Aging Process

Aging is not a disease; it is a normal progression in a healthy adult life.

However, you may notice characteristics in your clients that may not be a normal part of aging. Ombudsmen must be knowledgeable of what is normal and what is a deviation from the norm.

PHYSIOLOGICAL CHANGES

Physical Appearance:

- Skin loses some elasticity, becomes thin and more easily broke or torn; nose and ears appear longer, "onion skin;"
- Difficulty with adjustment of body temperature; susceptible to hypothermia, heat stroke or exhaustion; inability to adjust to environmental changes such as broken air conditioning;
- Muscles less elastic and less flexible due to disuse; unsteady gait, falls more prevalent, manual dexterity diminished;
- Loss of bladder control; incontinence, urgency, frequency; especially in women who have had multiple births
- Prostrate problems in men over 50 common;
- Restriction in blood vessels decreasing heart and brain function;
- Little change in sexual function;
- Information stored in brain, unaffected but may take longer to process and retrieve.

Sensory Changes:

- Vision: lens yellows, glaring light presents problems as eye can not adjust, cataracts cause milky blurred vision;

- Some hearing loss is common: Loss of high tones, sounds often distorted and persons may mistake one word for another, common to read lips;
- Loss of 50% of taste buds; can't tell if too salty or spicy
- Loss of taste also leads to a decrease in smell; oblivious to certain odors; decrease in appetite;
- Decrease in pain perception; greater potential for burns, irritation, and accidents;
- Need less sleep.

The effect of sensory deficits in residents makes your communication skills even more important. Please review the following:

Indications of hearing deficits:

- Talking loudly when not necessary;
- Constantly asking to repeat;
- Answers unrelated questions;
- Frustration, anger;
- Understanding spoken word only when speaker's face is in full view.

What to ask if hearing deficits are present:

- Where should I stand so that you can hear me most clearly?
- Can you hear when there is a knock on your door?
- Can you hear better when the area is quiet?
- Do you hear better on one side than the other?

Indications of visual deficits:

- Spilling;
- Feeling for objects;

- Misjudging distances;
- Inability to copy the written word.

What to ask if visual deficits are present:

- Do you have glasses?
- Where do you keep them?
- When was your last eye exam?
- Have you noticed floating or wavy spots, blinds spots?
- Do you take eye drops?

Indications of taste/smell deficits:

- Body odor;
- Increased or decreased weight or appetite;
- Bottles of condiments and seasonings in the room;
- Frequent complaints regarding bland taste of food.

What to ask if taste/smell deficits are present:

- Do foods taste/smell as they used to?
- How has your appetite changed?
- Have you noticed yourself gaining/losing weight?
- How have your food preferences changed?

Indications of touch deficits:

- Not responding to touch;
- Dropping objects such as utensils;
- Can't hold a pencil or pen.

What to ask if touch deficits are present:

- Can you pick up a penny off your tray?

- Can you tell which arm I am touching if you close your eyes?
- Are you cold/hot all the time?

Health Problems/Impairments

Ombudsmen should be aware that most nursing home residents have multiple chronic health problems. Aging is a state of mind, focusing on where the resident is in his/her life rather than on a disease that needs to be dealt with.

Ombudsmen need to build on the strengths the resident has rather than on his or her deficits.

Ombudsmen should be able to recognize some medical terms and diagnosis in order to define a complaint properly. This will be covered in depth in the care planning and assessment section.

Drugs

- An average nursing home resident takes 9 medications (2001 statistic);
- Polypharmacy has devastating effects on residents due to age related changes already discussed;
- Federal standards in the State Operations Manual describe the need to evaluate and not use unnecessary medications;
- Pharmacist is required to review at least quarterly and make recommendations to medical director;
- Medical director must review;
- Medications can not be given for staff convenience and must be based on medical necessity;
- Typical medications and side effects are listed in the "Common Illnesses and Conditions Associated with Aging" section;

This will be discussed in more detail in the care planning and assessment section in Module 4.

PSYCHOLOGICAL CHANGES

Intelligence

Intelligence does not decline with normal aging. When tested, older people respond less well on timed tests than do younger people. On tests with no time limits older people perform better than younger individuals.

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.

Senility

Senility has often been used as a "catch-all" word which covers a range of symptoms with various underlying causes. All older people do not become senile. In common usage the word generally refers to forgetfulness, confusion, and disoriented behavior. It has been estimated that 300,000 older Americans could presently be misdiagnosed. There are numerous, treatable causes for the symptoms frequently labeled senility. Many problems can be classified as either organic disorders or functional disorders.

Organic Disorders

Organic disorders are caused by impairment of brain tissue. The symptoms may include disturbed or impaired intellectual functioning, impaired

judgment, impaired orientation, or inappropriate emotional responses. The symptoms vary in intensity from individual to individual. A person who has an organic disorder may not know what day it is or may laugh when there is nothing humorous.

Acute Organic Disorders

Temporary, acute disorders are caused by physiological stress and are reversible if treated in time. There are numerous possible causes, all of which are treatable. Hypoxia, the lack of oxygen to the brain, may result from surgery or from very hot baths. During a very hot bath, blood vessels dilate which causes more blood than usual to remain in the hands, feet, and legs. That leaves less blood to circulate to the brain. Temporary confusion may result. Another cause may be the increased time required for an aged heart to circulate sufficient oxygen to the brain and throughout the body.

Other causes of acute organic disorders are heart failure, anemia, and fluid and electrolyte imbalance. A doctor may tell a patient to drink a glass of orange juice every day. If the patient skips the orange juice for several days, the person may become disoriented, or confused. The patient's medicine was depleting potassium from his/her system. The body's chemistry was out of balance. Nutritional deficiencies can have a similar effect. A person may lose interest in eating or decide not to cook. A meal is skipped, and then the person may decide to eat a snack instead of the next meal. Several days of nutritional deficiencies may result in mild confusion.

Elevated temperature, drugs or alcohol intake, and pathological conditions are other possible causes of acute organic disorders. Fever or an illness may produce some confusion. Drugs or alcohol can also cause disorientation, forgetfulness, or impaired judgment. Prescribed drugs may not be monitored closely enough or may have adverse interaction effects with other drugs.

Chronic Organic Disorders

In contrast to acute disorders, chronic disorders are irreversible. The result is permanent brain damage. Treatment for individuals with chronic disorders may slow the deterioration process.

There are several types of chronic disorders:

- Senile psychosis results from dissolution of brain cells. It is eventually fatal. The brain loses weight.
- Cerebral arteriosclerosis is caused by widespread brain tissue death due to a series of minor strokes. This accounts for 20 percent of the irreversible cases of mental impairment.
- Alzheimer's disease causes the death of a large number of cells in the outer layer of the brain. It affects 4-6 percent of the population over age 65. Of all elderly individuals with mental impairments, Alzheimer's disease accounts for 50-60 percent.

Functional Disorders

Other causes of symptoms often labeled senility are due to functional disorders. There are no physiological changes. The symptoms are triggered by the interaction of stressful situations and the individual's personality.

Depression

Depression, characterized by helplessness, sadness, lack of vitality, loneliness, or boredom, may become a functional disorder. It can disrupt an individual's ability to perform normal daily tasks. Physical reactions to depression include constipation, sexual disinterest, impotence, early morning fatigue, loss of appetite, or hypochondria. Depression may be caused by guilt, by loss or grief, or by a disease which produces pain and physical incapacity. It is also a cause of suicide in the elderly. Mental health counseling or psychotherapy can be beneficial for older people. It is not too late for an older person to work through emotional or psy-

chological problems. Older age can be a time for resolving conflicts or unresolved problems and for further personal growth.

Disorientation

A sudden environmental change sometimes produces disorientation. A move from home or hospital to a nursing home is an example of such a change. It may take a while for the relocated individual to think and behave in an ordered manner. The adverse affects of relocation can be minimized by involving the individual in planning for the move.

Grief

In reaction to mild or severe grief, a person may be unable to sleep, experience loss of appetite, forgetfulness, restlessness, or other symptoms. The grief may be due to the loss of a relationship, either through death or by a change of circumstances. Physical relocation and the resulting severing of ties with familiar places may also cause grief. A further source of grief is a reaction to loss such as the loss of mobility, independence, or decreasing physical abilities.

ADAPTATION TO CHANGE

Changes are experienced by everyone throughout their lives. When a person acquires senior citizen status, he has experienced numerous changes. He has gone from horse-and buggy to airplanes to space ships. Individuals who have witnessed those changes have established patterns of adjusting to change. He knows better what he can and can't tolerate and what is important to him.

Reactions to change vary from person to person. Sometimes older people are seen as resistant to change or "set in their ways." It may be their refusal to accept change is their 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. More information or different words may be needed to clarify the explanation of the change, even if it is about a service being offered. Older people may need more time

to consider the proposed change, to think it through, and to decide. To have assurance that the change can be tried on a temporary basis and then reevaluated may encourage someone to accept change. If an older person is offered a service or activity, the person may need reassurance about: the terms of the service, other people who have utilized the service, and that the service can be easily terminated, before 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's tough to find a balance between trusting their own priorities and understanding the enabling supports they need. Change, whether positive or negative, is stressful. All individuals need time to adjust.

Reminiscence and Grieving

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.

Reminiscence can also be a productive method of dealing with loss and grief. By verbally sharing the loss, an individual may come to accept it. In grief there is a need to remember, to relive past experiences. Reminiscence provides that opportunity. There may be conflicts in the past which are unresolved or which 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.

An emotional outlet is supplied through reminiscing. 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.

Identity and Self-Assessment

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 better understand the older person by listening to reminiscences.

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. Self esteem can be reinforced by allowing an older person to give advice, wisdom, or history to others through reminiscence. It may reinforce a person's feeling that her life has been worthwhile.

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Common Illnesses and Conditions Associated with Aging

DIGESTIVE

Malnutrition:

Causes of malnutrition include:

- Eating alone after the death of a spouse
- Depression
- Lack of ability of taste buds due to the effects of drugs
- Diminished absorption of nutrients due to physical decline of endocrine system
- Poor fitting dentures. Over 50% of people over 65 do not have teeth and shrinkage of jaws can cause improperly fitting dentures
- Not enough saliva which aids in the breaking down of food in the mouth
- Diminished ability to swallow, known as peristalsis
- Those who won't eat because they are rebelling through food. They may be angry with their relatives for deserting them in a nursing home, angry at being sick, angry with the staff or angry with their physician

Non-eaters are at risk due to limited protein reserve in the organs of the body. A person suffering from malnutrition will have little energy and, in its more advanced stages, will be mentally confused. Staff and relatives have a difficult task, and may become frustrated and resentful, thus caus-

ing further resistance from the resident and retaliation from the nursing home staff.

Hiatus Hernia:

Sixty-nine percent of people 70 years and older have 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.
- As part of treatment, smaller, more frequent meals are helpful.
- Staff may not realize the importance of positioning a person correctly.

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 and antacids

Residents may complain about or have:

- Abdominal pain
- Distention of stomach

- Cramping

Many older people are dependent on laxatives. This dependency becomes counter-productive. 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.

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.

Dehydration

Dehydration symptoms are:

- Sunken eyes
- Dry tongue
- Dry skin
- Cracks in the corners of the mouth
- Loose and less elastic skin
- Person may show signs of confusion

Having water available at all times is imperative to the health of the resident. Since the older person does not retain as much water, they need to drink more frequently. Many residents cannot drink by themselves or cannot reach the water left on their night stand. Some residents do not drink water late in the day to avoid getting up at night. Sometimes, an older person may not feel thirsty though they are dehydrated.

NEUROMUSCULAR-SKELETAL

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
- 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.

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:

- Poor grasp
- Poor mouth-hand coordination
- Inability to suck or close their lips well and limited ability to bite, chew and swallow
- As time goes on the resident will need frequent help with eating or drinking

- The resident may also need special utensils, special diets, and extended time to eat

Decubitus Ulcers (bedsores):

- Are caused by pressure due to laying or sitting for prolonged periods. Bedsores are most common in patients who are completely immobilized.
- Most ulcers appear on: heels, buttocks, back of heads, elbows or hips.
- The skin is reddened and usually is broken or blistered. There may be necrosis of the tissue (dead tissue) which can cause exposure to the bone.
- Decubitus ulcers are the most obvious sign of neglect; left unattended, they can lead to infection and ultimately to death. Sometimes these ulcers have been bandaged to cover up neglect. These ulcers have a very strong odor, similar to decaying meat.
- Development of these ulcers can be affected by unmade beds, or improper bedding, wet or soiled linen, radiation therapy, barbiturate sensitivity, sensory loss and the condition of the skin.

Prevention or treatment of decubitus ulcers include:

- Turning patients every two hours to avoid breakdown of the skin.
- Better nutrition can improve the condition of the skin, if the patient is malnourished.
- Using "egg-crate" or waterbed mattresses. These type of mattresses assist in shifting a resident's weight from one spot to spreading the weight out over a larger surface.
- Hyperglycemia (elevated blood sugar) increases the likelihood of developing the ulcers as does arteriosclerosis which reduces the blood supply to the tissues. Dehydration, which causes fragile, in-

elastic skin, is another factor. However, none of these conditions will cause sores in the absence of persistent pressure.

NEUROLOGICAL

Alzheimer's Disease

Estimates of the prevalence of Alzheimer's Disease in the older population continue to rise as medical research in the field refines advanced diagnosis procedures. Alzheimer's is a dementia whose diagnosis is accurately determined only after death. Alzheimer's is believed to become more prevalent with age so while 4 to 6 percent of persons over 65 have the disease, the estimated percentage is closer to 50% in those over 85 years old.

Alzheimer's is:

- A progressive disease that starts with a loss of short-term recall and progresses until death
- During the course of the disease the person becomes unable to do day to day functions due to progressive loss of short term and eventually long term recall.
- Persons will fail to recognize their family and become a danger to themselves when they are unable to remember to turn off their stoves or remember where they live.
- It is often the loss of memory that causes a family to seek institutionalization.
- Because of the lack of normal memory, the person needs to be watched constantly and protected from wandering into danger.
- Alzheimer's victims also can adopt screaming behavior that disturbs other residents.
- Some nursing homes have special wings for Alzheimer's patients that are geared to structuring the activities of patients and monitoring for wandering behavior.

URINARY

Incontinence:

- Inability to control excretory functions and occurs more frequently in the very old;
- Caused by weakness in the sphincter (valve) to the urinary tract, particularly common in people who get little or no exercise; and
- Diminishing ability to store urine in the bladder causing the frequency of voiding to increase.

The older person may not feel the sensation alerting him/her to void until the bladder is almost full. In a young person this sensation occurs when the bladder is about half full. When the older person realizes he has to go to the bathroom, it may be too late.

Incontinence can be caused by urinary tract infections, tumors and injury to the central nervous system.

Incontinence is common in people with Alzheimer's disease and other chronic brain syndromes, particularly in the later stages of these diseases, as these diseases affect the central nervous system. Incontinence also can be caused by stress, worry, anger, fear, frustration, anxiety, and confusion. Sometimes residents become incontinent due to lack of attention by nursing staff if they are made to sit for hours without assistance.

Incontinence can be devastating to the resident's self-esteem. They feel frustration and shame when they can no longer control their bodily functions. Insensitivity on the part of staff can further diminish the resident's self-esteem. Staff should check residents who are incontinent frequently so they can be changed to avoid discomfort or skin breakdown.

In many people, continence can be regained by bladder and bowel training. The changes of success with bladder and bowel training increases if the resident maintains adequate fluid intake (2000 cc, approximately 2 quarts, or more per day). Regular trips to the bathroom at designated times of day, prompt attention to the call light for assistance, and involv-

ing the resident and sometimes the family in the retraining plan, all are necessary steps toward retraining. If the resident is getting poor results, the plan may need to be changed. The chart should be marked as to time of the day the resident soils him/herself so the plan can be adapted to his/her personal schedule. Bowel and bladder retraining take time and consistent effort but the rewards in self-esteem and the quality of life more than make up for the effort.

Excerpted from the Illionois Ombudsman Curriculum, available through the National Long Term Care Ombudsman Resource Center, www.ltcombudsman.org.

Resident Sexuality in The Nursing Home

The following section is written from the perspective of providing guidance to nursing home staff, but will prove useful to you as an Ombudsman working with nursing home residents. The section is adapted from the *Staff Education Manual* of the The National Alzheimer Center of The Hebrew Home for the Aged at Riverdale.

INTRODUCTION

This training program deals with sexual expression. The program will include viewing a videotaped enactment of some forms of sexual expression that are seen frequently in nursing homes. You will also be instructed in the "ABC" approach to understanding and dealing with various resident behaviors. But first, make sure you understand sexual expression among elderly persons — particularly among those elderly persons who suffer from illness associated with dementia.

First, keep in mind that sex is not only a biological drive for pleasure and reproduction. It is also a powerful way for human beings to relate to one another and to express intimacy. In nursing homes, where relationships can be fleeting, it is particularly important to respect sexuality as an important aspect of adult life. Therefore, support resident sexuality as a basic human right that should not be denied simply because a person is living in a nursing home.

Consequently, the position of administration and clinical staff is that sexual expression is a resident right, which must be observed and preserved to the greatest extent possible. Having said that, recognize that there can be difficulties associated with residents' sexual activities. The purpose of this training manual is to help you to develop the skills necessary to deal with some of these problems, while not infringing on residents' funda-

mental right to sexual expression. The facility's policies and procedures which can help to protect this right will be discussed.

SEXUALITY AND QUALITY OF LIFE ISSUES

Sexual expression can be seen as a quality of life issue. Once survival needs are fulfilled, for example, food and shelter, the needs for intimate relationships and for feelings of being loved are vital. In fact, studies show that babies who are deprived of physical touch and emotional stimulation suffer serious gaps in emotional and physical development.

The need for intimacy does not change in old age. In fact, the desire for intimacy can intensify. As people lose their peers, they become attracted to others. Relationships develop and sexual feelings may become activated. For many people these feelings are a gift that brings a sense of pleasure and a feeling of being alive.

Aging is not fun, nor is moving to a nursing home. As people age, they lose many abilities that youth take for granted. Life often doesn't feel as enjoyable as it was before growing old. It's also important to acknowledge that for elderly persons, intimacy can trigger a myriad of feelings. Despite craving companionship, an elder may fear close relationships due to the remembered pain of previous losses that a relatively common among elders. Or, elders may desire social stimulation, but physical impairments can inhibit relationships with others. If intimate relationships develop within the nursing home, they are most apt to contribute positively to a person's quality of life.

DISCUSSION GUIDE

Sexual Attraction and Relationships

When connections are made between two people, everyone notices. Although the relationship focuses on the two individuals involved, the entire community is affected.

- How might these relationships change people's lives?
- How might relationships affect others on the unit?

Relationships can surface a host of difficult issues, for example:

- Sometimes residents desire romantic companionship but feel as if they're betraying their deceased or ill spouses.
- Sometimes residents develop affection for each other but fear that they cannot perform sexually. This can bring feelings of loss, sadness, inadequacy and shame.
- Sometimes residents feel that because they are old they are unattractive. Therefore they hesitate to think about love or shun the very idea of seeking out a loving relationship.
- Sometimes residents become jealous of other couples because seeing people in love triggers feelings of loss, loneliness and desire.
- Sometimes residents (and staff) are uncomfortable with public displays of sexuality.

There are many such complexities involved in geriatric sexuality, particularly within a nursing home. The upcoming sections will highlight some of these issues through scenarios and a discussion of interventions.

Residents' Rights Regarding Sexual Expression and Physical Protection

Residents have specific statutory and regulatory rights that are specified in state and federal laws. In New York State, these rights are set forth in the *Official Compilation – Codes of Rules and Regulations of the State of New, York, Chapter Title 10, Section 415*. These rights include the following:

- You (the resident) have the right to exercise your individual rights or have your rights exercised by a person authorized by state law.
- You have the right to be free from verbal, sexual, mental or physical abuse.

- You have the right to privacy. Resident and family groups shall be provided with private meeting spaces and residents shall be given access to a private area for visits or solitude.
- You have the right to share a room with your spouse, relative or partner when this person lives in the nursing home and both consent to the arrangement.
- If a spouse, relative or partner resides in a location outside the nursing home, you will be assured of privacy for visits.

The Sexuality Workgroup of The Hebrew Home for the Aged at Riverdale developed a set of policies and procedures relating to sexuality that help recognize the importance of emotional and physical intimacy. These policies and procedures support expressions of intimacy that do not infringe on the rights and sensibilities of the community. While recognizing that each nursing home will wish to adopt or adapt its own set of policies and procedures, it's worth citing some of these policies and procedures to provide an idea of what's covered.

Preamble A

Sexually-oriented expression is defined as:

"Words, gestures, movements or activities (including reaching, pursuing, touching or reading) which appear motivated by the desire for sexual gratification."

Residents have the following rights, providing in each instance that they do not involve non-consensual acts, acts involving minors, or acts and/or behaviors between persons who are cognitively impaired and/or with impaired judgment, and that they do not impact negatively on the resident community as a whole.

1. Residents have the right to seek out and engage in sexual expression as defined above.
2. Sexual expression may be between or among residents only, or may include visitors, subject to the conditions expressed in Preamble A.

3. Residents have the right to access and/or obtain, for private use materials with legal but sexually explicit content: books, magazines, film, video, audio, pictures or drawings.
4. To the extent possible, residents have the right of access to facilities, most notably private space, in support of sexual expression.
5. Residents have the right of access to professional counseling pertaining to sexual expression of self or others.

In instances where conditions expressed in Preamble A are not fulfilled, the relevant Interdisciplinary Care Team (ICT) will make clinical judgments regarding the relative benefits or potential harm associated with the resident's(s') sexual expression. In instances where any associated resident is cognitively impaired and/or with impaired judgment, and for whom there is a designated representative e.g. spouse or adult child), this designated representative will be involved in the decision-making process concerning possible course(s) of action to be undertaken with (but not necessarily on behalf of) the resident. Involvement of a designated representative is warranted only in instances where the involved resident is cognitively impaired and/or with impaired judgment.

Similar "rights" and "obligations" are spelled out for staff and for administration as well.

There are common misconceptions about geriatric sexuality, such as the following:

- Old persons can't have sex
- Old persons aren't interested in sex
- Old persons don't know what's going on
- Old persons are no longer interested in relationships
- Old persons have stopped living and growing

Statistics Regarding Sexual Expression In Elderly

There are approximately 1.3 million elderly persons living in nursing homes in the United States and at least three quarters of these people suf-

fer a dementing illness (Katzman, 1985; Holmes, 1994; Ory & Teresi, 1994). Despite the large numbers involved, relatively little attention is given to sexuality in this population (Allard and Poer, 1994). In some instances, nursing home staff simply deny the importance of sexual expression. For example, in a recent survey of social work staff in 29 nursing homes, staff from almost 30% claimed that "sex was not an issue" (Fairchild & Farrino, 1994). Others have noted, however, that "...sexuality is considered to be among the more disturbing behaviors (among residents) in skilled nursing home facilities" (McCartney, et al. 1987).

Szasz (1983) reported that nursing staff were able to detail the categories of sexual behavior which were troublesome, and that masturbation was reported by staff as being the single most troubling behavior. Furthermore, Holmes, Reingold & Teresi (1997) found that 13-20% of the respondents, in a three State survey of attitudes toward sexual expression among nursing home residents, reacted that the majority of residents exhibited some type of sexual behavior.

Changes in Attitudes

In the article by Holmes, Reingold & Bouru (1999), the authors also note that there is a beginning change in attitude about the "heretofore taboo topic." As a result, caretakers and administrators are becoming more open about discussing resident sexuality. For instance, not long ago a public discussion of sexuality among residents of nursing homes would have been ill received. Today, however, there are signs that the situation is improving. For example, in a survey of attitudes toward resident sexual expression (Reingold, Holmes, and Barrett (1993); Reingold & Holmes (1994)) the authors found that:

Most respondents agreed that additional staff training should focus specifically on dealing with resident sexual expression. Overall, the sample reported generally positive attitudes toward resident sexuality and sexual expression.

However, despite this new openness regarding resident sexuality, some nursing home administrators are reluctant to institute a liberalized policy regarding sexual expression. The reason for this is that sexuality is a complex subject with both positive and negative aspects. Holmes, Reingold, and Bouru (1999) cite these pros and cons. Here are a few of them.

Positive perceptions:

Sexual expression can:

- Provide tension release
- Abate loneliness
- Give a sense of belonging
- Lead to positive relationships
- Be mutually pleasurable
- Enhance self-esteem
- Enhance quality of life

Negative perceptions:

Sexual expression can:

- Provoke ageist sentiments
- Provoke guilt
- Constitute inappropriate behavior
- Constitute an impulse control problem
- Create social stigma
- Contribute to peer discomfort
- Lead to emotional hurt
- Lead to physical harm
- Potentiate family upset
- Involve unpredictable behavior
- Create jealousy
- Lead to victimization of more impaired partner
- Lead to discomfort
- Be offensive to staff, coercive to residents

Perhaps more realistically, in the context of dementing illness, sexual expression may lead to:

- Behaviors expressed in public without regard to others.
- Touching others sexually without being able to discern whether the desire for physical contact is mutual.
- The inability to verbalize yes or no to others' sexual advances.
- Inability to interpret facial and body language appropriately, e.g., misinterpreting smiles, touches and hugs as sexual invitations.
- Engaging in sexual acts with someone who is married to another.
- Disrobing.
- Making sexual comments that might be offensive.
- Avoidance of sexually evocative situations.

How a person responds to a resident's difficult behavior greatly influences whether it can be averted. This is particularly true when it comes to Alzheimer's and other related dementias. The key to redirecting behaviors lies in knowing how to anticipate a behavior before it becomes a problem. With practice, one can learn to anticipate many potential problems.

To help control behaviors use a system called the ABC approach developed by Linda Teri and associates at the University Of Washington.

According to this system:

A= Antecedent: the trigger for the behavior. It is what happened before the emergence of the behavior.

B= Behavior: the actual behavior such as crying, screaming, and/or touching someone, which one is trying to extinguish.

C= Consequence: the results, which happen after the behavior.

To break into the A-B-C cycle, change A or C or both.

Example: Mr. Smith sits in the nursing home lounge by himself. Others in the room are involved in a card game. Suddenly, Mr. Smith begins to masturbate. The other residents notice this and become upset, so a staff member tells Mr. Smith to stop masturbating and criticizes him for his behavior. This, in turn, makes Mr. Smith cry.

Now, using the A-B-C approach:

Identify the A, B and C in this situation.

What is the antecedent (A)?

A = The fact that this resident was off by himself probably triggered the behavior. When a dementia patient is not engaged in an activity, she/he is more likely to become upset or to act out because the lack of structure creates anxiety. In this situation, the resident was probably feeling lonely and had his hands free, so touching himself was a natural response to boredom and sadness.

What is the behavior (B)?

The resident's behavior was masturbation.

What is the consequence (C)?

There are two consequences in this example. One is that the residents became upset when Mr. Smith began to masturbate. The second is that Mr. Smith began to cry when he was criticized for his behavior.

What could have been done differently?

If the staff member had noticed that Mr. Smith was by himself, could the situation have been prevented? It is possible. If Mr. Smith had been playing cards with the others, his hands would have been occupied and he would have been less isolated. The staff member, in noticing that Mr. Smith was alone, could have invited him to join the others. This is one example of how really noticing and paying attention to residents can help avert behaviors or prevent them from developing.

What else could have been done differently?

For instance, once the behavior started, how could the outcomes or consequences of the behavior have been different?

They would have been different if the staff member had not criticized the resident. A kinder, gentler approach could have prevented the resident from crying.

Can you think of other interventions, different from these that also would have worked?

- The staff member could have offered to take the resident to his room for privacy.
- The staff member could have distracted the resident by engaging him in other activities.

Other things to consider…

- How could humor have served to help the situation?
- Do you use humor in your interventions? If so, how?
- Does humor help the residents? If so, how?
- Does humor help you get through the day? Elaborate.

Tips on the Identification of Potential Problems

- Be observant.
- Get as much information about the situation as you can before it becomes a problem.
- Always consider the when, where, who, what, and how in any given situation.
- Think about the problem before and after it occurs.

- Watch the time frame of certain behaviors. For instance, does the same behavior happen every day at the same time? Or does the behavior always last for the same amount of time?
- Look for changes over time.
- Look for repeating patterns.

Tips for Dealing with Difficult Behaviors

- Distance yourself from the situation.
- Try to keep angry feelings removed from the Situation - in other words, don't personalize a resident's behavior.
- Residents are not difficult because they want to antagonize you or to make your life miserable.
- Use your feelings to try to understand each resident's situation. Imagine what it would be like to be confused, hard of hearing, sensory impaired, unable to express yourself verbally, and living in a nursing home.
- Know that the resident is probably as frustrated as are you, if not more so.
- See what influences make the situation better or worse.
- Act immediately when a behavior starts, before it escalates.
- Know what to expect. It will make your job easier.
- Know there is no "wrong" or "right" in resident behavior.
- Seek help from other staff members.
- Take time for yourself before and after difficult situations so as to keep as calm and relaxed as possible. Self-care is very important for care-takers. If you are burnt out or exhausted, it will be hard to deal positively with a resident.

Tips for Intervention

When sexuality comes up on the floor, one positive and therapeutic approach is to ask residents individually about their feelings. Here are some examples.

"How does it make you feel to see other people kissing?"

Most likely this question will bring up responses such as, "It makes me sad," or, "I miss my husband." If this is the case, you might want to ask some follow up questions such as: "Why does it make you sad?" or "what was he/she like? Tell me about him/her."

Residents may also respond with comments like "Love isn't for old people," or "I wish I had somebody." Likewise, in a group setting someone might crack a dirty joke.

If an elderly person says nothing when you ask about sexuality and relationships, then the chances are it's a charged subject. However, even if a resident does not talk openly about sexuality, by acknowledging the subject you are communicating to the residents that you are a safe person to whom they can talk when they feel ready. This is very therapeutic. Also remember that even when residents don't talk about their feelings, they can still be experiencing them.

Remember to:

- Use effective communication.
- Make eye contact.
- Show respect.
- Use a warm, nurturing tone.
- Support what the resident can do. Don't emphasize what she/he cannot do.
- Stay calm and upbeat.
- Show kindness and patience.

- Move slowly and gently so the resident isn't startled or agitated.
- Show compassion.
- Help the resident maintain dignity.
- Redirect activity.
- Praise good behaviors.
- Set clear limits.
- Be consistent.
- Join with the resident instead of arguing with him/her.

Do not:

- Over-react and become aggravated.
- Demean/humiliate the resident.
- Shame the resident.

Be aware:

Sometimes a resident can misinterpret smiles and hugs as having sexual content. Observe how a resident responds to physical expression and modify your actions accordingly. For instance, if hugging the resident confuses him or her sexually, then show affection in different ways, like patting the resident's hand or shoulder in a friendly gesture.

Remember:

Sex is not in and of itself wrong. It is only a problem if it is abusive, without consent, and/or if it disturbs others.

> **Another Example:** The other day a recreation therapist was asked to lead a discussion on an early stage dementia floor. When she arrived, most of the residents were seated at tables and engaged in an arts and crafts activity. However, at the back of the room a man and woman sat next to one another holding hands. The arts and crafts instructor informed the recreation therapist that the "couple" had been kissing for awhile but that the other residents seemed

unaware of their peers' behavior. However, as soon as the arts and crafts instructor left and the recreation therapist attempted to lead a conversation with the residents, they became distracted. "Look at them! They shouldn't be doing that," some people cried out and heads turned toward the back of the room. The aide on duty appeared to be amused and embarrassed but did not intervene. There was an awkward tension in the room while the recreation therapist acknowledged that sexuality was a positive thing, but this did not appease the situation. Instead, one resident grumbled back, "Yeah, it's okay, but with privacy!" The residents were clearly upset and couldn't take their eyes off of the couple, even though an a activity was supposed to be taking place. As the situation grew worse, something needed to be done. Then the female resident began to grope the male resident's genitals. "Oh! Now look what she is doing!" a curious, yet dismayed, resident exclaimed. To everyone's relief, a male nurse appeared on the scene and with the most tactful, gentle voice he encouraged the couple to leave. "Here. Why don't you come with me? I can find you a more private place so the two of you can be alone. It's better if the two of you have a place to be alone." With little resistance, the couple got up from their seats and followed the nurse around the corner as he showed them to a bedroom. As soon as the couple left, the other residents calmed down and resumed the scheduled activity.

SEXUAL DYNAMICS BETWEEN STAFF AND RESIDENTS

Staff and residents should never have sexual relations and therefore it is essential to understand the impact staff and residents have on one another in conscious and subconscious ways, so that no acting out occurs. When working in the helping professions such as medicine, nursing, social work and psychology, this awareness of relationship dynamics is crucial to maintaining ethics. To cultivate this awareness, one must examine how one's attitudes and responses affect residents, particularly in relation to sexuality and vice versa, for you impact residents and they impact you. It is this interpersonal edge that makes working in health care so extraordinarily difficult and rewarding.

It is also important to remember that sexual dynamics are almost always present on the floor. In fact, sexuality will come up in many situations, some overt and some subtle. Sexuality surfaces in all areas of resident life. It is present in psychotherapy, humor, dancing, singing, watching television, talking and reminiscing about the past. Likewise, sex will become a topic of discussion when there are young, attractive people are on the floor, which is common in nursing homes. In fact, residents sometimes become attracted to staff. Responding in an appropriate, yet open way requires an understanding of each resident and an awareness of one's own sexuality and its impact on others.

Think about....

- Your comfort with flirting.
- Your comfort with sexual humor.
- Your comfort level with physical affection.
- Your comfort with dancing.
- Your comfort level when someone makes a sexual advance towards you.
- Your own sexual values and experiences.
- Then think about these questions in relation to your residents. How comfortable are they with these issues?

This is the territory that residents and staff have to navigate as delicately possible. This is not easy. It takes conscious awareness and often consulting with a supervisor. It also requires establishing appropriate boundaries that are clear and flexible.

The following are some examples in which resident/staff dynamics might come into effect:

- A person with dementia may think you are his/her spouse.
- A resident might think your occasional hugs mean more than innocent affection

- A resident may become jealous if you hug or pay attention to another resident in his/her presence.
- A resident may view dancing as overtly sexual.

What does one do in these situations?

- Do you avoid contact with the resident?
- Do you modify your actions?
- Is there any wrong or right way to deal with such situations?

Usually, there is no wrong or right way to deal with these issues because each situation will require a different intervention, based on the people involved. However, the best intervention is not to avoid what is happening.

Staff Support

Working in a nursing home is extremely difficult. You are exposed to situations that people in many other professions would not be able to tolerate. There is often extreme stress; there are often difficult behaviors to manage, and sometimes limits on staffing puts additional burdens on workers. Dealing with acting-out sexual behaviors or intricate interpersonal dynamics among residents, staff and families is one more aspect of the work that makes it challenging.

Many things about the work environment in a nursing home cannot be changed. However, knowing how to reduce stress and practice self-care can greatly change your experience at work. It also results in better resident care. After all, it is hard to take care of someone else when feeling drained, overworked and/or burned out. Therefore, staff self-care contributes to both staff and residents' sense of well being.

Mental Health Issues and Exercises

Twenty-five years ago, the reintegration of people with mental illness into their communities was the goal of the health care industry. Planners envisioned a system more responsive to patients' needs that would provide a range of options for care. Instead, there was no place for many of the discharged patients.

OMBUDSMAN RESPONSIBILITY

As Ombudsman for people with mental illness who are living in adult care home or in nursing homes, your role is not just to enforce standards and make sure facility operators are doing what they are supposed to be doing. It is to really see, talk to and hear the individuals for whom you are advocating.

UNDERSTANDING THE CONDITIONS

Individuals with schizophrenia have felt the impact of that disorder life long, particularly those who are older, and began treatment when the illness was less well understood. Living in a group situation, including a nursing home may be in some ways less stressful than the older adult who has had a lifetime of social connection now abruptly shut off.

The other thing that you need to understand about people who have had life long mental illness is they may have few memories of a time when we were doing better to help them get through difficult times. People who have achieved a certain amount of satisfaction either as parents, as spouses, as friends, in the work place, as students — can tap into that sense of success when they are feeling down and bolster their self-esteem.

People with mental illness who have not had experiences of being involved in their communities in similar ways are at a real disadvantage when they are having a bad day, because they don't have those internal resources to draw on. When you pit that against the fact that other people

are treating them as second-class citizens, you begin to see the challenges that must be faced.

Unlike many cognitively impaired and frail elders in nursing homes, adults with mental illness in group homes will want to be partners in advocating for themselves, but will need your help in knowing how to do this.

WHAT IS MENTAL ILLNESS?

Most simply, mental illnesses are disorders of thought, feeling and/or behavior which result in an inability to cope with life's ordinary demands and routines

Mental illnesses are not evidence of a character weakness, a punishment from God, an individual's "fault" anymore than getting cancer is, or the result of a poor upbringing.

Mental illnesses are illnesses, and like any illness such as diabetes, heart disease or high blood pressure, may be influenced by genes, environment, and health behaviors.

MAJOR MENTAL ILLNESS

Often a distinction is made between so-called "major" and "minor" mental illness. The distinction is important to Ombudsman only insofar as most states limit the public role and responsibility to those with major mental illness.

Major mental illness is also referred to as serious and persistent mental illness and includes psychotic disorders such as schizophrenia and delusional disorders as well as major depression, bipolar disorder (formerly known as manic depression) and severe personality disorders. Many individuals with major mental illness also abuse alcohol and other drugs.

"Psychosis" is a term used to describe a very specific set of symptoms and a very specific problem — "breaking with reality."

The primary manifestations of psychosis are the same, whether it is from depression, schizophrenia, dementia or from ingesting hallucinogens: hallucinations and delusions. A hallucination is when you hear something when no one is speaking; when you see something that isn't there; taste something when there is nothing in your mouth; feel something crawling on your skin when there is nothing there; and when you smell something that nobody else can smell. In other words, hallucinations are disturbed perceptions — you see, smell, hear, taste, and feel something that isn't there. This is also sometimes a break with reality about the external world.

For people with schizophrenia, the most common kind of hallucination is auditory. They hear people speaking when no one is speaking. People with substance problems, particularly during withdrawal, are more likely to see things than to hear things and to feel things crawling on their skin.

Mental Health Training Exercises

FACTS AND FICTIONS

Circle T for True or F for false for what you believe about each statement.

1. Mentally disabled persons can never be normal. T or F
2. If those with physical handicaps can cope on their own, people recovering from mental disabilities should, too. T or F
3. A person with mental illness can hold a low-level job but not a responsible, decision-making position. T or F
4. People who have a mental illness are prone to violence and should be considered dangerous. T or F
5. Recovered mental patients could go berserk at any time. T or F
6. There is nothing we can do to help. T or F
7. There are good reasons not to take medications. T or F
8. People with mental illness are best served in locked institutions. T or F
9. If people with mental illness stayed on medications, they wouldn't have to worry about relapse. T or F
10. My answers reflect what I really think, not what I think the answers are supposed to be. T or F

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PROBLEM SOLVING GROUP EXERCISES

PROBLEM 1:

A resident is not receiving all the services to which s/he is entitled.

Scenario

You (an ombudsman) visit an adult care facility (ACF). You notice that many of the residents seem to just be milling about, interacting little, smoking a lot and with little to do. You notice many seem overweight. One of the residents approaches you and complains there is no swimming pool. How do you respond?

After talking with the resident, it becomes clearer that the resident is concerned about weight gain, possibly related to his/her new medications and wants an exercise program. S/he used to like to swim, but now is open to any form of exercise. The resident has tried talking to his/her case manager and to one of the workers of the ACF without success. What might be the next step?

In the meeting with the case manager and ACF administrator, the administrator becomes defensive and states that s/he is under no obligation to provide exercise facilities and tells the resident s/he is lucky to have a nice place to live and shouldn't be so demanding. How do you respond?

The ombudsman has clarified for the administrator that indeed the NYS Rules and Regs. require attention to exercise and brings the conversation back on track to find a way to meet this resident's need and request. However, the administrator complains s/he does not have sufficient resources to either transport the resident to the gym, buy an exercise bike or have staff facilitate exercises in the day room. In fact, no matter what solution is proposed, the administrator gives a reason s/he can't or won't support it. How do you respond?

PROBLEM 2:

A facility has questionable practices regarding medications.

Scenario

You regularly visit adult care facilities. In one particular adult care facility, you notice that most of the residents seem to have little energy, while others pace restlessly; some have tremors; many appear overweight. Many just mill about, interact little, smoke a lot and have little to do. Sometimes you arrive when medications are being dispensed and you notice the following: the med cart is often left unattended, there is little interaction with the residents when being given their pills, i.e., no inquiry about side effects. All of this makes you wonder about the medication practice in the facility. What do you do?

PROBLEM 3

Medication module.

Scenario — Part 1:

You get to know one of the residents whom you have helped negotiate a membership at the local YMCA. This resident tells s/he is taking medication for his/her voices, that the medicine is helping and that s/he thinks it is responsible for his/her weight gain. The resident is disappointed that even though s/he is pretty faithful with his/her exercise, s/he still can't seem to lose weigh and wants to stop taking his/her medication and asks your opinion. How do you respond?

Part 2:

You set up a meeting with the resident's case manager. In the meeting, the resident tells the case manager s/he wants to come off the medication and why. The case manager tells the resident that the last time s/he went off his/her medication s/he wound up in the hospital and so the case manager doesn't support the request. The case manager reminds the

resident s/he has schizophrenia and will always be on medication. The resident shuts down. How do you respond?

Part 3:

The resident states that s/he would be willing to try another medication. The case manager tells the resident and the ombudsman that the Doctor knows best and that if there were any alternatives, s/he would have already changed the medication. The resident is becoming less able to or willing or able to negotiate and states: "Then I won't take any medication," and leaves the room. The case manager says "See? S/he's always been noncompliant!" How do you respond?

Part 4:

You and the resident decide to set up a meeting with the physician to discuss the resident's concern about side effects and to discuss alternatives to care. Although the physician appears to listen and to approach the resident more thoughtfully, the bottom line is the same: "I prescribe this because it is the best for you. You have been on many other drugs and they haven't worked. I won't support going down that road again". The resident, who has been silent, says, "'then I won't take any medication." The psychiatrist replies that if the resident doesn't take his medication, s/he will lose his placement in the group home and be forced to live in a shelter. How do you respond?

Part 5:

The psychiatrist encourages the resident to get a second opinion from an expert in pyschopharmacology (though clearly conveys s/he anticipates the second doctor will agree with him/her). The "expert" reviews the case and helps the resident weigh the risks and benefits. They conclude it is worth the risk to try one of the newer drugs that have come out since the last failed trials on other medications. The two Doctors talk and Doctor number one says, "I disagree," and won't make the switch. The expert expresses regret s/he cannot take any new patients. The resident has had it and quits participating in any aspect of treatment. The ACF operator

gives the resident an eviction notice saying, "I know you will decompensate. I can't have you here if you're not in treatment." Now what? What rights and responsibilities does the operator have? What are the resident's rights and responsibilities?

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Recovery and Advocacy

Historically, individuals diagnosed with a major mental illness or physical handicaps were viewed as being on an inevitable downward course, with no hope of recovery.

Contrary to this long held belief, there is now considerable evidence that a significant percentage of patients do recover. In several long-term follow-up studies published between 1960 and 1991, almost 1/3 of patients clinically recovered (ranged from a low of 6% to a high of 66%). The percentage of patients who showed a social recovery averaged 52% (ranged from a low of 17% to a high of 75%). Through use of medication, rehabilitation or simply a desire to recover, many patients with mental illness are able to lead normal, healthy lives.

In addition, people with debilitating mental illnesses have been viewed as unable to make their own decisions and in need of professionals to protect and make decisions for them. It is now understood that over-protection and restricting choice has deleterious effects.

Recovery is a way of living to make the most out of life. It is a process through which a patient or resident realizes that a mental illness or physical debilitation is not going to interfere with living his life and then takes the necessary steps to be able to coherently exercise self-determination.

Recovery is a way for a patient or resident with a mental illness or physical debilitation to deal with their problem and live and enjoy life on her own terms, not at the dictum of her illness or someone else, such as a doctor. The principles of recovery can be used to enhance self-determination and inform treatment planning and problem solving.

By taking back what was lost due to illness, the patient is able to reassert his ability to make his own decisions and live his life on the same terms as a person without a mental illness or physical debilitation. An Ombudsman can play an important role in the process by advocating

for the patient or resident's right to control his own life and by empowering the resident with knowledge of his rights and care and treatment options.