

Alzheimer's Disease

An Eclipse before Sunset

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Palabra Publications
Riviera Beach, Florida

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Alzheimer's Disease: An Eclipse before Sunset was originally published in *The Journal of Bahá'í Studies* (vol. 1, no. 3).

Printed in the United States of America
Design by Suni Hannan

ISBN 1-890101-19-2

Foreword

Professor Ghadirian's booklet captures the bittersweet experience of Alzheimer's disease. For sufferers, the eclipse is often painfully visible before sunset occurs. For those who support sufferers, the distress is equally intense and even longer lasting.

The dual roles of physicians and, by extension, those who support sufferers of any disease, are to restore functioning and relieve suffering. With Alzheimer's disease, lasting restoration of functioning is presently impossible but maintenance of remaining function at its best level is feasible through thoughtful structuring of supportive services and, sometimes, medications. Emphasizing what can still be done rather than lamenting the loss of faculties and functions is an appropriate and gratifying goal in Alzheimer's disease.

Relieving suffering is done more through care, concern and empathy for our universal humanness. Professor Ghadirian's pamphlet offers a great deal of helpful guidance. As Francis Weld Peabody said, "The secret of the care of the patient is in caring for the patient."

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Introduction

With the growing number of elderly people in society and with the rapid advancement of medical knowledge and technology, we are recognizing an increasing number of individuals who suffer from a progressive impairment of intellectual function first discovered at the turn of the century by Alois Alzheimer, a German physician. Alzheimer's disease usually strikes those who are elderly; its cause and cure are unknown. Caring for patients with Alzheimer's disease, whether by family and friends or by nursing home and health institution staff, is a formidable task. Even though patients in the advanced stages of the disease may be disturbed, suspicious, and ultimately become helpless, caregivers should be aware of the patients' psychological and spiritual needs. This booklet offers some thoughts and suggestions based on clinical observations and illumined by the Bahá'í teachings. This is a revised and updated version of a paper on the subject originally published in The Journal of Bahá'í Studies.

*Consider how the human intellect
develops and weakens,
and may at times come to naught,
whereas the soul changeth not.*

—‘Abdu’l-Bahá

Aging is one of the most important social phenomena of the twentieth century, and the aging population is rapidly increasing. According to the United Nations, it was estimated that in 1950 there were approximately 200 million persons aged sixty or over throughout the world. By 1975 their number had risen to 350 million. The United Nations’ projection for the year 2000 suggests that this number will increase to 590 million and by the year 2025 will rise to over 1,100 million. This is an increase of 224 percent in the fifty-year span since 1975. During the same period, the world’s population is expected to increase from 4.1 billion to 8.2 billion, an increase of almost 102 percent. It is therefore estimated that by the year 2025 about 13.7 percent of the world’s population will be aged people. In 1975 it was reported 52 percent of all individuals aged sixty or over lived in developing countries, and if this trend continues, that percentage will increase to 72 percent by the year 2025 (United Nations, *Vienna*). As the proportion of aging people increases, the problem of caring for and coping with elderly people suffering from dementias such as Alzheimer’s disease will be one of the greatest challenges facing medicine, public health, and society at large.

Alzheimer’s Disease in an Aging Society

Alzheimer’s disease is a type of dementia, and more than 50 percent of all dementia patients suffer from Alzheimer’s disease (Thal, “De-

mentia” 5). According to the most recent definition of the American Psychiatric Association, the diagnosis of dementia is based on the presence of the following symptoms: (1) demonstrable evidence of impairment in short-term memory with inability to learn new information and impairment in long-term memory with inability to recall information that was known in the past; (2) impairment in abstract thinking, characterized by the inability to find similarities and differences between related words and their meanings; (3) impaired judgment and disturbances of higher cortical (brain) function; and (4) personality changes and disturbances that significantly interfere with work, usual social activities, or relationships with others (American Medical Association, *Diagnostic and Statistical Manual* 107).

Due to the difficulty of establishing a precise diagnosis of Alzheimer’s disease, its prevalence is not clearly known. However, its risk of occurrence is age-related. According to the best estimates available, senile dementia including Alzheimer’s disease affects almost 15 percent of all individuals over the age of sixty-five (Glenner, *Alzheimer’s* 275). It has been estimated that approximately 1 percent of the population is at risk for this disease by the age of sixty-five. The risk of illness rises after age sixty-five to 5 percent and for those eighty years and older to 20 percent (Small, “Psychopharmacological” 8). This figure rises to as much as 47 percent for people who are eighty-five years or older (Small, *Alzheimer’s* 2562). There are over 300,000 Canadians who are affected by Alzheimer’s disease. It has been reported that “about 2 million individuals suffer from Alzheimer’s disease . . . ranking it as the fourth leading cause of death in the United States” (Glenner, *Alzheimer’s* 275). A diagnosis of Alzheimer’s disease indicates a 50 percent reduction in life expectancy (Glenner, *Alzheimer’s* 275).

Biological Dimensions

The biological cause of this illness is not clearly known, but some possible contributing factors have been identified. Age appears to be

the most important factor, and aging of the brain is being carefully studied. Alzheimer, who discovered this illness over ninety years ago, described the disease as a form of accelerated aging.

Genetic predisposition is also an important factor, for the illness is more prevalent in certain families. There is a higher prevalence of the illness among women, but it remains to be seen whether this is because of a greater longevity and higher number of older women in society as compared to men or whether it is due to some as yet unrecognized hormonal and environmental changes in the life of women, (Blass and Poirier ptd. in Gauthier *Clinical Diagnosis and Management*).

A number of theories of the cause of Alzheimer's disease—viral infection, aluminum toxicity, chromosomal abnormalities, cerebrovascular amyloidosis, immunological deficiencies, and deficits in the cholinergic system of the brain—have been proposed, but none has been proven. It is possible that the disease is not caused by a single factor but rather by a combination of factors or an accumulation of insults to the brain.

In the process of aging there is a loss of the larger neurons (nerve cells) of the brain. In patients suffering from dementia, particularly of the Alzheimer type, there are numerous plaques of degenerated neuronal cells (neurofibrillary tangles) in the hippocampus and cortical regions of the brain. The appearance of these plaques in the dominant or non-dominant hemisphere of the brain can make a difference in the symptoms of Alzheimer's disease due to the asymmetry of brain function.

Research towards discovering a cure for this illness has been intensified in recent years. Despite significant progress, finding a cure has been as elusive as uncovering a cause. Alzheimer's disease is a complex illness characterized not only by impairment of intellectual function but also by behavioral and personality deterioration, making its treatment is complex as well. In recent years the cholinergic theory of this illness attracted considerable interest and led to the discovery of medications which for the first time brought about symptomatic improvement of memory functioning in some patients. This

approach was based on observations suggesting loss of cholinergic neurons in some parts of the brain. (Gauthier, *Clinical Diagnosis and Management*)

Psychosocial Dimensions

It seems as if science and technology have paved the way for the rise of an aging population before the human mind and soul were prepared to cope with all the physical, psychological, social, and spiritual implications of this phenomenon. At a time when we are unraveling the mysteries of the universe and conquering nature to our advantage, we face one of our worst fears—the fear of losing our intelligence and memory.

Loss of conscious awareness and the intellectual ability to appraise life circumstances and to maintain a dynamic and effective relationship with the world can be devastating, particularly at a time when, due to aging, our physical, emotional, and psychological strength are declining. The power of understanding is described as the most valuable asset of human reality. The loss of this power presents itself like a monster at the end of the human journey or an eclipse before sunset.

The tragic impact of Alzheimer's disease affects not only the victim but also the relatives, who find a loved one slowly withering into confusion and oblivion or turning into a mistrustful and belligerent stranger in their midst. One patient with Alzheimer's disease was unable to remember that each night she would get up and go to the refrigerator for a snack. In the morning she would accuse others of stealing her food. For the caregivers, living with such an individual is a test of tolerance and love, particularly if they don't know the vicissitudes of the illness.

Patients with Alzheimer's disease show their symptoms in different ways according to their personality structure and the extent of their illness. It is believed that Alzheimer's disease progresses more rapidly when it appears in younger people. In general, after discover-

ing that they are losing their memory, a process over which they have no control, they may experience a sense of helplessness and despair.

In the next stage patients express considerable mistrust and anger—a protest against what they have lost. Loved ones can no longer be trusted, and home is no longer home. Life becomes very lonesome as they withdraw into a state of total resignation and progressively slip into a dark world of oblivion. At times a lucid presence of mind and clear memory reappear, but like the rays of the sun piercing through a dense cloud, they are sparse and momentary. As the illness progresses patients eventually move toward a vegetative state in which they become entirely dependent on others for their survival.

At other times patients may be totally confused and, in some cases, hallucinate and experience delusions. They may complain bitterly of persecutions. Their behavior may become inappropriate, entirely contrary to their personal values and hence a great embarrassment to their family. They may speak to people who are not present and who, in fact, may have died years ago. They may misidentify strange people as their relatives and reject some of their loved ones as total strangers.

People with Alzheimer's disease are very sensitive to rejection; in fact, symptoms of mistrustfulness may serve as a defense against rejection. As a result of fear of loss of control over themselves and their possessions, demented patients may decide to protect their belongings by hiding them. When they fail to find what they have hidden, they suspect others, usually the closest relative or friend, as the culprit. It is very painful for a loved one to be accused of wrongdoing and yet maintain a loving relationship with such a patient. But this is the very challenge that family members and caregivers face, as most of the mistrustful ideations are consequences of memory loss and symptoms of the illness.

Memory Changes

Although progressive memory impairment is a characteristic symptom of Alzheimer's disease, a distinction should be made between a normal memory loss and normal forgetfulness. The following table shows some features of normal and abnormal memory losses.

Average Person	Alzheimer's Patient	Older Person
Is seldom forgetful	Often forgets entire experiences (e.g., may not remember eating and demands a meal)	Forgets part of an experience (e.g., can remember eating but doesn't remember what fruit was served at lunch)
Remembers later	Rarely remembers later	Often remembers later
Acknowledges memory lapses lightly	Acknowledges lapses grudgingly after initial denial and attempts to compensate for lapse	Acknowledges lapses readily, often with a request for help in recalling information
Maintains skills, such as reading words or music	Skills deteriorate	Skills usually remain intact
Follows written or spoken directions easily	Increasingly unable to follow directions	Usually able to follow directions
Can use notes or reminders	Increasingly unable to use notes or reminders	Usually able to use notes or reminders
Can care for self	Increasingly unable to care for self	Usually able to care for self

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Spiritual Dimensions

Although patients with Alzheimer's disease lose their memory and intellectual faculties, they often maintain a sense of intuition and a mysterious spiritual awareness. This awareness, which they are unable to articulate and express, transcends the barrier of their illness.

In the Bahá'í writings, special emphasis has been put on the human spirit as a "Divine Trust." According to 'Abdu'l-Bahá this Divine Trust "must traverse all conditions, for its passage and movement through the conditions of existence will be the means of its acquiring perfections" (*Some Answered Questions* 200). Furthermore, 'Abdu'l-Bahá indicates that "The temple of man is like unto a mirror, his soul is as the sun, and his mental faculties even as the rays that emanate from that source of light. The ray may cease to fall upon the mirror, but it can in no wise be dissociated from the sun" (*Bahá'í World Faith* 346–47). From this remark we can discern that if mental faculties such as intelligence and memory (like the rays of the sun) become impaired, this by no means indicates that the soul has ceased to function; rather it means that the instrument (the brain or mirror) is unable to reflect the power of those faculties. Likewise, if the computer breaks down, it is not an indication that the programmer has ceased to exist.

In the Bahá'í teachings the relationship between mental illness and the human spirit is like the relationship between the cloud and the sun. Bahá'u'lláh states:

Consider . . . the sun when it is completely hidden behind the clouds. Though the earth is still illumined with its light, yet the measure of light which it receiveth is considerably reduced. Not until the clouds have dispersed, can the sun shine again in the plenitude of its glory. Neither the presence of the cloud nor its absence can, in any way, affect the inherent splendor of the sun. The soul of man is the sun by which his body is illumined, and from which it draweth its sustenance, and should be so regarded. (Bahá'u'lláh, *Gleanings* 155)

As the cloud prevents the sun from illuminating the earth, likewise mental illness prevents the soul from showing its power through the instrument of the body. The movement or the density of the clouds will have no effect on the natural quality of the sun, which is to shine. Likewise, the spirit, ‘Abdu’l-Bahá explains, is “changeless” and “indestructible” (*Paris Talks* 65).

Know thou that the soul of man is exalted above, and is independent of all infirmities of body or mind. That a sick person showeth signs of weakness is due to the hindrances that interpose themselves between his soul and his body, for the soul itself remaineth unaffected by any bodily ailments. (Bahá’u’lláh, *Gleanings* 153–54)

Therefore mental and physical illnesses have no bearing on the progress of the human spirit. The spirit will continue to advance, as progress is one of the essential qualities of the human spirit. Thus it is conceivable that a person may suffer from mental or neurological illness and yet maintain his inherent spiritual capacity.

There are certain misunderstandings concerning the relationship between spirituality and human involvement in life crisis and environmental stress. One of these is the assumption that “being more spiritual” means having fewer problems to deal with or having no problems at all. “Being spiritual” can also mean that we may have to face as many problems as anyone else but that our capacity for tolerance and our ability to accept stressful life events will grow with our vision of life and its destiny (Ghadirian, *Ageing*). A traveler on a long journey should realize that there might be unexpected surprises, such as changes in climate, hazards of the road, unfriendly encounters, and new adaptations that have to be made to arrive at the destination. Crises should be taken as new challenges for personal growth.

Caring for Patients with Alzheimer's Disease: A Family Challenge

The most formidable challenge facing the family is to accept the reality of the illness, that it exists, that it has struck a loved one, and that it will persist until the end of the victim's life unless medicine discovers a cure. Because there is no cure for Alzheimer's disease at present, long-term care for these patients is a major challenge for family members and other caregivers. Indeed, it has been reported that approximately one-third of those caring for patients with Alzheimer's disease suffer from exhaustion and stress as well as from injuries sustained as a result of the physical task of caring for these patients ("News & Notes").

There are a number of myths and misconceptions about patients with Alzheimer's disease, one of which is that because of loss of memory these patients do not suffer much from the impact of the illness. But close observation indicates that unless in the advanced stage, many of these patients show an intuitive awareness and painful realization of their intellectual impairment, which they very often deny. Another misconception is that, through intellectual stimulation, the caregiver can help patients regain their lost memory. Consequently in some families the spouse or other caregivers may resort to harsh and persistent memory exercises, whose only results are frustration and a feeling of helplessness. Patients with Alzheimer's disease will continue to lose memory and the ability to learn new intellectual skills unless a treatment is found.

Mace and Rabins in their book, *The 36-Hour Day*, extensively discuss issues pertaining to caring for patients with Alzheimer's disease. They urge caregivers to avoid confrontation or argumentation. Life should be made as easy and as simple as possible, avoiding complicated messages and signals, because patients with Alzheimer's disease cannot follow these for proper decisions. Decision making can become particularly difficult when there are many choices. In normal circumstances, decisions are made on the basis of facts; in Alzheimer's

patients, memory fails to assimilate and present the facts, often leading to decisions that are irrelevant to current situations.

Another misconception arises from the fact that patients with Alzheimer's disease generally look healthy prior to their terminal stage. Because of this healthy appearance, caregivers and friends are at times reluctant to recognize or accept the tragic impairment taking place within the patient. They expect sufferers to perform as well intellectually and emotionally as they appear physically.

In caring for patients with Alzheimer's disease, as in any other cases of dementia, one should look beyond the person who is mentally impaired and confused. According to 'Abdu'l-Bahá, the mind is circumscribed, but the soul is limitless. Caregivers should reach for that limitless soul. As the patient becomes increasingly inaccessible through verbal communication, greater effort should be made to establish and maintain a contact with his or her feelings and soul. But how do we know if we are in touch with the feelings of someone who cannot respond adequately to a question? How can we reach a person's soul when that person despises us as strangers, never to be trusted? This is a most difficult challenge, particularly in the Western world, where emphasis is more on the mind and intellect than on feeling and intuition. People don't know how to relate to one another through their soul, fearing that they may be accused of being superstitious. Spiritual contact through prayer and meditation and the unconditional love and affection shown by family and friends will facilitate the contact these patients need, a contact that becomes increasingly necessary when verbal communication becomes meaningless or impossible. If the caregivers make a new adjustment to the needs of the patient, a new journey can begin.

Often family members and caregivers of an Alzheimer patient are frustrated and are concerned with the "mirror" and not the "sun." They don't look for the rays of the soul beyond the "mirror." They judge the patient according to their own values and find the result disappointing. Caregivers are like the co-travelers of patients with Alzheimer's disease who need to complete their journey through this world with the help of their friends and loved ones. This journey is

too difficult for the patient to bear all alone. The co-travelers, for their part, will discover new mysteries of the reality of this journey of life. Although it appears a very strenuous, physical journey, it is also a spiritual companionship. It is an act of faith more than an act of reason.

There are a large number of demented patients who are being cared for and looked after by their families and relatives, who have their own share of pain and suffering. Caregivers receive little recognition or support for their never-ending hours of tedious responsibilities. Caring for a demented patient is a type of giving for which there is no return. With some rare exceptions, there is little expression of gratitude or joy of acknowledgment from these patients to brighten the days of their caregivers. The attention span, judgment, and the ability to recognize the loving care of others are too limited or impaired in the patient to allow him or her to appreciate the value of these services. Caregivers complain that they offer a great deal but see no improvement. They need to be heard and understood. The following words of Bahá'u'lláh point out the great importance of their task: "Should anyone give you a choice between the opportunity to render a service to Me and a service to them [parents], choose ye to serve them, and let such a service be a path leading you to Me" (*Lights of Guidance* 530).

Family members and other caregivers need a great deal of support and reassurance. They often feel guilty, thinking that they don't give enough; they may attribute the patient's deterioration to a failure of their care. Because of their constant involvement in caring they isolate themselves from others making themselves more vulnerable to burnout and exhaustion. In responding to a patient's needs, they overlook or deny their own needs, the result of which is a feeling of anger and resentment. They are "the hidden victims" (Zarit, Orr, and Zarit, *Hidden Victims*) of Alzheimer's disease to whom society has given little attention or recognition. Today, in many parts of the world there are local Alzheimer Societies where family members and other caregivers can meet on a regular basis and share their own views and feelings. Through such periodic contact they realize that they are not

alone in their predicament and discover new ways of coping and caring for their loved ones. They need not only to be understood but also to be relieved from their burden of caring periodically so that they may attend to their own needs and regain their strength.

Some Suggestions on Caring

The following are some thoughts and suggestions with respect to caring for patients with Alzheimer's disease.

- We need to reassess our attitude toward pain and suffering and to recognize the role of these difficulties in our personal growth and fulfillment. In a youth-worshipping and death-denying world, caring for old and aging people with or without dementia is a personal challenge that can give new meaning to our lives. It helps us grow spiritually and moves us away from our self-centeredness. To show love and care for someone who is helpless and impaired will help us develop the virtues we need in our journey through this world. It will serve as an impetus for spiritual growth.
- We need to pray and meditate with the patient whenever possible. The creative words of the divine Manifestation are invested with a potency that can comfort the soul and alleviate pain and suffering as they unfold the meaning and mystery of life before us. It is not always possible for a demented person to attend fully in reciting a prayer, but this does not mean that person's soul is unaware of the prayerful moment spent with others.
- We need to discover certain clues that make contact with these patients more practical and possible. One seventy-eight-year-old patient was reported to show her delight only at the birthday of her grandchildren when she would spontaneously start singing "Happy Birthday." These precious moments were her only fleeting contact with the world of reality. After the birthday celebration she would slip into her world of confusion.
- We need to be aware that the elderly, especially patients with Alzheimer's disease, are frightened of rejection and of being abandoned by their family members and friends. This view generates

a great deal of anxiety and insecurity. They need to be reassured frequently that they will not be abandoned.

- We need to accept the patients as they are, and not as they used to be or as they “ought” to be. They cannot be changed by our wishes, but we can make life easier for them. We must reflect and meditate on the nobility of the human soul in creation and respect this nobility under all conditions of the journey through this world. Illness is a condition that we do not choose but which comes to us as a challenge.
- We need, as long as possible, to keep the patient at home in an accustomed environment in which the individual feels secure. The impersonal and sterile atmosphere of professional institutions, in the absence of constant family contact, can reinforce patients’ belief that they are being abandoned. Care at home, however, is not always possible as the advent of the terminal stage and the need for constant care, often for medical reasons, will make it necessary to give consideration to nursing homes or similar environments. In some cultures this separation can create a great deal of anguish and guilt in family members, while in other cultures such a decision is welcomed at a much earlier stage of the illness. It is a personal decision to be made at the family level, and it is never easy.

In conclusion, the Bahá’í writings tell us that while we are still in this world, we should prepare our souls by acquiring the divine virtues that are essential for the progress of our souls in the next world. Among the attributes indicated in the Bahá’í writings are spirituality, faith, assurance, and the knowledge and love of God. ‘Abdu’l-Bahá states:

When our thoughts are filled with the bitterness of this world, let us turn our eyes to the sweetness of God’s compassion and He will send us heavenly calm! If we are imprisoned in the material world, our spirit can soar into the Heavens and we shall be free indeed!

When our days are drawing to a close let us think of the eternal worlds, and we shall be full of joy! (*Paris Talks* iii)

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The Bahá'í Faith

The Bahá'í Faith recognizes the unity of God and of His Prophets, upholds the principle of an unfettered search after truth, condemns all forms of superstition and prejudice, teaches that the fundamental purpose of religion is to promote concord and harmony, that it must go hand-in-hand with science, and that it constitutes the sole and ultimate basis of a peaceful, an ordered and progressive society. It inculcates the principle of equal opportunity, rights and privileges for both sexes, advocates compulsory education, abolishes extremes of poverty and wealth, exalts work performed in the spirit of service to the rank of worship, recommends the adoption of an auxiliary international language, and provides the necessary agencies for the establishment and safeguarding of a permanent and universal peace.

—*Shoghi Effendi*