive abilities. Learning is possible at any age.

2. Physical activity can continue throughout a person's life.
3. Creativity can occur at any age.
4. Individuals with more education have better health and appear able to adapt more successfully.
5. Personality does not normally change drastically with aging.
6. The sex drive and related behaviors often continue well into the 80's.
7. Age is a poor index of the differences between people in their abilities to find pleasure in living and to experience happiness.

Memory loss should not be confused with overall mental decline. Psychologists have found that while memory may decline with age, judgement often significantly improves with age, and the ability to comprehend what is seen also improves with experience. When rapid response is required, older people do not react as quickly as younger ones; they do not seem able to process as much information per unit of time. But this slow-down is normal, and is not a sign of mental decline. Some brain syndromes, formerly considered irreversible and included in the catch-all diagnosis senility, are not necessarily chronic or hopeless. Reversible brain syndrome, showing a variety of symptoms, confusion, disorientation, stupor, delirium, or hallucination, may result from any one of a number of causes: malnutrition, anemia, congestive heart failure, drugs, or infection, among others. If diagnosed quickly enough before

too much damage is done, reversible brain syndrome can be treated successfully.

Many factors should be taken into account when describing aging. One's physical, psychological, and sociological development must be taken into account. Each of us differs in how we age, as well as in how we adjust to all these changes. We have probably all heard of or know someone personally who is rapidly declining both mentally and physically and is only 60 or 65 years of age. On the other hand, some people age 98 or older are still very active.

All of us can expect a certain amount of change as we age. Successful adjustment depends on how much change we experience at the same time, how rapidly the change takes place, how many supports we have to rely on, and how well we have learned to cope in the past.

Aging is a continual, gradual, and individual process. Some people adjust to aging better than others. Successful aging depends on a person's ability to transcend and compensate for the physical limitations imposed on them by age. People who have learned to cope successfully earlier in life will, barring any unusual traumas, continue to do so into old age. Complications arise, however, when elderly persons find that most of the social supports on which they relied are no longer available.

The compounding impact of reduced social support from the

work-setting and community seems somewhat ironic, especially when you consider the fact that during no other period of life is one confronted with so much change or loss. To experience these changes and at the same time to have so little support or assistance, places an increasing responsibility upon family.

Problem-Solving Techniques

- Five Stages

- 1) General orientation
- 2) Problem definition and formulation
- 3) Generation of alternatives
- 4) Decision-making
- 5) Verification

1) General Orientation

- 1) Assume that problem situations constitute a normal part of life, and recognize the possibility that one can cope with many of these situations.
- 2) Identify problem-situations when they occur.
- 3) Inhibit the tendency to respond to one's first impulse.
- 4) Stop and think.

2) Problem Definition and Formulation

- 1) Define all aspects of the situation operationally - concretely.
- 2) Formulate or classify elements appropriately.

3) Generation of Alternatives

- 1) Generate as many alternatives as possible.
- 2) Brainstorming
 - criticism is ruled out
 - free-wheeling is welcomed
 - quantity is wanted

4) Decision-Making

- 1) A predication of the likely consequences of each course of action.
- 2) A consideration of the utility of these consequences in dealing with the problem as formulated.
- 3) A consideration of the amount of effort for trying one of the solutions.
- 4) Developing a balance of responsive to feedback and internal judgement.

TABLE 2-1
Myths, Stereotypes, and Realities of Aging

<i>Statement</i>	<i>Factual Answer</i>	<i>Emotional Response</i>
1. Most older people who live into their eighties or beyond become senile before they die.	T F	T F
2. Aged persons tend to regress and become more like they were as children.	T F	T F
3. Women are more likely to live into their later years than men.	T F	T F
4. All people start becoming more forgetful after the age of 20; older people cannot learn well.	T F	T F
5. Fewer than 10 percent of all older people are college graduates.	T F	T F
6. The majority of older people no longer have sexual desires.	T F	T F
7. As people age, they almost inevitably become more withdrawn and disengaged from life.	T F	T F
8. The majority of older people are in poor health by the age of 60.	T F	T F
9. The suicide rate is higher for the elderly than for any other age group.	T F	T F
10. As people become older, they tend to become more suspicious, complaining, and irritable.	T F	T F
11. Older people worry much more and are much more afraid than younger people; they are more cautious.	T F	T F
12. Older people can no longer produce on a job or be very active socially.	T F	T F
13. Senile behavior is always caused by brain damage.	T F	T F
14. Alcoholic beverages are more hazardous for the elderly than for other adult age groups.	T F	T F

professionals. Try to be aware not only of the "right" answer (what your logic or information tells you is true or false), but also of what you feel (your emotional response, which may be unrelated to what you have read or what "logic" tells you). Because your logical side and your emotional side are not al-

Ways of Defeating Guilt

The first potential distortion when you are feeling guilty is your assumption you have done something wrong. This may or may not actually be the case. Is the behavior you condemn in yourself in reality so terrible, immoral, or wrong? Or are you magnifying things out of proportion?

A second distortion that leads to guilt is when you label yourself a "bad person" because of what you did.

Inappropriate "should" statements represent a common pathway to guilt. Irrational "should" statements imply you are expected to be perfect, all-knowing, or all-powerful. Perfectionistic "shoulds" include rules for living that defeat you by creating impossible expectations and rigidity.

Methods to allow you to rid yourself of inappropriate guilty feelings:

1) "Should" Removal Techniques

Here are some methods for reducing all those irrational "should" statements you have been hitting yourself with. The first is to ask yourself, "Who says I should? Where is it written that I should?" The point of this is to make you aware that you are being critical of yourself unnecessarily. Since you are ultimately making your own rules, once you decide that a rule is not useful, you can revise it or get rid of it. Suppose you are telling yourself that you should be able to meet all of your parents' needs all the time.

If your experience teaches you that this is neither realistic nor helpful, you can rewrite the rule to make it more valid. You might say, "I can meet some of my parents' needs some of the time, but I certainly cannot at all times".

Another technique to combat "should" statements involves getting in touch with the limits of your knowledge. When I was growing up, I often heard say, "learn to accept your limits and you will become a happier person", but no one bothered to explain what this meant or how to go about doing it. Furthermore, it always sounded like a bit of a put-down.

In reality, it is not as bad as all that. For example, as you review your parents' situation: I shouldn't have let my parent walk to the store on his own. He fell and hurt his leg. As a way out of this trap, ask yourself, "Now, at the time he went for a walk to the store, did I know he was going to fall?" I suspect you will say no. Now ask, "If I'd known he would fall, would I have let him go on his own?" Again, you will answer no. So, "what you are really saying is that if you would have known this at the time, you would have acted differently. To do this, you would have to be able to predict the future with absolute certainty. Can you predict the future with absolute certainty? Again, your answer is no. You have two options: you can either decide to accept yourself as an imperfect human being with limited knowledge and realize that you will, at times, make mistakes, or you can hate yourself for it.

2) Learn to Stick to Your Guns

One of the big disadvantages of being guilt-prone is that others can and will use this guilt to manipulate you. Your obsession with pleasing others becomes more tragic when your decisions become so dominated by guilt that you end up trapped and miserable. The irony is that, more often than not, the consequences of letting someone manipulate you with guilt ends up being destructive not only to you but to the other person. Although your guilt-motivated actions are often based on your idealism, the inevitable effects of giving in, turns out to be quite the opposite.

An example, a parent who always expects their child to be there at all times. The child could rationalize by giving in to demands of parent by saying: He is my father and he took care of me when I was young. After all, a loving child should help their parent. At the same time, he was able to see the negative consequences of continually giving in: 1) He was supporting his dependent nature; 2) He felt trapped and taken advantage of; 3) The basis of the relationship was not love but blackmail - he was constantly having to say yes to his demands to avoid the tyranny of his temper and his own sense of guilt.

Certain principles should be kept in mind: 1) One does not have to say yes to all demands; 2) One can find some truth in another person's arguments, but one could then come back to their

position that love does not mean always giving in; 3) One must adopt a strong, decisive, and uncompromising position as tactfully as possible; 4) One must not buy into the role of the other person's weakness; 5) One must not respond to anger by getting angry because this would reinforce the belief that the person was a victim who was being unjustly deprived by a cruel, selfish person.

3) Anti-Whiner Technique

This method may be effective when a loved one - makes you feel frustrated, guilty and helpless through whinning, complaining, and nagging. The typical pattern works like this: The whinner complains to you about something or someone. You feel the sincere desire to be helpful, so you make a suggestion. The person immediately squashes your suggestion and complains again. You feel tense and inadequate, so you try harder and make another suggestion. You get the same response. Anytime you try to break loose from the conversation, the other person implies he or she is being abandoned, and you are flooded with guilt.

A method that may be helpful is, regardless of what is said agree (the disarming technique), and then instead of offering advice, one is to say something genuinely complimentary.

In fact, it is your urge to help complainers that maintains the monotonous interaction. Paradoxically, when you agree with their pessimistic whinning, they quickly run out of steam.

Perhaps an explanation will make this seem less puzzling. When people whine and complain, they are usually feeling irritated, overwhelmed, and insecure. When you try to help them, this sounds to them like criticism because it implies they are not handling things properly. In contrast, when you agree with them and add a compliment, they feel endorsed and they then usually relax and quiet down.

5) Verification

- 1) Observe the results of the decision.
- 2) Look at the process leading to the decision and determine outcomes.
- 3) Realize that the best decision was made for the situation
 - this is important because sometimes outcomes may not be what we wanted them to be.

The Decision-Making Process

If the aged parent is able to participate in the decision, then jointly:

- 1) Discuss the situation.
- 2) Evaluate the current living arrangements.
- 3) Consider needs and interests.
- 4) Make a decision on a trial basis.
- 5) Re-evaluate the situation.
- 6) Make changes as necessary.

If the aged parent is unable to participate in the decision, then:

- 1) Be realistic.
- 2) Thoroughly evaluate the situation.
- 3) Get professional advice.
- 4) Consider your needs and those of your family.
- 5) Make a decision for your parent on a trial basis.
- 6) Re-evaluate the situation.
- 7) Make changes as necessary.

Decision-making hints:

- 1) Plan ahead.
- 2) Take your time.
- 3) Be thorough.
- 4) Consider your options.
- 5) Have a trial period.
- 6) Try alternatives.
- 7) Be flexible.
- 8) Contact resources.
- 9) Preserve the parent's independence.
- 10) Be supportive and encouraging.

Shared Living Arrangements

Before settling on any type of shared living arrangements, certain considerations should be thought about:

- 1) Can you really, honestly, expect to live comfortably together? If you had problems getting along in the past, then you stand a very good chance of not getting along now.
- 2) How does the rest of your family feel?
- 3) What kind of living space will there be for everyone? You may both have to give up some of your privacy, some of your independence, and make a shift in your daily routine.
- 4) Will she depend completely on you and your family for companionship and entertainment?
- 5) Would she feel continually out of place in your home?
- 6) Can she take a back seat in the running of the household?

It is difficult for people to change long-established patterns of behavior and lifestyles.

Dealing with the Bureaucracy

Remember, when confronting the bureaucracy, anything is possible.

- 1) Be specific. Know exactly what you want before you call a particular agency.

Talk to your parents or your own doctor, clergyman, social worker, etc., and get a clear idea of the type of service you want.

If you are unsure of the exact type of agency you need, contact your local Area Agency on Aging. The Area Agency is required by law to have an Information and Referral (I & R) number which should be able to provide you with a direct reference or at least with an idea of the type of agency to call. Or call your local city or county Public and/or Mental Health Departments, Department of Social Services or Social Security Administration.

- 2) Be polite but firm. Do not lose your temper and hang up. Explain your problem or need as clearly and as often as necessary.

- 3) Try to call in the morning or right after lunch. These are probably the best times to reach case-workers.

- 4) Don't apologize when asking for help. If your elderly relative or you cannot afford even a minimal fee, say so!

Many times these agencies receive money through taxes, contributions, etc., which may pay or help to pay any charges for the services. Also, some agencies have free volunteer services.

- 5) Get the name of everyone you talk to. If someone is rude, refuses to help or is impolite, don't lose your temper, remain calm but demand to talk to their supervisor.

- 6) If the agency requires an intake interview, be prepared, take all relevant legal and financial papers with you. If you feel stressed, take someone along with you. If necessary, take notes during the interview and be sure you are clear as to what is going to happen and what responsibilities you have, including legal and financial.
- 7) In summary, be assertive and you'll end up with what you want or at least be on the right track.

* The following information was taken from Silverman,
Brahce, Zielinski (1981): Physical and Psychological Changes In
The Later Years; Behavioral Changes; Memory Aids; The Value of
Reminiscence For The Giver And Recipient.

(Continued)

difficult to perceive; older people are more likely to tip over glasses. Glasses with painted rims or brightly painted cups are handled more accurately. Also, sheer curtains let in light but cut down on glare. Outside, the effects of glare are often experienced. The older person may have difficulty reading street signs printed on white backgrounds or seeing cracks on sidewalks. Polaroid glasses are useful.

Hearing--Hearing is altered in the later years. Usually, high tones are difficult to perceive. Sitting close to and in front of the older person is a good beginning for a conversation. Talking slowly, repeating, and using low tones will also help. Communicating more clearly with the older person decreases misunderstandings and helps to prevent the development of suspicion and distrust. Hearing aids are available. Older persons often dislike wearing hearing aids, and adjustment to an aid is often trying and difficult. It is important to express patience with the older person during the period of adjustment.

Sleep--Sleeping habits are frequently another source of concern. With age, the deep sleep patterns of youth decrease. The older adult often has more difficulty falling asleep and also wakes more easily during the night. Regular exercise tends to produce a relaxed state conducive to sound rest. Sometimes, medication under a doctor's guidance is helpful as well as various personal techniques, such as massages, hot drinks, etc.

Stiffness--Muscles, tissues, and joints become less elastic with age. The overall feeling is that one's body is stiff; actions are performed more slowly, and accidents seem more of a possibility. In order to compensate, the older adult moves more slowly and with greater caution.

Chronic conditions--Chronic conditions affect 80% of those 65 years old and older. The most prevalent conditions are arthritis, heart disease, high blood pressure, partial loss of hearing, and vision impairments. Management of these conditions is a crucial issue for many elderly persons; at stake is their independence. Household equipment (rails and bars), utilitarian furniture (chairs that are easy to get into and out of), and public transportation are factors that may enable older persons to maintain their homes and their independence.

In conclusion, the older adult experiences numerous physical changes. However, for each of these changes, there are ways to compensate. Talking slowly with the older person, decreasing sources of glare, making a home more comfortable with utilitarian furniture and more accident-proof with the use of bright, contrasting colors--all of these actions allow the older person to live more comfortably, safely, and with a greater degree of independence.

(Continued)

Normal Psychological Challenges

Two major questions will be considered:

- (1) What are some of the major sources of psychological concerns in the later years?
- (2) What are some of the primary ways these concerns are expressed?

(1) Sources of Concern

Retirement--Retirement from a job requires the substitution of new activities for old ones; friendships acquired at work may be lost, and new friendships may need to be developed. Also marital relationships may undergo development as the husband begins to spend more time at home. Accompanying retirement may be a decline in income. As one woman said, "Since retirement, I have twice the husband and one-half the income!" Pre-retirement programs, such as AIM (Actions of Independent Maturity), can help individuals and couples prepare for retirement.

Loss of Independence--As an individual ages, he may find it increasingly difficult to move about his community with the ease of former years. Driving, especially at night, may be more difficult because of changes in vision and hearing and because of memory losses. Mobility may also be decreased by chronic conditions. The older person moves more slowly; fatigue may come more readily. Steps, curbs, and flights of stairs may present difficult barriers. Getting in and out of cars can pose a problem. All of these situations may restrict mobility and decrease outside contacts. The older person may become more dependent on his immediate environment for friendships and activities.

Memory--Older persons often mention that they have difficulty remembering names, especially new ones, as well as appointments, places where they put objects in their homes, etc. An excellent pamphlet is available, "Is My Mind Slipping?" It explains that the older a person becomes, the more he has stored in memory, and the longer it takes to sift through this information. Useful memory aids are also given.

Loss and death--Loss of friends may occur because of decreased mobility and also because of death. Widowhood is another source of loss. By age 65, almost 40 percent of the women in the U.S. are widows; by age 75, 60 percent are widows. The loss of a spouse may require adjustment to new responsibilities. For some, this task is overwhelming. Up From Grief was written by two widows and is considered a helpful book for the grieving person.

(Continued)

Life review--Almost everyone engages in an evaluation of past events and actions at various times during the life cycle. The life review is thought to be a universal process as a person nears the end of his life. Some people derive strength and dignity from their life review; others become depressed and withdrawn. In the latter case, it is often important to help the other person find concrete means of rectifying sources of guilt, despair, or anger.

In summary, all of these psychological developments in the later years may challenge the individual's ability to cope. A variety of emotional reactions may be experienced by the older person. Some of the most common will be described with suggestions for their management.

(2) Emotional Reactions

Grief--Grief can be unusually difficult for the older person because of the difficulty of finding any kind of substitute for losses. In addition to Up From Grief, Kavanaugh's book Facing Death is particularly helpful in guiding others about how to work with the grieving individual. All who write on the process of grieving stress the importance of friends who will listen, reflect feelings, and refrain from giving advice.

Guilt--In reviewing their lives, many elderly persons experience strong feelings of guilt. These feelings should not be denied or greeted with simple assurance; instead, the family or a counselor should try to help the older person find some concrete means of resolving these feelings.

Loneliness--Loneliness is perhaps the most difficult problem of old age. The loss of significant friends and family cannot be easily replaced. Support groups for older persons are beginning; also, some nursing homes have patients who make daily telephone calls to elderly individuals living in the community. Both persons benefit from this exchange.

Depression and anxiety--Both of these reactions often become intensified and more frequent with age. It is important to remember that one source of these reactions may be the considerable amount of new learning elderly persons undergo as they adapt to continual changes in their bodies, feelings, and environment. Listening to the older person, reflecting his or her concerns, and engaging in mutual problem-solving are sometimes constructive means of handling anxiety and depressions. Help from a community agency may be useful in order to prevent these feelings from overwhelming the older person and the family.

Sense of Helplessness--Feelings of helplessness are particularly common among older men who once held positions of power and influence. The highest suicide rates in the U.S. occur among men in their 60s, 70s and

80s. Relatives and friends may need to assist the older person in finding new and meaningful activities. Those close to the older person should also be aware that the combined symptoms of loss of appetite, difficulty sleeping, withdrawal, and depression may indicate severe distress.

Rage--Feelings of anger and rage are common among older persons. Part of this rage may come from the neglect shown by society once the older person is no longer economically productive. Anger may also arise in response to the physical aspects of aging as well as to the inevitability of death. These feelings should be acknowledged by those close to the older person. Being able to express anger freely to an understanding person may help the older person feel a greater sense of worth and more dignity.

APPENDIX E

Behavioral Changes

<u>BEHAVIORAL CHANGE</u>	<u>SOME REASONS</u>	<u>SOME SOLUTIONS</u>
Doesn't want to bathe.	Loss of sense of smell; change in body temperature may create a problem; fear of falling in shower or can't get into tub; may not care.	Provide an occasion to clean up; install handgrips or bathtub seat; be tactful but honest about the problem and discuss it.
Wears the same clothes over and over.	Loss of sense of smell; too much routine without occasions or need to dress differently; clothes may be comfortable or associated with eventful memories; no new clothes that fit.	Provide occasions; compliment on appearance and apparel; give new clothes as presents after asking what the person would like. Show real interest in the person.
Closes all the drapes and blinds.	Sight diminishes, but glare is a real problem.	Suggest a visit to the eye doctor; sunglasses or visor cap may help. Understand the problem.
Won't clean the house.	As vision decreases, fewer things are noticed. The house may look clean to the person.	Be understanding. Is the dirty house your problem or is it a threat to the safety and life of the person? Ask if the person would like help in doing the heavy chores -- that might be appreciated.
Can't sleep at night/ wanders/keeps the lights on.	The older person is not as able to have a deep sleep. He or she may not feel exhausted at the end of a boring day. The person may fear falling in the dark, being alone, or dying.	Plan more daytime activities with the person; provide a night light to guide the way to the bathroom. In particular, try relaxing with the person before retiring.

APPENDIX E

Physical and Psychological Changes in the Later Years

By Tamera Moeller, Ph. D.

Introduction

The adult's body undergoes many changes during middle and late maturity. These changes, which occur gradually and almost imperceptibly, may have a significant impact on an individual's psychological well-being. For example, chronic conditions sometimes require that the older person curtail activities and modify life-long habits: such changes may reduce the older person's degree of independence and alter self-esteem and confidence.

In addition to physical changes, the older adult faces new or intensified psychological concerns. Retirement may result in new roles and responsibilities for both husband and wife. Economic security is a common source of concern. Changes in memory may cause the older person to feel confused and disoriented. Also, the death of friends and of one's spouse can result in loneliness, grief, and the need for many adjustments.

In summary, the older adult is confronted by a wide range of physical, social, and psychological challenges. Adapting to these changes may require a range of resources -- inner strengths, as well as family understanding and community supports.

Normal Physical Changes

Vision -- Several changes occur in the ability to see:

- 1) Older adults often have difficulty reading and distinguishing objects. More light is needed. When reading, the adult should be in a room with at least two lights; diffuse lighting is superior to a single source. Magnifying lenses are helpful. Several types are available; it is advisable to try two or three before making a purchase.
- 2) Night vision often declines. The use of public transportation might be encouraged as a substitute for driving after dark.
- 3) At all times, greens and blues are difficult to distinguish. The use of bright reds, yellows, and oranges for rugs, walls, curtains, and steps will create more enjoyment and will help to prevent accidents.
- 4) Finally, glare is an ever-present condition that is the source of both confusion and accidents. Glare makes the edge of drinking glasses

APPENDIX E

Memory Aids

First recognize that we all have memory problems. Stress, illness, medications, and depression can affect our memory performance at any age. We ignore our lapses of memory or laugh it off until we grow older, then it is regarded as a sign of old age.

You can help improve memory skills by tactfully making some suggestions, by giving presents (calendars, diaries, photo albums) which can be used to record or collect what one wants to recall, and by showing with your own example techniques you use to retain information.

Memory Tools:

1. Carry a pad and pencil and make notes to yourself.
1. Use a large calendar or appointment book to record special dates for the future or to record daily events.
3. Ask the doctor to write down instructions.
4. Use a photo album, diary, journal, or scrapbook to collect and record events you want to retain.
5. Use a tape recorder to leave reminder messages.

Memory Exercises:

1. Draw associations between names and other images, the person's interests, or the occasion.
2. Do crossword puzzles or other games that jog your memory.
3. Review photo albums, diaries, and calendar events.

Memory Approaches:

1. Give other people time to recall and draw some associations for them -- "The man who always brought us candy, drove that red Chevrolet, and had a black dog named Spark." Be careful not to "quiz" the person.
2. Present small amounts of new information at a time rather than trying to present a lot of information at once.
3. Recognize when people are tired, sick, or tense, and avoid taxing their memory.

APPENDIX F

The Value of Reminiscence for the Giver and Recipient

Definition of reminiscence: "A way of reliving, re-experiencing or savoring events of the past that are personally significant."

Reminiscence gives the older person a means to:

1. Maintain self-esteem and reinforce a sense of identity.
2. Feel a sense of achievement and pleasure.
3. Cope with stresses related to the aging process.
4. Gain status by revealing selected elements of his/her life history.
5. Place both positive and negative aspects of the past in perspective.
6. Deal with emotions such as grief.
7. Establish a common ground for communication.

It helps the open and interested recipient to:

1. Gain knowledge and understanding about the older person and the period in which he or she has lived.
2. Build a bridge between past experiences and the present.
3. Establish a mutually satisfying relationship through the sharing of information and experiences.
4. Use a person's history as a therapeutic tool in building programming or establishing resources for others.
5. Have a context for gaining cues about the person's behavior in the present.

Source: Institute of Gerontology, The university of Michigan, Ann Arbor, Michigan.

APPENDIX E - Alzheimer's Disease Booklet will be included
in a folder after the Bibliography.

APPENDIX F

FEEDBACK QUESTIONNAIRE

1. What were your initial expectations of the group?

2. Were your expectations met?

If not, what could be changed or added to the sessions?

3. Was the information presented about aging helpful to you
in understanding the aging process.

4

3

2

1

Very
Helpful

Somewhat
Helpful

A Little
Helpful

Not At All
Helpful

4. Rate the effectiveness of the leader.

4

3

2

1

Very
Helpful

Somewhat
Helpful

A Little
Helpful

Not At All
Helpful

5. What did you find most helpful about the group?

6. What did you find least helpful about the group?

7. Overall, rate your satisfaction with the group.

5 4 3 2 1

Very Satisfied Satisfied Neutral Dissatisfied Very Dissatisfied

8. I would recommend this type of group to people in a similar situation.

4 3 2 1

Strongly Agree Agree Disagree Strongly Disagree

OPINIONS ABOUT PEOPLE

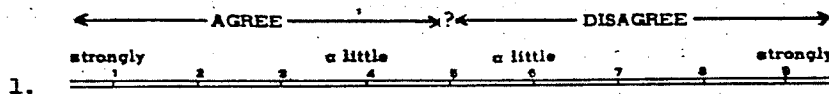
FORM A

Schedule..Answer Sheet

How To Answer The Schedule, OPINIONS ABOUT PEOPLE

The statements you are going to read are opinions. Anyone could agree with some of them, and object to some of the others. The question is which are the opinions with which you agree or disagree, as the case may be.

Please indicate your own judgment about each idea expressed by circling some number between 1 and 9 on the Answer Sheet. The low numbers 1, 2, 3 and 4 mean some degree of agreement, and the high numbers 6, 7, 8 and 9 mean some degree of disagreement. Five then means that you have no opinion one way or another. In other words you "measure" your opinion like the temperature on a gauge that looks like this:



A bit confusing? Perhaps a few examples will help:

"Life is a bowl of cherries"

You think that would be nice, but it just is not quite true. So you may want to circle "6".

"Men are taller than women"

If you think that this is quite true you would indicate it by circling perhaps "2".

"The man of 2500 will be much happier than man at the present time"

If you feel you have no way of answering that one, you will have to circle "5". We think however that you will not have to use the fence-sitting "5" too often.

Remember please: One, and only one number between 1 and 9 should be circled on the Answer Sheet for each sentence in the Schedule. Do not stop to think too long about the statements. All that is wanted is your first reaction.



ONTARIO MINISTRY OF COMMUNITY AND SOCIAL SERVICES
SENIOR CITIZENS' BUREAU
QUEEN'S PARK, TORONTO, ONTARIO. M7A 1E9
IN CO-OPERATION WITH
ONTARIO WELFARE COUNCIL - SECTION ON AGING
1240 BAY STREET, 4TH FLOOR
TORONTO, ONTARIO. M5R 2A7

OPINIONS ABOUT PEOPLE, FORM A
SCHEDULE

1. Some people stay young at heart no matter how long they live.
2. Things are getting better for most people these days.
3. You have to be old yourself to enjoy the stories old people like to tell.
4. Residences for retired persons should always work out their programs and routines with the old people concerned.
5. The best neighbourhoods are those where young families intermingle with retired people.
6. You can't expect other people to take care of you when you no longer can take care of yourself.
7. No one who is retired and over 70 should be allowed to drive a car.
8. The older people get, the more they think only of themselves.
9. You're further ahead if you always assume that everybody is out for Number one.
10. Most times I feel relaxed in the company of elderly people.
11. Old age is O.K. for those who are financially independent.
12. There is no point in talking about personal matters with people who are much older or much younger than yourself.
13. You can't cope with things the way you used to if you live to be a ripe old age.
14. Retired people are happiest in the company of people who are their own age.
15. Anyone could keep young if he only tried.
16. People in high offices aren't really interested in the troubles of the average person.
17. You're likely to get bogged down if you let elderly people help you with your projects.
18. No matter what the community can do it is up to the children to see that their aging parents have every comfort.
19. I cannot help feeling depressed at the thought of getting old.
20. You can't expect old people to exert themselves.
21. On the whole, people's chances in life are getting worse and not better.
22. When you retire you realize that the best years of life are yet to come.
23. You'll never get old if you don't let yourself go.
24. It is rather sad to be still alive after all your friends are gone.
25. Old age pensioners have a right to be taken care of in a dignified way even if younger people must contribute their taxes to make this possible.
26. By and large, young people don't care about anyone but themselves.
27. The future is so uncertain that there is little point in thinking or planning ahead.
28. People who spend all they make cannot expect much when they are no longer earning a living.
29. All community organizations should have some older persons on their boards.
30. It must be quite a shock to look in the mirror and find that you are showing signs of aging.
31. One shouldn't try to involve elderly people in things; all they really want is some peace and comfort.
32. Relatives who were close to the parents in former years rightly expect the children to care about their well being if they live a very long life.

OPINIONS ABOUT PEOPLE, FORM A ANSWER SHEET

← strongly AGREE a little ? a little DISAGREE strongly →

1. 1 2 3 4 5 6 7 8 9

2. 1 2 3 4 5 6 7 8 9

3. 1 2 3 4 5 6 7 8 9

4. 1 2 3 4 5 6 7 8 9

5. 1 2 3 4 5 6 7 8 9

6. 1 2 3 4 5 6 7 8 9

7. 1 2 3 4 5 6 7 8 9

8. 1 2 3 4 5 6 7 8 9

← strongly AGREE a little ? a little DISAGREE strongly →

9. 1 2 3 4 5 6 7 8 9

10. 1 2 3 4 5 6 7 8 9

11. 1 2 3 4 5 6 7 8 9

12. 1 2 3 4 5 6 7 8 9

13. 1 2 3 4 5 6 7 8 9

14. 1 2 3 4 5 6 7 8 9

15. 1 2 3 4 5 6 7 8 9

16. 1 2 3 4 5 6 7 8 9

← strongly AGREE a little ? a little DISAGREE strongly →

17. 1 2 3 4 5 6 7 8 9

18. 1 2 3 4 5 6 7 8 9

19. 1 2 3 4 5 6 7 8 9

20. 1 2 3 4 5 6 7 8 9

21. 1 2 3 4 5 6 7 8 9

22. 1 2 3 4 5 6 7 8 9

23. 1 2 3 4 5 6 7 8 9

24. 1 2 3 4 5 6 7 8 9

← strongly AGREE a little ? a little DISAGREE strongly →

25. 1 2 3 4 5 6 7 8 9

26. 1 2 3 4 5 6 7 8 9

27. 1 2 3 4 5 6 7 8 9

28. 1 2 3 4 5 6 7 8 9

29. 1 2 3 4 5 6 7 8 9

30. 1 2 3 4 5 6 7 8 9

31. 1 2 3 4 5 6 7 8 9

32. 1 2 3 4 5 6 7 8 9

SCORING

ATTITUDE 1			
Item #	Raw Score	Weight X	Weighted Score
6		3	
11		3	
12		2	
13		3	
14		2	
28		3	
Total			

ATTITUDE 2			
Item #	Raw Score	Weight X	Weighted Score
15		1	
22		1	
23		1	
Total			

ATTITUDE 3			
Item #	Raw Score	Weight X	Weighted Score
19		4	
24		3	
27		2	
30		4	
Total			

ATTITUDE 4			
Item #	Raw Score	Weight X	Weighted Score
8		5	
12		2	
13		2	
14		2	
17		4	
30		2	
31		2	
Total			

ATTITUDE 5			
Item #	Raw Score	Weight X	Weighted Score
10		4	
18		7	
20		4	
32		7	
Total			

ATTITUDE 6			
Item #	Raw Score	Weight X	Weighted Score
6		1	
14		1	
17		1	
21		1	
25		8	
29		5	
Total			

ATTITUDE 7			
Item #	Raw Score	Weight X	Weighted Score
7		4	
14		2	
20		2	
29		1	
Total			

ABOUT YOURSELF

We would like a few facts about yourself. This information is for statistical analysis only. Please check whichever description applies to you and fill in requested information.

33 SEX

1. Male _____
2. Female _____

34-35 AGE

_____(years)

36 MARITAL STATUS

1. Single _____
2. Married _____
3. Widowed _____
4. Divorced _____
5. Separated _____

37 EDUCATION

(Please check highest level completed.)

1. Elementary _____
2. Some High School _____
3. Completed High School _____
4. Some University _____
5. Degree (s) _____

38-39 OCCUPATION

(Type of work you do)

40 EMPLOYMENT STATUS

(Please check whichever applies to you - one or more.)

1. Working full-time _____
2. Working part-time _____
3. Not working _____
41 4. Housewife _____
5. Student _____
6. Retired _____
7. Employee _____
8. Employer/self employed _____

42-43 COUNTRY OF BIRTH44-45 If other than Canada, what was your
age when entering Canada?

_____(years)

46-47 What is your native language, the language
spoken in your family when you were a child?48 PARENTS

1. Both alive _____
2. Father only alive _____
3. Mother only alive _____
4. Both deceased _____

49 How often do you see your mother
or father or both? (Answer only
if at least one parent is alive
and you are not living with
parent(s).)

1. Once a week or more often _____
2. 1-4 times a month _____
3. Less than once a month _____

FRIENDS

Please think of the people you make
a point of seeing regularly and
that you consider your friends.
Write down the number of these
friends who are in each of these
age groups:

- 50-51 Under 15 _____
52-53 15-24 _____
54-55 25-44 _____
56-57 45-64 _____
58-59 65-84 _____
60-61 85 and over _____

By and large, would you say that
your favourite people (excepting
family) are: (Check one or more.)

- 62 About your own age _____
63 Much younger _____
64 Much older _____
65 65 years and over _____

66 Do you live on a farm or in a small
community (under 1000 persons)?

1. Yes _____
2. No _____

67 Did you grow up on a farm or in a
small community (under 1000 persons)?

1. Yes _____
2. No _____

68 RESIDENCE

(City or Town or Village)

(Province)

NAME

(Or complete initials)

APPENDIX H

BURDEN INTERVIEW

INSTRUCTIONS: The following is a list of statements which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way; never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

1. Do you feel that your relative asks for more help than he/she needs?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
4. Do you feel embarrassed over your relative's behavior?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
5. Do you feel angry when you are around your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
7. Are you afraid what the future holds for your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
8. Do you feel your relative is dependent on you?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
9. Do you feel strained when you are around your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

10. Do you feel your health has suffered because of your involvement with your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
11. Do you feel that you don't have as much privacy as you would like, because of your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
12. Do you feel that your social life has suffered because you are caring for your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
13. Do you feel uncomfortable about having friends over, because of your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
14. Do you feel that your relative seems to expect you to take care of him/her, as if you were the only one he/she could depend on?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
15. Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
16. Do you feel that you will be unable to take care of your relative much longer?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
17. Do you feel you have lost control of your life since your relative's illness?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
18. Do you wish you could just leave the care of your relative to someone else?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
19. Do you feel uncertain about what to do about your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

20. Do you feel you should be doing more for your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

21. Do you feel you could do a better job in caring for your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

22. Overall, how burdened do you feel in caring for your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

23A. Have you been involved in any caregiver support or self-help groups in the last year?

Yes	2
No	1
DK	9

B. Has any other family member been involved in any caregiver support or self-help groups in the last year?

Yes	2
No	1
DK	9

24. Have you been in therapy or received counselling in the past year?

Yes	2
No	1
DK	9

INSTRUCTIONS FOR THE BURDEN INTERVIEW

The Burden Interview has been specially designed to reflect the stresses experienced by caregivers of dementia patients. It can be completed by caregivers themselves or as part of an interview. Caregivers are asked to respond to a series of 22 questions about the impact of the patient's disabilities on their life. For each item, caregivers are to indicate how often they have felt that way, never, rarely, sometimes, quite frequently, or nearly always.

SCORING:

The Burden Interview is scored by summing the responses of the individual items. Higher scores indicate greater caregiver distress. The Burden Interview, however, should not be taken as the only indicator of the caregiver's emotional state. Clinical observations and other instruments such as measures of depression should be used to supplement this measure.

Norms for the Burden Interview have not been computed, but estimates of the degree of burden can be made from preliminary findings. These are:

0 - 20	Little or no burden
21 - 40	Mild to moderate burden
41 - 60	Moderate to severe burden
61 - 88	Severe burden

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Alzheimer's Disease

A Family Information Handbook

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La maladie d'Alzheimer:
renseignements à l'intention des familles

March, 1984

Preface

This handbook, prepared by the Alzheimer Society of Canada and published by the Department of National Health and Welfare, replaces a similar manual first issued in July 1982.

The purpose of the Society, which was founded in February 1978, is to promote public education and to advance research into the cause, control and cure of Alzheimer's disease. It is hoped that this publication will be helpful to family members and others who care for those with the disease or related conditions, including health professionals, the staff of home support programs, community health and social service agencies, nursing homes, homes for the aged and other related institutions.

The text of the manual was prepared by the Alzheimer Society's Family and Caregiver Support Committee, chaired by Dorothy Bloch, p.s.w. (Montreal, Que.) and Charles Poole (Toronto, Ont.), in collaboration with a wide variety of family caregivers and health professionals.

Carl Birchard, M.S.W.
Editor

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Introduction

Alzheimer's disease (pronounced altz'hi-merz) is a little-known but remarkably common disorder that affects the cells of the brain. It is a disease that produces intellectual impairment in adults. While experts formerly believed that the disease occurred mainly in persons under age 65, this disorder is now recognized as the most common cause of severe intellectual impairment in older people as well.

The changes most commonly associated with Alzheimer's disease (A.D.) occur in the proteins of the nerve cells in the cerebral cortex — the outer layer of the brain — leading to an accumulation of abnormal fibers. Under the ordinary microscope these changes appear as a tangle of filaments. These "neurofibrillary tangles" were first described in 1906 by Alois Alzheimer, a German neurologist.

New and highly sophisticated instruments and techniques — such as the electron microscope, which can magnify cells more than a hundred thousand times — have revealed other changes in the brain that are characteristic of the disease. Scattered throughout the cortex, groups of nerve cell endings degenerate and disrupt the passage of electrochemical signals between the cells. These areas of degeneration have a special appearance under the microscope and are called plaques. The larger the number of plaques and tangles, the greater the disturbance seems to be in intellectual function and memory.

Some Statistics

The fact that many people have never heard of Alzheimer's disease does not mean that it is a rare illness. Many individuals who have the disease never receive a precise diagnosis.* The best current estimates indicate that more than three million North Americans may suffer from it. In Canada, it has been estimated that at least 10,000 deaths a year are attributable to this disease, and as many as 100,000 to 300,000 may be affected to a varying degree. After cancer, heart disease and stroke, it is thought to be the fourth or fifth most common cause of death in Canada; however, this is difficult to verify because A.D. is not always listed as an official cause of death on death certificates, which all too often record only the events immediately prior to death.

Causes

Alzheimer's disease is an inexorable, degenerative, neurological disorder for which there is currently no known method of prevention or cure. Why plaques and neuro-fibrillary tangles develop in the cortex of the brain has yet to be determined.

It seems clear that the illness is not caused by hardening of the arteries. Nor is there any evidence that it is contagious. Although emotional upsets and stress may temporarily affect the person's mood and behaviour, they do not *cause* the disease but are more likely its effect.

The disease occurs in two to three per cent of the general population over 60 years of age, and in more than 20 per cent of those over 80. The probability of its occurrence within the same family is about one in six, if one's parents have been victims, and about one in twelve if brothers or sisters have had the disease. This represents a slight hereditary disposition in some families, possibly combined with undetermined environmental factors.

Scientists are applying the newest knowledge and research techniques to the study of human brain tissue removed at autopsy. Although there are now a number of promising clues, determination of the actual cause of A.D. must await much more extensive scientific investigation.

What Are the Symptoms?

At first, the individual experiences only minor and almost imperceptible symptoms that are often attributed to emotional upsets or other physical illnesses. Gradually, however, the person

becomes more forgetful, particularly about recent events. The individual may neglect to turn off the oven, may misplace things, may continually recheck to see if a task was done, may take longer to complete a chore that was previously routine, or may repeat already answered questions. As the disease progresses, memory loss worsens and other manifestations such as confusion, irritability, restlessness, and agitation are likely to appear, as well as changes in personality, mood, and behaviour. Judgement, concentration, orientation, and speech may also be affected. Eventually, the disease renders its victims totally incapable of caring for themselves.

There are many different patterns in the type, severity, and sequence of changes in mental and neurological functioning that result from A.D. The symptoms are progressive, but there is great variation in the rate of change from person to person. In a few cases, there may be a rapid decline; but more commonly, many months — even years — may pass with little change. Limitations in physical activity during the later stages may cause the person to have less resistance to pneumonia and other physical illnesses that may shorten remaining life expectancy by as much as one-half.

Although the person with A.D. may deny or be unaware of the full extent of his or her limitations — especially later in the course of the illness — the seemingly unexplainable changes in essential functions are a source of deep frustration, both for those afflicted and for the caregivers.

Early Indications

In the early stages, the disease is very difficult to detect. The changes are subtle. Patients may struggle to cover up their mental difficulties through hard work and altered personal patterns. Moreover, many of the early signs can easily be confused with depression, drug or alcohol induced dementia, or other acute and potentially reversible mental impairments. Early symptoms of A.D. involve an inability to learn new things, a memory loss for recent events, poor judgement, difficulty in communication and coping with decisions or new situations, a suspicious attitude, and possible outbursts of temper resulting from frustration, any of which may not alert family members to suspect a possible illness. And since memory for much earlier events is usually well preserved, the family may attribute forgetfulness of recent events to fatigue, depression or other causes.

Eventually it becomes apparent that there really is a problem. It is likely to be the spouse or other close family member who will realize it. But

* Strictly speaking, final confirmation of the diagnosis of Alzheimer's disease requires a post-mortem examination of the brain.

it could also be someone more removed from the situation such as an employer, neighbour, friend or doctor. Such a person would not have witnessed the minor day-by-day changes, and would more readily recognize the effects of months of deterioration.

Many people are reluctant to consult a doctor, especially when the changes are behavioural and there are no obvious physical problems. Therefore, it may take considerable urging by others before they will consider this as a possible medical problem.

How Is Diagnosis Made?

Before a diagnosis of Alzheimer's disease is made, other illnesses which may cause the same symptoms must be excluded. The condition must be differentiated from the mild and occasional forgetfulness that sometimes occurs during normal aging. Depression, which is fairly common in elderly individuals facing a variety of stressful situations, may also present symptoms.

More than one-half of elderly men and women with severe intellectual impairment are victims of A.D. About another fourth of the overall group suffer from vascular disorders, especially multiple strokes. The remainder have a variety of other conditions; for example, brain tumors, abnormal thyroid function, infections, pernicious anemia, adverse drug reactions, and abnormalities in the spinal fluid system (a type of hydrocephalus). The specific diagnosis is very important since many of these other causes of mental malfunctioning can be readily treated.

Each person suspected of having A.D. should have thorough physical, neurological, and psychiatric or psychogeriatric evaluations. Comprehensive blood studies, including tests for detecting metabolic disorders, must be carried out as part of the evaluation. The electroencephalogram may show a general slowing of the brain waves and may help confirm the presence of A.D. Computerized tomography (CT scan), electroencephalography (EEG), and occasionally special studies of the spinal fluid system are required for more accurate diagnosis.

After other diseases have been ruled out, in particular the dementia associated with previous strokes (multi-infarct dementia), a diagnosis of A.D. can usually be made on the basis of medical history, mental status, and the course of the illness. Periodic neurological examinations and psychological testing are very useful in confirming the diagnosis and evaluating the stage of the disease.

Misconceptions

The average person knows very little about dementia (so-called "senility"), and the myths which have developed about such disorders have prevented an accurate education of Canadians.

"Senility is just part of growing old."

If this were true, all old people would suffer severe memory loss, physical immobility and considerable intellectual impairment. In fact, only one in 10 over age 60 suffer from states of confusion; of these cases, about 70% are probably A.D. Secondly, this disease is not confined solely to the elderly; people as young as 40 have been diagnosed.

"The person doesn't suffer as a result of his/her condition because he/she doesn't know that anything is wrong."

There are indications that people with this disease may realize that something is wrong, well before anyone else becomes aware of a persistent change.

"The disease is contagious."

There is no evidence for this statement.

"It is the result of excessive strain or emotional stress."

Although emotional upsets and stress may temporarily affect the person's mood and behaviour, they are not the cause of the illness.

"Declining mental ability is due to laziness — people not using their brains."

While withdrawal from mentally stimulating activity could contribute to apparent intellectual decline, the loss of memory and changes in personality that A.D. patients show are due to physical changes in their brains; it is an actual disease of the brain.

Stages of Deterioration

Alzheimer's is a disease in which functions of the brain gradually and progressively deteriorate over a period of years — sometimes even months.

The *first stage* is manifested by slow, subtle changes in the person's ability to learn, problems in communication, memory loss for recent events, impaired judgement, difficulty in making decisions, coping with new situations, suspiciousness, and possible outbursts of temper resulting from frustration.

For example:

• *Mrs. V. of Victoria, B.C. relates that the first thing she noticed in her 55-year-old husband*

was "poor memory, slow movements and occasional weak legs."

● Mr. M. of Montreal, Que., when asked what symptoms or signs were first noticed, answered that his 61-year-old wife "could no longer add up a short and simple column of figures."

● Mrs. P. of P.E.I., reported "memory loss" as the first symptom in her 57-year-old husband. "The family doctor thought it was a case of early senility," she adds.

● Mr. L. of Toronto, Ont., said he and his 50-year-old wife just thought she had a hearing problem because she didn't seem to understand what was being said.

In the *second stage*, while memory functions continue to deteriorate, other aspects of intellectual abilities also decline, including language and the ability to communicate and to conduct daily activities without supervision or guidance.

The person may respond to people or objects in an aggressive way, due to misperceptions of what is happening. For example, someone approaching quickly to help with dressing may be seen as a threat, particularly if the approach is from behind or from one side (at the edge of the person's field of vision).

Increased disorientation to time and place occurs, and the person may be unable to recognize him/herself in the mirror. There may be inability to write or understand and use language. Often there is a struggle to maintain bodily functions, and some will be retained longer than others. The person may become restless, especially at night. There is a loss of dexterity, which may interfere with tasks such as dressing and other self-care routines. Body movements may begin to slow down and the person physically resists being helped. Some loss of bowel and urine control (incontinence) may begin.

For example:

● Mrs. G. of Gananoque, Ont., said that her father now "forgets where he has placed articles but he can remember tunes and lyrics to hymns. (He) forgets names of grandchildren, has loss of balance . . . (and) has difficulty in walking."

● Mrs. S. of B.C., said that her 53-year-old husband showed an "inability to concentrate and to work on figures." She added that "he seems a different person but is not too hard to handle." Later, however, she reported that he had visual and speech impairment, as well as loss of bladder and bowel control.

● Mrs. L. of Lachine, Que., said that her brother now shows so much impairment that

"comprehension (is) too poor to determine if there is still any memory." She added that he is "fearful, suspicious, has episodes of depression and weeping — and sometimes of giggling. He needs to be guided for he has just fallen and broken his hip."

In the *final stage*, 24-hour nursing care is usually necessary. In addition, hospitalization may be required to treat the increasing occurrence of physical disabilities and illness. The ability to speak or communicate disappears, along with increased immobility. Loss of bowel and urine control greatly increases. Twitches or jerking may develop, and seizures may occur. There may be an almost complete absence of any spontaneous movement or reaction to people or other stimuli. In some cases, a general, gradual stiffening of muscles can leave the person increasingly less mobile. Reflexes develop, such as one that causes sucking of anything put in the mouth. At this stage the person is prone to pneumonia, and to bed sores because of immobility.

As physical health deteriorates, there is increasing susceptibility to other conditions. Records indicate that between two and 19 years after the onset of the disease, death will occur. However, because the diagnosis often occurs late in the course of the disease, the length of survival after a doctor has made the diagnosis averages about five to eight years — a significant reduction from normal life expectancy. There is usually a secondary immediate cause of death which appears on the death certificate, such as pneumonia or heart disease. Two Alzheimer Society members, each with a spouse in a long-term care hospital, made these observations:

● Mr. G. of Guelph, Ont., stated that his 69-year-old wife is now showing a "general slowing of movements and recently has become bedridden due to a complete loss of mobility."

● Mrs. G. of Edmonton, Alta., reported that she had been nursing and caring for her 65-year-old husband at home for about two years "but finally I could no longer stand the physical and emotional strain and was able to have him placed in a nursing home — three months before he died!"

These stages illustrate a general trend of the disease. Every patient gradually deteriorates and the lost functions and abilities will never be restored, but the speed of the deterioration, and the symptoms which are manifest, will vary with each person.

Caring for Someone with Alzheimer's

This section provides a number of practical suggestions for coping with the problems and disabilities of the person with Alzheimer's. Some of these may or may not be relevant to your situation.

Overview

As the disease progresses, disabilities increase. Somehow, the caregivers must find that fine line where they are helping the person perform to the best of his/her ability, while recognizing that there are some things the afflicted person is just not capable of doing.

Caring effectively for an increasingly dependent person, yet still someone whose pride can be easily injured, is a tremendous challenge. The frustration of trying to help someone who at times seems bent on defeating every effort, can drive the caregiver "up the wall."

A general helping rule is to provide a consistent routine for the person. A regular rhythm of familiar household events, and of people who come and go, provides a reassuring structure on which the person can depend.

Coping with Emotional and Behavioural Problems

Patient's Awareness of Inabilities. A person with A.D. is often aware of lost abilities. This can result in frustration, tears, anger, embarrassment or humiliation — even in depression. When this occurs, remember that this is caused by the neurological disease and the person needs quiet reassurance and support, plus the message that he/she is still loved.

Some families have tried explaining the disease to the person. While this can sometimes help the family to feel better, and to know that they are doing the best they can, it is nevertheless true that persons with A.D. vary greatly in their ability to comprehend these explanations.

Memory Loss. The loss of short-term memory, a common early symptom of the disease, will cause those who suffer from it to forget things they have done just a few minutes ago. They may forget answers to their questions, and so ask them over and over again. They may forget names, addresses and other bits of information we use to orient ourselves. This can be as frustrating or humiliating to them as it is irritating for those taking care of them.

People suffering from a loss of memory tend to perform better with a consistent daily routine. They will need frequent and patient reminders that may be in the form of spoken words, calendars, clocks, diagrams, lists, schedules, and so on. It may be that simply laying out clothes in the morning will be enough to get them to dress themselves. It is a test of creativity and patience to guide someone with memory loss through the many daily routines we usually take for granted. Repeated instructions will be necessary. If the response is delayed, try it again five or ten minutes later.

It often requires more time and effort to remind them to do the task themselves than it does to do it for them. The extra effort, however, allows them to function to the best of their ability and feel better about themselves, particularly in the early stages. This is as important for their health as it is for the health of the caregiver. Sometimes they will try to hide their memory loss, or compensate for it in some other way. In these situations, for example, be sure that his or her teeth really *are* brushed, that lunch is *really* eaten, or your letter *really* mailed.

Poor Judgement. Mental disabilities involve more than memory loss. Poor judgement and/or erratic thought process also occur. Some actions and choices based on poor judgement may lead to unforeseen, even dangerous situations. It is important to watch for these behaviour changes, which tend to be subtle and are often disguised. You may notice a mistake playing cards, an unnecessary purchase from a salesman, or some unreasonable decision. The person may wander out alone. These things may be a response to a loss of orientation, or a searching for some type of satisfaction.

Wandering. No one knows precisely what causes a particular person to wander. It is very difficult to control and can be dangerous (e.g., there is the risk of getting mixed up in traffic, or getting lost). Certainly it is a constant source of worry and frustration to families and to institutions.

Generally, the most effective solution to wandering is to install a lock that the patient can't operate. Any locksmith can help with this. But there is no need to panic if the person does wander away; just have an action plan ready for finding him/her. For example, let two or three of your family neighbours know that he/she is a wanderer and ask if perhaps they would be willing to look after the person in their home if they see him/her wandering and you are out for a while.

If the person is found wandering, it is important not to startle or frighten him/her by a sudden approach. Also, you may want to sew an address label — not too conspicuously (perhaps on the back of the collar of the wanderer where it can't easily be removed) — or have him/her wear an identification bracelet which is hard to take off. By taking the person on frequent walks, or arranging for lots of exercise, the wandering may be reduced.

Repetitious Behaviour. Being asked a question repeatedly by someone who does not understand or remember the answer can try anyone's patience. A short, simple reply is often sufficient. Some A.D. persons may pace continuously. There seems to be no clear explanation for this. Whatever the cause, there is no real solution to repetitious behaviour. In some cases, comfort and support may be substituted for answers to questions. In other cases, repeated questions or other repetitious behaviour may be ignored in the hope that it will not persist. It is this kind of thing that is so trying and makes it necessary for caregivers to seek periods of respite.

Sleep and Night-time Problems. Manifestations of A.D. are often prominent at night. Some wander only at this time, others may not be able to sleep, or may be fearful at night, while still others may be prone to hearing or seeing things which aren't really there. Obviously, disruptions of this kind in the home can deprive caregivers of much-needed rest. But the A.D. person who has been physically active during the day is more likely to sleep at night. (See "Recreation," p. 12. Activities and exercises should be matched to individual abilities in various stages of the illness.) Neuroleptic medication, under the advice of a doctor, may have a role in helping to relieve confusion at night or to modify sleep patterns.

Remember that the A.D. person who is just waking up is subject to the same kinds of confusion and disorientation other people feel at that time — and even more so. Always try not to be too loud, or move too quickly, when approaching the A.D. person, and approach from the front so that he/she may feel less threatened. Also, identify yourself, explaining the time of day and what is expected of the person.

Night lights in the bedroom and bathroom are useful too. In some cases, shades which hide a street light can make the person sense it is sleep time.

Sometimes a simple reminder that it is still nighttime will keep the person from trying to get up. At other times, a change of location may help.

If you go into the bedroom at night, remember to address the person by name, identify yourself, and mention the time of night it is. This helps the person to more quickly orient him/herself. If all this fails, consult a health professional for other possible suggestions.

Fear. This disease often creates considerable fear in A.D. persons. When individuals are unable to learn or recall their surroundings, it must seem very strange and threatening to them if the environment is cluttered or continually changing. Objects and events become misconstrued, since they are perceived through a sort of "damaged brain filter." Anxiety makes for tension and irritability, so that some responses are exaggerated.

Gentle reassurance, preferably by a touch or hug, or in words, or simply by being present, can sometimes help. Simplified and consistent surroundings also help to keep the person secure and calm. Knowing that these fears and behaviours are a result of the disease often makes it easier for families to cope with them.

Aggressive Behaviour. A.D. persons can have quick changes of mind and angry outbursts. Some family members and professionals fail to recognize that these are due to the person's damaged grasp on reality. Because they misperceive what is happening, they react to misperceived threats, dangers or insults, or they explode with frustration that has been simmering beneath the surface. It is seen as rudeness or unacceptable behaviour, and is particularly disturbing to someone who is devoting so much attention to the person's care.

This emotional instability, when combined with some of the physical problems discussed later (e.g., a person who jerks away when guided or assisted) makes the life of the caregiver extremely difficult. Arguments can result, with frustration and anger building up, often for both parties.

Whenever possible, these outbursts should be dealt with calmly. You simply cannot use logic with someone who usually is quite unable to grasp an explanation. Raising your voice will only amplify the reaction. Therefore, trying to remain calm helps the A.D. person maintain composure as well.

But it is just not possible always to remain in control. When you feel this way, try calling a friend or another Alzheimer caregiver. This often helps to restore calm and get back in control. But remember, no caring person need feel inadequate or guilty for losing control or feeling angry under such circumstances. When other approaches fail, psychotropic medication under the advice of a

doctor may play a part in relieving anxiety and fear that can lead to irritability and apparent aggression. It may also, to some degree affect the thought disorder that contributes to the development of anxiety.

Communication. As has already been noted, the capacity to use and understand language deteriorates slowly and seriously, making other forms of communication gradually more important. Non-verbal means, such as facial expression, body position, or tone of voice, should help to convey ideas. Similarly, as speech may change to a stream of words, interspersed with only a few appropriate ones, the person will convey something through stance, tone, or facial expression. Yet feelings still remain, and the person may express his/her need for reassurance or complaints of pain without words. Remember always to look for the meaning behind behaviour that is puzzling.

When talking to the person, listen and observe the reaction carefully; from his/her words and actions you can sense the possible degree of understanding. In this way you can continue to communicate at the appropriate level of understanding and not make false assumptions. This prevents "talking down" and helps maintain dignity and respect for the individual.

Use short, simple sentences, spoken slowly and clearly. Present one statement or question at a time, allowing plenty of time for response. If necessary, repeat your question exactly as you did before. Sometimes questions requiring an answer may confuse the person. Even the answer "yes" or "no" may be difficult, or may not really convey his/her wishes. An affirmative statement such as "Here is your fruit" may be preferable to "Would you like some fruit?" Where possible, "either-or" questions should be avoided. Suggestions should be made very clearly.

Whenever possible, the speaker should be in front of the person to maintain eye contact. Calling him/her by name should direct attention to your verbal exchange. Whenever practical, reinforce the spoken message using real objects and demonstration.

If there is hearing loss, clarity of speech, facing the person, and lowering the pitch of the voice are more important than speaking louder.

Follow through on promises, or make explanations if for some reason a promise cannot be kept. Continue to bear in mind that the person's feelings are still sensitive and can be hurt just like anyone else's!

You should also share with other caregivers any and all effective ways of communicating. This will make things easier for all concerned.

Social Situations. While the social life of family members is dealt with elsewhere, that of A.D. persons deserves special attention. Some may retain many of their social skills for years, while others deteriorate in their ability to relate to others and to participate in social activities.

Careful thought should be given to the type of social situation in which the A.D. person can participate. Sometimes the disabilities make a formal situation uncomfortable for everyone. In other cases, a formal situation may remind the person to behave particularly well. Response is usually best in the kind of social situation in which the person was formerly comfortable — e.g., family or church groups, where repetition of earlier social patterns may be entered into quite naturally.

The family will also have to judge how much socializing the person wants, and with whom. But the lack of responsiveness to visiting, etc., does not necessarily imply a lack of interest. Try to watch for overall behaviour during a visit. Staff in hospitals and nursing homes have reported that even profoundly brain-damaged patients seem somewhat better on days they receive visitors.

Hygiene and Personal Care

A.D. persons gradually lose their ability to care for themselves. In encouraging them, families and professionals who care for patients must strike a balance between what they can and what they cannot do. In some cases, simple reminders may suffice; in others, tasks may need to be simplified and broken down into small steps so that the person can still manage them by him/herself. A medical social worker, occupational therapist, or public health nurse should be able to help with this. (See the "Who Can Help?" section on how to contact them, p. 15).

Here is a list of some things that might make hygiene and personal care easier:

- Install special hand grips for the toilet and tub so the person can lift him/herself more easily and safely.
- Watch the person in the tub, and be sure the tub has a rubber mat or non-slip strips. Use just a few inches of water and check the temperature to avoid burns. Colour indicator thermometers are available.
- Check the person frequently for red areas that can be the result of prolonged sitting or lying.
- Use clothes that can be put on and taken off easily. Avoid laces and buttons. If the patient

can't operate them, velcro strips can be used to replace buttons and zippers.

- If he can't tie a tie, use a clip-on; if that doesn't work, use a turtleneck or open-neck shirt.
- Help the person select clothing to avoid unnecessary confusion and inappropriate choices.
- Make sure that teeth are brushed. When the person is no longer able to do this, it needs to be done for him/her, gently and reassuringly.
- If the person has toilet accidents, see if there is a pattern to such incidents, then try to establish a regular toilet schedule by giving reminders. For example, someone may have "an accident" regularly an hour after meals. By giving toilet reminders you will be replacing the signals that the body no longer sends to him/her. Special pads in the underwear can be a reassurance for some persons, as well as a big help to caregivers.
- Try to keep such things as hairbrushes, toothbrushes, electric razors and so on, in a regular, visible place, so that the person will see them and be reminded to use them. Regular grooming is particularly important to maintain and enhance self-esteem and overall health.

Diet and Eating Tips

A well-balanced diet is essential for good health. The person may simply forget to eat, lose the ability to use a knife and fork, and become incapable of making proper choices of what to eat.

A doctor, nutritionist, or a public health nurse can help you in planning a balanced diet, or you may follow Canada's Food Guide*. It is very important to consult the doctor if you notice any major change in appetite or eating patterns, for this may indicate a medical problem.

If the person is responsible for feeding him/herself, don't just assume he/she is eating properly. See that the right foods are available and verify that they have been eaten. Programs such as "Meals on Wheels" should be considered where shopping or preparation is a problem.

The person may forget he/she has eaten and want to eat all over again. Also try to limit between-meal eating to such things as melba toast and fresh vegetables, or plan a number of very small meals per day.

As the disease progresses, a loss of table manners is normal. This will influence planning meals and setting the table. Notice which foods the person has trouble with. If he/she is using a knife and fork poorly, slices of meat should be cut

up. If the person is not chewing properly, avoid foods that are easily choked on, and be sure that all servings are bite-size. All of this is important because of the effect the disease has on swallowing. If eating is mostly with the fingers, try to prepare foods that are easy and convenient to grasp.

The table setting should be as simple as possible. Unnecessary cutlery, flatware and condiments should be removed to avoid distraction. Use plastic placemats and spill-proof cups. Consistency may help at meals. Setting the table the same way, sitting the person at the same place, and eating at the same time each day, may help him/her to act more appropriately.

Eating habits should determine the kind of clothes to be worn at mealtime. Some people may want to use a smock or apron; others prefer easy-to-wash clothes. You can explain to guests or hosts that the person has difficulty eating because of the illness. With the proper selection of food (non-messy) and cutlery, the person may be able to join the others at mealtime. A restaurant is strange for the person but he/she might surprise you by falling into earlier patterns of eating and enjoy the change, especially in the early stage of the disease.

Those who eat regularly with an A.D. person should be familiar with basic first-aid in the event of choking. Your local Red Cross, St. John Ambulance or Public Health Department can help you with this.

The temperatures of all foods, drinks and serving dishes should be watched so that the person doesn't burn him/herself. Ensuring that cups are not filled too full, and plates are not crowded, helps to prevent spilling.

Safety Suggestions

The impairment of judgement and memory creates many safety hazards. One of the hardest tasks facing family members is to help the person avoid potentially hazardous activities.

Driving. As soon as indications of deteriorating driving ability appear, the person must no longer be permitted to drive. The driver who forgets where he or she is going, or how to get there, is a hazard both to him/herself and others.

Smoking. Ideally, A.D. persons should be helped to give up smoking, if not for health reasons, then because of the fire hazard. They may forget they are smoking, and a smouldering cigarette could start a fire. If they are unable to give up smoking, then stay with them while they smoke.

* Available without charge, in English or French, by writing to: Health Promotion Branch, Department of Health and Welfare, Ottawa, Ont. K1A 1B4.

Stairs. To keep a family member from going up or down the stairs, place a wrought iron or wooden expanding gate at the top or bottom of the stairs. A fairly sturdy gate, at least waist-high, provides the best protection.

Door Knobs. Safety knobs can be very helpful in keeping your doors and cupboards closed.

Mirrors. These can frighten the person, so you may want to turn them around, cover them up, or remove them entirely.

Breakable Objects. Move these out of the way because they can injure the person if broken.

Dead Bolts. If you need to use a dead bolt lock without a turn latch, be sure to keep a key close by in case of emergency.

Cooking. You may want to consult your hydro or gas company about making your stove inoperative when no one else is around. It is too easy to turn on an unlit burner, or to put flammable materials in the oven, or to create a number of other fire hazards.

Hot Water. Adjust your water heater so that the temperature is low enough to prevent scalding.

Small Appliances. Essential electrical appliances should be used under supervision, and other small but potentially dangerous ones should be safely hidden away.

Poisons and Medications. The person may have poor judgement in handling these. Hide or lock them up, or get hard-to-operate lids.

Safety Devices. An occupational therapist or a public health nurse should be able to provide you with information on a whole range of clever safety devices and procedures. These include proper assists and handrails for balance in the bathroom and elsewhere, difficult-to-use latches and numerous other items.

Recreation

Recreational activities should be related to past interests and abilities which remain intact. Often, music and dancing are pleasurable, as are simple woodwork, knitting, crochet work, painting, food preparation and other simple household tasks. Again, speak to an occupational or recreational therapist for additional suggestions.

When particular leisure activities seem to frustrate the person, simplify them or try different ones. Since memory for much earlier events remains, reviewing and talking about them may be pleasurable. Photographs and treasured objects may stimulate enjoyable discussion and help with a "life review" of significant past events. Physical activity will keep the person in better health, possibly reduce wandering, and help him/her sleep

better at night. Adequate exercise and activity can often reduce the need for medication. For those who are still mobile, a daily walk may be the easiest and most enjoyable form of exercise. For others, including even those who are bedridden, information about different exercises is available from physiotherapists or public health nurses.

Physical Problems

Problems of Balance and Coordination.

Patients with this disease often suffer from loss of balance and coordination. Speak to the doctor about this. You may want to request a referral to a physiotherapist who can teach you how to lift the person without hurting yourself, and also tell you about handrails and other aids.

Beware of scatter rugs, carpets with curled up ends, sharp corners on furniture, steep stairs, loose handrails, icy walks and slippery floors.

Seizures. Some A.D. persons tend to have seizures. But remember, seizures are much harder on the observer than the victim.

Ease the person to the floor and loosen his/her clothing. Move any sharp or hot objects out of the way to prevent injury. If necessary, wipe away excess saliva. To prevent possible choking on the tongue, the person should be turned on his/her side. This can also be accomplished by simply turning the head to one side. Do *not* insert anything in the mouth, or interfere with the seizure in any way. When the seizure is over, call the doctor, since many types of seizures can be controlled by medication.

Impact on the Family

When someone suffers from Alzheimer's, it has an impact on the entire family.

Because it is usually one of the older members who is affected, and because the need for care and attention increases, all family members may have to take on new responsibilities and make changes in their lifestyle, which can be extremely stressful, both physically and emotionally, depending on the degree of involvement and the level of disability.

Each family will find its own way of coping. In some cases, the spouse will bear primary responsibility for the care of the person, while in others it will likely be the children. Eventually most, but not all, A.D. persons are institutionalized because of their chronic nursing care needs.

Coping with an Invisible Disease

One of the most difficult aspects for family members is that there are often no physical signs of anything being wrong, at least in the first two stages.* This makes it hard for family members to recognize or accept that the person is ill, rather than moody, depressed or "being difficult." It also means that outside sympathy and support, which friends and relatives normally provide for the spouse or child of the ill person, may not be forthcoming. However, after increasing their understanding of the disease, and realizing that the various changes in behaviour and the progressive loss of judgement and memory are characteristic of the illness, the family may also find it helpful to share this understanding with friends and relatives so that they, too, can realize the real cause of the disabilities and erratic behaviours.

Anger, Guilt and Other Feelings

Coping with someone who has Alzheimer's is an intensely emotional experience. Family members can resent the fact that it requires so much of their time; or resent other family members who don't seem to be pulling their weight. They may even feel guilty because they think they are not doing enough, or because they get impatient with the person. Discussing these feelings with family and/or friends, or seeking professional counselling, can often help. But it should be remembered that caregivers must somehow find ways to attend to their own physical and emotional needs.

Responsibility for Care

Caring for an A.D. person becomes a 24-hour-a-day job that is more demanding as time goes by. Some have even called it a 36-hour day! Each person must assess just how much she or he can do, and at what point to seek assistance — for caregivers must not lose sight of their own needs and push too far, overextending their energy and emotional reserves.

Assistance may take many forms: e.g., a relative helping out once in a while to give the caregiver a break; a friend doing some cooking or laundry; seeking professional or volunteer help in the home; arranging some sort of special day for caregivers to be on their own; or seeking residential relief or respite care. Additional information on these and other available services is discussed in the chapter "Who Can Help?" (p. 15).

Chronic illness tends to isolate family members from other people just when they need them most. Visiting and being with others is greatly reduced because of the time taken up with caring for a spouse or parent; or the family may be embarrassed to have others in the house; or the person may not wish to go out. Moreover, friends might not understand or know how to empathize with the family — at least until they have been helped to understand the nature of the illness. Yet, to emphasize again, it is essential for family members to seek assistance and support.

Role Changes in the Family

As pointed out earlier, this disease usually strikes older family members. Persons with A.D. and their spouses will require increasing help from their children, reversing the life-long pattern of parents helping their children. As well, a husband who had not previously been involved in helping to get the meals may find himself entirely responsible for this; or wives who had not previously managed the family finances may have to learn to pay the bills, balance bank accounts, and so on. This role reversal can be very stressful for both partners — even strongly resented by one or the other. Some, of course, will find ways of adjusting to it through family meetings, support from friends, etc.; others may need professional counselling. But however these changes are struggled with, they must be faced.

* See "Stages of Deterioration," p. 6.

Sex and Alzheimer's

One of the issues for some A.D. caregivers, but certainly not all, is a diminishing expression of sexual interest by the affected partner. This may occur earlier, later or not at all, depending on the onset of the disease. The caregiving partner may easily feel that he/she has become less stimulating or undesirable or unattractive. Why does the A.D. person no longer look at the caregiver with pleasure, or touch or embrace? Has he or she lost interest in the partner — or perhaps in sex? They used to respond with so much joy and excitement to touching, stroking and other sexual activities. But now there is little or no response. Is their sexual loving to end?

At some stage, and for this kind of loving, unfortunately the answer is "yes," at least in many cases. Nevertheless, although there may be little or no response, you may be sure that this is *not* a message to keep away. The need for warmth, tenderness and closeness remains. Just as with all of us, your partner continues to need caring and intimacy.

In other cases, where a somewhat greater erotic response is experienced, use your intuitive feelings drawn from your earlier lifetime style of response. For example, where the woman has usually tended to await her partner's initiative, her role may have to be reversed. She will need to take the lead — whether or not her guiding leads to intercourse — which is certainly not "the be all and end all" of an intimate relationship. Loving is loving, and can take many forms.

Two other aspects. *First*, sometimes an A.D. partner may mistake a friend or housekeeper for his/her spouse, leading to inappropriate sexual behaviour. Others may mistake a lingering hand-shake, or friendly embrace, as an erotic gesture. To avoid embarrassment, explain A.D. to the person and how this kind of thing can happen.

Second: For some afflicted persons, whether male or female, their sex drive increases. But, because of their neurological impairment, they are unable to perform adequately. They may clumsily reach out or awkwardly try to fondle or kiss. Not achieving satisfaction, their frustration and anger increases. As their partner understandably resists, they may respond with angry and unfair accusations, perhaps concerning an alleged mistress or boyfriend. In other cases, the A.D. partner may try to have sex two or three times a day. Of course, all of this is very difficult to handle without becoming quite upset. Try to comfort and give reassurance that you care, which may help your partner relax and sleep.

Changes in the Present and Future

When one partner has the disease, the relationship is drastically altered for the other. In many respects, the one with the illness becomes lost to his or her partner, lost as a friend, a confidant, a companion and lover. This adds immeasurable grief to the existing complexity of their relationship so that "mourning" often occurs, sometimes for the duration of the entire illness. At the time of death, the surviving partner may feel a sense of relief. Such feelings are not uncommon and should not be a cause for guilt, particularly if the partner has been mourning for some time.

Reflecting on the effects of having had to care for such a partner, and stressing the need to take future life into account, one person observed:

One can end up socially isolated, emotionally drained, and physically exhausted. But one should think about what lies ahead. What happens after your partner has become so ill that he or she must be placed in a nursing home, or after he or she dies? Will you have become isolated, without other interests, lonely, used up, and find yourself in a tight little world all your own? You must not let this happen! You need your friends and hobbies now more than ever. You must have a change of pace to relieve your job of caretaker, for this will bolster and carry you through that long night of never-ending illness. More than that, it will sustain the strength you will need when the time comes for you to be left alone.

Who Can Help?

Anyone caring for an A.D. person may need a wide variety of assistance throughout the course of the disease. That assistance may come from family and friends, health professionals and social workers, community services, nursing homes or homes for the aged, church or synagogue, social clubs, and of course, local Chapters of the Alzheimer Society. At some time during their illness most patients eventually are moved to a nursing home, home for the aged, or hospital. For many with a family member at home, a range of community support services is absolutely essential. These include: geriatric assessment services, social work, visiting nurses, visiting homemakers, physio and/or occupational therapists, transportation, day care, temporary respite care, personal or family counselling, and last — but not least! — Alzheimer Family Support Group services.

Family Doctors

It is important to remember that at all times the family physician is your major professional contact, and you should keep in touch with him or her regularly. Also remember, however, that there are no fool-proof signs to help the doctor recognize the disease. He or she will probably need as much help from you as possible. Consequently, he or she will be greatly assisted if you, and/or any of the friends who are close to the person, can describe, in as much detail as possible, the sequence of events which brought you to the doctor. He/she may well need extensive tests to help distinguish possible A.D. from a great number of treatable conditions which also cause mental dysfunction. Quite aside from whatever referrals the doctor may make to other medical specialists for additional assistance in the diagnosis, you should continue to keep in close touch with him/her, and report any and all changes which you observe in order that the doctor may discover any additional physical problems which should also be attended to.

The doctor should also communicate regularly with the caregiver(s) and explain the patient's progress to them. Some doctors may only give as much information as asked for. Consequently, do not hesitate to discuss with him/her any other questions which you may have. And if for any reason you feel the doctor is not a sufficiently understanding person, you should consider changing doctors, because throughout the entire course of the illness, medical consultation and guidance are so important — not only for the patient, but for you!

You may also want to put the doctor in touch with your local Chapter of the Alzheimer Society, or at least supply him/her with information about its functions and possible Family Support services.

Neurologists

The neurologist is a physician who has specialized in diseases of the nervous system and acts as a consultant to your family physician. He/she, or a geriatric psychiatrist, should nearly always be involved in the diagnosis of this disease, and may also do periodic assessments to evaluate changes. The family physician will get a full report from him/her indicating the diagnosis and how it was obtained.

The family doctor may assist the family, where necessary, by suggesting questions to ask the neurologist in order to obtain a clear understanding of the implications of any findings and the status of the patient.

Psychiatrists

Your doctor may refer the patient to a psychiatrist in order to determine whether changes in memory and other functions result from an organic disease process or are the result of stress, depression, or personal problems. Another reason for referral could have to do with understanding the personality changes seen in the patient, or emotional disturbance seen in the caregiver.

The psychiatrist uses more specialized methods to assess mental function than those used by the family physician. Medication may be prescribed by the psychiatrist to relieve anxiety, regulate sleep patterns, or to control other distressing symptoms, if and when they develop.

Psychologists

A psychologist may be called on to administer psychological tests, particularly assessments of the patient's mental capabilities, to help the psychiatrist and family physician distinguish between organic disease and emotional problems, and to determine the severity of any dementia. This can help in planning for the future, and can assist both the family and the patient in making the best use of their capabilities at any stage of the disease.

Social Workers

Most general or acute care hospitals have social workers on their staff. The family doctor or neurologist who diagnoses the patient can probably refer you to a social worker in the hospital or in other agencies such as local Family Service Associations, municipal or provincial social services, centres for seniors, or homes for the aged.

The social worker provides personal or family counselling and advice, or can refer you to the particular community service you may need. Social workers who know about and understand A.D., or who are associated with the Alzheimer Society, can help the whole family cope with and understand the changes in the patient, and the disruptions of family life that may be due to the stresses of caring for the patient.

Public Health Services

Public health nurses are available virtually everywhere in Canada. They can help families of patients by doing an assessment of the home environment, and by providing advice and assistance regarding other community services. They can also help you plan the daily care of the patient and assist with any health problems which may occur.

Families may ask the public health nurse about medical care, diet, bathing, dressing, relief care, first-aid, or any other health-related problems. The nurse should be able to secure an answer to many of your queries — if she doesn't already have them!

Many other services, such as Visiting Homemakers, are obtainable on referral by the local Public Health Unit, Department of Health, or Department of Social Service.

Community Information and Referral Centres

These centres usually exist in larger urban communities. They are a source of information on most services available in the community and can advise you about local resources and what to expect from them. Consult the Yellow Pages of your telephone book — usually under the heading "Social Services".

Other Voluntary Organizations

First, consult your local Chapter of the Alzheimer Society. In communities where there is no Chapter, senior citizens' groups may be able to provide information on available resources. In many parts of the country, organizations of friends and relatives of patients in a variety of care facilities have been formed; these organizations should be able to provide some information on different kinds of institutional care.

Home Support

In the provision of health care and social services, there recently has been increased awareness of the need for services to help the A.D. person remain at home. For various reasons, Canadians

sometimes tend to place people in institutional care sooner than is the case in other countries. This is changing as home support services, at varying rates, are becoming more available. These services may be rather expensive and, unfortunately, can be used by most families only as and when they become chargeable to Medicare or other insurance programs.

Visiting Nurses

These nurses will provide any nursing care required by the patient (e.g., changing dressings, teaching skills, etc.). They can also help with advice on health counselling and household management.

Visiting Homemakers

Homemakers help keep the household operating when family members are unable to do so themselves. They provide personal care, household assistance and emotional support. In some areas they are also beginning to provide short-term relief or respite care for family members who so badly need brief periods of time away from the A.D. person: time for shopping, going to the doctor or dentist, or visiting a neighbour or friend for a short while.

Occupational Therapists

Such a therapist can help the family to find ways of dealing with the patient's disabilities. This can include adaptation of the house to accommodate disabilities, techniques for simplifying tasks, minimizing the stress on caregivers, and teaching them how to help the A.D. person with eating and personal grooming, as well as referring you to other agencies when needed. Occupational therapists are available through hospitals, through home care or home support programs, or through referral by your physician.

Meals-on-Wheels

This service provides a meal for people who would not otherwise be able to prepare one. This may be appropriate for those who are still well enough to remain alone during the day but who might not otherwise eat properly. It can also be helpful when the partner or spouse is unwell, too tired, or otherwise unable to shop or prepare a meal.

Respite or Relief Care

This is perhaps the most essential service for caregivers of an Alzheimer patient. It provides substitute care in order to give the caregiver a

break. Unfortunately, this service is as yet very limited on any formally organized basis and depends mainly on personal arrangements.

Currently, there are three kinds of respite care: in-home services, day care and vacation care. In such situations, the regular caregiver should remain with the patient long enough to allow him/her to become comfortable with the respite caregiver.

In-home (or "sitter") services are limited and usually are run for a profit. With such an arrangement someone comes into the home to be with the person and to allow the caregiver to get away for a few hours. In some cases such a service may be provided by Visiting Homemakers or Visiting Nurses.

Day care centres and day hospital care provide activities for patients in a supervised setting away from the home. While day care programs for senior citizens are becoming more common, they often are not set up to cope with Alzheimer patients who may wander or become a bit agitated. These programs are usually attached to chronic care hospitals, homes for the aged or senior citizens' centres. Sometimes, however, specially adapted programs and a larger well-trained staff are provided to accommodate the mentally impaired within their existing program.

Short-term stay may sometimes be arranged with some nursing homes, homes for the aged, or chronic care and convalescent hospitals, to give the caregivers a rest or vacation. The length of stay permitted will vary. Locating this kind of service becomes more difficult for patients who are A.D. patients and who, it is assumed, are difficult to care for. Nevertheless, it is worth investigating, as a few weeks respite is a tremendous boon to anyone responsible for full-time care.

Home Care Programs

In some areas of the country, comprehensive home care health programs are being developed to offer a full range of services to ill or disabled people in the community. Unfortunately, a number of these programs provide only limited periods of service and, unless the service is renewable, the help may be of limited duration (e.g., 15 or 30 days). However, the Home Care Programs of each province should be checked, since these are now a priority in health care. As with other services, there are certain eligibility rules which vary from province to province, as do the various professional and other services which are provided.

Institutional Care

Most A.D. persons ultimately require some type of institutional care. Understandably, many families find this a very difficult decision to face. However, there is a limit to how long the caregiver can cope with the exhausting emotional and physical strain. Eventually it becomes much better for the patient to be in a setting that can provide care and safety on a 24-hour basis.

Assessing the A.D. Person's Needs and Abilities

There is a variety of situations in which residential care must be seriously considered. The person may live alone and become incapable of providing for his/her own needs. He/she may live with a spouse who becomes unable to provide the care that is essential. The person may live with other family members who, even in spite of outside community support, can no longer stand the strain of disruptive behaviour, incontinence, etc. The move may be prompted by the need for increased medical attention, or by other complications.

A social worker, public health nurse, or occupational therapist will be very useful in helping to assess the person's needs and abilities. They may also be able to find ways of communicating with the patient, and can help family members with the very difficult and stressful decision of placement.

Assessing the Family Situation

Families and individuals will need to assess periodically their ability to continue providing care. Personal limits of physical and emotional strength must be recognized and, if the stress becomes too great and health and family relationships are likely to suffer, it is time to consider institutional care.

Of great importance is a free and open discussion of the situation by everyone in the family, including any relative and close friend who may be involved. While their participation is important in discussions of the future care and the selection of an appropriate institutional facility, the feelings of the main caregiver must receive primary consideration.

Institutional Care Options

Options for institutional care differ in each community, but it is essential to plan in advance, since desirable facilities usually have long waiting lists. This means there may be a delay of six months or longer. Facilities that accept patients

with advanced mental impairment may be limited in your community. Whenever possible, professional assistance should be obtained from your local Health or Social Services Department, or from a Community Information Centre, where there is one.

The types of residential facilities which may be needed are: homes for the aged, nursing homes, chronic care hospitals and psychiatric institutions.

Homes for the aged are intended for seniors (60 years and up), but exceptions for underage applicants are sometimes made. These operate under provincial legislation but are administered by a municipal or non-profit agency, which may be a religious or ethnic organization. Specific admission policies of each institution must be ascertained to determine if the care provided will meet the requirements of the ill person. Some homes are for those who require only minimal supervision; others will accommodate the patient for life, unless some acute condition develops requiring alternative care. Some institutions employ the term "special care" for a unit in which the care and programs are adapted for patients with mental impairment.

Nursing homes are intended to care for those who require medical and nursing care, and the need for such is medically determined. They are usually privately owned and, while operating under provincial legislation, may vary greatly in the type of patients they admit and in the level of care they provide.

When deciding on institutional placement, check these important features:

- What is the philosophy of care? Since you know best the likes and dislikes of the patient, it is you who can best interpret these to the institution. Do you sense that they will be taken into consideration? In other words, will the staff be taking care of the patient as well as the disease?
- Do you see the staff talking to the patients and residents, rather than ignoring them?
- Check whether the home is licensed under provincial authority, or incorporated under provincial legislation and subject to inspection and accreditation by the Canadian Council on Hospital Accreditation.
- What are the eligibility requirements for admission, e.g., level of care, medical examination, age, residence requirement, etc.?
- Financial arrangement and cost of care: check for requirement of any contract or written agreements. Inquire about government subsidy,

and what services are and are not covered by the daily rate.

● Enquire whether the medical, nursing care and supervision are provided during the day and at night. Also, is it a safe environment, i.e., are there smoke detectors, fire drills, etc.?

● See that resources are available for maintenance of maximum well-being; e.g., is there on staff a consultant occupational therapist and physiotherapist? Is staff leadership given for appropriate physical, religious and social activities?

● Is there provision of well-balanced diets?

● Are there special services and comforts available, such as hairdressing, dental service, foot, teeth and eye care?

● Are there pleasant, clean, comfortable surroundings? Does the setting lend itself to bringing in personal possessions or pets so as to help retain a sense of identity and familiarity?

● Do the staff appear to be open and reassuring to residents? Discover if they orient new patients and families to what happens or is going to happen in the institution.

● Note the location for ease of visiting.

● Is there an active Residents' or Patients' or Family Council that speaks to the Administrator on behalf of the residents, and whose proposals and suggestions are considered seriously?

● The home should be a member of the provincial association of Nursing Homes or Homes for the Aged.

Chronic care hospitals provide medical and rehabilitative treatment where a mentally impaired person may, in some circumstances, be cared for. **Psychiatric institutions** may be appropriate for diagnostic or continuing care purposes.

Because mentally impaired persons may not fit neatly into the normal admission process of one of the above types of institutional care, there is an urgent need for more long-term care facilities for ambulant patients which provide constant supervision in appropriate surroundings, and which have activity programs geared to individual abilities.

Decisions and choices regarding placement are made based on a particular setting's ability to provide the best services available. These services should meet those needs felt to be the most important in the particular situation. Even with family conferences to share the decision, the admission of a loved one to a care facility can cause considerable feelings of anxiety and guilt. Social work or other professional counselling may help with this. A transition period of visits to the facility prior to final admission can be very helpful for

both patient and family, and such an arrangement should be made.

Your Local Alzheimer Society Chapter

Be sure to contact and join your local Chapter of the Alzheimer Society of Canada. These Chapters can be a source of considerable help and emotional support. Here you will be able to meet others who face many of the same problems that you encounter. Moreover, the Society needs your support in its efforts to bring about greater public understanding of the disease, promote even more research into its causes and prevention, and to work actively for the many improvements in facilities and programs which are so badly needed in local communities. Your participation in the Society's collective struggle to achieve these ends is not only needed, but will protect you — at least to some extent — from that inevitable sense of isolation and helplessness which is the lot of so many A.D. caregivers.

Family and Caregiver Support Groups

In a growing number of communities, Chapters of the Society are operating a service known as Family Support Groups. The purpose of these self-help groups is to help families or other caregivers share with one another ideas and methods of coping with an A.D. patient. The groups, which consist of about five to ten or twelve persons, usually meet every other week, depending on the particular community. The "program" is usually quite informal and the group is led by someone skilled in working with and leading groups, often a health professional or a person particularly knowledgeable about A.D. These Support Groups provide an opportunity for participants to discuss their problems, receive suggestions from group members, share ideas and work out practical ways of helping one another, as well as the A.D. person for whom they are caring. To date, these groups have been found to be very stimulating and helpful. If you are not already a member or associated with the Alzheimer Chapter in your community, this does not matter at all. You will be most welcome to join one of their Family Support Groups.

Drugs

A word of caution! Whenever drugs are prescribed for an A.D. patient there is the risk of side effects, some of which could cause further mental impairment. Most elderly people have several medical conditions for which medication may be prescribed, and the drugs in question may interact — whether they are prescribed or bought "over the counter." Consequently, it is essential that you discuss with your physician the degree of risk which will be involved should he or she wish to prescribe drugs, for you will be faced with a trade-off:

a) either you decide to take this risk because the behaviour for which the drugs are prescribed is just too much for you and your family to cope with; or

b) you decide not to take the risk — at least for the time being.

In any case, the potential risk should be seriously considered.

Should you consent to the use of drugs, be sure to monitor their effects and, if you observe *any* changes in the patient's behaviour, other than those for which the drugs were prescribed, report them *immediately* to the doctor. Also, it is equally important to find out from the doctor about how long it should take before you can expect to observe the results for which the drugs were prescribed. On this basis, advise the doctor if the expected changes do not occur.

Legal Aspects

In addition to medical concerns, A.D. raises many legal issues which require careful consideration, including mental incompetency proceedings, contractual liability, liability in "tort," testamentary capacity, power of attorney effectiveness, and medical consent liability, to name a few. For the purpose of this manual, the discussion of the legal aspects of the disease will be restricted to the issues of guardianship (in most jurisdictions, this is referred to as "committeeship") and power of attorney.

First, seek legal counsel. Laws and procedures vary significantly from province to province. This manual provides only a brief and general discussion; it cannot substitute for the services of a lawyer.

Guardianship or Committeeship

Persons with A.D. may suffer to such an extent that they are incapable of managing their own

affairs. Consequently, they will require the assistance of a person or corporation to manage their assets on their behalf, or to exercise certain personal rights on their behalf, such as giving consent to medical treatment. The person or corporation selected legally to do so is called a "guardian" or a "committee." (The term "committee" is used in what follows.)

There are two alternative ways in which a committee may be appointed to manage the estate of a mentally incompetent person. First, a disabled person receiving treatment in a psychiatric facility may be certified as incompetent without a court order if the attending physician examines the disabled person and declares him/her incapable of managing his/her affairs, pursuant to the provisions of the particular province's Mental Health Act. When such a declaration is processed under the province's Mental Health Act, the committee of the estate is the province's Public Trustee. In some provinces, he/she is referred to as the Estate Administrator or Curateur Publique. (In Ontario, the procedure and process are also applicable to residents of mental retardation facilities under the Developmental Services Act, and to outpatients of psychiatric facilities who reside in Homes for Special Care. Laws and procedures governing such declarations may vary in other provinces.)

The Public Trustee's jurisdiction is limited to property matters and does not extend to personal rights. The Public Trustee is a special corporation created by statute, and one individual is appointed by the provincial government to fill the office of Public Trustee. The staff of the Public Trustee administers the estate under the Public Trustee's care, with the Trustee him/herself having the final authority in all decision-making. As committee of an incompetent person's estate, the Public Trustee has all the rights over such property that the incompetent person would have if competent, including the right to prosecute or defend court actions in the incompetent person's name.

A second method of appointing a committee is pursuant to a court order and involves either those individuals who are not under the care of a psychiatric facility or those patients for whom a private committee is to be appointed to substitute for the Public Trustee. For a private individual to obtain such an appointment, his or her lawyer must bring a "motion" to a judge, a motion being the legal term for a request or application. It will include medical evidence of the disability, a recital of facts, the application by the person or corporation who wishes to be committee, an inventory of all property (money, goods, land, etc.,

of the incompetent person), and a scheme of managing such property, including plans for the disabled person's care and maintenance. All facts on the application are confirmed by sworn statements. Under this procedure, the court generally has authority to grant the committee personal rights over the incompetent person (e.g. the right to make decisions regarding the care of the person), and this authority varies from province to province.

A committee (whether the Public Trustee or a private committee) is entitled to compensation for services provided in administering an incompetent person's estate. However, a committee who is the spouse or relative of the incompetent person often waives any claim to such compensation, and the Public Trustee may waive compensation, in whole or in part, if economic hardship is evident.

Whether the committee be an individual, a trust company, or the Public Trustee, when it is making investment of the funds in the incompetent person's estate, such investments must be proper investments at law. For committeeships arising from court appointments, the investment scheme is supervised by the court. For committeeships by the Public Trustee under the provincial Mental Health Act legislation, the investment of funds follows the guidelines described with that legislation. Generally speaking, the investments permitted by the court are more limited than those provided by the provincial Mental Health Acts.

The question of who should be named the committee is one that must be examined carefully. Should it be the next-of-kin, a corporation, or the Public Trustee? There are advantages and disadvantages in each choice. An individual named as a committee of the estate of a mentally incompetent individual will be required in many cases to post security in the form of a bond to guarantee to the court that the incompetent person's estate will not be depreciated by improper management. Any committee must keep clear records of the property of the incompetent person, and of all income, expenses, investments, and re-investments of estate property. A trust company or the Public Trustee has the experience and business know-how to manage an estate, but will not have the same individual appreciation as the spouse or next-of-kin of the incompetent person. You can obtain valuable assistance with respect to the most appropriate choice by speaking to your lawyer, and with representatives of trust companies and the Public Trustee. The best choice will depend upon each person's circumstances.

Power of Attorney

The concept of power of attorney involves the legal ability of a duly delegated person (called an "attorney") to exercise certain property rights on behalf of another (called a "donor"). The basic element of a power of attorney is this delegation of authority. By signing a power of attorney, a person bestows upon another the right to handle some or all of his/her business affairs, as specified in the power of attorney (for example, banking, signing legal documents, selling property, etc.).

Only a person who is legally competent to manage his/her affairs may grant a power of attorney to another. The question is often asked: "If the donor of the power of attorney becomes incompetent after giving power of attorney to his friend, can the friend continue to act pursuant to the power of attorney?" The answer varies. In most provinces of Canada, the friend can only exercise the rights given by the power of attorney so long as the donor is mentally competent. However, Alberta and Ontario, with the proper wording of the power of attorney, allow the friend to continue exercising it up to the time when a formal declaration of incompetence is made. In any event, a person cannot delegate more authority than he/she has.

Brain Tissue Banks

Brain Tissue Banks have been established in Canada. Their purpose is to provide needed biological material for medical research that seeks the causes, develops treatments, and searches for cures for the many devastating neurological and psychiatric disorders affecting so many people today, including A.D. and related disorders.

Why a Brain Tissue Bank?

Human brain banks are necessary because several serious neurological and psychiatric conditions affect only humans, and animal models are not available for study. Clues to the cause and treatment of these disorders can be found only through analysis of human brain tissue that has been removed at autopsy. Scientists now have powerful new research techniques, and human central nervous system tissue is essential to them in order to understand and, ultimately, prevent or alleviate these distressing illnesses. There is no substitute. Tissue stored in the Bank will be available to all competent neuro-scientists carrying out studies of brain diseases, both in Canada and abroad. Autopsies must be performed very promptly after death occurs.

Everyone Can Help Brain Research

If the person for whom you are responsible is affected by a neurological or psychiatric disorder, you may wish to help thousands of others who are similarly affected by arranging for donation of brain tissue for research. By arranging now for donation of the A.D. person's brain tissue, you will be giving a unique and priceless gift.

The Alzheimer Society actively cooperates with three Canadian Brain Banks. For more information about these Banks, and to arrange for future donation of brain tissue for medical research, write to:

Canadian Brain Tissue Bank
Banting Institute, Room 128
100 College Street
Toronto, Ont. M5G 1L5
(416) 977-3398

or

Brain Tissue Bank
Douglas Hospital Research Centre
6875 LaSalle Blvd.
Verdun, Que. H4H 1R3
(514) 761-6131 Ext. 310

or

Brain Tissue Bank
Dementia Study Office
University Hospital
London, Ont. N6A 5A5
(519) 663-3384

For More Information

If you need more information on Alzheimer's disease, or wish to secure the address and telephone number of the nearest Chapter of the Alzheimer Society, contact the national office:

Alzheimer Society of Canada
185 Bloor Street East, Suite 222
Toronto, Ont. M4W 3J3
(416) 927-1580

Additional Reading

● **The 36-Hour Day**, by *Nancy L. Mace* and *Peter V. Rabins, M.D.*, Johns Hopkins University Press, Baltimore/London (1981) 233 pp. (available from Alzheimer Society of Canada, 185 Bloor Street East, Suite 222, Toronto, Ont. M4W 3J3). Price: \$10.00 (Can.) including postage and handling.

● **Journal of Geriatric Nursing (U.S.)**, Vol. 8 #2, Feb. 1982; and Vol. 9 #2, Feb. 1983.

● **Generations**, Fall, 1982. A journal of articles published by, and available from, the Western Gerontological Society, 833 Market Street, Room 516, San Francisco, Calif., U.S.A., 94103. Price: \$4.00 (U.S. funds) including postage and handling.