Equipping Long-Term Care Ombudsmen for Effective Advocacy: A Basic Curriculum

THE AGING PROCESS

Curriculum Resource Material for Local Long-Term Care Ombudsmen

Adapted from
the Long-Term Care Ombudsman Program
Resource Manuals of Alaska and Louisiana

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ABOUT THE PAPER

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PREFACE

OBJECTIVE

This document provides basic information about the processes that occur throughout life, and particularly in the later years, that are considered normal aging. It also discusses common illnesses in later life and the effects of medications. Ombudsmen must be able to work with older individuals and avoid stereotypes. Ombudsmen should be alert to the difference between the effects of normal aging and the results of diseases that afflict some elderly persons.

INTENDED USE

This document supplements the interactive module, *Aging*, developed and shared by the Louisiana Long Term Care Ombudsman Program, Governor's Office of Elderly Affairs. Long-Term Care Ombudsman Programs are encouraged to use that interactive module and this document as part of basic training for ombudsmen. However, this aging process resource document can be used independently.

SUGGESTIONS FOR USING WITH THE CURRICULUM

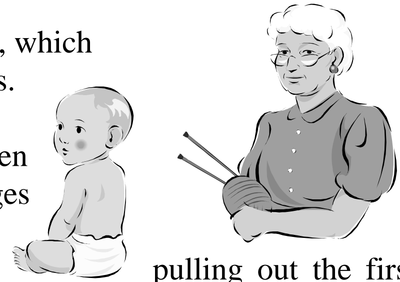
There are several ways to use these materials.

- One recommendation is to use them for individual self-study prior to attending class room training on other topics of the Basic Curriculum for Long-Term Care Ombudsmen. An understanding of the information on aging can be demonstrated via approaches to case studies and class room discussion on related topics.
- Another option is for students to read the resource materials prior to class, then project the inter-active module for use as a review and discussion prompt in class.
- If someone has a background in gerontology or long-term care, working through the interactive module could provide a review of relevant information. If any items are missed or spark curiosity, the person can read the related section of this resource material for further information.
- This document can also be used as a stand alone tool. It can be shared in electronic or hard copy versions for individual reading, assignments or to supplement a lecture. To facilitate learning and emphasize important points, programs could develop application questions to accompany this document.

Whatever method is used, the emphasis in training needs to be: What does this content mean to residents? What can caregivers do to support resident abilities and functioning? What is an appropriate ombudsman action?

I. The Aging Process

A. What is Aging



What is aging? Aging is a continuous process from birth to death, which encompasses physical, social, psychological, and spiritual changes.

Although aging is an ongoing process, the value of aging is seen differently at different points in the process. Some of the changes are anticipated with joy, such as a baby's first tooth or first step. Other changes are greeted with a less positive response, such as pulling out the first gray hairs that appear. Youth is valued in American culture; while signs of aging are masked with face-lifts, wrinkle creams, and hair dyes. The process of physical maturation that is so eagerly anticipated in the first stages of life is viewed very negatively when the youthful attractiveness begins to change.

These prevailing attitudes lead to a denial of the signs of aging. Some individuals quit celebrating birthdays after a certain age. The stereotypical perceptions of aging as a period of deterioration and decline are therefore perpetuated. The positive aspects of aging are ignored. Each stage of life has its own pluses and minuses. Sometimes in old age, the balance may seem to tip to more negatives than positives, but this is not due to the *natural aging process*.

There are many positive aspects of aging. After 70 or 80 years of living, individuals tend to have a clear sense of their values and priorities. Older persons can make definite choices about how to use their time and energy. Their priorities may be very different from what caregivers, family, or friends want them to be. Older people have learned ways to adapt to changes; they have managed to survive. Advanced age can bring a freedom to speak one's opinion. Because of retirement, many older individuals have greater freedom to pursue interests, to use time to think and to reflect. To paraphrase Jung, as we age, we become more ourselves.

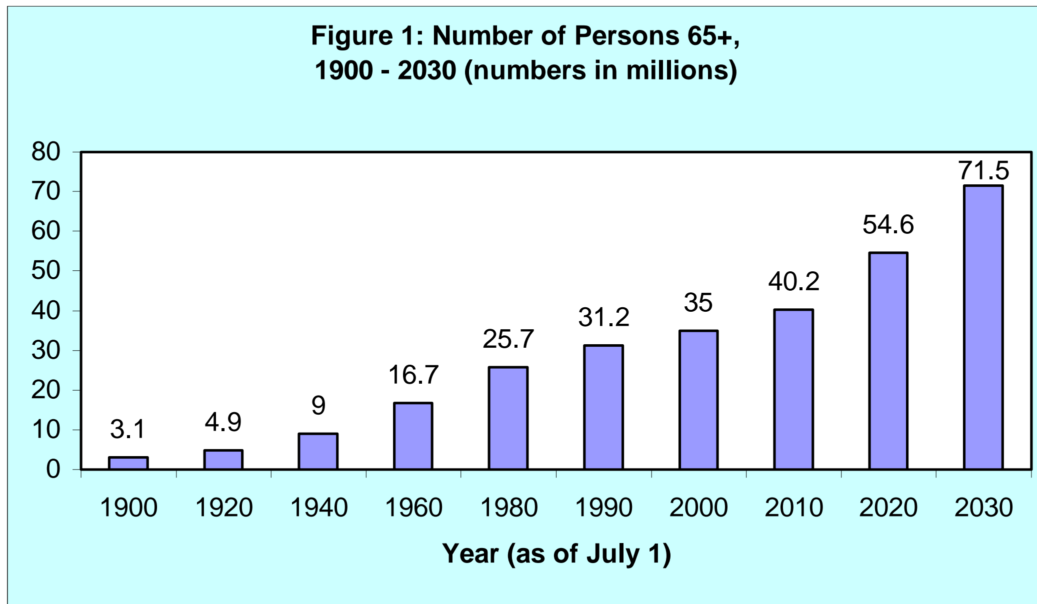
The advanced stages of aging are a normal, natural part of physical maturation. Instead of placing such a high value on youthfulness, it may be more productive to accept the changes throughout life without fear or denial.

B. Profile of Older People

As a long-term care ombudsman (LTCO), you will be working with older adults, their families, and their caregivers. To better understand the population of long term care residents who are your primary focus, you need to understand the "big picture" of the senior population, defined here as persons 65 years of age or older.

So who are aged people? At what age does a person become old? When a 64-year-old goes to bed and wakes up the next morning as a 65-year-old, has that person changed? Chronological age does not always correspond to a person's feelings. Although a person may be eighty years old, the

person may feel like he/she is forty. The age a person feels may vary with the time of day, the day of the week, and/or activities or stresses present in that person's life. A person may be very energetic on Saturday, but very tired and slow moving on Monday morning. Knowing a person's chronological age tells you almost nothing about that individual's feelings or abilities. Nevertheless, in this country, we categorize individuals by chronological age. Some key statistics[1] follow describing the population of seniors, persons 65 years or older.



Numbers and Growth

The older population—persons 65 years or older—numbered 35.6 million in 2002 (the most recent year for which data are available). They represented 12.3% of the U.S. population, about one in every eight Americans. The number of older Americans increased by 3.3 million or 10.2% since 1992, compared to an increase of 13.5% for the under-65 population. However, the number of Americans aged 45-64 – who will reach 65 over the next two decades – increased by 38% during this period.

The most rapid increase is expected between the years 2010 and 2030 when the "baby boom" generation reaches age 65. By 2030, there will be about 71.5 million older persons, more than twice their number in 2000. People 65+ represented 12.4% of the population in the year 2000 but are expected to be 20% of the population by 2030.

Minority Populations

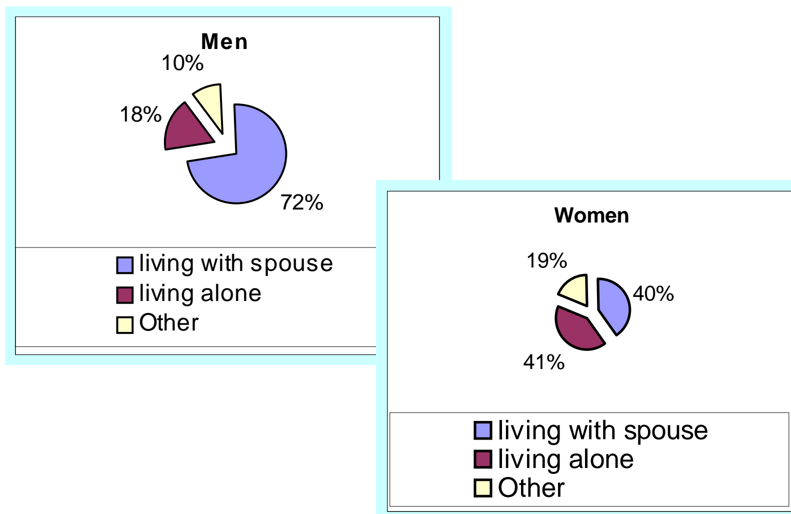
Minority populations are projected to represent 26.4% of the elderly population in 2030, up from 17.2% in 2002. Between 2000 and 2030, the white** population 65+ is projected to increase by 77% compared with 223% for older minorities, including Hispanics, African-Americans,** American Indians, Eskimos, and Aleuts,** and Asians and Pacific Islanders.**

[1] The statistics and narrative information in this section come from: *A Profile of Older Americans 2003*, the Program Resources Department, American Association of Retired persons and the Administration on Aging, US Department of Health and Human Services, Washington, DC. http://www.aoa.dhhs.gov/aoa/stats/profile/ The data is based on information from the US Bureau of the Census and the National Center for Health Statistics.

Age
The older population itself is getting older. In 2002, the 65-74 age group (18.3 million) was eight times larger than in 1900, but the 75-84 group (12.7 million) was more than 16 times larger and the 85+ group (4.6 million) was almost 38 times larger.

Living Arrangements
Over half of noninstitutionalized older persons lived with their spouse in 2002 (Figure 2). The proportion of individuals living with their spouse decreased with age, especially for women. **** About 30% of all older persons lived alone. The proportion living alone increases with advanced age. Among women aged 75 and over, for example, half lived alone (in 2000).

Figure 2: Living Arrangements of Persons 65+ : 2002



Health and Health Care
In 2003, 38.6% of noninstitutionalized older persons assessed their heath as excellent or very good, compared to 66.6% for persons aged 18-64. There was little difference between the sexes on this measure, but older African-Americans (57.7%) and older Hispanics (60.5%) were less likely to rate their health as excellent or good than were older Whites (75.4%).***** Most older persons have at least one chronic condition and many have multiple conditions. Among the most frequently occurring conditions of the elderly in 2000-2001 were: hypertension (49.2%), arthritic symptoms (36.1%), all types of heart disease (31.1%), any cancer (20.0), sinusitis (15.1%), and diabetes (15.0).

Nursing Homes
While a small number (1.56 million) and percentage (4.5%) of the 65+ population lived in nursing homes in 2000 the percentage increases dramatically with age, ranging from 1% for persons 65-74 years to 5% for persons 75-84 years and 18% for persons 85+.

II. Biological Aspects of Aging[2]

A. Introduction

Aging brings some changes in all people. These changes are continuous throughout life, from losing baby teeth to the loss of taste buds. The normal changes with advanced age have only recently been studied and are beginning to be understood. Some changes are obvious in the way they alter physical appearance or in their visible effect upon body systems. Other changes are less apparent, in that they affect internal body systems, such as the circulatory systems. These changes vary in degree and rate from individual to individual.

B. Structural

MUSCLES	Muscles lose mass and tone. While exercise helps to maintain strength and tone, it does not prevent some loss. This change is observable in the looseness of underarm skin, sagging breast, and thinner legs and arms reflecting the changes in musculature.
SKELETON	Another change affecting appearance is the flattening of the spongy "cushion" between the vertebrae. Over the years, this material loses its resiliency. Older people may be shorter than they were in younger years and have a stooped posture.
SKIN	There are several changes that affect the skin. • The skin loses some elasticity, which results in wrinkles. The skin does not stretch and conform to its original shape as it once did. • There is a loss in the natural oils in the skin, which may lead to dryness and scratchiness. Individuals may need to use moisturizer to replace the loss in oils. • The skin becomes thinner and thus more susceptible to being broken or cut. • Older people may become more sensitive to temperature changes. • Some individuals may develop "aging" spots, which are dark areas of pigmentation. The presence of such spots does not indicate a problem with the function of the liver. The spots are simple changes in the pigmentation of the skin. Creams do not remove the spots although they may temporarily camouflage them. Spots on the skin of older people should be closely observed for sudden growth or changes in appearance. Such changes should be reported to a physician.

[2] Excerpted from The New Mexico Ombudsman Curriculum developed by Sara S. Hunt.

C. Sensory

MOUTH	The bone structure of the jaws may change, which can alter the way dentures fit. It is possible for an individual to develop problems with a set of dentures that he/she has had for years. Problems with dentures may have a negative impact on a person's nutritional intake.	
TASTE	The sensitivity of taste buds decreases with age, especially with men. The tastes that decline first are sweet and salty, with bitter and sour decreasing more slowly. Those changes mean that foods may not taste like they used to older people. The elderly may over season food or may accuse others of omitting all seasonings in food preparation. Changes in taste may lead to a loss of appetite, which can lead to nutritional deficiencies.	
SMELL	Sensitivity to smell decreases as individuals age. Older individuals may be less aware of certain odors, even body odors, than younger people. The decreased sensitivity to smell may also adversely affect appetite.	
VISION	There are several eye disorders that occur more often in the aged, such as glaucoma and cataracts. In the fourth decade of life, visual capacity begins to decline.	
	DISTANCE	The lens of the eye may lose some of its ability to accommodate changes in distance vision. That means that it may take a person a few seconds longer to recognize someone who is across the room when the older person has been reading or doing handwork.
	LIGHT	The pupil of the eye tends to become smaller with age, permitting less light to enter the eye. This means eyes have a decreasing ability to adjust to changing amounts of light, and glare becomes a problem. Older people need more light than younger people do.[3] If an older person has been sitting in a semi-dark room and opens a door to find a visitor standing in bright sunlight, the older person may not immediately recognize the visitor. That does not indicate a problem with mental alertness, but it may indicate a longer than usual period of time required to adjust to differences in light.
	COLOR	Other changes in the lens of the eyes may make it difficult to distinguish blues and greens or pinks and yellows. An elderly person may comment on her green dress when it is actually blue. That kind of mistake does not necessarily indicate declining mental abilities; it may indicate changes in color identification. Colors that are very similar in shade like beige and brown may be difficult for older individuals to distinguish. Contrasting colors such as black and white may be more readily identified. Clothing can be tagged so those older individuals know which colors are complimentary.
	DEPTH	Changes in the eyes may affect an older person's mobility. The floor may appear to be rolling so that older people may shuffle along to ensure stable footing. Changes in depth perception can make it difficult to judge the height of curbs or steps. A person may take a large step and receive a jolt. It is helpful to edge steps or curbs in a bright, contrasting color to facilitate the elderly person's ability to judge depth. Baseboards that contrast with the walls and floor make it easier to

[3] Stuen, C., & Faye, E.E. "Vision Loss: Normal and Not Normal Changes among Older Adults." *Generations*. XXVIII(1), p. 8.

distinguish distances and surface areas.

PRINT The lens of the eyes also loses some of its ability to focus on small print, such as the body of a newspaper. Headlines are more readily discernible. That means many of the forms that have instructions in small print are very difficult for older people to complete. The same is true of reading the statements of benefits, an activity schedule, a list of resident rights, or learning to operate the control knobs on a piece of equipment.

The cumulative effect of these vision changes can alter a person's sense of independence and self-confidence. If vision changes make it difficult for senior citizens to negotiate a "strange" or unfamiliar environment, that person may limit shopping or take trips less often. An elderly person may appear to be two different people. One who is very efficient, steady, and independent may be observed in her own environment. In an unfamiliar environment, the same individual may appear confused, disoriented, and slow. That kind of difference may be due to vision changes. In the familiarity of a home environment, the person may function very well because he/she knows where everything is and how to operate the appliances.

It is important to allow older people the extra seconds needed for their eyes to accommodate to changes in light or distance. Eye examinations are also important to ensure that eye diseases or impairments are detected and promptly treated. Vision rehabilitation services such as the Lighthouse can be helpful in detecting problems and in offering tips to increase independent functioning.

HEARING Changes in hearing are multiple and can have a profound effect upon the life of an older person. Hearing loss can cause depression and social isolation. Because it can lead to paranoia and suspicion, hearing loss is potentially the most problematic of perceptual losses. Individuals who have some degree of hearing loss may not realize that they have a loss.

When an individual with a hearing loss is in a group, the person with the hearing loss may begin to think that others are talking about him/her, or are deliberately excluding that person from the conversation. In reality, group members may not realize the need to face the person and to speak so that he/she follows the conversation. Individuals with hearing losses may hear part of what is said and not know they have heard only part of the statement or question.

The mind may automatically compensate for unintelligible conversation by inserting information, which seems to make sense. The person may then give an inappropriate response and not realize that the communication has been misunderstood.

There are three major types of hearing loss.

- High frequency loss: low, deep sounds are more readily heard than higher sounds.
- Conductive hearing loss: sound waves are not properly conducted to the inner ear making sounds become muffled and difficult to understand.
- Central hearing loss: allows speech to be heard but not understood. Signals from the ear either do not reach the brain or the brain misinterprets them.

D. Systems

CIRCULATORY SYSTEM	The heart, like other muscles, weakens and loses pumping capacity. Arteries or veins may become rigid or blocked, which restricts blood flow and circulation. Under routine circumstances, these changes do not greatly alter the daily functioning of an individual. These changes may be observed when an aged person who has been sitting for a while suddenly stands and walks across the room. Unless a few extra seconds are allowed for the heart to supply sufficient blood to all the body extremities, the person may stumble, fall, or seem confused. After the heart has had sufficient time to pump the blood throughout the body, the unsteadiness or confusion disappears.
DIGESTIVE SYSTEM	One of the systems least affected by aging is the digestive system. As in earlier years, diet and exercise are extremely important to maintain proper functioning. Teeth become more brittle. Saliva, necessary to swallow food, decreases; the thirst response decreases. Peristalsis (the movement of the intestines) is slower, decreasing speed and effectiveness of digestion and elimination. Choking on food is a greater risk because of a decreased gag reflex.
URINARY SYSTEM	The urinary system experiences several changes. • A general weakening of the bladder muscles means that the impulse to urinate cannot be delayed as long as in earlier years. When an older person says, "I have to go to the bathroom," that usually means now. • The bladder doesn't stretch to hold as much as it used to, so urination may be more frequent. • With weakened muscles the bladder may not empty completely which increases susceptibility to urinary infections. • The kidneys filter the blood more slowly than in younger years. As a result, medications remain in the bloodstream longer than they do in younger people. That change in functioning compounds the danger of over-medication. Dosages of medicine need to be closely and continuously monitored. Interaction effects between prescribed medicine and over-the-counter drugs, even aspirin or Bufferin, are more likely to occur.
REPRODUCTIVE SYSTEM	In the reproductive system there is little change. Vaginal secretions diminish; erections may require more stimulation. In men, the prostate may become enlarged. Regular check-ups are particularly important for men. Prostate trouble may go untreated until it requires radical treatment.

E. Summary

The cumulative effect of these changes is minimal in everyday functioning. These changes occur gradually, which allows individuals to adapt to the changes. Normal, daily functioning continues. The impact of these changes is more apparent when an older person is in an unfamiliar environment or when an older person is subjected to physical or psychological stress. Exercise and diet significantly impact the rate of these changes by slowing down the processes. In spite of the normal, age-related changes, older people function well enough to maintain daily functioning.

III. Psychological Aspects of Aging

A. Memory

Short-term memory seems to decrease. It becomes more difficult to remember events in the immediate past, like what a person ate for breakfast, who came to visit yesterday, or the date and time of an appointment. There are ways to compensate for any decreases in short-term memory function. A person may write notes, which serve as reminders if they are kept in a specific place. Freedom from distractions or too much stimulation may also help with remembering immediate events or information. Long-term memory seems to improve with increasing age. Events, which occurred forty or fifty years ago, may become easier to remember. As events are remembered and retold, they become more vivid and detailed.

B. Adaptation To Change

Everyone throughout their lives experiences change. When a person acquires senior citizen status, he/she has lived through numerous changes. They have gone from the early days of automobiles to multi-lanes of traffic on interstates to airplanes to space ships. Individuals who have witnessed those changes have established patterns of adjusting to change. They know better what they can and can't tolerate and what is important to them.

Reactions to change vary from person to person. Change, whether positive or negative, is stressful. All individuals need time to adjust. Sometimes older people are seen as resistant to change, or "set in their ways." It may be that their refusal to accept change is a way of maintaining control. To say, "No," is to keep one area of their lives stable. At other times, change may be refused because it may not be understood. They may need more information or a clearer explanation, even if it is about a service being offered. Older people may need more time to consider the proposed change—to think it through, to decide. They may need assurance that the change can be tried on a temporary basis and then reevaluated. They may need reassurance about the terms of a service, information about other people who have utilized the service, and that the service can be easily terminated, before he/she accepts the service. There may be a very good reason for saying, "No." They need to be listened to in order to understand their needs. Sometimes it is tough to find a balance between trusting their own priorities and understanding the enabling supports that they need

C. Reminiscence

One method of coping with change is through reminiscence. There are several positive benefits of engaging in reminiscence. The present may be depressing or very unsatisfactory. By recalling a happier time, an older person may derive some contentment or the ability to endure the present. The strength to adjust to change may be derived from remembering previous successful adjustments.

Furthermore, reminiscence may provide an emotional outlet. Everyone reminisces. When something good happens, most people share the event with two or three friends. When friends meet,

they sometimes recall previous shared experiences and relive them at that moment. Some older people may not have several different people with whom to share an experience. If only one or two people are around that older person, those individuals may hear the same story several times.

Some of the common psychological purposes that reminiscence may serve are listed below.

IDENTITY	Through story telling, an older person can reveal personal achievements and characteristics. Indirectly, the older person may be saying, "*This is how I was before I became old*." It serves as an introduction to that person prior to any limitations on energy or functioning. Personal characteristics are often revealed; a new acquaintance can begin to understand what the older person has been throughout his/her life by listening to reminiscences.
SELF-ASSESSMENT	In recalling the past, an older person may engage in self-assessment, deciding what kind of life one has lived. A review of the totality of one's life imparts a sense of integration of self. Allowing an older person to give advice, wisdom, or history to others through reminiscence can reinforce self-esteem. It may reinforce a person's feeling that his/her life has been worthwhile.
GRIEVING	Reminiscence can be a productive method of dealing with loss and grief. In verbally sharing the loss, an individual may come to accept it. In grief, there is a need to remember and to relive past experiences. Reminiscence provides that opportunity. There may be conflicts in the past that are unresolved or need to be re-evaluated. By remembering past events, a person may decide to make amends with someone; to be forgiving or to seek forgiveness. Losses, which were suppressed, may surface. Grieving may need to be completed.

D. Intelligence

Intelligence does not decline with normal aging. When tested, older people scored lower on timed tests than do younger people. On tests without time limits, older people score better than younger individuals.

IV. Sociological Aspects of Aging

A. Introduction

As with individuals of any age, familial relationships are important to older people. With increasing age, family composition often undergoes some changes. Older men are much more likely to be married than older women. Almost half of all older women are widows. Divorced and separated older persons represent only 10% of all older persons. However, this percentage has increased since 1980.[4]

Family connections extend into later life as reflected by living arrangements. Almost 60% of older women and 78% of older men live with a spouse or with another relative.[5]

Relationship patterns which were established in earlier years prevail into later life. If a parent and child have always had personality clashes, they will continue to unless they learn new ways of dealing with each other. The parent who listened primarily to one child or turned to a child for advice will continue that pattern unless something intervenes.

B. Role Reversal

While it is true that an elderly person may become more dependent in some capacities, the person is still an adult. Sometimes individuals may appear to act like children because they feel they are being treated as children especially when living in an institution.

Dependencies in one area do not mean a person is dependent in all areas or is dependent all of the time.

An individual may need transportation and assistance in completing forms. That does not mean that person needs someone to make financial decisions for him/her. An aged individual may require temporary assistance in managing personal affairs until that person recovers from an illness or stress and is able to resume total responsibility. Sometimes families decide an elderly person is incapable of independence because the person makes a decision that disregards their advice.

Older people need to be encouraged to do as much for themselves as possible. Caregivers need to patiently allow sufficient time for persons to respond to questions or accomplish tasks. The emphasis should not be on perfection but on personal accomplishment. Ombudsmen should reinforce the decision-making ability of elders and expect and support as much independence in as many areas as possible.

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[4] *Profile of Older Americans 2003*, op.cit.

[5] *Older Americans 2000: Key Indicators of Well-Being.* Appendix A: Detailed Tables. Indicator 5, Living Arrangements. Federal Interagency Forum on Aging-Related Statistics. http://agingstats.gov

C. Crisis

In families, it is helpful to anticipate potential crises. Before a stressful situation develops, consider the possibility that it may occur, and explore the alternatives. Areas to discuss include living arrangements, finances, wills, and funeral arrangements. It may be helpful to mention the subject and then discuss it more fully at a later date. Prior discussion helps prepare mental strategies for resolving crisis situations. It is easier to make decisions when everyone's wishes are known.

D. Limitations

There are limitations to familial support, both financially and emotionally. Resources are limited and families may be pulled in more than one direction. It is not uncommon for a middle-aged couple to have dependent children in the home and increasing responsibility for elderly parents. A retired couple trying to adjust to less financial flexibility, may be caring for aged parents. There may be little time to spend with older relatives or to provide assistance. Priorities must be established, limitations acknowledged, and expectations discussed.

E. Guilt

Family relationships may involve some guilt. The guilt may be unjustified or due to unreasonable expectations. A personal re-assessment with realistic goals may be needed. If family members or an older relative makes excessive demands, a family conference or a one-on-one discussion may be in order. Problems, limitations, expectations, and responsibilities must be discussed. The aged relative should be involved in the discussion and in problem solving. A workable solution must be found.

F. Losses

Anger and grief are two primary reactions to loss.

We experience losses throughout our lives. Some losses are more difficult to overcome than others. Common losses include the loss of friends, relatives, objects, and opportunities. Objects that are representative of special relationships or of personal achievement may be particularly important to an older person. Physical abilities may be lost: the use of an arm or leg, eyesight may diminish, and/or manual dexterity may decrease. These losses are usually accompanied by losses in roles and activities. The activities or functions which once gave meaning to one's life may have been dramatically altered. Opportunities to make new friends, acquire new skills, or accomplish life long goals, may be gone or greatly restricted. Recovery from losses may not be as quick in late life as it is in younger years.

There are two primary reactions to loss: anger and grief. Both are natural and may be expressed in various ways, depending on the individual. Talking about the loss is a therapeutic way to come to terms with it, to grieve, and accept the loss.

G. Death

Although death and dying may trigger strong feelings, it is a natural part of the life cycle. *There are five major reactions to death or dying, which have been identified by researchers: denial, anger, bargaining, depression, and acceptance*. Individuals do not always experience every stage, nor do they always experience the stages in the order listed. Stages may be repeated or skipped. Families or friends of a dying individual may also experience these reactions, and may do so at different times than the individual.

Ombudsman Visits With Residents Who Are Dying[6]

Responses of a Dying Person		Role of Ombudsman and Caregiver
When the awareness of a serious or fatal illness comes, persons react with shock and denial: "*No, not me! It can't be me*!" "This is not really happening. Someone has made a mistake."	**DENIAL**	Listening is very important. The dying person may not talk much and should not be pushed. Daydreaming about happier things, regardless of how improbable things may seem, should be encouraged and supported.
When denial can no longer be maintained, anger takes over. The question becomes "*Why me*?" or "*Why did God let this happen to me*?" The person feels angry, bitter, and envious of others who won't die.	**ANGER**	Family and friends usually find this stage difficult and mistake the anger as a personal attack. Be careful not to shorten or avoid visits or to react with anger. The resident needs an opportunity to ventilate his/her feelings. If the person feels respected and understood and is given attention by those important to him/her, she/he may soon begin to reduce the angry demands.
The person hopes that if she/he carries out promises, she/he will be rewarded with a longer life. This postponement is expressed in the hope that she/he will live to see some special event. "*Yes me, but*..." Many of these bargains are made with God and may be kept secret from family or friends.	**BARGAINING**	The resident needs someone to listen to him/her and to recognize his/her feelings. Expressing fears often helps to relieve the resident's feeling of guilt and enables the person to work through this stage in a more satisfying manner.
Faced with the reality of such a great loss, the person is profoundly sad.	**DEPRESSION**	Our initial reaction to depression is to try to encourage the person to look at the bright side. This approach, however, can be an expression of our own needs and is not generally helpful in working through this stage. In dealing with reactive depression, the individual may have much to share. Listening is very important. The resident experiencing depression will often express his/her sorrow through silence. In these instances, a touch of a hand or just silently sitting together is usually more meaningful than words.
If the person has had sufficient time and the support and care of those around him/her, he/she will pass into a stage of acceptance of impending death: a calm, peaceful and comfortable readiness to face death. The person is not happy, but not terribly sad either.	**ACCEPTANCE**	The family may need more support than the dying person, who has already found some peace. It is a silent time in which the resident wishes to be left alone. He/she often prefers that visits be short and relatively silent. Our presence confirms that we will be around until the end and reassures him/her that he/she is not alone

[6] Adapted from Elisabeth Kubler-Ross

V. Myths and Stereotypes

A. Myths and Stereotypes about Senior Adults

Within American society, there are some common generalizations that are thought to be truths about older people. Many elderly people, who may expect these behaviors of themselves, believe these stereotypes. The myths, stereotypes, and negative attitudes greatly influence interactions with older people. Expectations about the later years are formed very early and are reinforced throughout life.

The truth is that there is great variety among individuals in later life. Individuals are what they have always been. There is as much diversity in personalities among older adults as there is among younger individuals. Problems arise when people act on their assumptions about the older person. Family members may unconsciously "watch" their elderly relatives to see when they will begin to exhibit these characteristics. Some major myths and stereotypes are listed below.

MYTH	REALITY
Older people are disengaged *–they live by themselves or with other older people; they lose interest in life and become more introspective and withdrawn; older people do not want to associate with other people.*	Opportunities for older people to associate with other people may be very limited. Physical handicaps, lack of transportation, lack of alternatives, and the death of a spouse or close friends may cause an older person to appear disengaged. Other people may have disassociated from the elderly person. Older people do prefer to stay involved in life as much as possible.
Older people are sick – *disease and disabilities are automatic with advancing age; older people are not expected to feel well.*	Chronic conditions such as arthritis or diabetes usually begin in middle age and may worsen with advancing age. Disabilities previously assumed to be automatic effects of aging, have been shown to have other causes, and can be influenced by diet, exercise, and life style. The elderly did not suddenly become sick when they became aged. Sometimes the elderly may use this myth to get out of activities or commitments. The older person may need or want some encouragement to participate in activity.
Once a man, twice a child – *they become childish, return to a second childhood, and must be treated like children.*	Adults remain adults and function as adults. If any person is expected by others to act like a child, that person may conform to those expectations over time.

MYTH	REALITY
Older people are dependent – *they need someone to take care of them.*	Most older people are independent, living in the community, and are taking care of themselves. Many times, "help" is given to older people because others are too impatient to wait long enough for the elderly to do the tasks themselves. While others may think they are helping older people by doing shopping or running errands, they may actually be denying the older person opportunities to go out, maintain control and independence in decision-making, and receive stimulation and mental and physical exercise. Older people may gradually become dependent on others for unnecessary assistance.
The old are unproductive -- *they have already made their contribution to society.*	The majority of older people remain actively and productively involved in life. However, opportunities for meaningful work, education, or leisure activities may be less available. When incapacity develops, it can be more directly traced to a variety of losses, diseases, or circumstances rather than aging. Productivity may have to be redefined to include sharing reminiscences or knowledge as well as producing tangible products or results.
The aged are asexual – *Sexual desire is "only in their heads", sexual function ceases in old age.*	In reality, sexual desire continues throughout life. With advancing age, sexual function may change, but it does not automatically cease. If a person has remained sexually active throughout adulthood, there is no reason that should change in the later years.
Grandparents are always eager to be with their grandchildren *– All grandmothers love to bake cookies, and all grandfathers love to tell stories to their grandchildren; grandparents are always glad to keep their grandchildren.*	All grandparents are entitled to their own lives and schedules. Most grandparents do enjoy time with their grandchildren but within limits. Sometimes grandparents prefer visits that are planned in advance. Grandparents may be expected to keep grandchildren and will feel guilty if they must say "No." Out of necessity, a growing number of grandparents have become surrogate parents for their grandchildren.

MYTH	REALITY
Old people become senile-- *Eventually all older people become forgetful, confused, and have reduced attention spans.*	"Senility" is one of the most misused words; it has come to be a catch-all term with little specific meaning. Similarly, "Alzheimer's" has become a general term used to describe all types of behavioral symptoms or memory loss that may have very different causes and therefore very different strategies for intervention. (See the discussion of dementia later in this material for more information.) The expectation of senility puts many elderly on guard against actions that may be viewed as indicative of mental loss. When an older person becomes distracted and lets cooking food burn, she may try to camouflage the odors to prevent family members from realizing the food was burned. Otherwise, they may begin to wonder if she is safe alone.
All old people end up in nursing homes – *if individuals live long enough, they will be institutionalized.*	About five percent of the elderly are institutionalized at any one point in time. The majority live in community settings. Although, nursing home care is not inevitable, particularly as alternative services are developed, about forty percent of the total elderly population will spend some time in a nursing home.

B. Myths and Stereotypes about Care

Stereotyping and myths also affect the medical treatment older individuals receive and the way caregivers treat them. Clinical expertise is beginning to challenge many commonly held perceptions about inevitable age-related declines and appropriate interventions.

It is critically important that you, as an ombudsman, know the myths, ask questions, and offer information at opportune moments.

As an ombudsman, you need to know which conditions indicate a need for more assessment and/or consideration of different treatment interventions instead of assuming that the conditions are simply manifestations of the aging process.

Since your job will be working with individuals in long term care facilities, this section will focus on applications in that environment. The same principles are applicable to individuals in home settings or other residences.

The Imperative for Good Care

In addition to challenging some of the long-held perceptions about the causes of decline and appropriate treatment, there is a solid legal basis for rethinking stereotypical responses.[7] The Nursing Home Reform Law (OBRA '87) challenges the mindset that "*this is the way we've always done it*," or "*we don't have the staff to do it.*"

OBRA challenges everyone to re-examine assumptions and practices: *that old people are hopelessly depressed; bedsores and incontinence are unavoidable, and residents must be restraints help residents.* There are practitioners[8] who have blazed the trail: finding that time spent on thorough assessment and care planning saves time in the long run; accommodating individual needs is possible and is more efficient; and eliminating restraints results in better care. Their experience shows the law's potential.

One of the principle provisions of OBRA, Quality of Care, says, *"A nursing facility must provide services and activities to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident in accordance with a written plan of care."*

The requirements for long term care facilities explains what Quality of Care means:

> *"Based on a comprehensive assessment of a resident, the facility must ensure that a resident's abilities in activities of daily living do not diminish unless circumstances of the individual's clinical condition demonstrate that diminution was unavoidable. This includes the resident's ability to bathe, dress, and groom; transfer and ambulate; toilet; eat; and use speech language or other functional communication systems."*

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[7] Most of this section is from Frank, B., "The Promise of Nursing Home Reform Is In Your Hands . . . An Advocate's Message to Surveyors," *Survey and Certification Review*, June 1992. pp3-8, and the *Ombudsman Guide to The Nursing Home Reform Law*. National Long-Term Care Ombudsman Resource Center, National Citizens' Coalition for Nursing Home Reform. Washington, DC. 2004.

[8] The Pioneer Network serves as a national focal point for this type of activity, promoting "culture change," cultivating and sharing best practices. P.O. Box 18648, Rochester, NY 14618. (515)271-7570. www.pioneernetwork.net

The regulation applies to vision and hearing, pressure sores, urinary incontinence, range of motion, mental and psychosocial functioning, naso-gastric tubes, and other areas of care.

In short, this provision means that people should not get worse because of what the nursing home does to them. In fact, they should reach the highest level of functioning and well-being that they are capable of achieving. If a resident was able to walk, transfer, bathe himself/herself, move his/her arms, or maintain his/her skin condition when he/she entered the facility, he/she should still be able to do so after six months or a year; actually, for the rest of his/her stay in the facility, unless circumstances of his/her clinical condition demonstrate that diminution or decline was unavoidable. There are only three reasons that diminution is unavoidable:

- A new disease or condition is experienced by a resident (e.g. heart disease added to the Parkinson's)
- A resident's disease progresses (e.g. the parkinsonian medicine no longer works and the individual becomes so rigid he is rendered immobile)
- A resident refuses care.

The following is a description of some common myths and stereotypes that are being proved untrue. The Resident Assessment Protocols, part of the mandatory resident assessment process, contain excellent guidance to assist in changing perceptions and treatment approaches for all the conditions in this section. The knowledge basis and educational resources are available to alter *the way we've always done things.* As we change our way of thinking about conditions, there will be dramatic differences in what happens to individuals who enter nursing facilities.

LOSS OF MOBILITY

MYTH OR STEREOTYPE

Given the frail condition of residents, movement is not as important for them as it is for other adults. They will experience a decline in mobility as an inevitable part of growing older.

REALITY

"Movement, like other basic human needs, is lifelong and doesn't end with [old age and] institutionalization. The ability to meet these needs may fluctuate with physical and mental ability, but the drive that initiates the pursuit is forever. Frail, elderly persons who enter nursing facilities retain the drive to meet their need for movement, just as they do for the other basic needs. Institutions often fail to assist residents in meeting movement needs because they fail to recognize movement as a basic human need."[9]

All individuals need to move. "Impaired mobility can lead to a number of harmful physical and mental complications, which taken to their extreme, can be fatal."[10] Immobility negatively affects every body system. The effect of immobility, as well as ways to *maintain* mobility, is documented.

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[9] Tempkin, T., *Mobility: A Basic Human Need, Quality Care Advocate Special Section*, National Citizens' Coalition for Nursey Home Reform, Washing DC, 1993, p.i.

[10] Ibid.

In a limited study of nursing home residents, those who walked outdoors reported less fatigue than residents who did not.[11] Residents in the walking group slept better and reported better appetites than others in the study. Mobility is essential to life. It affects more aspects of life than just the physical ability to move.

PRESSURE ULCERS

MYTH OR STEREOTYPE

Because of the age-related changes in the skin and the frailty of nursing facility residents, pressure ulcers/sores are inevitable for individuals who are not independently mobile. Pressure sores are an unfortunate part of normal aging for frail, elderly persons.

REALITY[12]

A pressure ulcer is an injury caused primarily by unrelieved pressure that damages the skin and underlying tissue. An ulcer of this type is a serious problem that can lead to pain, longer hospital or nursing home stays, slower recovery from health problems, even death. Over 7% of residents in nursing facilities have pressure ulcers.[13] Sixty percent (60%) or more of residents will typically be at risk of pressure ulcer development.[14] Individuals who are at risk of developing pressure sores are those with limited mobility, incontinence, diabetes, decreased mental states, confusion, or apathy.[15] *Almost all pressure ulcers can be prevented.*

The assessment of risk factors is critical to prevention and/or early detection and intervention. The primary risk factors are:

- immobility or unrelieved pressure, including pressure from use of a restraint,
- laying in urine or feces,
- poor nutrition and hydration.

All of the major causes can be addressed by facility staff and relate to basic, daily care routines.[16]

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[11] Gueldner, S. H., and Spradler, J., "Outdoor Walking Lowers Fatigue," *Journal of Gerontological Nursing*, Vol. 14, No. 10, pp. 6-12.
[12] Most of this section is from: *Clinical Practice Guidelines No. 3: Pressure Ulcers in Adults: Predication and Prevention*, US Department of Health and Human Services, Public Health Service, Agency for Health Care Policy and Research, Rockville, MD, May 1992.
[13] Harrington C., Carillo, H., Wellin, C., et al, *Nursing Facilities, Staffing, Residents and Facility Deficiencies.* University of California, San Francisco. August 2003.
[14] Resident Assessment Protocol: Pressure Ulcers, Appendix C. HCFA's *RAI Version 2.0 Manual*. US Department of Health and Human Services, Health Care Financing Administration, Baltimore, MD. August 1999.
[15] DiDomenico, D.L., and Ziegler, W.Z., *Positioning and Skin Care, Practical Rehabilitation Techniques for Geriatric Aides*, Aspen Publishers, 1989, p. 73.
[16] *Ombudsman Guide to the Nursing Home Reform Law*, op.cit.

URINARY INCONTINENCE

MYTH OR STEREOTYPE

Urinary incontinence – the involuntary loss of urine – is to be expected, especially among residents in nursing facilities. It is another signal of advanced age and physical decline. Once it occurs, there is nothing that can be done except to keep individuals clean and dry.

Despite the high prevalence of urinary incontinence and the fact that it is associated with social and physical problems that impair general well being, nursing home staff often overlooks urinary incontinence as a potentially curable phenomenon.

REALITY

"Contrary to myth, incontinence is not a normal part of aging. It is actually easier to treat in the elderly than in the young. It is not inevitable, even in those with dementia (25% of the bedridden with dementia are continent), and is manageable in a third (33%) of those with dementia."[17]

It is estimated that more than one-half of all nursing home residents experience urinary incontinence. *Urinary incontinence is a symptom rather than a disease.*[18] In some cases, the disorder is temporary, secondary to an easily reversed cause such as a medication or an acute illness (e.g., urinary tract infection).[19] The most probable cause of urinary incontinence is immobility caused by chemical or physical restraints or lack of a toileting program. In 2002 only 5.8% of residents in facilities had bladder training programs.[20] Many cases are chronic, lasting indefinitely unless properly diagnosed and treated.[21]

"Despite the high prevalence of urinary incontinence and the fact that it is associated with social and physical problems that impair general well-being, nursing home staff often overlook urinary incontinence as a potentially curable phenomenon. Care plans that address incontinence often are custodial rather than rehabilitative in nature. In an attempt to keep residents dry, staff may diaper them, change clothing and linens frequently, toilet regularly, limit fluid intake, or use a catheter. Such approaches have their place under certain circumstances, but not until the resident has been evaluated properly to uncover the underlying cause of incontinence and treated when applicable."[22]

"Continence depends on many factors. Urinary tract factors include a bladder that can store and expel urine and a urethra that can close and open appropriately. Other factors include the resident's ability (with or without staff assistance) to reach the toilet on time (*locomotion*);

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[17] Siegal, D.L., "The Nursing Home Incontinence Project," prepared for *Living is for the Elderly*, January 1992.
[18] Harrington, C., op.cit.
[19] "Urinary Incontinence in Adults: Acute and Chronic Management." Agency for Health Care Policy and Research, Public Health Service, Department of Health and Human Services Clinical Practice Guideline #2. 1996 Update.
[20] Harrington, op.cit. 2003.
[21] Burger, S. G., National Citizens' Coalition for Nursing Home Reform, in a telephone conversation, January 14, 1994.
[22] *Long Term Care Letter: Special Report: Incontinence*, Vol. 3, No. 9, Brown University, May 8, 1991.

his/her ability to adjust clothing so as to toilet (*dexterity*); cognitive function and social awareness (*e.g., recognizing the need to void in time and in an appropriate place*); and the resident's motivation. Fluid balance and the integrity of the spinal cord and peripheral nerves will also have an effect on continence. Change in any one of these factors can result in incontinence, although alterations in several factors are common before incontinence develops."[23]

In summary, incontinence not only affects skin conditions and care routines, but also has a profound effect on an individual's dignity, self-esteem, and social relationships. Minimizing risk factors and a thorough assessment and appropriate interventions are essential to helping individuals maintain, or regain, urinary continence. Restorative care is also important.

DEPRESSION

MYTH OR STEREOTYPE

Older individuals tend to withdraw, slow down, and become depressed. Sadness is a natural response to loss of physical abilities and other life stage changes; therefore, depression is a normal part of living to an advanced age.

REALITY

"The ability to think, feel, interact with others, share a sense of purpose, work, love, experience gratification, care for others, and maintain self-responsibility are precious human attributes that elderly people strive to maintain. In only a few circumstances, are these elements of our experience and capacity so broadly and deeply challenged, as with depressive disease."[24]

Depression in the elderly is being diagnosed and treated.[25] A depressed mood may not be as noticeable a symptom among the elderly as are other symptoms such as loss of appetite, sleeplessness, lack of energy, and loss of interest and enjoyment of the normal pursuits of life. Depression affects many aspects of an individual's life. The risk of depression among women is over two times higher than that of elderly men.[26] One study suggests that a result of not treating depression in the elderly is a heightened risk of death.[27] White men over 80 are at greatest risk for suicide of all older people.[28] Treatment is effective, and depression can be alleviated in many cases. Proper assessment, detection, and intervention are critical.

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[23] Resident Assessment Protocol: Urinary Incontinence and Indwelling Catheter, Appendix C. HCFS's *RAI Version 2.0 Manual*. US Department of Health and Human Services, Health Care Financing Administration, Baltimore, MD August 1999.
[24] *Diagnosis and Treatment of Depression in Late Life, Consensus Statement*, Vol. 9, No. 3, National Institutes of Health, Bethesda, MD, November 4-6, 1991.
[25] Levenson, S., *Psychoactive Medications, Politics, The Unconventional "Wisdom" of LTC,* Caring for the Ages, February 2002.. In fact, Dr. Levenson says antidepressants are being overused without regard to the adverse effects that may accrue.
[26] Haight, B. and Hendrix, S., (1999) *Suicidal Intent/Life Satisfaction: Comparing Life Stories of Older Women,* Suicide and Life Threatening Behavior, 28(3) 272-284.
[27] Golman, D., "High Death Risk is Found in Depressed Nursing Home Patients." New York Times, February 27, 1991.
[28] Cronwell, Y., *Suicide in the Elderly,* in Schneider, LS., Reynolds, BD., Leowitz, BD., et al Diagnosis and Treatment of Depression in Late Life: Results of a NIH Consensus Conference, American Psychiatric Association Press 1994.

SAFETY CONCERNS

MYTH OR STEREOTYPE

As individuals become older and more physically frail, they need to be protected. Safety becomes very important; thus, minimizing risk is desirable. Using restraints is sometimes necessary to keep individuals from harming themselves by falling or other actions that may result in harm.

REALITY

All of life has risks. It is impossible to create a totally risk-free, 100% safe environment. However, some of the care practices that have been justified on the basis of safety may need to be questioned. "Physical restraints do not make people safer. In fact, restraints are often harmful. Caregiver experience and medical research now show:

Physical restraints do not make people safer.

When a person stops using a body part, that part no longer works very well. The old saying, 'use it or you'll lose it' is true—people who are able to get up to try to walk and are restrained become weaker. Also, restrained residents often try to get out of restraints, sometimes resulting in serious injuries, such as broken bones, cuts requiring stitches, and concussions.

Some people also fall if they are not restrained. But research shows that these residents, when they do fall, have less serious injuries than those who are restrained."[29]

In talking with residents, families, and home staff, remember that individuals have the right to take risks and need enough information to allow them to make an informed decision. Advanced age does not remove an individual's ability to accept risks. More information on restraints can be found in *Nursing Homes: Getting Good Care There*[30] or in the fact sheets on the web site of the National Citizens' Coalition for Nursing Home Reform, www.nursinghomeaction.org.

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[29] Burger, S.G. *Avoiding Physical Restraint Use: New Standards in Care: A Guide for Residents, Families, and Friends*. National Citizens' Coalition for Nursing Home Reform. Washington, DC, 1993, p. 7.

[30] Burger, S.G., Fraser, V., Hunt, S., Frank, B., *Nursing Homes: Getting Good Care There*. Impact Publishers, Second edition, 2002. Available from the National Citizens' Coalition for Nursing Home Reform, Washington, DC. (202)332-2275. www.nursinghomeaction.org.

VI. Common Illnesses and Conditions Associated with Aging[31]

This section is included to provide *basic* information about selected conditions and illnesses that you might hear about as you visit residents. This information is not to be used as a medical guide. **Do not advise residents about treatment or make a diagnosis based on the following information.**

A. Hiatus Hernia

Sixty-nine percent (69%) of people 70 years and older have hiatus hernias.

Hiatus hernias:

- Are protrusions of the stomach upward through the esophageal opening of the diaphragm.
- Can be somewhat minimized if the resident is sitting up straight while eating.
- Are helped by smaller, more frequent meals as part of treatment.
- Require the staff to realize the importance of positioning a person correctly.

B. Constipation

The most common digestive problem among bedridden or inactive people is constipation.

Constipation can be caused by:

- Lack of fiber and fluid intake
- Decreased muscle tone
- Ignoring or being unable to heed the normal urge to defecate
- Laxative abuse
- Prolonged bed rest
- Insufficient food intake
- Tumors
- Certain medications, primarily tranquilizers, sedatives, pain medications, and antacids

Residents may complain about or have:

- Abdominal pain
- Distention of stomach
- Cramping

Many older people are dependent on laxatives. This dependency becomes counterproductive. If the person uses laxatives for any length of time, their digestive system will not function without them. Excessive use of laxatives impairs the absorption of fat and fat-soluble vitamins.

[31] Excerpted and adapted from the Illinois Ombudsman Curriculum.

Extreme constipation can become a medical emergency. It also can cause mental confusion as the system becomes poisoned by waste products that cannot be eliminated. However, a person who is dependent on laxatives needs to be taken off them slowly. A hearty breakfast, six or more glasses of liquid a day, and moderate exercise all are helpful in improving elimination.

C. Osteoporosis

Osteoporosis is:

- Loss of calcium from the bones
- Caused by insufficient calcium intake
- Lack of exercise
- Responsible for over 5 million spontaneous fractures every year; 55,000 people die annually from osteoporosis-related fractures. It is possible for bones to spontaneously break without being caused by a fall or applied pressure.
- Most prevalent in elderly white women

The vertebrae and other bones decrease in mass. This causes a gradual loss of height accompanied by a "dowager's hump" (curving of the upper spine). Inactivity increases calcium depletion. Upon admission to a nursing facility, the older resident is generally less active than they would be in their home, which further accelerates the problem. Facility staff must include restorative nursing practices in resident daily routines including range of motion, standing and walking.

D. Dementia

"Dementia is a loss of mental function in two or more areas such as language, memory, visual and spatial abilities, or judgment severe enough to interfere with daily life. Dementia itself is not a disease but a broader set of symptoms that accompanies certain diseases or physical conditions." [32]

"The two most common forms of dementia in older people are Alzheimer's disease and multi-infarct dementia (sometimes called vascular dementia). These types of dementia are irreversible, which means they cannot be cured. In Alzheimer's disease, nerve cell changes in certain parts of the brain result in the death of a large number of cells. Symptoms of Alzheimer's disease begin slowly and become steadily worse. As the disease progresses, symptoms range from mild forgetfulness to serious impairments in thinking, judgment, and the ability to perform daily activities. Eventually, patients may need total care.

In multi-infarct dementia, a series of small strokes or changes in the brain's blood supply may result in the death of brain tissue. The location in the brain where the small strokes occur determines the seriousness of the problem and the symptoms that arise. Symptoms that begin suddenly may be a sign of this kind of dementia. People with multi-infarct dementia are likely to show signs of improvement or remain stable for long periods of time, then quickly develop new symptoms if more strokes occur. In many people with multi-infarct dementia, high blood pressure

[32] *Alzheimer's Disease and Related Dementias Fact Sheet*. The Alzheimer's Association. February 2004. (800)272-3900, www.alz.org

is to blame. One of the most important reasons for controlling high blood pressure is to prevent strokes."[33]

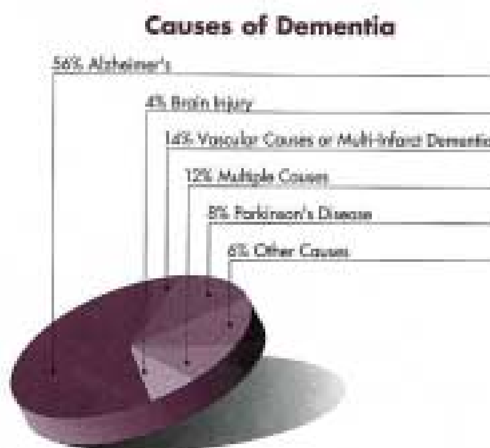
Before *dementia* became a common part of our vocabulary, the term *senility* was used. Senility and pre-senile dementia are still used as medical diagnoses. Regardless of the specific diagnosis, ombudsman approaches to residents with conditions that impair cognitive functioning are the same as described in this document.

Conditions that can cause ***reversible*** *dementia, if detected early, are:*

- Depression
- Drug interaction
- Problem with the thyroid gland
- High fever
- Minor head injury
- Poor nutrition
- Vitamin deficiency

Diseases that can cause ***irreversible*** *dementia are:*

- Alzheimer's Disease
- Multi-Infarct Dementia or vascular disease caused by multiple strokes in the brain (MID)
- Parkinson's Disease
- Creutzfeldt-Jakob Disease
- Huntington's Disease
- Pick's Disease
- Lewy Body Dementia



From *What is Alzheimer's Disease*[34]

[33] *Forgetfulness: It's Not Always What You Think.* Age Page. Alzheimer's Disease Education and Referral Center. National Institute on Aging. US Department of Health and Human Services. http://www.alzheimers.org/pubs/forgetfulness.html.
[34] *What is Alzheimer's,* The Alzheimer's Association. November 2003. op. cit.

E. Alzheimer's Disease[35]

Alzheimer's is:

- A disorder that destroys cells in the brain
- A degenerative, irreversible disease that usually begins gradually, causing a person to forget recent events or familiar tasks
- Variable in the rate with which it progresses from person to person
- Diagnosed as "probable Alzheimer's" based on a variety of tests. The diagnosis has an accuracy rate of 90%. Exact diagnosis can only be determined via a sample of brain tissues after death.

Residents have:

- Memory loss
- Confusion
- Personality and behavior changes
- Impaired judgment
- Difficulty communicating as the affected person struggles to find words, finish thoughts, or follow directions
- Inability to care for themselves as the disease progresses

Progression of Alzheimer's

Alzheimer's disease causes the formation of abnormal structures in the brain called plaques and tangles. As they accumulate in affected individuals, nerve cells connections are reduced. Areas of the brain that influence short-term memory tend to be affected first. Later, the disease works its way into sections that control other intellectual and physical functions.

Alzheimer's disease affects people in different ways, making it difficult for medical professionals to predict how an individual's disease will progress. Some experts classify the disease by stage (early, middle, and late). But specific behaviors and how long they last vary greatly, even within each stage of the disease.

As more is learned about the progression of the disease, new assessment scales are being developed to help physician's track, predict, and treat symptoms of Alzheimer's. New medications can slow the progression of memory loss in its early stages.

Statistics/Prevalence[36]

- Approximately 4.5 million Americans have Alzheimer's disease.
- 11 – 16 million Americans will have Alzheimer's by the middle of the next century unless a cure or prevention is found.

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35 *Facts: About Understanding Alzheimer's Disease*. The Alzheimer's Association, January 2004, op.cit.
36 *Fact Sheet Alzheimer's Disease Statistics*. The Alzheimer's Association, April 2004. op. cit.

- One in 10 persons over 65 and nearly half of those over 85 have Alzheimer's disease. A small percentage of people in their 30s and 40s develop the disease.
- A person with Alzheimer's lives an average of 8 years but can live as many as 20 years or more from the onset of symptoms.

Understanding Behavioral Symptoms

Damage to the brain from Alzheimer's disease can cause a person to act in different or unpredictable ways. Some individuals with Alzheimer's become anxious or appear aggressive, while others repeat certain questions or gestures. Often these behaviors occur in combination, making it difficult to distinguish one from another. Behavioral symptoms do not always become apparent immediately after the onset of disease and often change as the disease progresses. Challenging behaviors not only cause discomfort to individuals with the disease, but also can be frustrating and stressful for caregivers who cannot understand them.

When behavioral symptoms surface, the individual first needs to be evaluated by a physician for potential treatable underlying causes. Behavioral symptoms often result from a variety of unmet needs or treatable problems that the individual cannot communicate, such as:

- physical discomfort,
- medication side effects,
- chronic pain,
- infection,
- nutritional deficiencies,
- dehydration, or
- impaired vision or hearing.

When behavioral symptoms are brought on by causes other than physical problems, further evaluation should try to identify the unmet need and find ways to address it. Unmet needs include the basic human needs: need for toileting, sleeping, food, pain treatment, drink, warmth, companionship, and something useful to do. If a resident with dementia can no longer speak, behavior is the only form of communication. [37]

Non-Drug Treatments

Non-drug treatments of behavioral symptoms are recommended as a first option, since symptoms are best modified without the use of medication. Some suggestions for caregivers and families are:

- **Family education and counseling.** Learn what to expect when afflicted with or caring for someone with Alzheimer's. Family members who are familiar with the disease and know how to effectively communicate with their loved one may be able to better cope with behavioral symptoms. Counseling and support for individuals with the disease and their families is available through local chapters of the Alzheimer's Association.

[37] *Ombudsman Guide to the Nursing Home Reform Law*. 2004. op.cit.

- **Modifying the environment.** Environmental factors such as lighting, color, and noise can greatly affect behavior. Dim lighting, for example, makes some individuals uneasy, while loud or erratic noise may cause confusion and frustration. The noise of a television set may be frightening. Modify the environment to reduce confusion, disorientation, and agitation. Keep familiar personal possessions visible to ensure comfort and feelings of warmth in your loved one's surroundings.

- **Planning activities.** The key to planning activities is in "knowing the details of a person's life." [38] Help individuals with Alzheimer's organize their time and know what to expect each day. Planned activities help individuals feel independent and needed by focusing their attention on pleasurable or useful tasks. Daily routines such as bathing, dressing, cooking, cleaning, and laundry can be turned into productive activities and may be pleasurable for a housewife. Working on a motor for a mechanic, walking and gardening for a farmer are other examples. Other more creative leisure activities can include singing, playing a musical instrument, painting, walking, playing with a pet, or reading. Planned activities may relieve depression, agitation, and wandering, as well as help affected loved ones enjoy the best quality of life.

Drug Treatments

Non-drug treatments are not always effective; therefore, severe behavioral symptoms may be best treated with medication. In some cases, drugs that are available for the treatment of cognitive symptoms [such as donepezil HCl (Aricept®), or tacrine HCl (Cognex®)] also may improve behavioral symptoms.[39]

Several drugs are available for treating behavioral symptoms, and many more are being studied for specific use in helping individuals who suffer from Alzheimer's. Drugs commonly used to treat behavioral symptoms such as agitation, aggression, paranoia, delusions, or depression associated with Alzheimer's include:

Anti-psychotics (neuroleptics)

- Haloperidol (Haldol)
- Olanzapine (Zyprexa)
- Quetiapine (Seroquel)
- Risperidone (Risperdal)

Anti-anxiety drugs

- Alprazolam (Xanax)
- Buspirone (Buspar)
- Diazepam (Valium)
- Lorazepam (Ativan)

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[38] *Nursing Homes: Getting Good Care There*. 2002. op.cit.

[39] New drugs come on the market continually. While manufacturer's will claim they are safer than prior ones, that is rarely the case once the drug has been used in the general population for a time. Sarah G. Burger, April 2004.

Antidepressants

- Amitriptyline (Elavil or Endep)
- Bupropion (Wellbutrin)
- Desipramine (Norpramin or Pertofrane)
- Fluoxetine (Prozac)
- Fluvoxamine (Luvox)
- Nefazodone (Serzone)
- Nortriptyline (Pamelor or Aventyl)
- Paroxetine (Paxil)
- Sertraline (Zoloft)
- Trazodone (Desyrel)

Like any other drugs, these treatments can cause undesirable side effects. Because individuals with Alzheimer's may have difficulty identifying medication side effects, caregivers should ask the physician or pharmacist about what to expect and warning signs to watch for with any drug that is prescribed. Key questions to ask about any medication is, "Does it *enable* an individual to function more independently or at a higher level? Does it *improve* an individual's quality of life?"[40]

Resources

The Alzheimer's Association is the only national voluntary health organization dedicated to research for the causes, cures, treatments and prevention of Alzheimer's disease and to providing education and support services to affected individuals and those who provide their care.

The Alzheimer's Association
919 N. Michigan Avenue, Suite 1000
Chicago, IL 60611-1676
800-272-3900
www.alz.org

The Federal Government funds this service of the National Institute on Aging. It offers information and publications on diagnosis, treatment, patient care, caregiver needs, long term care, education and training, and research related to Alzheimer's disease. Staff responds to telephone and written requests and makes referrals to national- and State-level resources.

Alzheimer's Disease Education and Referral (ADEAR) Center
PO Box 8250
Silver Spring, MD 20907-8250
800-438-4380
www.alzheimers.org/adear

[40] Sarah G. Burger, consultant, April 2004.

F. Parkinson's Disease

Parkinson's is:

- A disease of the central nervous system
- Characterized by tremors in the extremities, rigidity, and slowness of movement
- An incurable, degenerative and progressive disease

Residents have:

- Tremor, which is a rhythmic shaking of a body part when it is at rest[41]
- Poor grasp
- Poor mouth-hand coordination; the resident may need special utensils, special diets, and extended time to eat
- Rigidity or stiffness of muscles that may cause difficulty in walking, moving, or using one's arms and hands such as an inability to suck or close their lips well and limited ability to bite, chew and swallow
- Loss of balance and slowness of movement, as well as handwriting that gets smaller and smaller; loss of arm swing while walking
- Impassive facial expression
- Decreased volume and clarity of the person's voice

Tips For Ombudsmen

Regardless of the cause of confusion, or whether it is reversible or irreversible, there are positive ways to respond to individuals. The expectation for improvement needs to be present. Individuals sometimes rise to meet our expectations, in spite of confusion. Voice tones as well as words and actions convey much meaning. As an ombudsman, you must be aware of all messages you are giving.

[41] Movement Disorder: Old Age or a Treatable Disease? *Board & Care Quality FORUM*. Titus, S. Vol.2, No. 1. Reisacher Petro and Associates: Pittsburgh, PA, Jan/Feb 1999.

VII. Drugs and Their Side Effects in the Elderly[42]

Most nursing home residents are on five or more drugs at any time. Ombudsmen, in visiting in nursing homes, will notice the side effects these drugs can have on residents. This section familiarizes ombudsmen with common drugs in nursing homes and the side effects many residents experience. Ombudsmen should be familiar with this basic terminology of drugs so that when residents'/families' complaints involve drugs, ombudsmen recognize the terms. Ombudsmen can thus refer or investigate the complaint reliably.[43]

Over a four year period, two-thirds of nursing facility residents have adverse drug events (ADEs) and one out of seven of these results in hospitalization. [44] Ombudsman should be aware of the Beers Criteria that identify 48 commonly used individual drugs or classes of drugs to avoid in older adults and 20 diseases or conditions and medications to be avoided in older adults. [45]

The decision on prescribing appropriate drugs is the domain of the physician. Advance Practice Nurses (Nurse Practitioners and Clinical Nurse Specialists) in some states have prescriptive authority.[46] Pharmacists in nursing homes review the drug regime of residents on a monthly basis to ascertain if there are adverse drug reactions, allergies, contraindication, or ineffectiveness.

Remember: your role is not to second guess a medical decision regarding medications. You are to listen, observe, ask appropriate questions, and suggest that an individual ask his/her physician for additional review or more information. Ombudsman should know that all drugs given to the elderly should be started at a low dose and raised slowly. This is especially true for individuals who have a dementia. [47]

If more specific information related to medications is needed, call the State Long Term Care Ombudsman. You can also consult the following documents for excellent information about geriatric conditions, medications, and alternative treatments.

- F329: "Unnecessary drugs," Guidance to Surveyors. State Operations Manual, Appendix P, Survey Protocol for Long Term Care Facilities. Health Care Financing Administration, Baltimore, MD. PP-114+. Also available online: http://www.cms.hhs.gov/manuals

- "Psychotropic Drug Use," Resident Assessment Protocol. Resident Assessment Instrument Training Manual and Resource Guide. Health Care Financing Administration, Baltimore, MD.

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[42] Adapted from the Illinois Ombudsman Program Curriculum

[43] For more information see Nguyen, C., and Williams, B. *Reducing Medication Problems in the Elderly*, USC School of Pharmacy 1995.

[44] Cooper, JW. *Adverse Reaction Related Hospitalization of Nursing Facility Patients: A Four Year Study*, South Med Journal, 1999. 92:485-490.

[45] Fick, D, Cooper, J., Beers, M et al, *Updating the Beers Criteria for Potentially Inappropriate Medication Use in Older Adults.* Archives of Internal Medicine 2003. 163:2716-2724 (Google the Beers Criteria).

[46] *Ombudsman Guide to The Nursing Home Reform Law*, 2004, op. cit.

[47] *Resident Assessment Instrument for Long Term Care*, Centers for Medicare & Medicaid Services, Transmittal #8, Psychotropic /Drug RAP, 1999.

SUMMARY OF DATA ON MAJOR PSYCHOTROPIC MEDICATIONS[48]

A. Neuroleptics (Major Tranquilizers, Anti-psychotics)

Used for psychosis, which is a severe mental disorder in which thinking and emotion are so impaired that the individual is seriously out of contact with reality. Examples of psychotic disorders include:

SCHIZOPHRENIA – *A group of psychotic disorders characterized by major disturbances in thought, emotion, and behavior.*

- Ideas are not logically related.
- Perception and attention are faulty.
- Bizarre disturbances occur in motor activity.
- Emotions are flat, inappropriate, and ambivalent.
- There is reduced tolerance for the stress of interpersonal relationships, causing withdrawal from people and reality, often into delusions (a belief contrary to reality) and hallucinations (any sense perception without adequate external stimuli).

MANIA – *An emotional state characterized by intense and unrealistic feelings of elation.*

DEPRESSION WITH HALLUCINATIONS

TOXIC PSYCHOSIS--LSD, PCP

ORGANIC BRAIN SYNDROME – *Associated with psychotic behaviors or agitated behaviors that can be quantified. Organic problems caused by:*

- Infection such as encephalitis or neurosyphilis
- Trauma as in concussion, contusion, or laceration
- Nutritional deficiencies such as Korsakoff's psychosis, beriberi, or pellagra
- Cerebrovascular accident and brain tumors
- Degenerative diseases such as Alzheimer's, Pick's, Huntington's Chorea, and Parkinson's
- Cerebral arteriosclerosis
- Endocrine disturbances

Ombudsman should know that all drugs given to the elderly should be started at a low dose and raised slowly. This is especially true for individuals who have a dementia. [49]

Most common drugs used with these conditions:

- Haldol
- Loxitane
- Navene
- Moban
- Stelazine
- Prolixin
- Trilafon
- Thorazine

[48] From the Louisiana Ombudsman Program Manual.
[49] *Resident Assessment Instrument for Long Term Care*, Psychotropic /Drug RAP, op.cit.

Common side effects (stopping the medication will clear up symptoms in few days):
- Sedation (more common with low-potency drugs)
- Dry mouth, nausea, constipation, sweats, and/or blurred vision
- Tremor, muscle spasms, and restlessness
- Low blood pressure/dizziness (more common with low-potency drugs), causing falls
- Tardive dyskinesia: The involuntary movement of tongue and mouth, sometimes of arms, legs, torso. (Can become a permanent condition and needs to be watched very carefully.)
- High fever: Narcoleptic Malignant Syndrome, which is a medical emergency
- Acute Confusion and delirium

Summary
Generally safe medications; equally effective; the physician must weigh benefits versus side effects.

B. Minor Tranquilizers (Anti-Anxiety Agents)

Used for:
DISABLING ANXIETY: (Panic disorders, phobic disorders, post-traumatic stress disorder, and social phobia)

ALCOHOL WITHDRAWAL

STATUS EPILEPTICS

MUSCULAR SPASMS

Most common drugs used with these conditions are all listed as potentially inappropriate according to the Beers Criteria. Older persons are very sensitive to them. Avoid using the long acting ones. The drugs are grouped according to length of time it remains in a person's system:
- Long Life (18-36 Hr.), Valium, Paxipaim, Xanax (avoid these)
- Medium Life (10-12 Hr.), Tranxine, Ativan, Serax
- Short Life (4-12 Hr.), Librium, Centrax

Side effects:
- Common: Sedation
- Uncommon: Dry mouth, nausea, dizziness, confusion, withdrawal, tremor

Summary
All are potentially inappropriate for older persons, seldom habituating; usually used on short-term basis.

C. Antidepressants

Used for depression (when depression lasts more than two weeks):

NOREPINEPHRINE TYPE DEPRESSION – *characterized by:*

- Sleepiness
- Overeating
- Weight gain

SEROTONIN TYPE DEPRESSION – *characterized by*:

- Restlessness
- Anxiety
- Loss of appetite/weight

PANIC ATTACKS

OBSESSIVE COMPULSIVE DISORDERS: *Where the mind is flooded with persistent and uncontrollable thoughts or is compelled to repeat an act again and again*

Most common drugs used with these conditions:

– Asendin	– Impipramine	– Pamelor	– Sinequan	– Vivactil
– Desyrel	– Ludiomil	– Prozac	– Surmonti l	– Zoloft
– Elavil	– Norpramin	– Paxil	– Tofranil	

Common side effects:

- Sedation (more common with serotonergic)
- Dry mouth, nausea, constipation, sweats, and/or blurred vision

Summary

Very effective in endogenous depression; adverse reaction in people with cardiac problems and epilepsy; often requires two or three different medications before one is found that is effective and has the fewest side effects.

> **IMPORTANT:** *These medications are toxic in overdoses. They can be quite dangerous. A small "mg" dosage is given for this reason.*

D. Lithium Therapy

Used for:

BIPOLAR DISORDERS: Manic/depressive, manic, depression

ALCOHOLISM

Medication used:
- Lithium

Side effects:
- Common – Tremor, nausea, diarrhea
- Less common – Muscle weakness, muscle cramps, abdominal cramps, convulsions, acne, confusion

> **IMPORTANT:** *Can be toxic when too much Lithium is in a person's system or sodium levels drop. Effects when one of these occurs: tremor, nausea, diarrhea, loss of coordination, confusion, and coma.* ***Blood levels must be checked regularly by a physician.***

Summary
Most people take this medication without side effects. Therapy is long term (five years without a relapse). The patient is checked for blood levels and vital functions regularly.

E. Miscellaneous

NASAL DECONGESTANT SPRAYS
- Used for the relief of nasal congestion

Adverse Effects
- "Rebound congestion"
- Burning/stinging
- Sneezing

Examples:
- Dristan
- Neo-Synephrine
- Sinex

Caffeine

- Used as an aid in staying awake
- Found in several beverages like coffee, tea, colas, and cocoa

Adverse Effects of Caffeine

- Insomnia
- Excitement
- Increased Urination
- Nausea/Vomiting
- Nervousness
- Ringing in the ears
- Restlessness

VIII. NOTES

*Principal sources of data for the Profile are the U.S. Bureau of the Census, the National Center on Health Statistics, and the Bureau of Labor Statistics. The Profile incorporates the latest data available but not all items are updated on an annual basis.

**Excludes persons of Hispanic origin.
***Calculated on the basis of the official poverty definitions for the years 2000-2002
**** Census 2000 figure
***** 2000 figure

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