

# **Exploration of Caregiver Transition**

*An Exploration of Caregiver Transition through the Grieving Process*

**By**

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## Abstract

The purpose of this exploratory research study was to examine the transition of caregivers through the grieving process in order to discover what caregivers experience as they transition from caregiving to grieving and from grieving to post grief recovery.

The purpose of this research was not to explore all the illnesses which require care provided by caregivers but a sampling to gain general insight into caregivers' responsibilities, experiences and personal needs.

The methodology of this research took a primarily explorative /investigative approach. Exploration of the history, evolution and role of caregiving revealed the major role played by unpaid family caregivers in the United States.

The research revealed up to seven periods of caregiver transition. These periods of caregiver transition fall into two major time frames: (1) from initial diagnosis until death of the patient receiving care (2) from the impending death of the patient through post grief recovery of the caregiver. The feelings and needs of unpaid family caregivers, who pass through these periods of transition, are investigated, analyzed and critiqued.

The study revealed the need for awareness of caregiver periods of transition by unpaid family caregivers, family members of caregivers, friends, community and church or synagogue congregations. The study also suggested resources and methods to help caregiver awareness and support during these periods of caregiver transition.

## **Dedications and Acknowledgements**

1. This thesis is dedicated to the many unsung, unpaid family caregivers who spend days, months and years providing care for their aged, debilitated or terminally ill family members.
2. Special recognition and appreciation is given to my wife Amy for her unconditional support in this project and her hours of proofing the document.
3. Special thanks to my faculty advisor Dr. Raymond L. Parker, Jr. for his practical guidance and support during the thesis process.

**Declaration Concerning Thesis Presented for the Degree of  
DOCTOR OF PHILOSOPHY**

**I, Roy W. Harris**

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**Solemnly and sincerely declare, in relation to the Doctoral Thesis  
entitled:**

**Exploration of Caregiver Transition**

*An Exploration of Caregiver Transition through the Grieving Process*

- (a) That work was done by me, personally
- (b) The material has not previously been accepted  
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diploma

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

## Table of Contents

EXPLORATION OF CAREGIVER TRANSITION.....	i
Abstract .....	ii
Dedications and Acknowledgements .....	iii
Author’s Declaration .....	iv
List of FIGURES.....	ix
CHAPTER I: INTRODUCTION TO THE PROBLEM.....	1
Statement of the Problem .....	1
Importance of the Study .....	2
Methodology and Organization .....	4
Delimitations .....	6
Definition of Terms .....	8
CHAPTER II: CRITICAL LITERATURE REVIEW.....	11
Historical Caregiving Progression .....	13
Health Care Transition .....	16
Nursing Homes .....	17
Assisted Living Facilities .....	19
Inception Assisted Living Facility .....	20
Health, Housing and Hospitality .....	20
Growth of Assisted Living Facilities .....	21
Residential Care Homes .....	22
In Home Care .....	23
Live-In or Privately Hired Caregiver....	31
Unpaid Volunteer Caregivers.....	31
Gender.....	33
Ethnicity.....	34

Household Income.....	35
Employment Status.....	36
Economic Impact of Caregiving.....	36
Stages of Patient Care.....	36
Exampld Diseases.....	37
Alzheimer's.....	37
Cancer.....	42
Multiple Sclerosis.....	43
Stroke.....	44
Amyotrophic Lateral Sclerosis.....	46
Other Debilitating Diseases.....	47
Muscular Dystrophies.....	47
Cerebral Palsy.....	47
Cystic Fibrosis.....	47
Caregiver Support.....	48
Secular Resources.....	48
The Final Transition.....	48
CHAPTER III: THE PROCESS OF CARE GIVING.....	49
Introduction.....	49
Family Caregivers.....	49
Gender of Caregivers.....	50
Ages of Caregivers.....	51
Caregiver Transition.....	53
Caregiver and Care Recipient Relationships.....	53
Caregiver Employment.....	54
Time Spent in Caregiving.....	56
Years Providing Care.....	56

Distance between Caregiver and Care Recipient.....	57
Impact on Caregivers' Health.....	58
Value and Cost of Informal Caregiving.....	60
Caregivers and Developmental Disabilities.....	61
Technology.....	62
Veterans.....	63
Periods of Family Caregiver Transition.....	64
Caregivers' Transition.....	74
Time For Grief.....	76
Death is Approaching.....	77
The Dynamic of Transitional Hope.....	81
The Clergy.....	82
Death Has Arrived.....	82
The Final Transition.....	85

#### CHAPTER IV: CAREGIVER AWARENESS AND MINISTRY

CARE.....	86
Awareness of Caregiver Needs.....	86
Stress.....	87
Depression.....	91
Grief and Loss.....	96
Anticipatory Grief.....	97
Post-Mortem Guilt.....	99
Normal and Abnormal Grief.....	99
Spousal Grief.....	100
Roadblocks to Grief.....	101
Coping With Grief.....	102
Caregiver Resources.....	108

Religious Support.....	108
Secular Support.....	111
CHAPTER V: SUMMARY AND CONCLUSIONS .....	120
Summary of Study.....	120
Final Conclusions.....	121
References.....	122



List of FIGURES

FIGURE 1: Labor Force Participation of Women.....15

FIGURE 2: Services Provided By Home Health Agencies.....26

FIGURE 3: Medical Reasons for Receiving Home Health Care.....27

FIGURE 4: Homecare Patients by Age.....28

FIGURE 5: Who Pays for Home Health Agency Services for the Elderly?...30

FIGURE 6: Caregiving Hours by Caregiver Age.....52

# CHAPTER I: INTROCUCTION TO THE PROBLEM

## Statement of the Problem

In a perfect world there would be no illness, suffering death or dying. But we know that human beings do not live in a perfect world. They become ill, suffer and eventually die. Physical and mental impairments, ailments and death affect all ages, races and cross economic and social lines. These vary in intensity and longevity but eventually become the great equalizer confronting every human being with his or her mortality.

This mortality of necessity generates a number of concerns and questions that are prudent to express and merit answers. One such question is what is the normal path of progression from initial diagnosis of debilitating or terminal illnesses through final termination of life? A second question is who will provide the day to day attention and primary care for those who experience long term physical or mental illness? A third question is what is the role and responsibilities of those who provide this primary care? What are the periods of transition which those who are providing primary care must pass through? How can a primary caregiver successful move through these periods of transition? What happens to caregivers when the object of their care dies and they enter the grieving process? How can caregivers survive the grieving process and eventually thrive at its conclusion?

There are also some questions which directly impact the pastor and church family. How well do pastors and churches understand the transition of those providing primary care from initial diagnosis through the grieving process? How are churches addressing the needs of those providing primary care as they transition through the care giving process? What can churches and pastors do to improve awareness of caregivers needs and put in place tangible programs of assistance?

The purpose of this thesis is to explore the transition which primary

caregivers traverse on their journey through debilitating or terminal illnesses of family members and friends which many times end with death and requires passing through the grieving process.

### **Importance of the Study**

People are living longer. The life expectancy of Americans continues to rise. The average American lifespan in 1776 was 33 years. By 1850 it had risen to 43 years. It climbed 47.3 years in 1900 and took a huge jump to 68.2 years in 1950. It had risen another ten years to 78.3 by 2010 and moved to 78.7 years in 2012. (Homer Hillis 2012)

Not only are people living longer but more quantitatively, there are more Americas in the population pool. The American population age demographics are changing. Many of the last of the greatest generation have passed away but many also are now in their mid-eighties or older. The first of the Baby Boomers, those born between 1946 –1964, turned sixty-five and became eligible for retirement in 2011. Projections are that ten thousand will retire per day for the next nineteen years. American life expectancy is projected to rise to age eighty-seven as the last Baby Boomers retire. (NEWSMAX 2010)

With American population life expectancy increasing, the frailty of mankind marches front and center in ever increasing numbers impacting not only their lives but also the lives of others. One such group impacted is family members and friends who are thrust into roles of providing primary personal care required at this juncture in life. The ranks of these unpaid volunteers called caregivers are increasing. The need for understanding of the transition periods they experience during the caregiving process is very important now but will become even more important in the coming years.

Exploring the transition experienced by caregivers as they pass through each life changing event of their family members or friends is important for the caregiver. Understanding the probable course that may lay

ahead for their loved ones and the markers which will arrive along the way can be a good source of help and encouragement. Understanding the care giving role required at each level of care will aid caregivers in recognizing when one level is nearing completion and a new one is about to begin. Compartmentalizing the transition process into smaller more manageable episodes will aid the caregiver in abating the tide of being overwhelming with the magnitude of the care giving role.

A possible outcome for the caregiver is recognition of each level of care as they arrive. A second possible outcome is determining what the caregiver will face in each level. A third possible outcome might be to become spiritually and emotionally equipped to transition through each level of care. A fourth outcome might be not only to survive the caregiver journey but to transition through it and thrive beyond it.

This study is important for family members of primary caregivers because it will provide a general but thorough understanding of what caregivers do, experience and feel as they transition through the entire care giving process. Family members who are not providing primary care will gain knowledge that can be of tremendous value as they seek to assist not only the family members who are ill, but also those family members who provide care on a daily basis.

Caregiver needs and assistance are low priorities in many churches and ministries. They are not low on the list by design but mainly because of oversight with an out of sight out of mind mentality. The old principle of “everything rises or falls based on leadership” not only relates to the secular world but also can be true of the church.

Pastors are trained in a variety of ministry skills such as bible study, sermon preparation, public speaking, hospital and home visitation, pastoral counseling, performing baptisms, wedding ceremonies and etc. One very

important area that many pastors have not received training in is how to minister to caregivers as they move through caregiver transition.

This study is important because it will provide a general but thorough understanding of what caregivers do, experience and feel as they transition through the entire care giving process. Pastors and churches will gain knowledge that can be of tremendous value as they seek to minister not only those who are ill but also those who care for them on a daily basis.

A possible outcome of this study for the pastor is on the job training as he better understands the levels of care and caregivers' role at each level. A possible outcome might be churches becoming more enlightened to what caregivers do, experience, feel and need at each level of care. Another possible outcome of this study could be the creation of avenues of ministry by the church to aid the caregiver during their transition period and labor in each level of care. A possible outcome could be defining specific ways to involve individual church members in assisting caregivers throughout the care giving process.

### **Methodology and Organization of the Study**

The main goal of this study will be to learn what caregivers do, what caregivers experience; how caregivers feel; how they can become better equipped to care for themselves as they provide care for others; how to survive emotionally when the object of care giving dies and how to successfully move on through life after caregiving.

A secondary goal of the study will be to gain a better understanding how pastors and churches are ministering to caregivers.

The study will be conducted from a unique vantage point. The writer is a care giving survivor who traversed the waters of caregiver transition having arrived safely on the shores of post grief and has secured a new life after care giving.

The researcher preparing this study is uniquely qualified to gather information, analyze that information and formulate conclusions. He gained personal knowledge of the care giving process and the role of caregivers through a three year journey he made with his wife who passed away with terminal breast cancer. He has firsthand knowledge of the major caregiving transition periods which rise to the forefront in the lives of caregivers. He has transitioned through the entire process of the role of caregiver from initial diagnosis through post-mortem grief. He was asked to write and authored *Caring for the Caregiver*, a book designed to help and encourage caregivers, which is now available in twenty-eight countries around the world. (Harris 2009)

The major transition periods of the care giving process, which is encountered by most caregivers, will be identified and examined in detail. A chronology of those transition periods will be documented and a care transition order of events will be created.

Exploring caregiver transition through the grieving process will take an exploratory approach. The study will seek to identify and authenticate major events in the caregiving process, the necessary transition of caregivers through each event and the appropriate role of other family members, pastors and church family in assisting caregivers through these transitions.

Information used to address caregiver transition through the grieving process in the study will be gained from a variety of sources. A critical review of written materials pertaining to care giving and grief will be conducted.

There are a number of basic caregiving attributes which many illnesses regardless of age have in common. This study will focus on these shared attributes of care.

## **Delimitations**

There is a plethora of debilitating and terminal illnesses impacting mankind and requiring varied levels of care by caregivers. It would be impossible to investigate each illness and the transitioning impact on caregivers that each one produces.

Infants with birth defects, children who are mentally challenged and parents who developed old age enhanced diseases to name only three age groups will be discussed on a limited scale. These would require more in-depth individual group studies to adequately discuss the health issues and unique care giving responsibilities which caregivers are called upon to provide.

The race of caregivers will be explored on a limited basis in this study. There are differences in life expectancy between races in America. There are also specific illnesses which tend to impact some races more than others. The topic of how race impacts the level of care needed is worthy of an in-depth study of its own and would lengthen this study beyond a reasonable point.

Years of care provided by caregivers will be explored briefly in the study. There are huge differences between short term and long term care. Short term care may last only a few days. Long term care may last decades. The types of illnesses that require short or long term care vary and the topic is too broad for the present study.

Examination of paid commercial forms of care inside and outside the home such as assisted living, nursing home and etc. will be part of this study. These commercial entities are quickly becoming a major part of the caregiving scene. Since only one in five people are receiving care through these venues and over eighty percent or four out of five are cared for by a family member or friend, this area is only relevant when family members reach the point of no longer being able to provide care without the help of these outside entities.

There is a number of basic care giving attributes which many illnesses regardless of age have in common. This study will focus on identifying those shared attributes of care.

The study will explore the following questions:

1. What are stages or periods of illness in the care giving process?
2. What generally happens to people who are ill during each of these periods or stages?
3. How can caregivers recognize when a new stage or period of care is about to begin?
4. How do caregivers make the transition from one stage or period to the next?
5. What are the responsibilities of caregivers during each stage or period of care?
6. What emotions do caregivers experience during each stage or period of care?
7. When does the grieving process begin for the caregiver?
8. What happens during the grieving process of the caregiver?
9. What specific things should caregivers remember during their time of grief?
10. When should caregivers cease their grieving?
11. How can caregivers recover from the caregiving role and move on with life?

The study will also focus, in a smaller way, on the role of family members of caregivers, medical personnel, friends, community and religious leaders and congregations in the aiding the transition of caregivers throughout the caregiving process.



## Definition of Terms

**Caregiver** - The term caregiver refers to anyone who provides assistance to someone else who is, to some degree, incapacitated and needs help performing the daily tasks essential to living a normal life.

**Unpaid Caregiver** - A caregiver is an unpaid individual (a spouse, significant other, family member, friend, or neighbor) involved in assisting others who are unable to perform certain activities on their own. (Institute of Medicine Report, Retooling for an Aging America: Building the Health Care Workforce. 2008)

**Family Caregiver** – A family caregiver is a spouse, child, sibling or other family member who provides varying levels of care and assistance to family members who are debilitated, aged or terminally ill. This would include persons providing care for a husband who has suffered a stroke, a wife with Parkinson's disease, a mother-in-law with cancer, a grandfather with Alzheimer's disease, a loved one with traumatic brain injury, a friend with AIDS, a child with muscular dystrophy, an elder who is very frail and etc.

**Formal Caregiver** – Is a paid care provider associated with a service system.

**Nursing home** is defined as having at least three beds and being either certified by Medicare or Medicaid or licensed by a government agency. A nursing home provides twenty-four hour skilled nursing care for residents who cannot live on their own.

**Assisted Living** is a type of elderly care that offers a level of attention and independence between those offered by nursing and independent living (which would fall on the lower end).

**Residential Care homes**, also known as adult family homes, board and care homes, residential care or personal care homes offer personalized service to small groups of adults. These residential homes provide lodging, meal services and assistance with daily living activities.

**Abnormal Grief** is prolonged, delayed, or otherwise unresolved grieving over a long period of time. Abnormal grief may include thoughts of suicide, a loss of contact with reality, significant weight loss or significant weight gain.

**Anticipatory Grief** is grief which begins with the knowledge of approaching loss that has not yet occurred. Relative to this study, anticipatory grief begins with knowledge of the caregiver, and sometimes the care recipient, that a loved one will not recover and will ultimately die.

**Spousal Grief** in this study refers to the feelings experienced by the remaining mate after the death of their married husband or wife.

**Ethnicity** is groups of people classed according to common racial, national, tribal, religious, linguistic, cultural origin or background. Ethnicity is used in this study to focus on caregiver characteristics of selected racial groups.

**Caregiver Transition** – Relative to this study, caregiver transition refers to the movement of unpaid family caregivers through stages of care provision for family care recipients.

**Transitional Hope** in this study is the dynamic power of optimism for the future that strengthens caregivers as they move through each stage of the caregiving process.

## **CHAPTER II: CRITICAL LITERATURE REVIEW**

A critical review of literature may be written in a variety of ways according to the University of North Carolina College of Arts and Sciences Writing Center at Chapel Hill. The review may be chronological by publication or trend, thematic or methodological. (U.N.C. Writing Center 2010-2012)

While there are number of acceptable approaches in developing a critical literature review, the researcher chose to embrace the exploratory approach. A good definition of the exploratory method of critical review would be investigation into a problem or situation which provides insights to the researcher (Business Dictionary.com 2013). The research is meant to provide details where a small amount of information exists. It may use a variety of methods for the purpose of gaining information.

The critical review of literature reveals the researcher's scholarship in the field of caregiving, particularly in this study, transition of caregivers through the caregiving process. The research looks at one facet of the huge field of caregiving. If the one facet is to be understood, then an overview of the whole must be undertaken.

The critical review was organized in the following way:

1. Historical Caregiving Progression
  - a. Health Care Transition
  - b. Nursing Homes
  - c. Assisted Living Facilities
  - d. Residential Care Homes
  - e. In Home Care
  - f. Unpaid Volunteer Care
2. Stages of Patient Illness
  - a. Exemplified Diseases
    - 1) Alzheimer's

- 2) Cancer
- 3) Multiple Sclerosis
- 4) Stroke
- 5) Amyotrophic Lateral Sclerosis
- 6) Muscular Dystrophies
- 7) Cerebral Palsy
- 8) Cystic Fibrosis

### 3. Caregiver Periods of Transition

- a. Caregiver Stages
- b. The Final Transition

This approach provided a systematic orderly way of investigating caregiving and caregivers during periods of transition. The literature review using the explorative/investigative approach, guides the reader in a systematic way through the material gaining insights from experts who have written in the field. The theories and practical applications of caregiving as gleaned from the literature supplied the foundation for the methodology used in Chapters Three and Four.

The purpose of this critical literature review was to investigate the field of caregiving as it relates to avenues of care provided for the terminally ill especially unpaid family caregivers. The investigation of the avenues of caregiving centers the focus of this research primarily on the role, experiences, feelings and transitions of unpaid family caregivers through the completed caregiving process. The information compiled, concerning caregiving and caregivers, will serve as a great source of understanding for the health care community, family members of terminally ill loved ones, unpaid family caregivers, friends of unpaid caregivers and the religious community.

This investigative research project revealed caregiving is a broad field in which unpaid caregivers are one facet. Thus the elements of the broader field of caregiving directly impact the narrow field of unpaid caregiving.

## **Historical Caregiving Progression**

There are several factors which influence care giving provided to those with debilitating or terminal diseases in America. One such factor is the change in geographical population demographics in the United States. When the thirteen colonies declared their independence from Great Britain in 1776 the total population of the colonies was about two and one half million people (Yun 2012). The largest city of the day was Philadelphia with a population of forty thousand (Ibid). All of the citizens of 1776 Philadelphia could attend a Tennessee Titan's football home game at LP Field and the stadium would be barely half filled (Tennessee Titans 2006). Ninety percent of the population lived on farms and it was not uncommon for three generations to live in the same house.

The population of the United States passed 313 million in 2012 according to U.S. News. (US News 2012) The geographical demographics of those who are farmers have completely reversed. Less than 1% claim farming as an occupation and about 2% actually live on farms. There are only about one million persons claiming farming as their principal occupation and a similar number of farmers claiming some other principal occupation. The number of farms in the U.S. stands at about two million. (U.S. Environmental Protection Agency 2012)

Multiple generations lived under the same roof and the older family members were cared for by the rest of the family.

A second factor that directly impacted caregiving was the introduction of women into the labor force outside the home. In 1900, only 6% of married women worked outside the home, usually when their blue-collar husbands were unemployed (Wattenberg 2010). Among wives with children at home, very few worked at all. Almost half of single women held jobs, but they usually stopped working when they married or, at the latest, when they got pregnant, and most never worked for pay again (Ibid). About a third of

widowed and divorced women worked, typically out of economic necessity. Never-married women with children were virtually unknown (Ibid).

The labor force participation rate of single women peaked in World War II and then declined as large numbers of them pursued higher education. The sharp jump in their work force participation in 1967 is a statistical artifact reflecting an increase in the defined minimum age of the labor force from fourteen to sixteen years old. In the early 1970s, the labor force participation rate of single women began a steady rise to nearly 70% by 1998. See FIGURE ONE below (Ibid).

The labor force participation rate of widowed, divorced and separated women remained fairly stable until 1940, when it began a gradual rise to nearly 50%. See FIGURE ONE below. These women were considerably older on average than those in the other three groups, and many had income sources such as survivors' benefits or alimony payments (Ibid).

The steady movement of married women into the labor force began around 1920, spiked during World War II, and never abated (see chart lower left on FIGURE ONE). In 1998, more than 60% of all married women living with their husbands worked for pay outside the family home. Their labor force participation was only slightly lower than that of single women and considerably higher than that of widowed, divorced, and separated women (Ibid).

Data on the labor force participation of married women with children under age six go back only to 1950, but the rise since then has been sharp (See FIGURE ONE). Their labor force participation rate increased more than fivefold, from 12% in 1950 to 64% in 1998, helping to create an entire industry of paid day care in the process (Ibid).

**Labor Force Participation of Women**  
 Percentage of each group in labor force

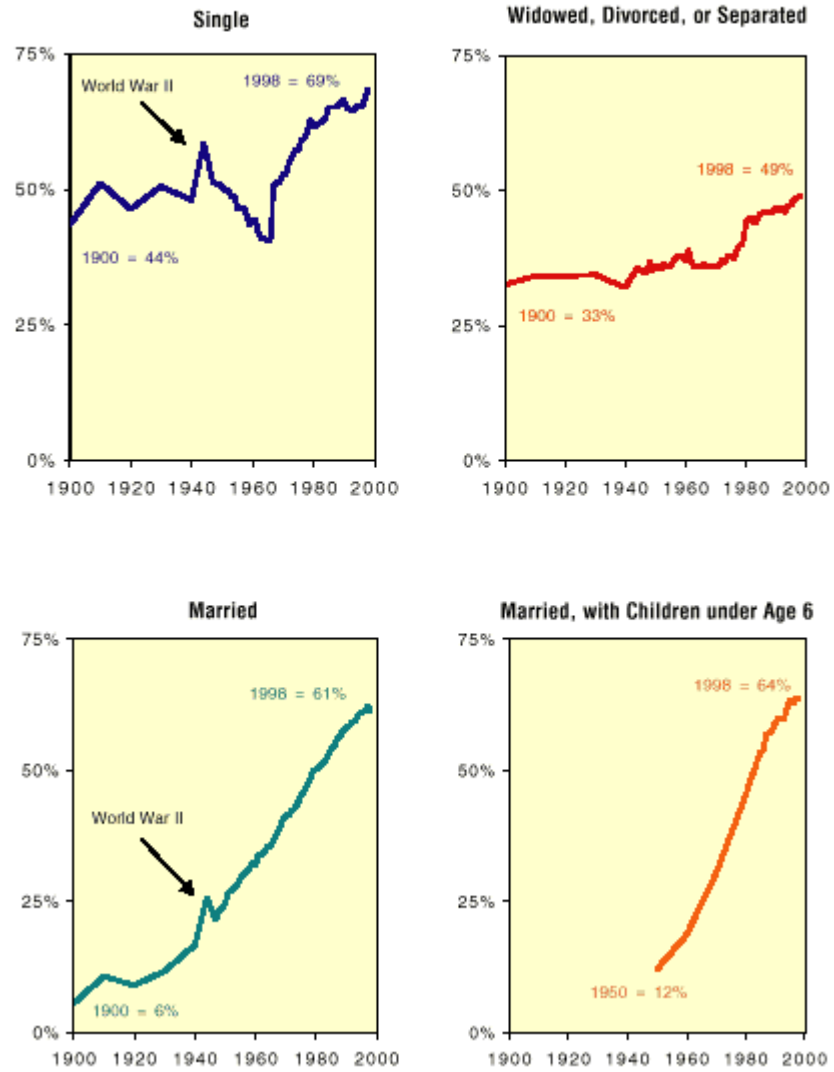


FIGURE ONE

Source: 2005 Statistical Abstract of the United States, Health and Nutrition



The migration of the majority of single, married, divorced and widowed women into the work force further reduced the number of available unpaid caregivers in the home. With an economy demanding two incomes per family, the need for paid caregivers from outside the home has risen quickly (Ibid).

### **Health Care Transition**

With the major geographical shift from rural to urban and more women securing employment outside the home, the approach to caring for the debilitated, aged and terminally ill made a huge transition. By the early 1900s it became apparent that the state would have to assume at least part of the role that once had taken place under roof on family farms. Without a federal assistance program to help pay for the care of elderly or disabled, most states sent their impoverished citizens to *Poor Farms* or *Almshouses*.

These facilities had been in existence as early as 1491 in Plymouth, England (Stevenson 1968). The homes were known for their dilapidated facilities and inadequate care. States appeared to encourage the stigma as a motivating factor to keep people from relying on them. Some immigrant communities established organizations in the United States that helped newcomers and the aging instead of using public services. (P.B.S. Online News Hour 2012)

In the 1920s, hospitals began to be seen as *Houses of Hope*, whereas before they were places where poor people recuperated or died. The Depression and World War II, however, limited the number of facilities that could live up to that ideal. By the time WWII ended, there was an enormous backlog of need in almost every community for modern health care facilities. (P.B.S. Online News Hour 2012)

The Social Security Act was signed by President Franklin Delano Roosevelt on August 14, 1935. The act provided matching grants to each state for Old Age Assistance (*OAA*) to retired workers. There was an effort to discourage folks from living in almshouses by refusing to make them

eligible for Social Security funds. This of necessity created an environment for privately owned and operated old-age facilities. People could reside in these private old-age homes and still receive Old Age assistance from the government. (P.B.S. Online News Hour 2012)

## **Nursing Homes**

In 1946 a law was passed which provided funding for the construction of state of the art hospitals. This law was called the Hospital Survey and Construction Act. This law has become commonly known as the Hill-Burton Act after its sponsors (Newman 2004).

States were required by law to develop licensing procedures for nursing homes as a result of further amendments to the Social Security Act. The amendments also made possible funding for health service providers by allowing residents of public facilities to receive government benefits (P.B.S. Online News Hour 2012).

1954 saw a huge change in federal law regarding nursing homes. Federal law provided grants for the construction of nursing homes. This would be done in cooperation with hospitals. This was an attempt to raise the quality of care for residents. Nursing home construction used hospital models in their construction designs. This was an important step forward because nursing homes made a huge transition from the welfare system to becoming part of the health care system. (P.B.S. Online News Hour 2012)

President Lyndon Johnson expanded the role of Social Security in 1965 to include provisions to care for the aged:

"Thirty years ago, the American people made a basic decision that the later years of life should not be years of despondency and drift. The result was enactment of our Social Security program. Compassion and reason dictate that this logical extension of our proven Social Security system will supply the prudent, feasible, and dignified way to free the aged from the fear of financial hardship in the event of illness."  
--President Johnson, July 30, 1965 (U.S. National Archives 1965)

The Medicare program was signed into law by President Lyndon B. Johnson on July 30, 1965. The ceremony took place in Independence, Missouri at the Truman Library (U.S. National Archives 1965).

This is important because up until this time, only about half of those who were sixty-five or older could afford health insurance. Regardless of income or medical history, those who were sixty-five and older would now receive guaranteed health care (Ibid).

Effort to improve nursing homes was made with the 1967 legislation known as the Moss Amendments. This legislation was passed in an effort to improve nursing homes by raising institutional standards. (Elderweb 2012) The Moss Amendments authorized the department of Health Education and Welfare (*HEW*) as it was named then, to standardize the regulations for the Medicare and Medicaid programs. It also had power to withhold funding from nursing homes that did not meet those standards (P.B.S. Online News Hour 2012).

The government standards and regulations were overly demanding and by 1971 most nursing homes were not able to comply. Relief came in the form of the Miller Amendment which offered states a new standard which became known as intermediate-care facilities (Ibid). This major change no longer required the former amount of skilled resources. This change reduced operating expenses of nursing homes and also the cost to the government. One downside was that it had the unintended effect of lowering the quality of care received by nursing home residents.

The Boren Amendment passed by Congress in 1981 was another step forward. It required the states to make sure that nursing homes received reasonable and adequate reimbursement rates providing care. The Federal legislation known as the Boren Amendment required states to ensure reasonable and adequate provider reimbursement rates (Thomson 2003).

A 1985 report by the Institute of Medicine on nursing home regulation became the basis for legislation contained in the Omnibus Reconciliation Act (*OBRA*) in 1987. This produced the largest overhaul of

federal regulations for nursing homes up to that point (Center for Gerontology and Health Care Research, Brown University 1999).

In 1997, after a period of particularly rapid growth in Medicare nursing home expenditures, the Balanced Budget Act cut the amount of money Medicare paid nursing homes. This also had an unintended effect. The reduction in funds provided by Medicare triggered the bankruptcy of four large nursing home chains. The Boren Amendment was repealed as a result (Haber 2012).

By the year 2000, nursing homes had become a 100 billion dollar a year industry. Nursing home related costs were largely paid by Medicaid and Medicare. Only 2 percent of all elderly individuals between sixty-five and seventy-four reside in such institutions. The proportion of those over eighty-five increased to 25 percent (Ibid).

### **Assisted Living Care**

Although the population has increased and people are living longer, a smaller percentage of the population is depending on nursing homes for care. According to the U.S. Bureau of the Census, slightly over 5 percent of the population who are sixty-five or older live in nursing homes, congregate care, assisted living and board-and-care homes. Only about 4.2 percent are in nursing homes at any given time. The rate of nursing home use increases with age from young to old from 1.4 percent of the young to 24.5 percent of the oldest. Almost 50 percent of those ninety-five and older live in nursing homes. (Breytspraak 2007)

One of the best definitions for assisted living can be found within Oregon's care philosophy. It states assisted living is a program that promotes resident self-direction and participation in decisions that emphasize choice, dignity, privacy, individuality, independence and homelike surroundings (Portland, OR Guide to Assisted Living 2012). Assisted living provides the best of both worlds to their residents. It offers the privacy and comforts of

home and also the necessary means to assisting in activities of daily living. Most residents of assisted living facilities need more supervision and assistance than can be received at home without outside support, but they do not require the intensive medical or custodial care that is provided in a skilled nursing facility (Ibid).

Assisted living facilities provide assistance with basic activities of daily living. They sometimes provide medical care for those who do not require the care of a skilled nursing facility. The trend in assisted living facilities is for more assistance with physical, occupational and speech therapy to help residents function at their highest capacity level (Assisted Living.org January).

Personal care, board homes, group homes and residential homes are included under the assisted living umbrella. These are smaller facilities which are privately owned and usually located in residential settings They do not require the staff an overhead of full blown assisted living facilities (Ibid).

### **Inception of the Modern Assisted Living Facility**

The concept of the modern assisted living facility came to the forefront in the 1970s. It became apparent that the setting of institutionalized nursing homes was becoming no longer acceptable for most aging seniors and their families. One huge reason for this was that advances in medicine were allowing seniors to age in place. They pushed back against placement in nursing homes and changes came (Assisted Living.org January).

### **Health, Housing and Hospitality**

Dr. Karen Brown Wilson's contribution to development of the concept of assisted living facilities was monumental. In the mid-1970s, Wilson's mother motivated her to take a stand for the frail and aging.

Custodial care was the main function of nursing homes at that time. Dr. Wilson examined the institutional attributes of nursing homes. She discovered a number of things which take away one of the most basic rights, the right to privacy. She identified shared bathrooms, communal showers and doors that could not be locked as basic inhibitors to personal privacy and affronts to personal dignity (Assisted Living.org January).

She wanted to devise a way to keep providing medical and daily care for older adults while also providing them with the dignity and respect they so deserved. Dr. Wilson told the Oregonian in 2010: “We basically combined what I call the three H’s: health, housing and hospitality.” (Ibid)

Dr. Wilson is affectionately known as the architect of the assisted living model. Park Place in Portland, Oregon was the first recognized assisted living facility in the nation. It opened its’ doors in 1981 (Ibid). Dr. Wilson said, “It did things that weren’t prohibited, but that weren’t popular at the time, like letting people have locks on their door.”

## **Growth of Assisted Living Facilities**

Assisted living facilities have grown to over 40,000 nationwide since 1981 (Assisted Living.org January). The top three states for assisted living are Minnesota, Virginia and Oregon with a combined total of 193 beds per 1,000 persons who are sixty-five and over (Ibid). West Virginia, Connecticut and Hawaii are the lowest with only Thirteen beds per 1,000 (Ibid).

The study also showed that the vast majority of assisted living facilities are located in wealthier and better educated areas and are less likely to be located in rural areas or those with minority populations. The author of the study, David Stevenson, believes this is simply due to the fact that most costs for residents who live in the assisted living facilities are paid by private resources (Ibid).

Between the mid-1990s and 2000, the number of assisted living facilities grew exponentially. From mom and pop private establishments to large corporate for-profit and not-for-profit establishments, assisted living

quickly became a mainstream option for aging adults. Companies like Presbyterian Homes, Genesis HealthCare and Heartland have paved the way for advances in assisted living (Ibid).

Independent Living communities provide housing for seniors who for all intents and purposes live independently as the name implies. Many of these communities consist of private homes or apartments and offer only minimal assistance with home maintenance. The underlying goal of many of these communities is to eliminate the social isolation that plagues many seniors as they become older (Ibid).

Assisted living facilities do not have to adhere to the same regulations that skilled nursing facilities are subject to. There are general rules that are usually passed down from the state level, but since many do not offer any type of medical care, they fall under the basic laws of rental homes (Ibid).

Assisted living facilities offer private or shared rooms. Some offer apartment or town home settings. They also offer a variety of indoor and outdoor senior mixing activities (Ibid).

Assisted living facilities differ from nursing homes because they appeal to seniors who do not need twenty-four hour supervision. These facilities also offer a great deal more freedom to their residents. They are able to live like they are still in their original homes (Ibid).

## **Residential Care Home**

Residential care homes, adult family homes, board homes and personal care homes are industry terms which describe another community of care providers. (Place for Mom 2000-2013)

Residential care homes offer a smaller, more home-like family setting for seniors. They offer food services and assistance with daily living. They typically do not have a medical professional on-site. Some limited, part-time medical care is offered, but it's not a primary focus of this type of senior living community (Ibid).

Care homes will normally have ten or less residents fostering a family like atmosphere. The setting is usually in residential neighborhoods in traditional houses/homes (Ibid).

One great appeal to care homes is the cost comparison with nursing homes and assisted living facilities. Living in a residential care home is often up to half the cost of the other two (Ibid).

Basic services offered in care homes (Ibid):

1. Comfortable private, or semi-private, rooms
2. 1-to-3 daily, home cooked meals
3. Housekeeping and laundry service
4. Medication management
5. Social programs and activities
6. Transportation to doctor's appointments

## **In Home Care**

In the year 2000, about 12,800 home health agencies served approximately 8,600,000 clients across the United States (Moyle 2012). In that year Medicare paid an estimated 85 to 90 percent of the total cost of home health agency services amounting to \$8,700,000,000 (Ibid). Although current 2012 figures are not yet available, the number of home health agencies has been going up year after year as well as the number of people being served.

Although home health agencies are privately owned, Medicare is the principle payer for their services. Home health services through Medicare are available under parts A and B. In order to qualify for Medicare homecare a person must have a skilled need, must be homebound and there must be a plan of care ordered by a Physician (Ibid). Prior to 1997 Medicare typically paid for home care for as long as it was needed. Prior to 1997 annual



Medicare costs were almost double the amount cited above. In order to save money Medicare has since gone to a prospective payment system where, according to the plan of care, a certain amount of money is allocated to resolve the skilled care need for the patient (Ibid). Monies are typically provided for a period of up to 60 days. If the patient recovers sooner, then money may have to be reshuffled to other patients who are not responding as well. At the point where the patient does not respond or improve, no more Medicare money is forthcoming. After Medicare funds are cut off, people who continue to need long-term care services must find sources other than Medicare (Ibid).

Home health agencies deliver a variety of skilled services outlined in FIGURE TWO below. The plan of care always includes well custodial services to help the care-recipient remain in his or her home. These would include an aide for an hour or two a day who would help with bathing, dressing and mobility transferring within the home. Other personal services may be offered as well if time will permit during the visits. These personal services are also covered by Medicare (Ibid).

Recently Medicare redefined what it means by homebound to allow recipients to leave home on a limited basis. Beginning in 2003 and ending in 2006, Medicare tested a small group with a program where selected home health agencies provided adult day health care instead of home health services. The program if successful would offer a new dimension in Medicare home care. In addition, under the new definition, Medicare will also allow and pay for home visits from doctors who specialize in homebound elderly patients. Limited office visits are also allowed under the new definition (Ibid).

Finally, in the past few years Medicare has begun paying for home telehealth visits through a home telehealth, computer work station. Telehealth is being used with some success to provide home care in rural areas where it

would be difficult to arrange the personal visit from a home health care agency (Ibid).

### What Services for The Elderly Are Provided by Home Health Agencies? (Percent of All Visits)

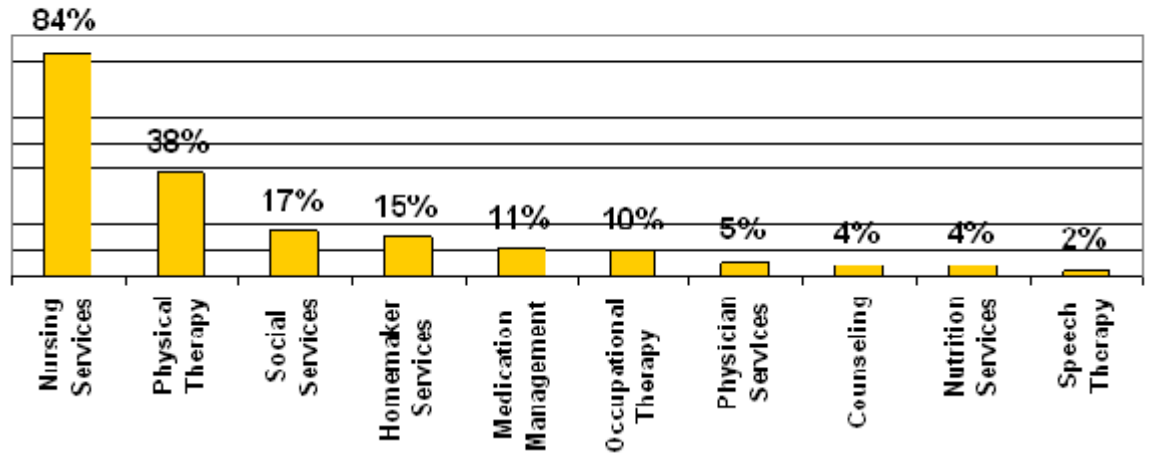


FIGURE TWO

Source: 2005 Statistical Abstract of the United States, Health and Nutrition

## Medical Reasons for Receiving Home Health Care (Percent of All Patients)

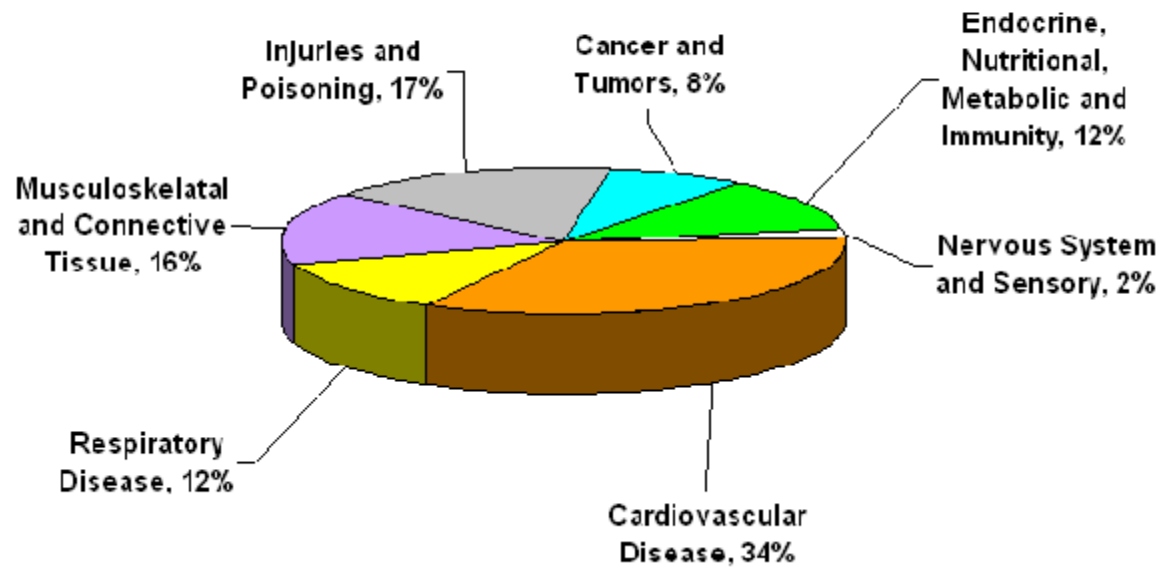


FIGURE THREE

Source: 2005 Statistical Abstract Of The United States, Health And Nutrition

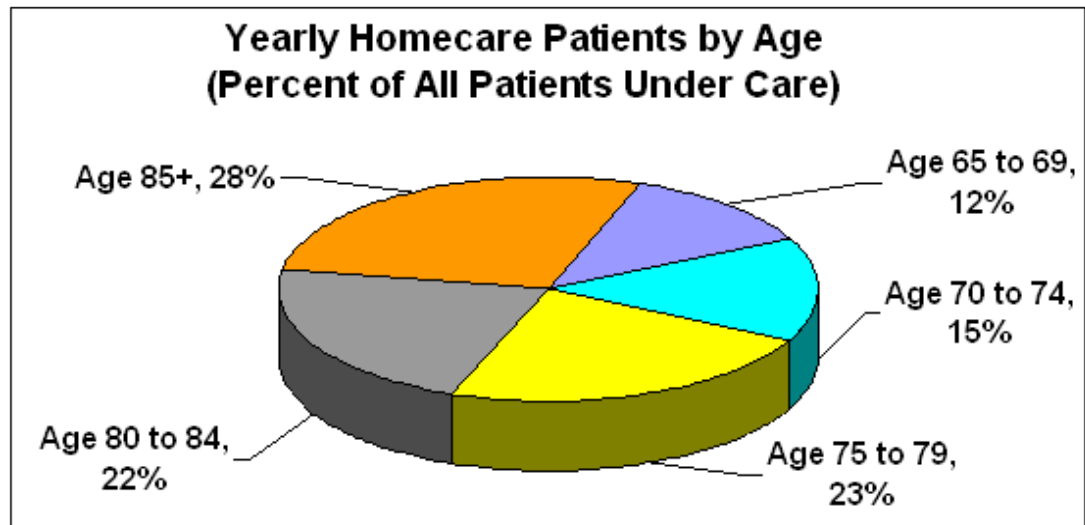


FIGURE FOUR

Source: 2005 Statistical Abstract of The United States, Health And Nutrition

Medicare will authorize up to sixty days of home care at a time, according to the Centers for Medicare and Medicaid Services. The average length of stay for Medicare home care services is 41.5 days. Many times a person continues to need supervision or care after Medicare ceases paying. The payment for the additional days has to come from a source other than Medicare. (Moyle 2012)

The number of home care patients, as a percent of all individuals in that age group, rises drastically with age (See FIGURE FOUR). Even though the age group of eighty-five and above represents only 4% of all the aged population, it accounts for about 28% of all patients. The bulk of the aged population is between the ages of sixty-five to seventy-five but only accounts for about 27% of all home care patients. Total patients for the aged over age seventy-five account for the other 73% (Ibid).

A common statement from individuals who are confronted with the need for long-term care planning is: "I'm in good health, I'm going to live a long time and I won't need long-term care." The facts show otherwise. In fact it is estimated that about half of the population over age eighty-five is receiving long-term care (Ibid).

Since about 90% of all home health agency care is paid for by Medicare or Medicaid, the cost of care is not absolutely necessary for this study but good to know (See FIGURE FIVE). This is important because some families do pay for this service out of their own pockets (Ibid).

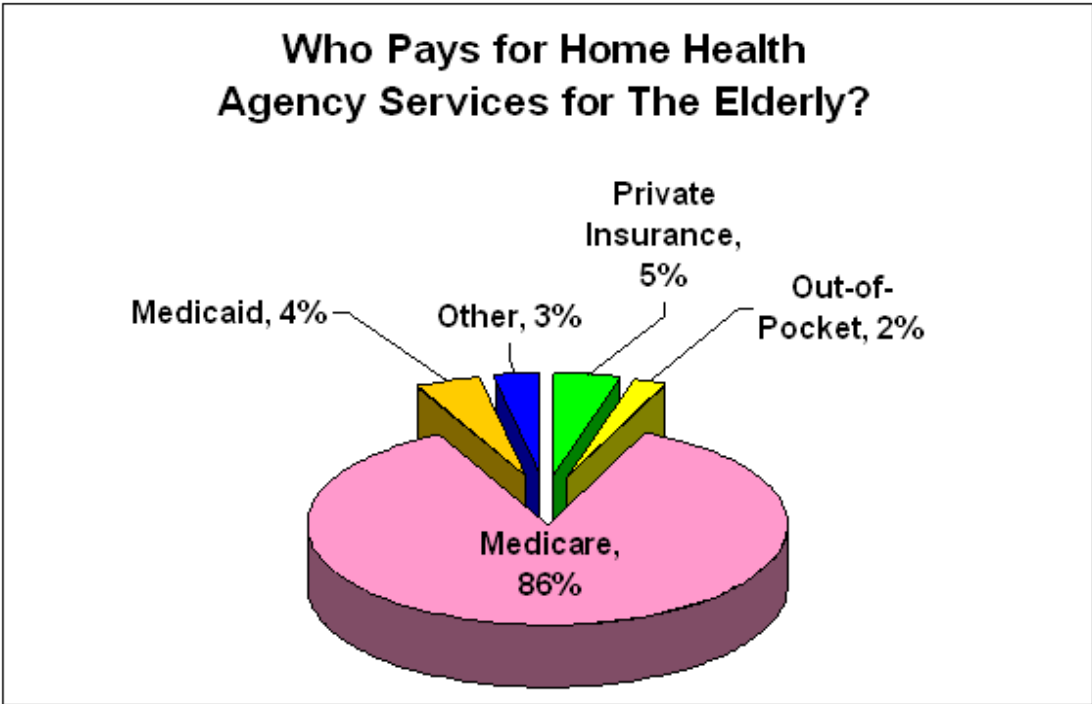


FIGURE FIVE

Source: 2005 Statistical Abstract Of The United States, Health And Nutrition

## **Live-In or Privately Hired Caregiver**

Most people would like their aged, debilitated or terminally ill family member to stay at home as long as possible. The care needed for these individuals can be overwhelming. When care requires twenty-four hour attention by the caregiver, one of the least expensive ways to secure the help needed is to employ someone to help in the home.

The research indicated that these providers do not typically have medical skills. Medical care by a nurse or therapist would also be hired from a home health agency (Moyle 2012).

The research showed this type of care, provided by a live-in caregiver, afforded the opportunity for the live-in-caregiver to have a place to live and this arrangement served as partial or even complete compensation for providing that care. Even without a living arrangement, a family hiring a caregiver not living with the care-recipient would normally spend considerably less than paying the cost of an aide from a home health agency (Ibid).

The research indicated that a major disadvantage of hiring somebody privately is ensuring this new employee is trustworthy and will provide the care needed. A wise step indicated by the research was to make sure the new caregiver is bonded to protect the family from theft. Also great care should be taken to investigate the person's background and history of employment.

A great outcome of this according to the research of this private care arrangement is that help can be found to allow a care-recipient to remain in the home for as long as possible. Ideally, that person could die in their home surrounded by loved ones in an atmosphere more supportive of a positive end-of-life experience. (Ibid)

## **Unpaid Volunteer Caregivers**

The research led back to when the term caregiver initially first began to be used in the early 1960s. The word caregiver was first used on a broad



scale in 1974. The term is comprised of two words; *care* a noun and *give* an agent noun. (Online Etymology Dictionary 2001-2012) Its' meaning originates from the word *caretaker* which was first used in 1858. The word caretaker is a combination of two words; *care* and *take*. The Old English words *caru*, *cearu* (which mean care, concern, anxiety, sorrow and grief) and *carian* (to sorrow, grieve, and be troubled or anxious) produced the Middle English words *caren*, *carien* which eventually became the 1858 word *care*. (National Council of Science Editors 2013) The relative general definition in the twenty-first century is a person who provides direct care for children, elderly people or the chronically ill. (Encyclopedia Britannica 2013)

Thus the caregiver is one who provides care for others, passing through well-defined periods of caregiving, while experiencing a variety of emotions. Investigating caregiver transition through the grieving process of necessity requires the exploration of the periods of care experienced by care recipients. It further requires exploration of the emotions and feelings encountered by the caregiver.

Research discovered that unpaid family caregivers span all racial and sociological lines. Almost one third of American households or 65.7 million provide some form of care (National Alliance for Caregiving 2009). A study conducted interviews with 1,480 caregivers in the U.S. The study was funded by the MetLife Foundation and conducted for the National Alliance for Caregiving in collaboration with AARP by Mathew Greenwald & Associates and is based on interviews with 1,480 caregivers who were chosen at random and provides a good overall description of caregivers in America (Ibid). Among the findings: American caregivers are predominantly female (66%) and are an average of 48 years old. By 2012 the average age had climbed to 49.4 years old. Most care for a relative 86%, most often a parent 36%. Seven out of ten caregivers provide care for someone over age fifty. One in seven caregivers provides care, over and above regular parenting, to children with special needs. Caregiving lasts an average of 4.6 years (Ibid).

65.7 million caregivers make up 29% of the U.S. adult population providing care to someone who is ill, disabled or aged (National Alliance for Caregiving and AARP 2009). 52 million caregivers provide care to adults aged eighty years old and older with disabilities or illnesses (Coughlin 2010).

43.5 million care for someone fifty years of age or older (National Alliance for Caregiving and AARP 2009). 14.9 million provide care for someone who has Alzheimer's disease or other dementia (Alzheimer's Association 2011). Lesbian, Gay, Bisexual and Transgender (LGBT) respondents are slightly more likely to have provided care to an adult friend or relative in the past six months: 21% vs. 17% non-LGBT (MetLife 2010).

Caregivers of adults are now older, on average, than were their counterparts in 2004. Their average age now 49.2 years in 2012, compared to 46.4 in 2004 (Ibid).

## **Gender of Caregivers**

More women than men are caregivers. An estimated 66% of caregivers are female according to the National Alliance for Caregiving. One-third or 34% take care of two or more people (National Alliance for Caregiving and AARP 2009).

Research suggests that the number of male caregivers may be increasing and will continue to do so due to a variety of social demographic factors (Thompson 2002). Caregivers who provide care for eighteen to forty-nine year-old care recipients are nearly half male 47%. Among the fifty and older recipients of care, more females provide care at 78% female and 22% male (Ibid).

Research indicated that men may be sharing in caregiving tasks more than in the past, but women still shoulder the major burden of care. For example, while some studies show a relatively equitable distribution of caregiving between men and women, female caregivers spend more time providing care than men do 21.9 vs. 7.4 hours per week (Ibid). However,

among spousal caregivers seventy-five and older, both sexes provide about equal amounts of care (L.A. Beckett 2000).

Other studies have found that 36% of women caregivers handle the most difficult caregiving tasks such as bathing, toileting and dressing, when compared with 24% for their male counterparts, who are more likely to help with finances, arranging care and other less burdensome tasks (National Alliance for Caregiving and AARP 2009). A number of studies have found that female caregivers are more likely than males to suffer from high stress due to caregiving 35% vs. 25% (Ibid).

Men and women in both populations are likely to be caregivers in near equal proportions: 20% men vs. 22% women in the LGBT group, and 17% men vs. 18% women in the general population sample. Male caregivers report providing more hours of care than female caregivers: the average weekly hours of care provided by women from both the LGBT and general population samples is similar—26 vs. 28 hours—but LGBT men provide far more hours of care than men from the comparison sample: forty-one hours vs. twenty-nine hours. This reflects that about 14% of the gay men indicate that they are full-time caregivers, spending over 150 hours per week in this capacity, compared to 3% of the lesbian and 2% of the bisexual respondents (MetLife 2010).

## **Ethnicity**

Ethnicity in the research suggested that rates of caregiving vary somewhat by ethnicity. Among the caregiving U.S. adult population eighteen and over, approximately 72% are white and 13% are African-American (Ibid). The percentage in the Hispanic community is only slightly lower at 12% and 2% for Asian-Americans (Ibid). These African-American, Asian-Americans and Hispanic caregivers were eighteen years of age and older and provided assistance to someone fifty or older. (Alzheimer's Association 2011) African-American caregivers on average were younger than other races represented forty-eight years and were more likely to be single or never have

married at 28% vs. the overall caregiver average of 5% of their Caucasian counterparts at 12% (Ibid).

The research showed that 27% of Hispanic caregivers indicate their health is fair or poor compared to 15% for white caregivers and 15% for Asian-Americans (Ibid). More than half of African-American caregivers find themselves being divided between caring for an older person, providing basic necessities for a younger person under age eighteen and providing care for more than one older person. African-American caregivers are also more likely to live with the care recipient and spend an average of 20.6 hours-per-week providing care. In addition, 66% of African-American caregivers are employed full or part-time (Ibid).

Ethnic differences also surfaced in the research which found that 41% African-American caregivers were more likely to provide help with more than three activities of daily living for care recipients than Caucasian caregivers at 28% or Asian-American caregivers at 23%. Activities of daily living included getting in and out of bed, dressing, feeding, managing incontinence or getting to and from the toilet (Alzheimer's Association 2011).

### **Household Income**

The following household income for unpaid caregivers is generally accurate according to the research (Coughlin 2010).

1. 22% of unpaid caregivers' median household income was under thirty-thousand dollars per year.
2. Income between thirty thousand to fifty thousand dollars was 18%.
3. Household income from fifty to just under one hundred thousand dollars was 32%.
4. Those with one hundred thousand or more at 19%. 9% did not respond to the survey.

## **Employment Status of Unpaid Caregivers**

According to the research the employment status of unpaid caregivers was as follows (Coughlin 2010)

1. Those who were still working and providing care numbered 57%.
2. Those who were retired made up 15% of unpaid caregivers.
3. 10% were homemakers.
4. Unemployed, disabled or students made up another 17% of unpaid caregivers.

## **Economic Impact of Caregiving**

Caregiver services were valued at \$450 billion per year in 2009—up from \$375 billion in 2007 (AARP Public Policy Institute 2011) . Unpaid family caregivers will likely continue to be the largest source of long-term care services in the U.S. The aging population of sixty-five and older will more than double between the years 2000-2030, increasing to 71.5 million in 2030 from 35.1 million in 2000. (Coughlin 2010)

## **Stages of Patient Care**

To understand the periods of transition of caregiving through the grieving process a sampling of illnesses requiring care from unpaid caregivers should be explored. Research indicated that terminally ill or debilitated patients pass through a number of stages, periods or phases of gradual decline which require care by the caregiver. These stages, periods or phases will differ in length and severity based on the particular illness. It is a given that each patient is unique and the findings are therefore not absolute but the medical community would generally agree on the general descriptions of the stages, periods or phases.

## Exemplified Diseases

**Alzheimer's Disease** - According to the Mayo Clinic medical staff, Alzheimer's disease can last more than a decade (Mayo Clinic Staff 2013). They also describe the disease's behaviors which are common with the disease and divide them into three easy to remember stages; mild, moderate and severe.

These are described as follows (Ibid):

1. **MILD Alzheimer's** - Alzheimer's disease is often first diagnosed in the mild or early stage, when it becomes clear to family and doctors that a person is having significant trouble with memory and thinking. In the MILD Alzheimer's stage, people may experience:
  - a. Memory loss for recent events. Individuals may have an especially hard time remembering newly learned information and repeatedly ask the same question.
  - b. Difficulty with problem solving, complex tasks and sound judgments. Planning a family event or balancing a checkbook may become overwhelming. Many people experience lapses in judgment, such as when making financial decisions.
  - c. Changes in personality. People may become subdued or withdrawn, especially in socially challenging situations, or show uncharacteristic irritability or anger. Decreased attention span and reduced motivation to complete tasks also are common.
  - d. Difficulty organizing and expressing thoughts. Finding the right words to describe objects or clearly express ideas becomes increasingly challenging.
  - e. Getting lost or misplacing belongings. Individuals have increasing trouble finding their way around, even in familiar places. It's also common to lose or misplace things, including valuable items.

2. MODERATE Alzheimer's - During the moderate, or middle, Alzheimer's stage, people grow more confused and forgetful and begin to need help with daily activities and self-care. People with moderate Alzheimer's disease may:
  - a. Show increasingly poor judgment and deepening confusion. Individuals lose track of where they are, the day of the week or the season. They often lose the ability to recognize their own belongings and may inadvertently take things that don't belong to them. They may confuse family members or close friends with one another, or mistake strangers for family. They often wander, possibly in search of surroundings that feel more familiar and right. These difficulties make it unsafe to leave those in the moderate Alzheimer's stage on their own.
  - b. Experience even greater memory loss. People may forget details of their personal history, such as their address or phone number, or where they attended school. They repeat favorite stories or make up stories to fill gaps in memory.
  - c. Need help with some daily activities. Assistance may be required with choosing proper clothing for the occasion or the weather and with bathing, grooming, using the bathroom and other self-care. Some individuals occasionally lose control of their urine or bowel movements.
  - d. Undergo significant changes in personality and behavior. It's not unusual for people with moderate Alzheimer's to develop unfounded suspicions for example; to become convinced that friends, family or professional caregivers are stealing from them, or that a spouse is having an affair. Others may see or hear things that aren't really there.
  - e. Individuals often grow restless or agitated, especially late in the day. People may have outbursts of accusing, threatening or

cursing. Others may bite, kick, scream or attempt inappropriate sexual activity.

3. SEVERE Alzheimer's - In the severe or late stage of Alzheimer's, mental function continues to decline and the disease has a growing impact on movement and physical capabilities. In severe Alzheimer's, people generally:
  - a. Lose the ability to communicate coherently. An individual can no longer converse or speak coherently, although he or she may occasionally say words or phrases.
  - b. Require daily assistance with personal care. This includes total assistance with eating, dressing, using the bathroom and all other daily self-care tasks.
  - c. Experience a decline in physical abilities. A person may become unable to walk without assistance, then unable to sit or hold up his or her head without support. Muscles may become rigid and reflexes abnormal. Eventually, a person loses the ability to swallow and to control bladder and bowel functions.

The rate of progression for Alzheimer's disease varies widely. Alzheimer's tends to progress more slowly in those who are diagnosed at a younger age and in those who don't have other serious health issues. On average, people with Alzheimer's disease live four to six years after diagnosis, but some survive as long as twenty years (Ibid).

Research revealed an expanded seven stage framework of the course of the disease by Dr. Barry Reisberg (Reisberg 2012). Dr. Reisberg is clinical director of the New York University School of Medicine's Silberstein Aging and Dementia Research Center. Not everyone will experience the same symptoms or progress at the same rate.



The stages are listed below (Ibid).

1. Stage I - No impairment, normal function. The person does not experience any memory problems. An interview with a medical professional does not show any evidence of symptoms of dementia.
2. Stage II – Very mild cognitive decline. May be normal age-related changes or earliest signs of Alzheimer's disease. The person may feel as if he or she is having memory lapses, forgetting familiar words or the location of everyday objects. But no symptoms of dementia can be detected during a medical examination or by friends, family or co-workers.
3. Stage III – Mild cognitive decline. Early-stage Alzheimer's can be diagnosed in some, but not all, individuals with these symptoms. Friends, family or co-workers begin to notice difficulties. During a detailed medical interview, doctors may be able to detect problems in memory or concentration. Common Stage III difficulties include:
  - a. Noticeable problems coming up with the right word or name.
  - b. Trouble remembering names when introduced to new people.
  - c. Having noticeably greater difficulty performing tasks in social or work settings.
  - d. Forgetting material that one has just read.
  - e. Losing or misplacing a valuable object.
  - f. Increasing trouble with planning or organizing.
4. Stage IV – Moderate cognitive decline. Mild or early-stage Alzheimer's disease. At this point, a careful medical interview should be able to detect clear-cut symptoms in several areas. Forgetfulness of recent events. Impaired ability to perform challenging mental arithmetic for example. Counting backward from one hundred by sevens. Greater difficulty performing complex tasks, such as planning dinner for guests, paying bills or managing finances. Forgetfulness about one's own personal history. Becoming moody or withdrawn, especially in socially or mentally challenging situations.

5. Stage V – Moderately severe cognitive decline. Moderate or mid-stage Alzheimer's disease. Gaps in memory and thinking are noticeable and individuals begin to need help with day-to-day activities. Those with Alzheimer's at this stage may: Be unable to recall their own address or telephone number or the high school or college from which they graduated. Become confused about where they are or what day it is. Have trouble with less challenging mental arithmetic; such as counting backward from forty by subtracting fours or from twenty by twos. Need help choosing proper clothing for the season or the occasion. Still remember significant details about themselves and their family. Still require no assistance with eating or using the toilet.
6. Stage VI – Severe cognitive decline. Moderately severe or mid-stage Alzheimer's disease. Memory continues to worsen, personality changes may take place and individuals need extensive help with daily activities. At this stage, individuals may: Lose awareness of recent experiences as well as of their surroundings. Remember their own name but have difficulty with their personal history. Distinguish familiar and unfamiliar faces but have trouble remembering the name of a spouse or caregiver. Need help dressing properly and may, without supervision, make mistakes such as putting pajamas over daytime clothes or shoes on the wrong feet. Experience major changes in sleep patterns, sleeping during the day and becoming restless at night. Need help handling details of toileting for example, flushing the toilet, wiping or disposing of tissue properly. Have increasingly frequent trouble controlling their bladder or bowels. Experience major personality and behavioral changes, including suspiciousness and delusions such as believing that their caregiver is an impostor or compulsive, repetitive behavior like hand-wringing or tissue shredding. Tend to wander or become lost. Remember that it is

difficult to place a person with Alzheimer's in a specific stage as stages may overlap.

7. Stage VII – Very severe cognitive decline. Severe or late-stage Alzheimer's disease. In the final stage of this disease, individuals lose the ability to respond to their environment, to carry on a conversation and eventually to control movement. They may still say words or phrases. At this stage, individuals need help with much of their daily personal care, including eating or using the toilet. They may also lose the ability to smile, to sit without support and to hold their heads up. Reflexes become abnormal. Muscles grow rigid. Swallowing impaired.

**Cancer Disease** – There are so many different types of cancer with varying symptoms and long term implications that it would require a separate in-depth study to adequately examine the subject matter. The research for this present thesis suggests that a simple explanation of the accepted scientific model of stages of cancer is appropriate. The Cancer Research Center of the UK, along with most authorities on the subject, suggests that most types of cancer have 4 stages which are numbered from one to four (Cancer Research Center 2012). Often doctors write the stage down in roman numerals.

Sometimes doctors talk about stage zero cancer, for example in skin cancer. Stage zero is also called carcinoma- in-situ. It means that there are cancerous cells present, but they are contained within the tissue they developed in (Ibid). They haven't broken through the basement membrane, which means they can't spread through the bloodstream, the lymphatic system or into other nearby tissues. Doctors may also describe this as a non-invasive cancer (Ibid).

Here is a brief summary of the stages and what they mean for most types of cancer (Cancer Research Center 2012).

1. Stage I usually means the cancer is relatively small and contained within the organ it started in.
2. Stage II usually means the cancer has not started to spread into surrounding tissue, but the tumor is larger than in stage I. Sometimes stage II means that cancer cells have spread into lymph nodes close to the tumor. This depends on the particular type of cancer.
3. Stage III usually means the cancer is larger. It may have started to spread into surrounding tissues and there are cancer cells in the lymph nodes in the area.
4. Stage IV means the cancer has spread from where it started to another body organ. This is also called secondary or metastatic cancer.

**Multiple Sclerosis Disease** – Multiple Sclerosis by its very nature affects each person differently. As an example, generally the younger the person is, the less likely they are to suffer with prolonged symptoms and generally make a quicker recovery when symptoms first appear. Generally people with Multiple Sclerosis will progress through each stage of the disease. However, some people may never progress through all four stages and may stop during the first or second stage (Turner 2009).

1. The first stage is called Benign. This first stage of multiple sclerosis occurs in approximately 20% of people. It consists of only two symptoms, which neither has long lasting effects or disability. Some people may never exhibit any symptoms and thus they may never get diagnosed with Multiple Sclerosis unless it progresses into the next stage. However even though the symptoms can be the same as full blown early Multiple Sclerosis, there is usually a full recovery with no further problems (Ibid).
2. The second stage is also very common and is called the relaxing/remitting stage. A person may live within this relaxing/remitting stage for many years and in some cases it may even

stay in this stage for the rest of their life although this usually uncommon. This stage is characterized by occasional symptoms and attacks more commonly referred to as relapses or exacerbations. The symptoms are typically optic neuritis, speech problems or muscle spasticity (Ibid).

3. The third stage of multiple sclerosis can be split up into two categories. These categories are primary progressive and secondary progressive. The first category, primary progressive, is slow but steady stream of symptoms such as loss of motor functions and difficulty walking which ultimately can lead to disability. However in secondary progressive the progression of MS is somewhat quicker and has less time between the relapses and the recovery. This is a more permanent disability because of the continued attacks from the lesions (Ibid).
4. The last stage of Multiple Sclerosis is the progressive/relapsing. This last stage of Multiple Sclerosis is very similar to primary progressive however it is far more damaging. The amount of disability is increased because of the exacerbations which cause more permanent damage that cannot be repaired. The functions that are lost due to this stage of Multiple Sclerosis are never recovered. A consequence of these losses is that the mortality rate is high (Ibid).

**Stroke** – A stroke is the sudden death of brain cells due to lack of oxygen. Research described strokes as usually two types: Ischemic which is caused by a blockage in an artery or Hemorrhagic which is caused by a tear in the artery's wall that produces bleeding into or around the brain ( American Accreditation HealthCare Commission 2010). The consequences of a stroke, the type of functions affected and the severity, depend on where in the brain it has occurred and the extent of the damage it has caused.

Stroke recovery occurs in two stages (WiseGeek 2012). The first stage is acute recovery and the second is long-term rehabilitation. Each stage

is an important part of the stroke recovery process and working hard through the entire process ensures the best chance of regaining skills damaged during the stroke. The length of time that it takes to recover from a stroke depends on the extent of the damage by the stroke, the skill of the rehabilitation team and the willingness of the stroke victim and family to work on rehabilitation (Ibid).

Eventually the progress slows according to research, and the stroke patient may become frustrated. It is important that the stroke recovery program continue. Although progress will slow, it will continue. 10% of stroke victims will recover almost completely. An additional 25% will recover with only minor physical or mental impairments. (Ibid)

To become one of the 35% of people who are able to regain a good portion of their lives after suffering from a stroke, research emphasized how important it is to continue with all prescribed therapy. Physical and occupational therapists will help the stroke patient regain as much mobility as possible and then show them how to compensate for any lost skills (Ibid). A speech therapist works to help the patient regain as much speech as possible, and then refine those skills so that they can communicate with others. (Ibid)

If insurance stops paying for stroke recovery, the rehabilitation team deems it nonproductive to continue, the stroke patient can continue to work on their own. Nearly all rehabilitation efforts focus on the directed and highly focused practice of skills. The key to regaining lost skills is repetition. Endless repetitions of lost skills will eventually help the brain rewire itself so that the function can become automatic (Ibid).

During the initial acute recovery stage, the rehabilitation team will encourage the stroke victim to move as much as possible. They will engage in what is known as passive movement. During passive movement, a therapist or nurse physically moves body parts that the stroke patient is

unable to move on their own. If speech was affected by the stroke, speech therapy will also begin very early on. This rehabilitation begins as soon as the patient is stabilized from the stroke, ideally within twenty-four hours. (Ibid)

The second phase of stroke recovery involves intensive therapy. This therapy can last for weeks, months or years. During the initial days of therapy, the improvements to a patient typically occur rapidly. This rapid improvement provides the patient incentive to continue with his stroke recovery program. (Ibid)

**Amyotrophic Lateral Sclerosis (ALS)** – Lou Gehrig’s Disease is the name most generally associated with ALS.

Six Stages and symptoms of ALS according to the research were as follows (Physical Therapy 1998):

1. Stage I - Early disease, mild focal weakness, asymmetrical distribution symptoms of hand cramping and fasciculation LMN signs.
2. Stage II - Moderate weakness in groups of muscles some wasting (atrophy) of muscles modified independence with assistive devices.
3. Stage III - Severe weakness of specific muscles, increasing fatigue mild to moderate functional limitations, ambulatory
4. Stage IV - Severe weakness and wasting (atrophy) of les mild weakness of UEs, moderate assistance assistive devices required, wheelchair user (Ibid).
5. Stage V - Progressive weakness with deterioration of mobility and endurance, increased fatigue, moderate to severe weakness of whole limbs and trunk spasticity; hyper-reflexia (UMN signs); loss of head control maximal assist.
6. Stage VI - Bedridden, dependent ADL, FMS progressive respiratory distress.

## **General Description Other Debilitating Diseases**

**Muscular dystrophies:** A group of related and inherited disorders that contribute to muscle loss and weakness over time. Each type of Muscular dystrophy can affect children and adults, though the most severe forms usually occur in early childhood. There is no cure for these diseases, making their debilitating effects even more upsetting. The effects can target all muscles or just a group of muscles in the body, causing severe decreases in mobility, lung failure, scoliosis, cardiac fibrosis and tightening of muscles around main joints that cause complications that lead to death. (Health Executive News 2012)

**Cerebral Palsy** - There are several different types of cerebral palsy which affect the functions of the brain and nervous system. The cause for this disease is abnormalities or injuries to the brain during fetal development and also can occur up to the age of two years, when brains are still developing. There are several different types of this disease: spastic, dyskinesia, ataxic, hypotonic and mixed with symptoms ranging from mild to severe. These symptoms include muscle tightening, tremors, speech problems, slow growth and problems swallowing. There is no cure for cerebral palsy, though there are treatment plans that include therapies, surgeries or even medications to help lessen the severity of symptoms. Long-term care is usually required as this is a life-long, debilitating disease. (Ibid)

**Cystic Fibrosis** – The cause of this disease stems from a defective gene that causes the creation of thick mucus in the lungs and pancreas, leading to life-threatening breathing problems, lung infections and digestive problems. If caught early, a treatment plan can be formulated to help lessen symptoms and improve the rate of survival. Treatments usually include antibiotics, oxygen therapy and sometimes even lung transplants, along with healthy lifestyle changes. Most children diagnosed with this disease lead relatively normal lives and can go through school and college with little or no



interruptions to their daily routines. Later, however, the lung disease eventually worsens. Life expectancy is age thirty-seven (Ibid).

### **Caregiver Support**

The research indicated a number of support avenues for unpaid caregivers. These include secular and religious resources.

**Secular Resources** - The internet offers a path to many available supporting organizations and services. The research found that there are secular support groups available for most caregivers and caregiving situations. These are discussed more fully in Chapter Four.

**Religious Resources** – The research indicated a number of religious support resources available to caregivers. These are also discussed more fully in Chapter Four.

## **CHAPTER III: THE PROCESS OF CARE GIVING**

### **Introduction**

Care needed by those who are suffering with debilitating or terminal illnesses is a process that can last for days, months and even years. The major portion of care is provided by unpaid volunteer caregivers. The care provided by caregivers is of tremendous value. Caregiving is impacted by many factors. Exploring the characteristics, responsibilities and relationships of caregivers will better aid in understanding the feelings and needs of caregivers. Also understanding the overall periods of care provided by caregivers will help caregivers, family of caregivers, healthcare professionals, community and religious organization with awareness of caregiver needs. This may be best understood by dividing the overall caregiving role into periods of care. These periods are often called stages of care. These stages vary in number and required care depending on the physical or mental illness.

### **Unpaid Family Caregivers**

We observed through the earlier research that about one in three adults in the United States provide unpaid care to someone who is ill, disabled or elderly. (National Alliance for Caregiving and AARP 2009). Over fifty-two million caregivers provide care for adults who are eighteen years or older (Coughlin 2010) with a large percentage providing care for those who are fifty years old or older (Ibid).

Caregivers of adults are now older on average than were their counterparts in 2004, with their average rising from 46.4 years old to a little over 49 in 2012 (MetLife 2010).

Research has shown that caregiver services were valued at \$450 billion per year in 2009, the last estimate available, which is up from \$375

billion in 2007 (AARP Public Policy Institute 2011). Unpaid family caregivers will likely continue to be the largest source of long-term care services in the U.S. We learned in earlier research that those who are sixty-five and older will more than double by 2030, increasing to 71.5 million from 35.1 million in 2000 (Coughlin 2010).

## **Gender of Caregivers**

We learned that more women than men are caregivers with an estimated 66% of caregivers are female. We also learned that about one-third or 34% take care of two or more people and the average age of a female caregiver is 49.2 years (National Alliance for Caregiving and AARP 2009).

Research suggests that the number of male caregivers may be increasing and will continue to do so due to a variety of social demographic factors (Thompson 2002). Caregivers who provide care for ages eighteen to forty-nine year-olds care recipients are nearly half men at 47%, while more women care for the fifty and older recipients at 68% women compared to 32% male (Ibid).

Men are sharing in caregiving tasks more than in the past, but women still provide the majority of care. We learned that female caregivers spend more time providing care than men do with women spending about twenty-two hours per week and men about seventeen and a half (Ibid). Men and women, who cared for their spouses seventy-five or older, provide equal amounts of care (L.A. Beckett 2000).

36% of women caregivers handle the most difficult caregiving tasks such as bathing, toileting and dressing, while 24% of men caregivers are more likely to help with finances, arranging care and less burdensome tasks (National Alliance for Caregiving and AARP 2009).

We learned that a higher percentage of women caregivers suffer from high stress due to caregiving than men with 35% of women and 25% of men (Ibid).

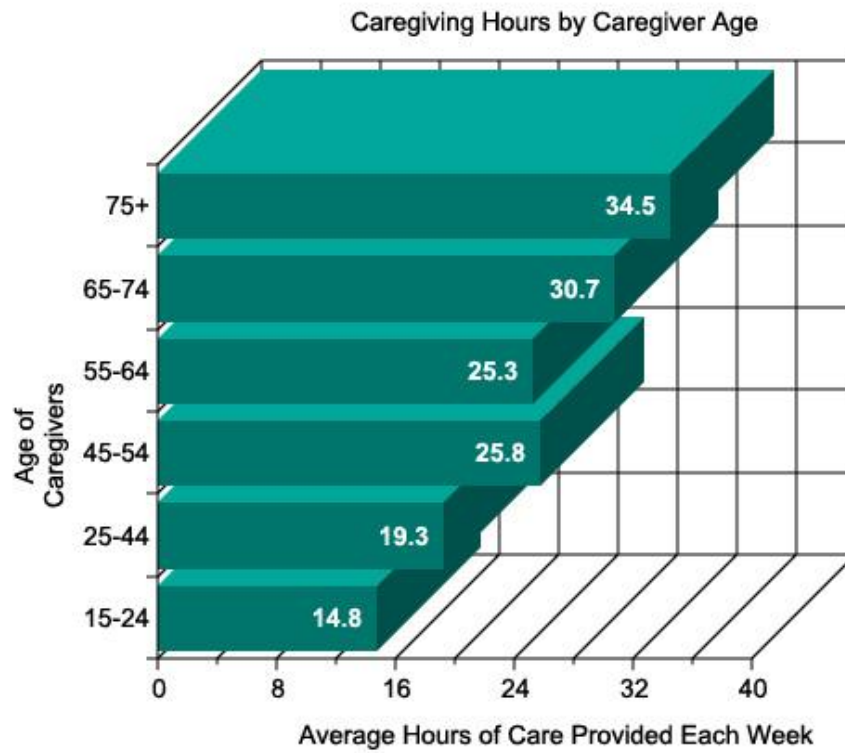
## **Ages of Caregivers**

Caregivers are at several age levels, but the average caregiver is a little over forty-nine years old with about half or 51% between eighteen and forty-nine (National Alliance for Caregiving and AARP 2009).

The research suggested that older caregivers are more likely to care for a spouse or partner than middle-aged or younger caregivers with 25% being older, 4% middle-aged and 1% younger caregivers (Ibid).

The age span of family caregivers providing care for fifty year olds or older is fifty to sixty-four years old (Ibid). The average age of those caring for someone sixty-five or older is sixty-three years old with about one third of those are in fair to poor health (Administration on Aging 2011). Our research shows the number of hours dedicated to caregiving increases with the age of the caregiver.

About half of those who receive care are seventy-five years old or younger with almost one-third who are under age of fifty (National Alliance for Caregiving and AARP 2009).



Partnership for Solutions. (2004). *Chronic Conditions: Making the Case for Ongoing Care*. Johns Hopkins University, Baltimore, MD. (2004)

**FIGURE SIX**

## **Caregiver Transition**

### **Caregiver and Care Recipient Relationships**

The percentage of caregivers, caring for individuals over eighty-five years old, has increased across all three National Alliance for Caregiving and AARP's national surveys of informal caregivers conducted in 1997, 2004 and 2009 (Tagai 2010). Caring for parents is the primary caregiving situation for mid-life caregivers with 70% of caregivers who are between the ages of fifty and sixty-four (Ibid).

Caring for a spouse is the most commonly reported care situation for caregivers over seventy-five years of age.

We learned that a good number of people in this age group are involved in caring for:

1. A friend or non-relative 20%.
2. A parent 20%.
3. A sibling 18%.

This is likely a factor in older adults relying on peers for the help they need (Ibid).

Most of those who are receiving care, about 58%, live in their own and about one in five or 20% live in their caregiver's home (Ibid).

Residency of Care Recipients (National Alliance for Caregiving and AARP 2009)

1. 47% Live alone.
2. 28% Live with Spouse.
3. 13% Lives with Grown Children.

The close relationship between the caregiver and care recipient is a shared relationship with involved emotions, experiences, and memories, which can place a caregiver at higher risk for psychological and physical illness. (Alzheimer's Association 2011)

A 2009 survey reports that 86% of caregivers care for a relative, with 36% caring for a parent and 14% caring for their own child. The typical care

recipient is a female at sixty-one years of age. (National Alliance for Caregiving and AARP 2009)

Care Recipient's Relation to Caregiver (Ibid)

- 1. Relative ..... 86%
- 2. Parent .....36%
- 3. Child .....14%
- 4. Grandparents .....8%
- 5. Spouse/Partner .....5%
- 6. Grandchild .....3%
- 7. Friend .....11%
- 8. Neighbor .....1%

**Caregiver Employment**

Research indicated that about six out of ten caregivers were employed at some time during the last twelve months while still providing care for a relative or friend (National Alliance for Caregiving and AARP 2009).

The majority of adult caregivers are employed. 74% of caregivers were employed while taking care of a relative or friend (Ibid).

The Employment Status of all unpaid caregivers (Ibid).

- 1. Employed full-time .....50%
- 2. Employed part-time .....11%
- 3. Retired .....17%
- 4. Not employed .....5%

Caregiver work related difficulties (Ibid).

- 1. 70% of working caregivers suffer work-related difficulties due to their dual caregiving roles.
- 2. 69% report having to rearrange their work schedule, decrease their hours or take an unpaid leave in order to meet their caregiving responsibilities...
- 3. 5% turn down a promotion.
- 4. 4% choose early retirement.

5. 6% give up working entirely (Ibid).

Difficulties due to work and caregiving are even more challenging among those caring for someone with dementia (AARP 2009).

Working women caregivers suffer high levels of economic hardship due to their caregiving. Female caregivers are more likely than males to have made alternative work arrangements. Examples (Ibid):

Economic hardship created for caregivers (Ibid):

1. Took a less demanding job -16% females vs. 6% males.
2. Gave up working entirely - 12% females vs. 3% males.
3. Lost job related benefits - 7% females vs. 3% males.
4. Women who had assumed caregiver roles during their working years were 2.5 times more likely to live in poverty when they became elderly compared to women who had not been caregivers during their lifetimes (National Alliance for Caregiving and AARP 2009).

Research revealed that 20% of employed female caregivers over fifty reported symptoms of depression compared to 8% of their non-caregiving peers (MetLife 2010). Caregiving reduces work productivity by 18.5% and increases the likelihood of leaving the workplace (Coughlin 2010).

The 2008 economic downturn create a harsh impact on the working family caregiver. Six in ten caregivers felt less comfortable with risking taking time off from work to care for a family member or friend. About half expressed added stress caused by their need to care for a loved one when faced with increased work challenges (National Alliance for Caregiving and AARP 2009).

Employed family caregivers were less willing than non-caregivers to risk taking time off from work. 50% sought additional jobs. 33% sought to return to the work force in order to cover mounting caregiving costs (AARP Public Policy Institute 2011).



## **Time Spent in Caregiving**

We learned from the research that caregivers spend 20.4 hours per week providing care. Those who live with their care recipient spend 39.3 hours per week caring for that person. Those caring for a child under eighteen spend 29.7 hours per week (National Alliance for Caregiving and AARP 2009).

Older caregivers, who are sixty-five and older, provide approximately thirty-one hours in an average week of care while middle aged caregivers report spending about nineteen hours per week. About 33% of older caregivers bathe and shower their care recipients while about 22% of younger caregivers perform these tasks (Ibid).

14.9 million families and other unpaid caregivers of people with Alzheimer's disease and other dementias provided about 17 billion hours of unpaid care in 2010 (Alzheimer's Association 2011). This represents an average of 21.9 hours of caregiving per week or 1,139 hours of care per caregiver. This care was valued annually at \$11.93 per hour or an estimated \$202.6 billion in 2010 (Ibid).

## **Years Providing Care**

We learned from research the following insight about the duration of the role of caregivers (Ibid):

1. Three out of ten caregivers spend less than one year providing care.
2. One out of three caregivers or 34% provide care from one to four years.
3. The average caregiver spends 4.6 years in the role of caregiver.
4. About three in ten or 31% of caregivers have provide care for five years or more

5. Less than two in ten or about 15% of caregivers provide care for ten or more years.

Alzheimer's and dementia caregivers provide care from one to four years more than caregivers caring for someone with an illness other than Alzheimer's disease. They are on the high end of caregiver duration, more likely providing care for five years or longer (Ibid).

### **Geographic Distance Between Caregiver and Care Recipient**

The majority of caregivers, about three out of four or 72%, live within twenty minutes of the person they are providing care for. 13% live within an hour of the care recipient. This reflects a decline from 19% in 2004 (National Alliance for Caregiving and AARP 2009).

We learned from the research that the older the caregiver, the more likely they will be living under the same roof as the person they are caring for (Ibid).

1. More than one-third or 37% of older caregivers live with the person they are providing care for.
2. One in five or 20% of middle-aged caregivers live with the person they are providing care for.
3. About one in six or 14% of younger caregivers live with the person they are providing care for.

The recession of 2008 was a big factor to the increase in the proportion of caregivers living less than twenty minutes from the home of the person they provide care. This is an increase from 44% to 51% (Ibid).

Those caregivers who live the longest distance away logically have more expenses on average than their closer caregiver counterparts as illustrated below (AARP Public Policy Institute 2011).

### Caregiver costs associated with distance of care

1. Long-distance caregivers have the highest annual expenses with an average of \$8,728 per year.
2. Expenses for those who live under the same roof with the person they are caring for annually are about \$5,885 per year.
3. Those who care for someone nearby have annual expenses of about \$4,570 per year.
4. Long-distance caregivers spend an average of \$392/month on travel and out-of-pocket expenses as part of their caregiving duties (National Alliance for Caregiving and AARP 2009).

### **Impact on Caregivers' Health**

Research revealed that caregiving can have a tremendous negative impact mentally and physically on caregivers. Almost two out of ten caregivers indicate they feel their health in general has gotten worse as a result of their caregiving responsibilities (Ibid). 23% of family caregivers, who have provided care for five years or more, report their health has declined to only a fair or poor condition (National Alliance for Caregiving and AARP 2009).

Research revealed some interesting comparisons shown below (Ibid):

1. Women are more likely to rate the physical strain of caregiving as high at 17% vs.10% of men caregivers.
2. Women tend to have annual income under \$50,000 with women at 19% vs.11% of men. Mental stress is associated with the financial strain as a result.
3. 31% of caregivers said they experienced a high level of burden in providing care.
4. 9% of caregivers said they experienced a moderate level of burden in providing care.

5. 5% of caregivers said they experienced a low level of burden in providing care.
6. 11% of family caregivers report that caregiving has caused their physical health to deteriorate.
7. 21% of older caregivers, who provide care for those who are sixty-five or older, report a higher degree of physical strain compared to 13% who provide care for those care receivers under sixty-five.
8. Women, at 16% more than men at 11%, report having more mental and emotional stress in caregiving responsibilities.
9. 40% to 70% of family caregivers have significant symptoms of depression with up to half of these caregivers meeting the criteria for major depression (Zarit 2006, 12-37).

Providing care for persons with dementia is reported to impact a person's immune system for up to three years after their caregiving experience ends, thus increasing their chances of developing a chronic illness (Ibid).

There is a correlation between a caregiver's health and income. Of caregivers with less than \$30,000 in household income, 34% report fair or poor health as compared with 3% of caregivers with \$100,000 or more. The same pattern is also found with a caregiver's level of education (Ibid).

Emotional or mental health problems, of the person receiving care from unpaid caregivers, result in a decline in the health of the caregiver. About one in four experience a decline in their own health compared to only one in ten for those providing care where these emotional and mental health problems are not present (Ibid). One in twelve caregivers feels their overall health is improved by caring for a loved one. (Ibid)

## **Value and Cost of Informal Caregiving**

What is the estimated economic value of informal caregiving? If the services provided by informal caregivers including family, friends and neighbors were to be replaced with paid services, it would cost an estimated \$450 billion annually (AARP Public Policy Institute 2011).

Informal caregiving in 2011 was valued at \$450 billion. This exceeded the value of paid home care and nearly exceeded the total expenditures for the Medicaid program (AARP Public Policy Institute 2011). Informal unpaid caregiving value surpassed the \$408 billion sales of Wal-Mart for 2011.

A study funded by Met Life suggested that the cost of caregiving in terms of lost productivity to U.S. business was somewhere between \$17.1 and \$33 billion as illustrated below (Met Life 2010):

1. Costs of caregiver absenteeism; \$5.1 billion.
2. Costs of caregivers changing from full-time to part-time work; \$4.8 billion.
3. Cost of replacing caregivers with new employees; \$6.6 billion.
4. Cost of workday adjustments for caregivers; \$6.3 billion.

The economic value of the care provided by family and other unpaid caregivers of those with Alzheimer's disease or other dementias was \$202.6 billion in 2010 (Alzheimer's Association 2011). This was almost half of the total value of all unpaid caregiving for 2011.

Caregivers pay a price financially for rendering care to those they love. Almost four out of ten caregivers, who provide care for someone fifty years old or older, either reduce their hours or quit their jobs (AARP Public Policy Institute 2011). This selfless act brings with it serious financial consequences for the caregiver. The caregiver's losses include; lost wages, health insurance, other job benefits, retirement, savings and Social Security and other benefits.

## **Caregivers and Developmental Disabilities**

There are an estimated 641,000 adults age sixty and older with intellectual disabilities including but not limited to; mental retardation cerebral palsy, autism, epilepsy and brain injuries (Heller 2011). With the avalanche of baby boomers who began to turn sixty on January 1, 2011, That number is projected to double to 1,242,794 by 2030 (Ibid).

Families are still the primary caregivers for adults with developmental disabilities and are themselves aging. Approximately 76% of individuals with developmental disabilities live at home and in 25% of these homes, the family caregiver is over age sixty. Of these households, the average age of the individual with a developmental disability is age thirty-eight (Ibid).

## **Caregiver Assistance and Support**

49% of caregivers report using at least one of three specific types of help on behalf of their care recipient. Most commonly used was an outside transportation service at 29%, followed by requesting financial assistance at 28%. Only 12% used a respite service. About 44% of caregivers, who provide care for adults between ages eighteen to forty-nine, were more likely to have sought out financial help. Those providing care for younger care recipients at 32% or older care recipients at 25% were less likely to seek financial help (National Alliance for Caregiving and AARP 2009).

One in five caregivers' or 19% report they had training but would like more. Three in four or 78% report needing more help and information with at least fourteen specific topics related to caregiving. About four in five caregivers or 83%, who are in high burden situations, are more likely to seek help while 73% of low burden caregivers would seek help (Ibid).

The top concerns to caregivers are (Ibid):

1. Keeping their loved one safe.
2. Managing their personal stress.

3. Finding easy activities to do with their care recipient.
4. Finding personal individual time.

The demand for information by caregivers has increased in the last five years from 67% to 77% (Ibid).

Caregivers are more open to receiving outside help from individual/group therapy, educational/training support, home-based visits and technology, depending on how they are delivered (Alzheimer's Association 2011).

66% of caregivers find it very or somewhat easy to coordinate care given by health professionals and service providers while 25% had some difficulty (National Alliance for Caregiving and AARP 2009). About two in three or 66% of caregivers report using other unpaid caregiver help with one in three or 35% using paid help (Ibid).

Transportation is a vital component provided by the family caregivers including spouses and adult children. Four in ten of those who receive Medicare benefits accompany care recipients to medical appointments. Family or friends provide transportation for 1.4 billion visits per year for relatives who are seventy years old or older who cannot drive themselves. (AARP Public Policy Institute 2011).

## **Technology**

Caregivers under the age of fifty are more likely than older adults to use the benefits of caregiving technology. Early adopters of technology report they would likely try each of the new technologies available, but cost is a concern (Ibid). Racial and ethnic minorities who are fifty and older are more likely than non-minority caregivers of the same age to rate technology as helpful (Ibid). Among younger caregivers, no difference was noted by race.

Caregivers with a medium to high burden of care are more likely than those with a low burden of care to use technology (National Alliance for Caregiving 2011).

The most important technological benefits rated by caregivers are (Ibid):

1. Saving time .....77%
2. Caregiving made easier logistically .....76%
3. Making the care recipient feel safer .....75%
4. Increasing their feelings of being effective .....74%
5. Reducing stress .....74%

Caregivers are most receptive to technologies that help them deliver, monitor, track, or coordinate their loved one's medical care (Ibid).

## **Veterans**

The United Health Foundation revealed some interesting insights, listed below, into caregivers who provide care for Veterans (United Health Foundation 2012).

1. Nine out of ten caregivers or 96% who provide care for veterans are female.
2. About three out four or 70% provide care to their spouse or partner.
3. About one in three or 30% provide care for ten years or more as compared to 15% of other caregivers nationally.
4. Nine out of ten or about 88% report increased stress or anxiety as a result of caregiving.
5. Three out of four or 77% say that being deprived of sleep is an issue for them.

Caregivers who provide care for Veterans deal with unique Veteran illnesses such as; traumatic brain injury, post-traumatic stress disorder, diabetes and paralysis resulting from spinal cord injury (Ibid).



## Periods of Family Caregiver Transition

There are loosely defined periods of caregiving in which unpaid family caregivers provide care and transition through. These periods can be referred to as stages and vary in number and length depending on the type of illness.

Carolyn McIntire, in her article *A Careful Look at the 3 Stages of Caregiving*, provides a practical and compact guide to caregiver understanding and transition (McIntyre 2012). Her three stages include insights in understanding the different caregiving stages, tips and resources to help caregivers as they transition through an ever changing and evolving role.

### McIntyre's Three Stages of Caregiving

#### 1. The Early Stage: What is happening to my loved one?

Caregivers' experience: Surprise, Fear, Denial, Confusion, Sadness

McIntyre describes this early stage as the initial step of the caregiver assuming the role of caring for a relative who is suffering from a significant health need. The routines and roles of the family are thrown into chaos and the normal gives way to a state of disorganization and maybe chaos.

McIntire suggests that the first thing that should happen, to begin the caregiver's transition through this stage, is the siblings and spouse of the loved one begin sorting through options of available care for their loved one. She warns that this step should not be taken lightly because it can be a challenge, bringing to the surface old family tensions. The most important thing to remember and emphasize is what the loved one needs.

The second thing that should happen with caregivers, in this first stage, is becoming educated on the illness and getting accurate diagnostic information and prognosis. This will take time. McIntyre suggests that it's normal to hear spouse and siblings offer different views on the illness and

ways of handling it. Usually those who spend the most time with and are closest to the person receiving care will assess the severity of the illness more quickly than others who live farther away or are less involved.

McIntyre suggests that recognizing the seriousness of the illness and confronting denial of the situation will help families mobilize more quickly and move forward as they begin to reorganize from the chaos that has resulted. The best outcome occurs, when everyone chips in by researching literature, organizations and websites that could be helpful and then sharing this information with each other.

A third thing to remember, according to McIntyre in moving through this stage, is that your loved one is dealing with some normal but difficult feelings of denial and loss. To acknowledge the illness and ramifications from it will require a change in personal perception by the loved one. Most people have trouble accepting the changes that they may see coming. This leaves them vulnerable and many times afraid. It's important for caregivers to recognize this and to exhibit the patience and love that may be needed at this juncture.

A fourth thing to remember is there are resources out there which can help you and your loved one. These resources include doctors, nurses, social workers, the Department of Aging in your state, company Work/Life benefits, Employee Assistance Programs, geriatric care managers, clergy and elder care attorneys.

2. The Middle Stage: How long does this last?

Caregivers' experience: Frustration, Guilt, Resentment, Conflicting Demands

A number of things should be done to successfully transition through this stage. McIntyre indicates first of all that the family should have confronted their denials by this point and negotiated their relationships so it is clearer to each member what most of the caretaking tasks are and how the

tasks should be divided. The process now moves to the increasing needs of the loved one. Conflict is still possible if the primary caregiver does not have the support of the other family members.

The second thing to remember is that assessing their loved one's needs is an ongoing process. Appropriate resources should be found to meet needs and needs change. The loved one's doctors should be in communication with each other concerning treatment and medications. The caregiver must keep abreast of prescription refill dates, when medications should be taken and follow up to make sure the loved one has actually taken the medications. Insurance forms and paperwork are an ongoing challenge for the caregiver but must be pursued with vigor. The house may need modifications to better accommodate the loved one. Special equipment such as oxygen machines or handicap accessories may be needed.

A third thing to remember is that caregivers will have less personal time to spend with friends, other family members, hobbies, recreation and other activities. Caregivers should keep in mind that personal emotional needs may not be recognized by medial personal and other family members. Most will be focused on the patient and the patient's need and not the caregiver.

McIntyre encourages caregivers continue as much as possible with their jobs, regular exercise, outside activities and relationships. This may require adjusting the frequency of such activities, but continuing them is very important. There is a tendency to become guilt driven and make damaging personal sacrifices in trying to do too much which many times will result in caregiver depression.

McIntyre suggests that caregivers should remember a fourth thing. There are resources available in transitioning through this stage. These are not limited to but include; home healthcare services, senior citizen centers,

day-treatment programs, assisted-living facilities, *Meals on Wheels*, geriatric care managers and caregiver support groups.

### 3. The Late Stage: How do I respect the needs of my loved one?

Caregivers' experience: Sadness, Guilt, Surrender, Regrets, Relief, Solace, Closure

Much has transpired when this stage is reached. Primary caregivers have established themselves as advocates on behalf of those they are caring for. McIntyre suggests this is the first thing to remember in this stage and is important because by this point hospitals, doctors, nurses nursing homes and other institutions and their staffs can become overpowering and this should be remembered while dealing with them. Caregivers should make sure that close attention continues to be paid to their loved ones by medical personnel.

The second thing McIntyre suggests for caregivers to remember is that questions of quality of life versus longevity will need to be addressed by tactfully finding out the ill person's wishes. Hopefully by this point, legal documents of the loved one such as a living will, power of attorney and health proxy are in place. If not, they should be addressed in a sensitive manner but this must be addressed. Hospice care is valuable in assisting the loved one and the family in providing a loving environment for the last moments of life. More detail about Hospice and its' services is mentioned in Chapter Four.

Some important resources during this stage are hospitals, doctors, nurses, social workers, elder care attorneys, hospice, nursing homes, clergy and counselors.

Researchers at Emory University's Work Life Resource Center located in Atlanta, Georgia have developed a model showing four stages of caregiving that sick or aging adults typically go through (Emory University

2009). The model includes what caregivers can do for themselves, what type of care to provide at each point for their family member and what probably will transpire in the future (Ibid). This model expands and differs slightly from Carolyn McIntire's three stages of caregiving (McIntyre 2012).

#### Emory University's Work Life Resource Center Four Stage Model

##### 1. Stage I: Anticipatory Caregiver (Ibid)

This stage begins with the individual entertaining the possibility of becoming a caregiver. It may be much shorter, but the usual time frame is twelve to eighteen months. The caregiver observes the declining health of their loved one and concludes that they will probably become that person's caregiver.

This Anticipatory Caregiver stage is similar to McIntyre's first stage of caregiving because it also suggests researching and gathering information about the illness and best approaches to diagnosis and treatment.

Emory University suggests that this stage is good time to enquire about the loved one's wishes for the future. McIntyre suggests doing this during stage three of her three stages of caregiving (McIntyre 2012).

Emory University suggests gaining a good understanding of the loved one's finances and also discussing important legal documents. This is also mentioned in McIntyre's third stage (McIntyre 2012).

Experts also suggest beginning to research community services, health programs, and any safety measures that need to be put in place. It is important to note that this type of research and gathering of information is time consuming.

##### 2. Stage II: Freshman Caregiver

Emory University defines a Freshman Caregiver as one who has filled the role of a caregiver for approximately six to nine months. During this stage, a person will come to realize the enormity of the tasks ahead of them in caring for their loved one.

It would be wise for caregivers in this stage to seek help from others. Freshman Caregivers should do their research to discover what types of help are available and if or how it will be paid for. Loved ones should be included in the decision making process if possible. Freshman Caregivers should then trust their instinct in making decisions that must be made. They should make sure they clearly communicate plans concerning their loved ones to other family members keeping in mind that it may need repeating again.

### 3. Stage III: Entrenched Caregiver

A person in this stage has been providing care for some time and may be feeling overwhelmed and exhausted. This stage compares well with McIntyre's stage two (McIntyre 2012). Caregivers have made compromises to their own well-being or immediate family as a result of their caregiving responsibilities. The Entrenched Caregiver should remember that this may jeopardize the quality of care they are providing their loved one. Emory University encourages the Entrenched Caregiver to accept help from others even asking and delegating some caregiving responsibilities to them. Failure to do this often leads the caregiver to become resentful, angry and depressed. Steps should be taken by the Entrenched Caregiver to take good care of him or herself physically, emotionally and spiritually.

### 4. Stage IV: Caregiver in Loss

Emory University suggests that the loss of the loved one is the final stage for a caregiver. Emory University defines as to when loss occurs with a number of possibilities:

- a. Loss occurs when a caregiver has made the decision that they are no longer able to care for their loved one.
- b. Loss occurs when a caregiver is no longer able to provide care in the kind of way their loved one requires.
- c. Loss occurs when a caregiver may places their loved one into a care facility such as a nursing home or Hospice.
- d. Loss occurs when a caregiver experiences the death of their loved one.

Whichever way it occurs, caregivers experience grief and loss at the ending of their roles and responsibilities, the departure of their loved one or both. This is the stage when it's important for caregivers to remember that they must move forward with their lives. Support from friends, family and colleagues is important and recovery will take time.

Emory University's studies indicate that some caregivers may need to seek professional counseling to help them or perhaps find a support group. The grief experienced in this stage is completely natural and will become less over time.

Lindsay Jackson further expands the stages of caregiving role by reflecting on caregiving for seniors to five stages in her article *The five stages of caregiving* (Jackson 2011).

#### Lindsay Jackson's five stages of caregiving

##### 1. Stage I: Independence

This may not seem like a caregiving stage at all, but stage I is the period when elderly parents don't want any help. It is often a time when adult children see their parents as older being less capable than the parents see themselves.

Some adult children take pleasure in seeing their parents at this stage. But many others worry about their parents' health, judgment and what will happen if a parent becomes seriously ill. Besides worrying, there are some proactive things that adult children can do at this stage.

##### 2. Stage II: Interdependence.

At this stage, seniors may need substantial assistance due to disabilities. However, they are firmly resistant to hiring outside help because of the cost, denying they need it or both.

Most seniors will accept help from family at this stage. Caregivers can help by preparing meals, taking mom or dad to the doctor, driving mom or dad to the bank, or supermarket or finding things to assist in other practical ways will usually be accepted.

### 3. Stage III: Supportive living

In Stage III, seniors are trying to cope with multiple disabilities and often chronic pain. This is the stage at which seniors will begin to accept outside caregivers who can help with personal care and/or healthcare. Family members are often heavily involved in assisting their elderly loved one with activities of daily living and helping to find, hire and coordinate formal caregivers such as; personal support workers, nurses and therapists.

### 4. Stage IV: Complex care/crisis management

Stage IV is a difficult and often painful stage for all concerned. The loved one's physical and/or mental condition has declined to such a degree that he or she is dependent on others for most of the care. There are usually multiple health conditions challenging the parent, requiring a variety of treatments and therapies. If cognitive problems like thinking, memory, impulse control and judgment are part of the problem, then close skilled supervision is also required, often around the clock.

Despite the involvement of formal caregivers, the levels of care in the home available to the family at this stage may be inadequate or too expensive, leading to one crisis after another. It is common at this stage, that the only thing preventing a nursing home admission is an earlier promise to the elderly parent or to one's self to never place the parent in such an institution.

### 5. Stage V: Dependence

At some point, many families come to realize that the well-being of their elderly loved one and of the remaining family will be better served by a nursing home admission. In fact, at this stage the patient is often safer and more comfortable with twenty-four hour institutional health and personal care than with a patchwork of homecare services.

## Finale

Not all aging individuals and their families pass through all of these five stages. Nor do they pass through all stages at the same pace.



Most people die at home or in a hospital and never even see the inside of a nursing home. But the five family caregiving stages provide a framework for understanding the main needs and issues for families at any point in time, and help in anticipating what the next stage in their journey might be.

Dennis Brown expands the understanding of the stages caregiver transition through to six stages in her book *The Caregiving Years, Six Stages to a Meaningful Journey*. Her six stages is a more comprehensive and broad view of caregiving (Brown 2012).

#### Brown's Six Stages to a Meaningful Journey

1. Stage I: The Expectant Caregiver – Caregiving will begin in the near future.

The caregiver and loved one realize that the caregiver may soon begin the caregiving role. Steps are taken together to prepare for the process that will soon come. This step corresponds to McIntyre and Emory University's suggestion that this is the time to get the loved one's affairs in order. This includes but is not limited to a visit with an attorney, setting up of necessary processes, consulting with doctors, discussing with your loved one what level of care he or she may need and their wishes. Together, preparation is made for every possible circumstance that can be anticipated.

2. Stage II: The Freshman Caregiver – The caregiving role has begun. As this stage evolves, it provides a sneak preview of the future.

The caregiver may begin by providing meals and running errands at first. The caregiver should fully educate himself on all aspects of the loved one's condition and decide how best to help. Caregivers should consider joining support groups that are specific support for the illness with which he or she is dealing with and providing care for. Support groups can provide a needed outlet and help the caregiver learn how to take care of his personal needs and also better care for their loved one.

3. Stage III: The Entrenched Caregiver – The caregiver is providing care.

The caregiver is firmly grounded in all aspects of giving care to a loved one, which plays a large part in defining who the caregiver is as a person. Feelings at this point may be bittersweet. Caregivers are glad they can help but do not understand why this has happened to them or their loved one.

During this stage, caregivers become physically and mentally exhausted. Caregivers' re-evaluation during this stage is critical. Their main focus should be receiving help from others like Comfort Keepers respite care services. Breaks from responsibilities should be taken by caregivers so they can rejuvenate themselves and continue on a healthy caregiving path. Establishment of a routine for caregiver and the loved one should be established and limits of care with which both are comfortable with should be determined.

Help from the family and friends of caregivers should be accepted and help from a paid care provider sought if financially able. Leaning heavily on support groups during this time can be invaluable for the caregiver. The sharing of feelings with others will help maintain focus and also caregiver sanity.

4. Stage IV: The Pragmatic Caregiver – The caregiver continues care.

The caregiver has been providing care for quite some time. The caregiver should look at himself and determine where he is physically, emotionally and physically. The caregiver should seek to forgive their care recipient for past hurts and find ways to add fun to their days together. This can be done by singing songs, engaging in other activities and together finding humor in the situation. The caregiver should involve their loved one in helping determine the caregiver's future goals and dreams. This is also the time for the caregiver to begin thinking about his or her future.

5. Stage V: The Transitioning Caregiver – The caregiver’s role is changing.

Caregiver duties are coming to an end in this stage. Either because the caregiver can no longer continue in the caregiving role or possibly because the person being cared for either needs a level of care the caregiver is unable to provide or their life is coming to an end. Brown suggests that the caregiver allow himself to mourn and reflect on the shared memories. Openly discussing those feelings with the care recipient now will make performing the final stages of care easier in the end.

6. Stage VI: The Godspeed Caregiver – Caregiving has ended.

The days of caregiving have been over for some time now and the caregiver has his life after caregiving ahead of him or her. The caregiver has many things to choose from. He or she may choose to become an advocate of caregiving. He may offer advice to others. He may write about his or her caregiving experiences. He may begin or head up a caregiver support group. He may become a go-to person for other family and friends who may be embarking on the caregiving journey themselves.

The caregiver is now moving forward in life now. He or she is now able to look back on the caregiving years with happy thoughts and sweet memories of the loved one cared for.

The caregiver’s journey is special, but full of emotional ups-and-downs. Brown’s steps give permission to experience caregiving at its worst and also at its best. Most of all, her words and advice let caregivers know that they will get through the caregiving experience. She concludes by encouraging caregivers to enjoy their lives to its fullest after their caregiving days have ended (Brown 2012).

## **Caregiver Transition**

The caregiving journey requires a combination of the knowledge of care needed for a loved one and the stages of caregiving caregivers will probably experience. Also needed is a general understanding of what is going

on in the lives of caregivers. If caregivers are to successfully traverse the sometimes deep and dark waters of caregiving then they must be able to keep their bearings and seek to understand their feelings.

Dr. Nancy B. Miller in her book *Nobody's Perfect: Living with Children Who Have Special Needs* clearly defines four stages which caregivers enter and transition through (Miller 1998). She describes these stages as developmental tasks which can be a tremendous aid to caregivers comprehending where they are in the process and how to successfully transition through. One important thing which should be remembered is that these stages may occur at the same time or in any order and may repeat themselves during the course of a caregiving relationship. By understanding how each one works, caregivers will better understand their emotions, what is going on and may be about to happen with their own lives. Understanding these stages will also help caregivers feel better when uncomfortable feelings suddenly arise (Ibid).

#### Dr. Nancy B. Miller's Four Stages of Caregiver Transition

##### 1. Stage I – Surviving:

Miller states that Surviving is what caregivers do to keep going when they feel completely helpless. Surviving consists of coping, doing what has to be done and expending one's energy to just get by.

##### 2. Stage II- Searching:

Searching is a time of acting and moving forward from the reactive state of just surviving according to Miller. It begins with caregivers' sense of control over their emotions and over life itself. This period awakens a source of energy caregivers do not realize they have. This is a time for caregivers to ask questions about the goals, values and priorities their lives. Questions like:

- a. What's wrong?

- b. Can it be fixed?
  - c. Why him, her, me or us?
  - d. What does this mean for me and for our lives?
  - e. Searching also involves seeking answers and interventions related to the illness or condition.
3. Stage III - Settling In:

The caregiver in this stage sees the world for what it is and sees himself for what he or she is. The caregiver moves beyond the intense emotions of surviving, feeling less of the sense of urgency of searching and is gaining a greater sense of control and balance in his or his daily life. Settling In is a time of relative equilibrium for the caregiver. He may never forget the reality this precarious time, but it can become a time of experiencing deepening precious moments in the relationship.

4. Stage IV – Separating:

Miller's final stage of caregiving called Separating is a normal and necessary process in caregiving. Letting go by the caregiver is difficult at best but will be even more difficult if the caregiver is unwilling or unable to be separated from the loved one at least for short periods of time beforehand. Allowing others to help with caregiving responsibilities and getting needed periods of diversion and rest are absolutely necessary. This will help avoid caregiver fatigue and allow the care recipient to attain or retain some level of independence as well.

## **Time for Grief**

Normally there are up to seven stages of caregiver transitions in the life of caregivers. These stages may appropriately be divided into two major periods. The first period is the care provided by caregivers from the initial recognition and diagnosis of a debilitating or terminal illness of a loved one,

until their final approaching of their death. This period was thoroughly explored in earlier sections of this thesis. The second period for caregivers begins with the realization that death is certain for the loved one and ends when the grieving process for that loved one has been completed.

This second period called grieving is an essential part of the caregiving process and necessary for the future recovery and well-being of caregivers. It is not only possible for caregivers to survive this final period of caregiving but to thrive beyond it. Grieving also requires periods of transition by caregivers as they pass through its' multiple stages.

“When someone we love faces death, caregivers are likely to pass through the psychological stages of dying. Over a period of time depending on the length of the illness after the terminal prognosis is confirmed slowly and with much emotional pain, we come to the acceptance stage. Knowing the stages helps us understand some of our own feelings and see that we and the dying person may be at different places . . . . Sensitivity to what is said and what is left unspoken helps us know what stage the dying person is at and how best to sustain and comfort.” (Delbene 1988, 13)

### **Death is Approaching.**

Research revealed that grief generates a number of stages through which caregivers must pass. Grieving may begin long before the actual death of the loved one. If the illness is long term with gradually declining health, anticipating the approaching loss of a loved one can begin long before they actually pass away. Anticipatory grief, as it sometimes referred to, is the grief caregivers experience when they recognize that the loss of a loved one or friend will happen in the future but it has not actually yet happened (Erickson 2012)

Anticipatory grief is absent from many grief models. However it is an important part of the grieving process. Anticipatory grief provides an

opportunity for loved ones and caregivers to prepare for the end game they know is coming. This preparation could include seeking forgiveness, finalizing family affairs and making plans with loved ones about their impending exit from this life (Ibid). Anticipatory grief normally creates emotional highs and lows bringing up and down periods on the emotional roller coaster for caregivers.

Dr. Elisabeth Kubler-Ross created the Grief Cycle Model first published in *On Death & Dying* in 1969 which has commonly been used to describe feelings of both unpaid family care providers and those receiving care. Research revealed that, although every situation is different, most caregivers will pass through at least one or more of the stages of Kubler-Ross's grief model. They will experience many of the feelings mentioned in her model (Kubler-Ross 1969).

Dr. Elisabeth Kubler-Ross' Grief Cycle model includes these five stages:

1. Stage I: Denial. A good definition by Kubler-Ross of denial is a conscious or unconscious refusal to accept facts, information, reality, etc., relating to the situation concerned. She suggests that denial is a defense mechanism and perfectly natural.

There is real danger here. Some people can become locked into this stage when dealing with a traumatic change which they choose to ignore. We know that death is not easy to avoid or hide from indefinitely.

2. Stage II: Anger. Kubler-Ross suggests that anger can be manifested in different ways. People who are dealing with emotionally upsetting events can become angry with themselves and/or with others but especially those close to them. This is important to remember for friends and families of caregivers. This will help them better understand what is happening and keep a detached and non-judgmental attitude when experiencing the anger of caregivers who have entered the grieving process.

3. Stage III: Bargaining. Traditionally the bargaining stage of grief is done by people facing death or realization that the death of a loved one will probably occur. An attempt is made to make a deal with God in exchange for one's own life or the life of a loved one. People facing less serious trauma than death often bargain or seek to negotiate a compromise with God. Bargaining rarely provides a sustainable solution, especially if it's a matter of life or death.

4. Stage IV: Depression. Kubler suggests that depression is often referred to as preparatory grieving. She describes it as the dress rehearsal or the practice run for the things that are coming, although this stage means different things depending on whom it involves. This stage begins the acceptance of what may be coming without the full emotional attachment that it will require. It is natural to experience the emotions of sadness, regret, fear, uncertainty and etc. When caregivers reach this stage, they will have begun to accept the reality of the loss that is about to happen or already has happened.

5. Stage V: Acceptance. This stage definitely varies according to the caregiver's situation. Kubler suggests that in a broad way, this stage is an indication that there is some emotional detachment and objectivity on the part of the caregiver. People dying can enter this stage a long time before the caregivers they leave behind, but caregivers must also pass through their own individual stages of dealing with their grief.

Anticipatory grief can impact the family caregiver in a number of ways but the three most common ways are physically, emotionally and spiritually.

David L. Cowles a retired Hospital Chaplain, Minister, Pastoral Counselor and retired Social Worker developed and teaches an online course called: *Journey Through Grief* (Cowles 2003). He takes Dr. Elisabeth Kubler-Ross' five stages of grief and his own grief experiences and the passing of his mother and develops those into an overview which lends great insight the grieving process. His three point outline discusses Anticipatory



Grief - the awareness of Dying, Acute Grief - the reality of death and Acceptable Grief - the grieving process.

Cowles defines the thoughts that characterize many caregivers' feelings through the grieving process.

1. Stage I: Denial. The immediate reaction is No, Not Me! There must have been a wrong diagnosis.

This may involve seeking another opinion or asking for further tests to verify an accurate diagnosis and prognosis. This delays any attempt to provide surgery or treatment that may be crucial to stop the progression of disease to other parts of the body.

2. Stage II: Anger. The normal response is Why Me? The awareness of the diagnosis is realized. There are varied responses, which may include anger towards God.

3. Stage III: Bargaining. The response is Not Now! Time is crucial in this stage. Time is needed to complete personal goals like graduation of a loved one, birth of a grandchild, visits by family and close friends. Time is urgent in an intense search for a cure, seeking other treatment options, praying for healing and remission of the disease.

4. Stage 4: Depression. The response is "Oh Me!" The awareness of dying is beginning to settle in with feelings of helplessness and hopelessness. Focus is on less pain and relief from discomfort for the loved one. It is a time with a lot of introspection and self-preoccupation.

5. Stage 5: Acceptance. The response is this is O.K.! There is a desire for family support and a need to make final arrangements for death. Focus on unfinished business and preparation for the transition from this life to the next.

## The Dynamic of Transitional Hope

The term HOPE is not mentioned by Dr. Kubler-Ross but is important especially for a person with faith in God. HOPE moves the caregiver through each stage to the ultimate hope which is eternal life. David Cowles suggests the value of hope and how it may be reflected in the five stages of Kubler-Ross' grief model (Cowles 2003).

Hope found by Cowles in the Kubler-Ross model is reflected below:

1. Stage I: Denial. The HOPE is to find a second opinion or to have further tests to verify an accurate diagnosis and prognosis.
2. Stage II: Anger. The HOPE is to find a cure, seeking other treatment options, healing and remission of the disease process.
3. Stage III: Bargaining. The HOPE is for more time to complete personal goals in the immediate future.
4. Stage IV: Depression. The HOPE is for less discomfort and maximum pain relief for the loved one.
5. Stage V: Acceptance. The HOPE is for family support and preparation for the end of this life and transition to eternal life.

“Looking back it was my relationship with God, my friends, and the psychologist that gave me hope to continue,” Georgia Shaffer reflected on her grief journey. “God took all that was lost and used it to transform my life.” (Shaffer 2000, 27)

## The Clergy

Ron Delbene and Herb Montgomery mention three key contributions that clergy make to caregivers and their dying loved ones (Delbene 1988).

These are listed below:

1. The caregiver, clergy or family member may need to encourage the dying person to seek forgiveness and reconciliation (Delbene 1988, 23,25).
2. It is not uncommon for entire families to want to have their pastor or a chaplain to assist in a ritual of forgiveness and reconciliation (Ibid).
3. This experience results in healing, peace of mind and heart (Ibid).

## Death Has Arrived

One of the most traumatic times in life is the loss of a husband, wife, child, parent, sister, brother, grandparent or grandchild. Sometimes death comes suddenly, without warning. Other times it approaches like a slow-moving evening shadow. No matter how it arrives, death is always accompanied by a far-reaching, often devastating impact (Harris 2009, 9).

With the case of a terminal illness, grief many times begins before the actual death takes place. Once death has occurred, the caregiver moves into another period of transition in the caregiving process. The responsibilities of caregiving abruptly come to a halt and a time of refocusing of necessity begins.

A broad description of the periods can be found in Dr. Roberta Temes' book *Living with an Empty Chair - a guide through grief*. Temes describes three particular types of behavior exhibited by those suffering from grief and loss (Temes 1992, 17).

Dr. Dr. Roberta Temes three periods of grief:

1. Numbness - mechanical functioning and social insulation.
2. Disorganization - intensely painful feelings of loss.
3. Reorganization - re-entry into a more 'normal' social life.

Dr. Larry Lachman, a licensed clinical psychologist expands the thinking in these three periods further into six phases in his article *Grief and Loss, Caring For The Caregiver After Death* (Lachman 2013).

1. Phase I: Crisis and shock. This phase is the initial emotional reaction to the death of the caregiver's beloved family member. This phase many times includes but is not limited to panic, denial, shock and disbelief.

2. Phase II: Isolation and awareness of loss. This phase is characterized by the caregiver's lack of ability to talk about his or her grief because of overwhelming feelings of pain and sorrow. Emotions such as anger, guilt, shame and fear are common during this phase of grief.

3. Phase III: Anger and the need to withdraw. Many do not realize that anger is a natural part of grief.

Grief expert and author, Dr. Catherine Sanders, writes in chapter three of her book, *Surviving Grief and Learning to Live Again*, that: "new grief always reminds us of old grief. The pain that has diminished with time is revitalized and experienced anew, when we are again exposed to death." (Sanders 1992)

The death of a spouse, child or parent may bring up memories of other significant losses that caregivers have experienced. Grieving can be very fatiguing as a result of this.

4. Phase IV: Reconstruction and healing. Lachman suggests that when this stage arrives caregivers will begin to feel less overwhelmed by their circumstances. They will find themselves gradually developing more energy will begin to reconstruct themselves emotionally.

5. Phase V: Intermittent sadness/depression. This phase is characterized by periods of on-and-off sadness for the caregiver Lachman says. This kind

of reactive sadness or depression is normal. Lachman gives encouragement to caregivers when he suggests that these periods of sadness or depression will be only temporary and should be recognized as a good sign that the grieving process is moving forward.

6. Phase VI: And finally, Renewal. In this final phase, caregivers find themselves going on with life, establishing new goals and forming a new identity, separate from the one they had with the person who has been lost.

Temes first stage and Lachman's first phase both have merit and accurately describe some of the initial experiences of the caregiver beginning the grieving transition. The initial reaction of many caregivers to the loss of their loved ones is a sense of relief. The nonstop twenty-four hour a day seven days a week and three hundred and sixty-five days a year caregiving responsibility pressure has suddenly vanished. The reality of the loss of the loved one has not yet been realized.

A feeling of emotional numbness many times sets in due to the emotional and physical energy drain brought on by the caregiving and dying processes just experienced by the caregiver. The stress of the previous hours and/or days has just been removed. A feeling of relief replaces the stress. The isolation of the caregiver is temporarily replaced by the presence, attention and support of family, friends and church during the funeral and burial process. The reality of loss may not surface until weeks after the death of the loved one (American Cancer Society 2012)

After a few weeks or so, the initial shock and numbness begin to wear off. A sense of displacement emotionally begins to usher in. This is characterized by feelings of pain and sorrow resulting in a period of withdrawal and isolation (Lachman 2013). The grieving caregiver may find it difficult to share his/her feelings. There is a real sense of disorganization with a realization that the caregiver's world has again been turned upside down (Temes 1992). This period can last for several weeks.

At some point, feelings of being overwhelmed with sorrow and sadness will begin to give way to thoughts of going on with life. This period is a major part of the healing process. Temes refers to this as the reorganization stage and Lachman as the reconstruction/healing and renewal phases. This is a very important time of establishing new goals and forming a new identity, separate from what caregivers had with the person they have lost (Lachman 2013).

### **The Final Transition**

Living beyond grief is the final chapter in the caregiving process. The caregiving process began with the initial diagnosis of terminal illness and transitions through several periods. It culminates with the recognition that life is not over and God still has wonderful things in life ahead of the caregiver. There is a conscious recognition that there is life beyond caregiving, the loss of a loved one and the horrible pain of grief.

## **CHAPTER IV: CAREGIVER AWARENESS AND MINISTRY CARE**

### **Awareness of Caregiver Needs**

When diagnosis of serious illnesses are made and the prognosis is seemingly not a good one, much attention is focused on the person who has become ill and rightly so. However, caregivers are often overlooked. They move quietly through the dying process of their loved ones providing care and comfort as they go (Harris 2009). They are content to lay aside their own feelings, hurts, needs and wants in order to help make the waning days of their loved ones lives and as pleasant and comfortable as possible (Ibid). They are content to stay in the shadow of their loved ones focused on the needs of the seriously ill or dying (Ibid).

Recognition of caregiver needs is important for caregivers, family members of caregivers, employers, medical personnel and the religious community. Maintaining good physical, emotional and spiritual health of caregivers is of paramount importance to both the recipient of care and also the person providing the care. Caregivers are very courageous, but in spite of their courage, they desperately need encouragement, love, appreciation, comfort and a helping hand (Ibid).

Physical, emotional and spiritual needs of caregivers are many times interwoven and are present throughout the entire caregiving process. Rather than isolate these by category, the research indicated how closely related they are and the best approach appears to be discussing these in tandem with one another.

## Stress

Caregiver stress is the emotional and physical strain of caregiving. It can take many forms (Greene 2008). Caregiver stress appears to affect women more than men. About seventy-five percent of caregivers who report feeling very strained emotionally, physically, or financially are women (Greene 2008).

Examples of feelings of Caregiver Stress (Greene 2008) :

1. Caregivers become frustrated and angry while taking care of someone with dementia who often wanders away or becomes easily upset.
2. Caregivers feel guilty because they feel that they should be able to provide better care, despite all the other things they have to do.
3. Caregivers feel lonely because the excessive amount of time they are spending caregiving is preventing them to interact with others socially.
4. Caregivers are exhausted when they finally go to bed at night

Caregiving stress can affect the health of caregivers. Although most caregivers are in good health, it is not uncommon for caregivers to have serious health problems.

Research by Greene shows the following about the health of caregivers below (Greene 2008):

1. Caregivers are more likely to have symptoms of depression or anxiety.
2. Caregivers are more likely to have a long-term medical problem such as heart disease, cancer, diabetes, or arthritis.
3. Caregivers have higher levels of stress hormones.
4. Caregivers spend more days sick with an infectious disease.



5. Caregivers have a weaker immune response to the influenza and the effectiveness of the flu vaccine.
6. Caregivers have wounds that take longer to heal.
7. Caregivers have higher levels of obesity.
8. Caregivers may be at greater risk for mental decline, including problems with memory and attention span.

One research study found that elderly caregivers, who felt stressed while taking care of their disabled spouses, were sixty-three percent more likely to die within four years than other caregivers who were not feeling stressed (Greene 2008).

There are warning signs that caregivers can recognize when too much stress is present from caregiving responsibilities. According to Greene, caregiving may be putting too much stress on caregivers when they are experiencing the following symptoms (Ibid):

1. The caregiver is feeling overwhelmed.
2. The caregiver is sleeping too much or too little.
3. The caregiver is gaining or losing a lot of weight.
4. The caregiver is feeling tired most of the time.
5. The caregiver is losing interest in activities he or she used to enjoy.
6. The caregiver is becoming easily irritated or angered.
7. The caregiver is feeling constantly worried.
8. The caregiver is often feeling sad.
9. The caregiver is having frequent headaches, bodily pain or other physical problems.
10. The caregiver begins to abuse alcohol or drugs, including prescription drugs.

Stress associated with caregiving is real. Caregivers cannot completely escape it. There are measures that can be taken by caregivers to reduce stress

to tolerable levels. Greene gives some great suggestions on how to reduce stress. They are listed below (Ibid).

Greene's tips for reducing caregiver stress:

1. Caregivers should find out about caregiving resources in their communities.
2. Caregivers should ask for and accept help.
  - a. They should prepare a mental list of ways that others can help.
  - b. They should let the helper choose what he or she would like to do.
  - c. One person might be happy taking the person the caregiver is providing care for on a walk a couple times a week. Someone else might be glad to pick up some groceries for the caregiver.
3. If financial help is needed, caregivers should ask family members to contribute their fair share.
4. Caregivers must learn to say no to requests that are draining, such as hosting holiday meals or volunteer activities outside their caregiving role.
5. Caregivers should not feel guilty because they are not perfect caregivers.
  - a. They should remind themselves that just as there is no perfect parent, there is no such thing as a perfect caregiver.
  - b. They should remember they are doing the best they can.
6. Caregivers should identify what can and cannot be changed.
  - a. Caregivers should remember they may not be able to change someone else's behavior.
  - b. They should remind themselves that they can change the way that they react to the behavior of others.

7. Caregivers should set realistic goals by reducing larger tasks into smaller steps that can be done one at a time.
8. Caregivers should prioritize, make lists and establish a daily routine.
9. Caregivers should stay in touch with family and friends.
10. Caregivers should consider joining caregivers support groups who have similar situations.
  - a. This is a great way to make new friends.
  - b. This also a good way to pick up caregiving tips from others who are facing the same problems.
11. Caregivers should make time each week to do something that they enjoy doing such as going to a movie.
12. Caregivers should find time to be physically active on most days of the week.
13. Caregivers should plan and eat healthy diets.
14. Caregivers should get enough sleep. Recognizing that this can sometimes be difficult based on the level of care required by the loved one.
15. Caregivers should see their doctors on a regular basis.
  - a. For annual checkups.
  - b. Caregivers' doctors should be informed of the caregivers' role of providing care for loved ones.
  - c. Caregivers' doctors should be informed about symptoms of depression or sickness of any kind experienced by caregivers.
16. Caregivers should try and keep their sense of humor.

Caregiver stress can lead to many serious health problems. Stress should not be dismissed easily and wise caregivers will take appropriate steps to reduce as much stress as possible. Research has shown that caregivers who take an active, problem-solving approach to caregiving issues are less likely to feel stressed than those who react by feeling helpless and worrying about the situation (Greene 2008)

Medical personnel, through hospital classes, make available resources for caregivers on how best to provide care for loved ones with the disease the loved ones are facing. Usually the best place to start is enquiring about them with the caregivers' doctors, organizations whose main focus is on the loved one's disease, the internet and by word of mouth from other caregivers who have or are presently providing care.

## **Depression**

Caregiving doesn't cause depression but it is not unusual for caregivers to develop mild to serious levels of depression. The constant demands of caregiving can bring on depression (Family Caregiver Alliance 2002). The feelings of sadness, loneliness, anger or symptoms of depression will not be experienced by every caregiver.

Caregivers often sacrifice their own personal physical and emotional needs in an effort to provide the best possible care for a loved one. This sacrifice many times results with the onset of depression for even the strongest and most capable caregivers. Feelings of anger, anxiety, sadness, isolation and the guilt for even having those feelings can take a heavy toll on caregivers.

It is not uncommon for caregivers to experience negative feelings which come and go from time to time. When these negative feelings become more frequent and intense, leaving caregivers drained of energy, finding them frequently crying and easily angered by their sick loved one or others, then the careful examination should take place of these tell-tale signs of depression. When sadness and crying will not go away or negative feelings are unrelenting, these may be warning signs of caregiver depression (Family Caregiver Alliance 2002).

Feelings of caregiver depression are often seen as a sign of weakness for the caregiver when it should be seen as a life out of balance. Many times

caregivers are told that it is all in their heads or they need to snap out of their feelings. This too is unfortunate because this reflects a belief that mental health concerns are not real. Caregivers who try to deny or ignore these feelings will find that they do not simply go away (Ibid).

If depression symptoms are recognized early, then preventive steps such as exercising regularly, eating a healthy diet, receiving positive support from family and friends and consultation with a trained medical health professional may help prevent more serious depression from occurring (Ibid).

The Family Caregiver Alliance suggests that caregivers may experience depression in different ways (Ibid). Some caregivers may feel a general low level sadness for months, while others suffer a sudden and intense negative change in their outlook. The degree of symptoms experienced by caregivers can change over time as well (Ibid).

The Family Caregiver Alliance National lists the following as signs of caregiver depression (Ibid):

1. A change in eating habits resulting in unwanted weight gain or loss.
2. A change in sleep patterns with too much sleep or not enough.
3. Feeling tired all the time.
4. A loss of interest in people and/or activities that once brought them pleasure.
5. Becoming easily agitated or angered.
6. Feeling that nothing done is good enough.
7. Thoughts of death, suicide or attempting suicide.
8. Ongoing physical symptoms that do not respond to treatment, such as headaches, digestive disorders and chronic pain.

Depression should be given the same attention as other illnesses like diabetes or high blood pressure. Caregivers may feel uncomfortable using the term depression. Using words like feeling blue or feeling down will help

professionals understand and get the message. The important thing for the caregiver is to recognize their need and seek help (Ibid).

A brief side note here: If caregivers perceive that their ill loved one may be suffering from depression, then they should look for opportunities to share their concerns with them. If they are reluctant to talk about it, caregivers should encourage a trusted friend to talk with them or consider leaving a message for the loved one's doctor regarding concern prior to their next appointment.

Depression can make caregivers feel exhausted, helpless and hopeless. Negative thoughts and feelings such as these can make caregivers feel like giving up. It is important to remember that these negative views are part of the depression and may not accurately reflect what is really going on.

The National Institute of Mental Health offers the following recommendations for dealing with depression (National Institute of Mental Health 2012):

1. Caregivers should set realistic goals in light of their depression and assume a reasonable amount of responsibility.
2. Caregivers should break large tasks into small ones, set some priorities and do what can be done as soon as it can be done.
3. Caregivers should try to be with other people and confide in someone. It is usually better than being alone and secretive.
4. Caregivers should participate in activities that may make them feel better, such as mild exercise, attending a movie, watching a ballgame, attending religious services and social or community events.
5. Caregivers should expect their moods to improve gradually and not immediately, recognizing that feeling better will take time.
6. Caregivers should postpone important decisions until the depression has been diminished. Decisions such as changing jobs, get married or

divorced should be discussed with others who know the caregiver well and have a more objective view of their situation.

7. Caregivers should remember they can feel a little better day-by-day.
8. Caregivers should remember that positive thinking should replace negative thinking and that is part of the process of recovering in depression. Caregivers' negative thinking will be reduced as their depression responds to treatment.
9. Caregivers should let family and friends help them.

Caregivers sometimes cannot conquer depression without professional medical help. This should not be a source of embarrassment to caregivers. They are journeying into unexplored territory for them. They are experiencing feelings and laboring under responsibilities of caregiving they never imagined would one day be required of them.

Sometimes medications, viral infections and other medical conditions can cause the same symptoms as depression. Caregivers who feel they are displaying symptoms of depression should meet with their own personal physician and have an evaluation done by him or her. These evaluations should include but not be limited to lab work, interviews that tests mental status and a determination of whether speech, memory or thought patterns have been affected.

It is not unusual for a physician to prescribe anti-depressant medication. But medication alone may not be the most effective treatment for depression. The Family Caregiver Alliance suggests that the next step in receiving help with depression is to meet with a mental health professional such as a psychiatrist, psychologist or social worker (Family Caregiver Alliance 2002). The guidance of a mental health professional throughout caregiver treatment is strongly recommended. The therapist or counselor will listen to concerns, screen for symptoms of depression and assist in setting up appropriate courses of treatment (Ibid).

There are a number of ways in which caregivers may locate mental health professionals. One way to find a professional to ask another caregiver or a friend for the name of someone they know and trust. A second way is for caregivers to ask their doctors for suggestions. Ministers or rabbis may be possible sources. Employer's health insurance provider may contain a suggested list of appropriate mental health professionals. National mental health organizations can provide contact information for mental health professionals in the caregivers' community (Ibid).

The important thing for caregivers is to feel they can trust and be comfortable with the professionals they choose. Caregivers may want to request a free introductory phone or in-person meeting to help determine if the professional is the right match for their particular needs and style. Costs of professional care, amount the caregivers' insurance will pay and how many scheduled sessions can be expected with the mental health therapist should be discussed and determined at the outset. Caregivers should have their treatment evaluated regularly to ensure that it continues to contribute towards improving their health (Ibid).

Although caregiving can be challenging, it is important to note that it can also have its rewards. It can give caregivers the feeling of giving back to a loved one. It can also make them feel needed and can lead to a stronger relationship with the person receiving care. About half of caregivers report that (Ibid):

1. They appreciate life more as a result of their caregiving experience.
2. Caregiving has made them feel good about themselves

Part of the reason caregivers often have health a problem is they are less likely to take good care of themselves. For instance, women caregivers, compared with women who are not caregivers are less likely to (Ibid):

1. Get needed medical care.



2. Fill prescriptions because of the cost.
3. Get mammograms.

Also, caregivers report that, compared with the time before they became caregivers, they are less likely to (Ibid):

1. Get enough sleep.
2. Cook healthy meals.
3. Get enough physical activity

## **Grief and Loss**

We learned from the research the first major period of caregiving begins with the initial diagnosis of a debilitating or terminal illness and ends with the death of the loved one. This period of grief involves transition through the various stages of caregiving until the final transition of dealing with the death of the loved one.

It is important for caregivers, family members of caregivers, medical personnel, employers and the religious community to recognize caregiver needs during the first major period of caregiving. It is equally important that they recognize caregiver needs in the second major period of caregiving.

The second period of giving may begin at any point during the transition stages of the first period of caregiving and will come to a close when the grieving process has ended after final stage of caregiving. This second period of caregiving causes grief and loss in the life of the caregiver. Research suggests that caregivers experience both of these simultaneously when the object of their care is approaching death and finally dies. Dr. Larry Lachman suggests the following six phases of loss are the most common reactions which family survivors will experience after losing a loved one (Lachman 2013).

1. Phase I: Crisis and shock. This is the initial emotional reaction to the death of the beloved family member. As with the loved one, this stage frequently includes panic, denial, shock and disbelief in the life of the caregiver.
2. Phase II: Isolation and awareness of loss. This is characterized by not being able to talk about personal grief because of being engulfed with overwhelming feelings of pain and sorrow. Emotions such as anger, guilt, shame and fear are common.
3. Phase III: Anger and the need to withdraw. Anger is a natural part of grief. Grief expert and author, Dr. Catherine Sanders, writes in her book, *Surviving Grief and Learning to Live Again* (Sanders 1992):

“New grief always reminds us of old grief. The pain that has diminished with time is revitalized and experienced anew, when we are again exposed to death. So your spouse's, child's or parent's death will bring up memories of other significant losses that you have experienced. Grieving, therefore, can be very fatiguing.”
4. Phase IV: Reconstruction and healing. Caregivers begin at this stage to feel less overwhelmed and will find themselves gradually having more energy to begin emotional reconstruction.
5. Phase V: Intermittent sadness/depression. This phase is characterized by periods of on-and-off sadness. This kind of reactive sadness or depression is perfectly normal. It is temporary and is to be expected during the grieving process.
6. Phase VI: Renewal. Caregivers find themselves going on with life in this final phase. They begin establishing new goals and forming a new identity that is separate from the one they had with the person they just lost.

## **Anticipatory Grief**

Anticipatory grief can impact the family caregiver in a number of ways. A thorough discussion of the stages of Caregiver Anticipatory Grief was undertaken in an earlier part of this thesis. The purpose in referring to it here is to illustrate three common ways in which caregivers may be impacted by anticipatory grief and thus reveal caregiver needs associated with it. The three ways in which caregivers may be impacted by anticipatory grief are physically, emotionally and spiritually. According to the Kubler-ross, the caregiver may experience a number of grief symptoms during anticipatory grief (Kubler-Ross 1969).

These include but are not limited to:

1. Physical symptoms of anticipatory grief may include the following:
  - a. Low energy
  - b. Exhaustion
  - c. Headaches
  - d. Upset stomach
  - e. Sleeping more than usual
  - f. Pushing themselves to extremes at work
2. Emotional symptoms of anticipatory grief may include:
  - a. Memory Gaps
  - b. Preoccupation
  - c. Irritability
  - d. Depression
  - e. Euphoria
  - f. Rage
  - g. Passive resignation
  - h. Imitate loved ones feelings
3. Spiritual symptoms of anticipatory grief may include:
  - a. Feel closer to God than the past.
  - b. Outrage towards God.
  - c. Feel cut off from God and wondering where He is.
  - d. Temporary paralysis of one's spirit.

## **Post-Mortem Guilt**

Research suggests that Post-Mortem Guilt is one emotion that may interfere with the normal grieving process. Caregivers should remember this is normal and can be expected (Lachman 2013). Caregivers in mourning begin to remember things they did or did not do and should or should not have done to or for their loved ones who have died.

Normally in twelve to thirty-six months, as caregivers' transition through Lachman's six phases of grief, caregivers and their families are able to work through their regrets. They arrive at the conclusion that they tried hard and did the best they could for their loved one (Lachman 2013).

## **Normal and Abnormal Grief**

The inability by caregivers to discern the difference between normal bereavement and what is not normal makes caregiver grieving more difficult. Strange new feelings may make caregivers feel they may be losing it mentally. It is not unusual for caregivers to mistake normal grief for clinical depression (Lachman 2013).

Caregivers should become aware of the differences between grief and depression as described by Lachman (Ibid). With grief, caregivers look at the world as empty while with depression caregivers feel empty. With grief, caregivers maintain their sense of high self-esteem. With clinical depression, caregivers experience low self-esteem. Serious depression may include;

thoughts of suicide, homicide, inability to sleep, not able to converse, sleeping day and night, loss of appetite and refusal to seek or accept help.

Remembering the four Ds that must be present in a person who has a serious psychological disorder will help caregivers' awareness of their mental state.

The four Ds are (Ibid):

1. Distress: The caregiver's feelings and state of mind bothers them intensely.
2. Deviance: Society deems the behavior and state of mind as being abnormal.
3. Dysfunctional: Caregivers' feelings or state of mind prevents them from doing anything such as; working, recreating, schooling or socializing.
4. Dangerous: Caregivers' feelings or state of mind pose a potential or imminent threat to themselves or others.

If caregivers do not have the four Ds, then they should be relieved to know their feelings are normal and they are transitioning through the grieving process.

Caregivers who are grieving should become aware of what general symptoms of grief to look for in their own lives. These include but are not limited to; rage, guilt, terror, fear, dependency, denial, sadness, anger, guilt, loneliness, fatigue, helplessness, shock, relief, acceptance or even numbness.

## **Spousal Grief**

The death of a spouse is experienced by approximately one million Americans each year. Two of three or 65% of surviving spouses are women. About half of the women in America who are sixty-five or older are widows. Less than 10% of those widows ever remarry (Schulz 2001). The majority of widows adjust to their loss within two to four years. About one in five or

20% develop complications during their grieving process (Ibid). These complications include depression, alcohol or prescription drug abuse and or lowered immune systems resulting in greater susceptibility to illnesses (Ibid).

An article in the June 27th, 2001 edition of the Journal of the American Medical Association titled *Involvement in Caregiving and Adjustment to Death of a Spouse*, suggests that the death of a spouse may impact people differently depending on whether or not they served as caregivers (Schulz 2001). The Journal Article examined individuals who had lost their mates and were between the ages of sixty-six and ninety-six. The study indicated that people who did not serve as caregivers tended to have more depression and weight loss after their spouse died, than those who did serve as caregivers (Ibid). What's more, those who were former caregivers took better care of themselves, were less likely to miss doctor appointments and were more likely to get adequate sleep and exercise.

## **Roadblocks to Grief**

We learned from the research that some caregivers find themselves having difficulty transitioning through the grieving process. Unfortunately well-meaning friends and family members may unknowingly contribute to the slowing of this process. Caregivers are almost chastised for their feelings. They are made to feel guilty when told they should not be feeling what they are experiencing or they should get it together and move on with life. The caregiver is hearing that they shouldn't be feeling what they are feeling, their loss is not important, they should not share their feelings with others and the value of their loss is not important and should be replaced (Lachman 2013).

Caregivers in grief should make themselves aware that buying into wrong, though well intentioned comments of others, will only prolong the grieving process and make it more painful than it should be. The original

pain will be compounded by suppressing feelings rather than allowing them to naturally surface. The end result may be the buildup of psychological pressure that over time can lead to a volcanic like psychological explosion (Ibid).

There are more productive and effective ways to cope with grief. Suggestions for how caregivers in grief can better cope with their grief will be discussed in the next section of the thesis. The primary goal in the grieving process is to survive the pain and live beyond it. Three things must happen if the caregivers in grief are to be successful through the grieving process.

1. They must accept that fact emotional pain is part of the grieving process.
2. They must make up their minds they are going to survive the grieving process.
3. They must have faith that there will be life beyond this painful time of grief.

## **Coping With Grief**

Coping with grief for the grieving caregiver begins with becoming aware of what will come their way during this transition in the caregiving journey. Dr. Therese Rando in her book *How To Go on Living When Someone You Love Dies* provides great practical insight into what caregivers can expect during the grieving process in her section called *Grief: Appropriate Expectations* (Rando 1991, 79-80). Caregiver awareness of what to expect can be a tremendous help as caregivers transition through the grieving process.

*Grief: Appropriate Expectations* – Caregivers in grief should expect (Ibid):

1. Their grief will take longer than most people think.

2. Their grief will take more energy than they would have ever imagined.
3. Their grief will involve many changes and be continually developing.
4. Their grief will show itself in all spheres of their lives including psychological, social and physical.
5. Their grief will depend upon how they perceive the loss.
6. They will grieve for many things both symbolic and tangible, not just the death alone.
7. They will grieve for what they have already lost and for what they have lost for the future.
8. Their grief will entail mourning not only for the actual person lost but also for all of the hopes, dreams and unfulfilled expectations they held for and with that person, and for the needs that will go unmet because of the death.
9. Their grief will involve a wide variety of feelings and reactions, not solely those that are generally thought of as grief, such as depression and sadness.
10. Their loss will resurrect old issues, feelings and unresolved conflicts from the past.
11. They will have some identity confusion as a result of this major loss and the fact that they are experiencing reactions that may be quite different.
12. They may have a combination of anger and depression, such as irritability, frustration, annoyance or intolerance.
13. They will feel some anger and guilt or at least some manifestation of these emotions.
14. They may have a lack of self-concern.
15. They may experience grief spasms, acute upsurges of grief that occur suddenly with no warning.



16. They will have trouble with thinking, memory, organization, intellectual processing and making decisions. They may feel like they are going crazy.
17. They may be obsessed with the death and preoccupied with the deceased.
18. They may begin a search for meaning and may question their religion and/or philosophy of life.
19. They may find themselves acting socially in ways that are different from before.
20. They may find themselves having a number of physical reactions.
21. They may find that there are certain dates, events, and stimuli that bring up surges in grief.
22. Society will have unrealistic expectations about their mourning and may respond inappropriately to them.
23. Certain experiences later in life may resurrect intense grief for them temporarily.

There is a combination of factors that impact caregiver grief.

Caregivers should become aware that their grief will bring an intense amount of emotion that will surprise both caregivers and those around them. Their grief will not only be more intense than they expected, but it will also be manifested in more areas and ways than they anticipated. Caregivers in grief can expect brief upsurges of emotion on anniversaries and holidays. These times remind caregivers of what they have lost.

Caregivers' coping with their grief will be depend greatly on how much they have lost, their personalities, the type death the care receiver experienced, how much support caregivers receive from family and friends and caregivers' physical health (Lachman 2013).

Dr. Lachman's article *Grief & Loss: Caring for the Caregiver after Death* overs a number of steps will help caregivers transition through the grieving process (Lachman 2013).

1. Caregivers should review the six phases of grief that people in mourning typically go through, mentioned earlier in this thesis, and normalize the bad feelings they are experiencing.
2. Caregivers should be aware that it didn't take an hour to become close and connected with their recently departed loved one, so it will take more than an hour to get over the pain of their loss. The relationship they established with their spouses, parents or child took place over time. Likewise, the grief process and the painful feelings associated with it will also take time to resolve.
3. People grieve at different rates in different ways. There is no fixed way of grieving, including the six phases mentioned earlier. Caregivers should take their time. There is no ONE right way to grieve. The most intense feelings of loss can take from one to three years to dissipate before emerging from the emotional abyss of grief.
4. Caregivers should keep in mind they will grieve as deeply as they loved. The more they loved someone, the deeper they will grieve.
5. Beware of reminders. When caregivers are grieving, almost anything and everything can remind them of their loved ones. Simple things like songs on the radio, smells at restaurants and favorite cereals at the supermarket to name a few. Anniversaries, birthdays, Christmas, Thanksgiving, Mother's Day and Father's Day are typically the most difficult times a year for those who are grieving. Caregivers should be prepared. It is absolutely normal to sink into the emotional abyss and feel deeply saddened, to feel pain and miss the person loved during these times. The first two years are the most difficult for getting through the holidays. Beginning with the third year, the pain is less painful; the sadness is a little less sad and the sobbing less intense. When one of these significant holidays comes about, expect to take a step or two backwards for every step forward made in grief. Caregivers should surround themselves with soulfully supportive

people. They should do what they need to do for their mind, body and spirit to ritualize and acknowledge their pain.

6. Caregivers in grief sometimes either idolize or demonize the person for whom they are grieving. Either the spouse or parent continues putting the deceased partner or child up on a pedestal as if they could do no wrong or they concentrate on all the bad and inconsiderate things that the person did while they were still alive. Both of these tendencies are to protect the soul. These protective maneuvers reduce pain. It's very hard for a recently bereaved person to think about all the bad things that their departed love one did when they were alive, without feeling pangs of guilt for thinking such thoughts. However, by not doing this, it causes caregivers to become soulfully out of balance and keeps them stuck in their grief. Caregivers in grief must work through the fear of thinking that anything negative about their departed loved one would be disrespectful in some way. Sooner or later, they must be able to do this in order to fully let go and say good-bye to the person who they've lost.
7. Similar dynamics are also true for caregivers who demonize their lost loved one. It's always easier to say good-bye or let go of someone when angry and indignant instead of being hurt or feeling sad. Our anger masks the pain and empowers us to say what we need to say and move on. However, anger is a secondary emotion which is fueled by two other primary emotions: hurt and fear. These feelings frequently arise from the shadow side of our soul. Until those feelings of hurt and fear are brought out and dealt with, caregivers in grief will not be able to move forward in their mourning process. Caregivers in mourning must say good-bye and do this by looking at the whole person for whom they are grieving, both the good and the bad.
8. Caregivers in grief need to be aware that they will often come out of their experience of caretaking feeling like a battle-fatigued soldier

returning from war. In addition to normal feelings of grief, caregivers may experience symptoms of Post-Traumatic Stress Disorder, which includes: nightmares, flashbacks, depression, anxiety and avoiding all places, people and activities that were associated with the trauma of caregiving. This is normal, but sometimes may have to be dealt with in one-on-one therapy with a licensed psychologist familiar with treating PTSD. Sometimes medication, twelve weeks or so, may be needed to help caregivers sleep and feel less depressed or anxious. Sleep aides like Ativan, and anti-depressants like Paxil, Prozac or Celexa may be needed. These can be prescribed by family physicians or consulting psychiatrists. Caregivers in grief who feel that may be suffering from PTSD, you should make an appointment with their physician or get a referral to a psychiatrist who can provide the proper medication needed.

9. Caregivers in grief sometimes begin to feel lost as if they are like a ship without an anchor. They had defined themselves through familiar roles such being a wife, mother, or daughter. Once their husband, child or parent is gone, they now feel like they no longer have any roles. In essence, they feel role-less! Caregivers must find ways to find new roles. They must re-define who they are by determining what they want out of life. They must establish a new set of goals. This is a difficult process, but with time, sharing and bouncing ideas off of others, they gradually develop their own new normal.
10. Grieving is fatiguing. Caregivers in grief should give themselves permission to be less than perfect. Caregivers may not be able to do the things they normally did before their loss due to not enough energy to keep up with their current obligations. Caregivers in grief, who experience grief related fatigue, will often feel guilty for not being super mom, super husband or super human being. This is a difficult issue because it's connected with self-worth stemming from

personal history and how much encouragement was given while caregivers were growing up. Many caregivers were raised with the admonition to put other people's needs first rather than becoming self-absorbed or being selfish by tending to their own needs.

Lachman reminds caregivers that they can only show others love, care and compassion if they first have it for themselves. Caregivers must be okay with giving to themselves first, before they can successfully give to others. Caregivers must be willing to nourish their own souls before they can help nourish someone else's.

Caregivers should remind themselves about all that they sacrificed providing care and now it's time to allow them to receive some of that very same care from others while grieving.

## **Caregiver Resources**

### **Religious Support**

The Stephen Ministry (The Stephen Ministry 2013)

The Stephen Ministry offers courses and ministry systems to fit the needs of every congregation and adult education ministry. Lay caregivers, called Stephen Ministers, provide one-to-one Christian care to the bereaved, hospitalized, terminally ill, separated, divorced, unemployed, and relocated and others facing a crisis or life challenge. Stephen Ministry helps pastors enhance caring ministries by ensuring that quality follow-up care is available for as long as it is needed.

The Stephen Series is a complete system for training and organizing laypeople to provide one-to-one Christian care to hurting people in and around your congregation.

Since 1975, the Stephen Ministries organization, based in St. Louis, Missouri, has helped more than 11,000 congregations implement The

Stephen Ministry. These congregations represent more than 150 denominations and come from all fifty states, ten Canadian provinces and twenty-three other countries.

There are a number of ways the Stephen Ministry benefits pastors, laypeople, hurting people and congregations.

These are (Ibid):

1. *Pastors* don't carry the burden of being the congregation's sole caregiver. They have a team of gifted, trained and committed lay caregivers ready to minister to hurting people inside and outside the congregation.
2. *Laypeople* have a chance to use and strengthen their leadership and caregiving gifts in meaningful ministry, serving others while experiencing tremendous spiritual growth.
3. *People who are hurting* no longer suffer alone. A caring Christian friend comes alongside them to provide emotional and spiritual care for as long as the need persists.
4. *Congregations* have a practical, powerful way to:
  - a. To equip God's people for the work of ministry, for building up the body of Christ as Ephesians chapter four and verse twelve instructs.
  - b. To love one another as I have loved you as John chapter thirteen and verse thirty-four instructs.
  - c. To bear one another's burdens and in this way fulfill the law of Christ as Galatians chapter two and verse six teaches.
  - d. Go make disciples as Matthew chapter twenty-eight and verse nineteen commands. .

National Caregiver's Library (National Caregivers Library 2013)

The National Caregivers Library was created by Family Care America, Inc. and is one of the largest single sources of information and tools for caregivers and seniors in the country. It makes its resources available to caregivers for free through alliances with professionals, businesses and other organizations who serve seniors and their caregivers with a variety of products and services (Ibid).

The library consists of hundreds of useful articles, forms, checklists and links to topic-specific external resources. It is organized into logical categories that address the key needs of caregivers and their loved ones (Ibid).

The library also includes an entire section for employers. It provides tools to help employers understand the impact of caregiving on their people and on the organization itself. It provides tools to help identify the organizational costs of working caregivers and ways to analyze, justify, develop and implement Caregiving and Eldercare programs to help employees (Ibid).

*Caregiving Ministries* ([www.CaregivingMinistries.org](http://www.CaregivingMinistries.org)) provides valuable resources for clergy, church leaders and caregivers including tools and support for starting ministry programs, organizing and motivating volunteers, and funding ministry programs (Ibid).

As a clearinghouse for the exchange of ideas and programs that minister to those in need, Caregiving Ministries serves as a repository for the best of breed ministry programs in order to accelerate the creation and implementation of care ministries by shortening the research and study process (Ibid).

*How To Reach Caregivers* provides integrated business development, networking and prospecting programs for businesses, professionals and organizations that sell to, support seniors and their caregivers (Ibid).

Someone Who Cares (Leal 2013)

Their mission is to help churches and caregivers focus on the One who cares for them as they care for those they love.

In an effort to meet their mission, they create and present inspiring conferences for caregivers, church staff, lay leaders and others who care. Conferences are designed to reach those who are searching for spiritual comfort, relief and direction as they experience the loss, frustration, anger, grief and joy of caregiving.

Their first goal is to help the church community learn how to more effectively serve the caregiver by:

1. Praying for the Caregiver.
2. Learning from the Caregiver.
3. Caring for the Caregiver.
4. Grieving with the Caregiver.

The second goal is to help caregivers understand that part of having their needs met comes from learning to ask and also understanding what churches can and can't do for them. The conference is an opportunity for respite while participants gain better caregiver skills.

#### The Christian Caregiver (Frommer 2013)

The Christian Caregiver, a fellowship of support, is a ministry looking to Jesus as our primary shepherd in the calling as caregivers. Caregivers will learn to see Jesus at work in and through their service. While caregivers may find their task difficult, they learn to accept this time as God's calling.

#### Christian Forums (Christian Forums 2013)

Caregivers & Family Support is a new forum for caregivers and family members of the unwell.

## **Secular Resources**



Taking some time off from caregiving can reduce stress. Respite care provides substitute caregiving to give the regular caregiver a much-needed break. Below are the various types of respite services that are available (Greene 2008):

1. *In-home respite*. In this type of service, someone comes to the caregiver's home to provide care. The type of care can range from simple companionship to nursing services.
2. *Adult day-care centers*. Many adult day-care centers are located in churches or community centers. Some day-care centers provide care for both elderly adults and young children. During the day, the two groups meet for several hours to share in activities such as reading stories. This type of contact seems to benefit both young and old.
3. *Short-term nursing homes*. If loved ones need occasional nursing care and caregivers must leave town for a short periods of time, some nursing homes will provide care for loved ones on a short term basis while caregivers are gone.
4. *Day hospitals*. Some hospitals provide medical care to patients during the day and then the patient returns home at night.

There are devices that caregivers can purchase that can help caregivers make sure that their loved ones are safe (Greene 2008).

Below are some examples:

1. *Emergency response systems* involve a button on a necklace, bracelet, or belt that loved ones wear. If an emergency arises and caregivers are not home, the loved one simply presses the button to alert a monitoring center. The center then alerts medical personnel and caregivers. These systems are intended for people who can press the button and do not have dementia.

2. *Intercom systems* allow caregivers to hear their loved ones from another area of the house.
3. *Webcam* is a video camera that allows caregivers to observe their loved ones from another area of their homes.
4. *Mobility monitors* use a small transmitter to help keep track of people with dementia. When loved ones wearing a transmitter strapped to their ankle or wrist moves out of a set range, the transmitter alerts caregivers that their loved one is wandering away.
5. Researchers are developing technologies to allow doctors and nurses to examine and treat patients from locations different than the patient's. This new field is called *telemedicine*. It uses a communication system, like the Internet or two-way television, to collect medical information and provide instructions to the caregiver and patient. *Telemedicine* will be most useful in rural areas where few doctors are available. Some states already have limited *telemedicine* programs in operation.

There are normally numbers of caregiving services available in most communities. Caregivers should contact their local *Area Agency on Aging* to learn about caregiving services where they live (Greene 2008). *Area Agency on Aging* is usually listed in the city or county government sections of the telephone directory under Aging or Health and Human Services. The *National Eldercare Locator*, a service of the U.S. Administration on Aging, can also help caregivers find local *Area Agency on Aging* (Greene 2008).

Caregivers may also consult with eldercare specialists, professionals who specialize in aging related issues. Eldercare specialists assist older adults and their family members by assessing their needs and identifying the best services and devices available to meet those needs (Ibid). Caregivers should consult with their doctors or local *Area Agency on Aging* in finding an eldercare specialist in their area (Ibid).

Caregivers often face the challenge of paying for caregiving services. Medicare, Medicaid and private insurance companies will cover some of the costs of home health care. Other costs will have to be paid for by caregivers themselves (Ibid).

Costs associated with home care depend on what services are used. Non-medical workers like housekeepers are much less expensive than nurses or physical therapists. Also, some home care agencies are less expensive than others (Ibid).

Caregivers can determine their eligibility for Medicare home health care services by reading the free publication *Medicare and Home Health Care* Publication number CMS-10969 which is available at <http://www.medicare.gov/Publications/Pubs/pdf/10969.pdf>. They can also call Their *Regional Home Health Intermediary* or MEDICARE directly at 1-800-633-4227 (Ibid).

Caregivers' income must be low and they must possess few other assets to qualify for Medicaid help. Caregivers may call their local State Medical Assistance Office to enquire about qualifications to receive Medicaid.

There is another federal program called the National Family Caregiver Support Program which helps states provide services for family caregivers.

To be eligible for the program caregivers must (Ibid):

1. Care for an adult aged sixty and older.
2. Care for a person of any age with Alzheimer's disease or a related disorder.
3. Be a grandparent or relative fifty-five years of age or older who is the primary caregiver of a child under age eighteen.

4. Be a grandparent or relative fifty-five years of age or older providing care to an adult aged eighteen to fifty-nine who has a disability.

The types of services offered in each state vary but include services like (Ibid):

1. Information about which services which are available.
2. Help with accessing support services.
3. Help with individual counseling and organization of support groups.
4. Caregiver training.
5. Respite care.
6. Supplemental services, supplies and equipment such as home modifications, emergency response systems, nutritional supplements, incontinence supplies, etc.

Typical caregiving services include but are not limited to (Ibid):

1. Transportation
2. Meal delivery
3. Home health care services such as nursing or physical therapy.
4. Non-medical home care services such as housekeeping, cooking or companionship.
5. Home modification. Changes to the home that make it easier for loved ones to perform basic daily tasks such as bathing, using the toilet and mobility.
6. Legal and financial counseling.

#### Hospice (NHPCO 2013)

The National Hospice and Palliative Care Organization was founded in 1978 as the National Hospice Organization. The organization changed its name in February 2000 to include palliative care (Ibid).

Many hospice care programs added palliative care to their names to reflect the range of care and services they provide as hospice care and palliative care share the same core values and philosophies. Defined by the World Health Organization in 1990, palliative care seeks to address not only physical pain, but also emotional, social and spiritual pain to achieve the best possible quality of life for patients and their families (Ibid).

Palliative care extends the principles of hospice care to a broader population that could benefit from receiving this type of care earlier in their illness or disease process. To better serve individuals who have advanced illness or are terminally ill and their families, many hospice programs encourage access to care earlier in the illness or disease process. Health care professionals who specialize in hospice and palliative care work closely with staff and volunteers to address all the symptoms of illness, with the aim of promoting comfort and dignity (Ibid).

A wide range of services is provided by nurses and other health care providers within the hospice program. The variety of services provided by the hospice care team include but are not limited to the following (National Association of Home Care and Hospice 2013):

1. *Nursing Care*: Registered nurses coordinate the care for every patient, provide direct patient care and check symptoms and medication. Patient and family education is an important part of every visit. The nurse is the link between the patient and his or her family and the physician. The nurse can also help evaluate the patient's condition.
2. *Medical Social Services*: The social worker provides advice and counseling to the patient and all family members during the crisis period. The social worker assists other care team members in understanding the family dynamics and acts as an advocate for the patient and family in making use of community resources.
3. *Physician Services*: The patient's physician approves the plan of care and works with the hospice team. In a full hospice program, a hospice

medical director is available to the attending physician, the patient and the hospice care team as a consultant and a resource.

4. *Spiritual Support and Counseling*: Clergy and other counselors are available to visit and provide spiritual support to the terminally ill at home. Programs also use churches and congregations to aid the patient and family as requested.
5. *Home Care Aide and Homemaker Services*: Home care aides provide personal care for the patient, such as bathing, shampooing, shaving and nail care. Homemakers may be available for light housekeeping or meal preparation.
6. *Continuous Care in the Home*: If the patient's needs require it or if the family can no longer manage the level of care required around the clock, hospice staff will provide care for eight-hour to twenty-four hour periods on a short-term basis.
7. *Trained Volunteers for Support Services*: Early hospices were founded and operated by volunteers. These dedicated people continue to be the backbone of today's hospice. They are trained in good listening skills and provide compassionate support for both patient and family. They offer companionship and help with everyday tasks such as shopping, babysitting and car-pooling which are parts of the family's routine. Volunteer services may also include professional and personal care services as described in the above sections.
8. *Physical, Occupational, and Speech Therapies*: Daily living tasks such as walking, dressing or feeding oneself can become frustrating and impossible during an illness. Therapists help the patient develop new ways to accomplish these tasks.
9. *Twenty-four Hour On-call Availability*: A hospice team member is on call twenty-four hours a day, seven days a week. If a problem should arise, the team member may offer advice over the phone and make a visit if necessary.

10. *Hospice In-patient Care*: Although hospice care is centered in the home, it sometimes becomes necessary to admit the patient to a hospital, extended care facility or the hospice in-patient facility. The hospice team can arrange for this care and will stay involved in the patient's treatment and with the family, resuming in-home care when appropriate.
11. *Respite Care*: To provide relief for family members, the hospice may arrange a brief period of in-patient care for the patient.
12. *Bereavement Support*: Bereavement is the time of mourning that we all experience following a loss. The hospice care team works with surviving family members to help them through the grieving process. Support may include a trained volunteer or counselor visiting the survivors at specific periods during the first year, or phone calls and/or letter contact and the opportunity for family members to participate in support groups. The hospice will refer survivors to medical or other professional care if necessary.

Carol J. Farran in her article in *The American Journal of Alzheimer's Care and Related Disorders & Research*, November/December, 1989 issue suggests twelve steps for caregivers to consider that are applicable to most caregiving situations (Farran 1989). Farran encourages caregivers to personally commit themselves to each one of the following steps:

1. I cannot control the disease process, but I can control many aspects of how it affects me and my relative.
2. I will simplify my lifestyle so that my time and energy are available for things that are really important at this time.
3. I will take care of myself so that I can continue doing the things that are most important.
4. I will cultivate the gift of allowing others to help me, because caring for my relative is too big a job to be done by one person.

5. I will take life one day at a time rather than worry about what may or may not happen in the future.
6. I will structure my day, because a consistent schedule makes life easier for me and my relative.
7. I will keep my sense of humor, because laughter helps to put things in a more positive perspective.
8. I will remember that my relative is not being difficult on purpose, rather that his/her behavior and emotions are distorted by the illness.
9. I will focus on and enjoy what my relative can still do rather than constantly lament over what is gone.
10. I will increasingly depend upon other relationships for love and support.
11. I will frequently remind myself that I am doing the best that I can at this very moment.
12. I will draw upon the Higher Power, which I believe is available to me.



## **CHAPTER V: SUMMARY AND CONCLUSIONS**

### **Summary of Study**

This former caregiver examined the transition of caregivers through the grieving process and discovered caregivers' feelings and experiences as they move through two very important periods of caregiving.

1. Period One: From caregiving to grieving.
2. Period Two: From grieving to post-grief recovery.

The explorative method of research was used to investigate, analyze and critique caregiver's needs during these caregiving transition periods. The researcher discovered the following:

1. Four out of five or eighty percent of care recipients receive care by an unpaid family member.
2. One in three Americas is a primary unpaid family caregiver.
3. The average age of these family caregivers is 49.2 years of age.
4. Family caregivers spend an average of 4.6 years providing care for each care recipient.
5. Family caregivers transition through up to six stages care provision for care recipients beginning with the initial diagnosis of illnesses through the dying process.
6. Family caregivers' final transition stage begins with anticipatory grief and culminates with post-grief recovery.
7. Caregiving places caregivers' health at high risk.
8. Caregiving impacts caregivers on three levels; physically, emotionally and spiritually.
9. Caregivers experience feelings of high levels of stress.

10. Caregivers feel isolated and alone.

11. Caregivers need recognition, encouragement and support from family, friends, church and community as they fulfill their roles as primary care providers.

The study created needs awareness for caregivers and developed methods to help and minister to caregivers during their time of caregiver transition. The study compiled information to help caregivers become better aware of what the role of caregiver entails and what to expect as the role evolves. This includes stages of care their care recipients will pass through and caregiver responsibilities during each stage. Caregivers are also provided with tools to help them transition through the caregiving process.

## **Final Conclusions**

The research shows the importance of unpaid family caregivers in America. These family caregivers will become even more important as the baby boomer generation continues to age and need care.

The research affirms the reality of periods of transition for caregivers through the grieving process. It correctly reinforces how difficult the caregivers' role becomes as caregivers transition through the periods of caregiving. The study affirms this former caregiver's assertion of the need for caregivers' awareness of their own feelings and needs. It also educates family members of caregivers, medical professionals, congregations, religious leaders and members of the community about the important role unpaid family caregivers fulfill and how they may be helped and encouraged. This understanding can be used by others to enhance physical, emotional and spiritual help for caregivers and to develop programs of assistance for them.

The study has effectively demonstrated *caregiver transition through the grieving process*.

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