# NURSING HOMES

THE COMPLETE GUIDE

MARY BRUMBY FORREST, L.P.N.
CHRISTOPHER B. FORREST, M.D.
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*For the nursing home residents,*
*their families,*
*and the nurses and aides who care for them.*

# NURSING HOMES

## THE COMPLETE GUIDE

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# INTRODUCTION

In our collective minds there are certain words that conjure feelings of dread, distaste and even fear. **Nursing homes are two of those words.**

It would be a gross understatement to say that the nursing home industry has had a bad press. The unfavorable news stories, magazine articles and television exposés on this topic are legion. Their number make acid rain, depletion of the rain forests and holes in the ozone layer appear nearly beneficial. Unlike these other issues, nursing homes make many of us uncomfortable because we don't live in a rain forest, can't tell acid from regular rain and think ozone layers are somewhere up near the North Pole. But, we know that we, our parents or at least a good friend might be forced into a nursing home. The odds are good that we are going to have to deal with this unpleasant topic at some near or far juncture, and we don't like the prospect.

There are good nursing homes. They offer intelligent, skilled and compassionate care to their residents. These facilities are not only medically necessary, but often provide a desirable alternative to other types of living situations.

There are nursing homes which should be avoided at all cost. These facilities provide such poor care and undesirable quality of life that the morbidity and mortality rates of their patients increase in an alarming manner. In 1989 state investigators from the New York State Department of Health found a nursing home where 68% of the patients were restrained, 36% had contractures (permanent stiffening of the joints) and 13% had bedsores. They also concluded that this nursing home did not meet state standards for resident rights, infection control, nutrition, nursing services, administration of drugs and patient care management.

This book will provide the criteria for finding the good nursing homes and avoiding the bad nursing homes. Since this is a "complete guide," it will attempt far more than that, but if it keeps one person from spending one day in such a place as described above, it will have succeeded.

## A Myth

There is a myth in the American psyche that evokes a past perfection. This legend is composed of elm–shaded streets that are lined with comfortable homes fronted with wide porches filled with high wicker chairs and slatted swings swaying gently on their chains. An occasional iron deer is poised proudly on a neatly trimmed front lawn. Every house is home to a large multi–generational family. Each morning Father leaves for work, resplendent in a starched shirt with Celluloid collar. He walks a few blocks to the trolley line with a newspaper neatly folded under his arm. Mother spends the morning baking fresh bread, and her afternoons are busy with volunteer work in one of her many charities. Obedient children hurry to school where they are sternly taught the basics.

Grandmother lives comfortably in a sun–splashed bedroom on the first floor that is filled with her memorabilia of a productive life. She is a vision of sweetness and gentility, and her sage wisdom and placid personality are the keystones of family solidarity. At an advanced age Grandmother becomes ill with a painless but weakening disease of vague origin.

The loyal family doctor, who seems to resemble Robert Young, spends countless hours at her bedside before announcing solemnly to the family that, "She is leaving us now."

The family's solicitude is boundless as they surround the deathbed. They are rewarded with a few parting gestures of love and advice as Grandmother passes from this vale surrounded by her adoring and grieving family.

For the moment, let us disregard how hard those Victorian barns were to heat. Let us put aside how many hours a day Mother toiled at tedious household chores, or the 60 hours a week that Father worked. We will forget that although the kids may have been taught basics, few of them finished high school. Let us realistically consider Grandmother in the front bedroom.

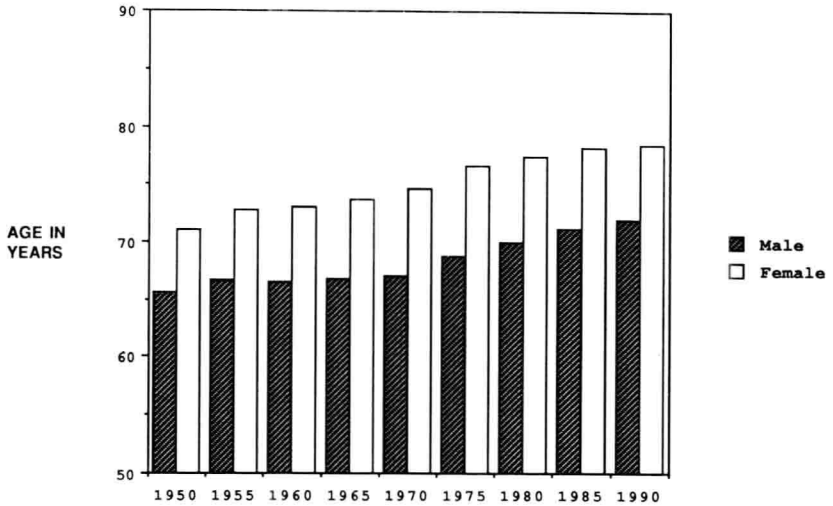
Our 1900 grandmother simply wasn't there. If she were one of the few, who through chance or heredity reached 60, she probably died during the first difficult winter from pneumonia or influenza.

## Life Expectancy

Life expectancy in 1900 was 47. Only 4% of the population reached 65. If this sounds bleak, remember that in ancient Greece you lived to 18; in 1600 you lived to a ripe old 33; and you were a senior citizen at 40 during the Civil War.

Since the turn of the century, life expectancy has increased 28 years, and

FIG. 1: LIFE EXPECTANCY FROM 1950–1990




Source: U.S. National Center for Health Statistics

is now over 75. Two-thirds of mankind's increase in life span since prehistory has taken place during the last 50 years.

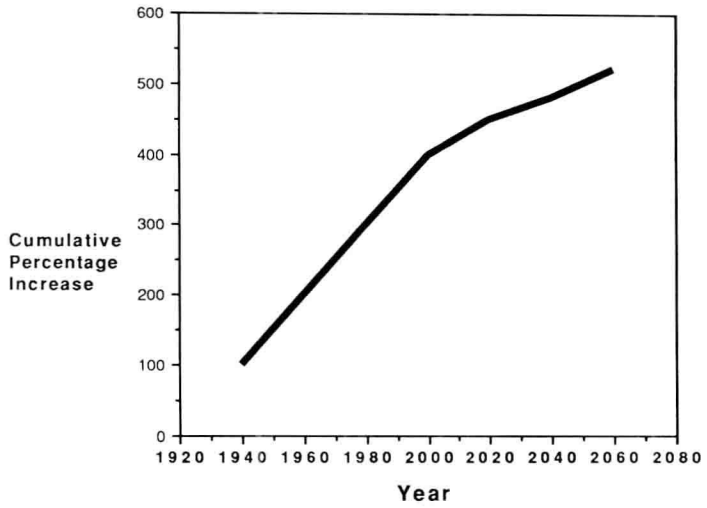
In 1950 a man in the United States could expect to live 65.6 years and a woman 71.1 years. The projected life expectancies for men and women in 1990 are 72 and 78.5 years respectively (see Figure 1).

During this same 40 year period, Americans over the age of 65 have doubled so that they now number over 28.5 million or 12% of the population.

The older population grows older. The 75–84 age group is 11 times larger than it was in 1900, while the 85+ group is 22 times larger. Figure 2 shows past and projected figures from the Census Bureau for the 85+ group and demonstrates that the size of this segment of the U.S. population will continue to escalate. By the year 2060 there will be five times as many people over 85 as there were in 1940.

The major part of this increase in life expectancy occurred because of reduced death rates for children and young adults due to improved sanitation, decreased crowding, vaccinations and better nutrition. The longevity of the elderly has increased due to an explosion of knowledge in medical science during the past 50 years. A few decades ago pneumonia was considered the "great remover" of the elderly. It was a common disease, and its onset was a virtual death sentence. Today, a host of effective antibiotics and other drugs can control, cure or mitigate the effects of countless afflic-

FIG. 2: CUMULATIVE PERCENTAGE INCREASE IN THE UNITED STATES OF PEOPLE OVER 85, 1940–2060.




tions that would have been deadly in the past. Improved anesthesia and surgical techniques have made operations routine for individuals in their 70s, 80s and even 90s.

## WHO ARE THE ELDERLY? AND HOW DID THEY GET THAT WAY?

Over 50 years ago when social security was established and pension plans began to flourish, the age of 65 was arbitrarily selected as the time of retirement. It seemed to make sense then, but increased longevity due to changes in life–style and the march of medical progress has tilted this arbitrary demarcation point in a skewed fashion.

Alzheimer's disease can strike individuals in their 40s, while 70 year-olds occasionally run the Boston Marathon. Progeria, a rare childhood disease, causes premature aging and affected individuals die in their teens. We know of nursing home patients in their 60s, and octogenarians living full lives in their own apartments. For some, aging seems to cease somewhere in their middle 60s and they continue into their late 80s without apparent change, while others of us seem old before our time.

Although social security and many retirement plans may be based on the

still arbitrary age of 65, "old age" or "the elderly" is usually defined as those over 75. Those elderly with one or more medical conditions that inhibit full function have been termed the "frail elderly." Longevity, or the longest life span possible, is marked at 115 years for humans; while life expectancy, the life span for the average person, is now calculated at the mid–70s and will probably plateau at 85 in the future.

*Webster's Ninth New Collegiate Dictionary* defines aging as, "to become old, to show the effects or the characteristics of increasing age." Aging is defined by the 22nd edition of *Dorland's Medical Dictionary* as, "the gradual structural changes that occur with the passage of time, that are not due to accident or disease, and that eventually lead to increased probability of death as the organism grows older."

These definitions are circular, for they seem to say that we age because we get older—which really doesn't tell us very much. What we do know is that growing older brings certain physical changes as normal aspects of aging. These may be discomforting and even disconcerting, but they are not necessarily incapacitating. As we age we have less endurance, our reaction time and our agility slow and we tire more easily. The female looses capacity to bear children after menopause, and both sexes may have a loss of hearing in the higher tones, less visual acuity and more brittle bones. There is no loss of cognitive functions as part of aging, although we may be less plastic in our response to environmental changes. Some intellectual functions, such as word usage, actually increase with age.

At the turn of the century, the Russian zoologist and bacteriologist Elie Metchnikoff theorized that noxious bacteria flourished in our systems and produced toxins that ultimately killed us. In the 1920s research focused on endocrine glands, and in the 1950s one theory held that random biological damage eventually accumulated to a lethal dose.

In 1920 an American, Raymond Pearl, performed an aging study which resulted in what to us now is not a remarkable conclusion: Individuals with grandparents who lived long tend to have long life spans. This was the first scientific study to imply that aging may have an inherited (i.e., genetic) component.

Modern scientific theory seems to hold that there is some sort of programmed aging built into our genes. The life span of identical twins, two individuals with the same genes, is closer than that of fraternal twins or siblings. Descendants of centenarians, when compared to a group of people with ancestors of average life span, live longer. In general, life expectancy of any individual is best gauged by family history. You live about as long as your family.

The body continuously replaces worn–out cells by the millions each day of our lives. As the years pass, this rate of replacement slows down very gradually. It is so gradual that between the years of 40 and 60 it is hardly noticible. The process of aging may be hastened by environmental conditions, disease, emotional stress or nutrition.

In the early 1960s Leonard Hayflick provided solid experimental evidence for a genetically determined aging process. He observed that certain types of skin cells that grow well in a petri dish have a limited number of times they replicate. They seem to die after 50 divisions. The same types of cells from older individuals and individuals with diabetes, a medical condition which is known to accelerate the progress of age–related disease, divide fewer times than those of younger people. Hayflick feels that some inherent mechanism must exist in the cell which flips on the aging switch. The exact nature of this switch is presently unknown.

The immunologic theory of aging is based upon changes in the immune system observed in the elderly. Older people have a diminished ability to produce antibodies, infection fighting proteins, which are found in the blood and produced by white blood cells. The immune system becomes less able to distinguish between what is part of the body and what is foreign, such as bacteria. As a consequence of this immune confusion, the amount of autoimmune diseases, a disorder in which the body actually destroys itself, increases. Examples of autoimmune diseases include rheumatoid arthritis, thyroid disease, and adult–onset diabetes. These factors enhance a person's susceptibility to infection and chronic disease including cancer.

There are several points which argue against this theory as a complete explanation of aging. One argument is that many lower animals lack the elaborate immune system of humans, and yet still undergo aging. An increased amount of autoimmune disease may simply be a consequence of a changing body; aging produces changes which baffle the immune system.

Today, despite millions of words in scholarly journals, hundreds of scientists working on the problem and a few novel theories, the answer to why we age is still unknown. A consensus opinion is probably that the answer lies hidden in DNA. This would fit with theories postulating that aging is a result of evolutionary pressure which exerts its effects on DNA templates. Some form of genetically programmed mechanism for aging seems most likely. A genetic program would account for differences in inter–species longevity, and also human family histories of long life spans. Other physiologic effects (such as changes in the immune system) would be secondary to an inherited program. A tremendous amount of research is oriented toward molecular mechanisms of aging and genetic programs.

## The Cost of Prolonged Life

Nearly 50% of those over 65 will have a stay in a nursing home. Twenty–five percent of those over 85 will live in a nursing home.

The dramatic increase in life expectancy has carried a heavy societal financial burden, and often great emotional stress on individuals. As the el-

derly survive longer, they are often faced with one or more chronic medical conditions requiring care that they and their family are not able to provide. An example of this is Alzheimer's disease.

Only a few years ago this affliction was defined as a presenile dementia that usually had an onset at middle age. As people began to live longer, we began to see more cases in the elderly. We now understand that as many as 2.5 million Americans suffer from Alzheimer's disease, and for those over 80 there is a 20% chance of its occurrence.

As spouses and other family members struggle with this disease they are nearly overwhelmed with the caretaking responsibilities. As the disease progresses, home care usually becomes impossible and institutional placement must be arranged. This stay may last for years, at great cost to families or governmental agencies.

It is not only the financial costs of health care for the aged that are important, but also the emotional trauma as difficult choices are made for alternative life–styles.

In order to provide alternatives for the growing numbers of our elderly, there has been explosive growth in the nursing home industry. However, there are other factors which also must be noted in order to understand the reasons for this astounding increase in nursing home facilities:

1. Congressional passage of the 1965 Older Americans Act not only provided for Medicare, but created a state–federal partnership in Medicaid. Medicaid (called Medi–Cal in California) funds pay for nearly 50% of all nursing home patients. This attracted many profit–making corporations into the field.
2. Recent attempts to curtail acute care hospital costs have focused on shortening inpatient stays. Hosptials have been encouraged—in fact penalized if they did not—to release patients to home care or nursing home care when acute care was not medically indicated.
3. With a national divorce rate of 50%, and the subsequent growth of serial families, combined with the need and desire for women to have careers, there are fewer families with full–time care givers available in the home.
4. Although home care for the elderly is less expensive than a nursing home, the proper mix of skilled and custodial home care is often not available.
5. Our mobile society without the past constraints of church and community has changed perceptions of family duty. Today's family is more apt to consider the quality of life for all members of the family rather than one individual, and therefore is less willing to make disruptive family accommodations.

## Nursing Home Fears

"Promise me that you won't ever send me to one of those homes!"

How tempting it is to answer this plea with a quick social lie. How easy it is to make the promise, to ignore the realities of a situation, and to respond from the heart. How can we forget the years of marriage? Can we ignore our parents who brought us into this world?

We may ignore the facts that our marriage was less than blessed, that the tension between father and son kept them estranged, or that mother has now become impossible to handle. Even if we were objective, can we still sentence a family member to one of those places? If we do, what happens when it's our turn?

There are few decisions in life that are more difficult or emotionally wrenching than placing someone in a nursing home. The very word, "home," evokes Dickensian specters. We envision gloomy buildings with dark halls and a leaking roof.

We think these places are staffed by sadistic aides who abuse the elderly on the few occasions when they are actually in their presence. The staff makes their rounds on roller skates in order to speed their way back to the lounge where they drink whiskey and when not asleep, bawdily discuss their love lives.

The establishment is presided over by a greedy owner whose lust for profit is insatiable. His rapacious appetite for money keeps him constantly busy in his quest to purchase even cheaper cuts of meat, further reduce the staff and completely do away with the laundry service. When not engaged in those activities, he is involved in the ongoing battle to circumvent governmental regulations or creating new accounting methods to increase patient billings.

And yet, half of us who reach 65 will spend some time in one of those places!

Contrary to the bleak picture portrayed above, the modern nursing home is not an annex to a medieval torture chamber. There are many homes that are light and airy in appearance, provide excellent skilled nursing care and are staffed by dedicated people who not only care, but actually love their residents. There are also nursing homes which have attractive exteriors, well-appointed interiors and yet for any number of reasons do not deliver good patient care. There are also homes that resemble the hypothetical nightmarish situation portrayed above.

## THE SEARCH

Some of us will have the physical and mental vitality to investigate, research and visit nursing homes in order to make an intelligent decision. Others will act as advocates and perform this function for spouses, parents or friends. Many of us will be discharged from an acute care (general) hospital for a condition that is temporarily incapacitating, but which will only require a short–term nursing home confinement. The new diagnosis related grouping (DRG) rules which the federal government uses for hospital reimbursement has converted many hospital stays into revolving door confinements. This early release often means the necessity for nursing home care after hospital discharge. In such instances, the time available to select a convalescent facility is greatly curtailed.

Unless you have visited nursing homes and have some experience with them, your initial exposure is likely to be overwhelming. Patients use various types of ambulation devices to walk the halls. Some are restrained in wheelchairs, while others speak in gibberish. At the same time, other residents will play chess, read the newest novel or discuss current events in an animated manner. Even in the best of facilities, there is often the faint odor of urine or feces and the mutterings of confused patients.

And from this initial exposure you are expected to make a deicison that will establish the future quality of life for yourself or a loved one.

In most cases the decision to enter a nursing home and the selection of the facility is not made by the resident alone. Due to chronic disabilities often suffered by the elderly which render them frail, or the nature of an acute care hospital stay, the future resident is often removed at least partly from the decision making process.

This book, therefore, must be directed not only to the future resident, but to the family or friends of the potential patient. An exception to this is in the area of life care facilities. These increasingly popular retirement villages offer on–site nursing homes or maintain an arrangement with a nearby nursing home for use by its residents. Individuals selecting this type of alternative living arrangement are not only choosing retirement housing, but selecting a nursing home for possible use in the future.

## THE BOOK'S MISSION

This book provides guidelines that will aid in making the nursing home decision. It explains how to evaluate and choose the proper facility.

It examines the cost of such services, Medicare and Medicaid, long–term care insurance and other important financial data concerning the nursing home resident and family.