

The Foundation of Resident Advocacy: Residents' Rights

- **The right of citizenship.** People who live in long-term care facilities do not lose any of their rights of citizenship, including the right to vote, to religious freedom and to associate with whom they choose.

Residents have the right to visits:

- By a resident's personal physical and representatives from the state survey agency and Long-Term Care Ombudsman programs
 - By relatives, friends, and others of the residents' choosing
 - By organizations or individuals providing health, social, legal, or other services
 - Residents have the right to refuse visitors
- **The right to dignity.** The Long-Term Care Facility is the resident's home, and non-residents should act as if they were guests in the resident's home.

Residents have the right to:

- Be treated with consideration, dignity, and respect
 - Be free from mental and physical abuse, corporal punishment, involuntary seclusion, and physical and chemical restraints
 - Self-determination
- **The right to privacy.** Long-term care residents have the right to privacy, including the right to privacy with their spouse, the right to have their medical and personal records treated in confidence, and the right to private, uncensored communication.

Residents have the right to:

- Private and unrestricted communication (including phone conversations) with any person of their choice
 - Total privacy during treatment and care of one's personal needs
 - Privacy regarding medical, personal, or financial affairs
 - Receive unopened mail and send any mail or parcels without question
- **The right to personal property.** Residents have the right to possess and use personal property and to manage their financial affairs.

Residents have the right to:

- Security of possessions
- Manage one's own financial affairs

- **The right to information.** Residents of long-term care facilities have the right to information, including the regulations of the facility, and the costs for services rendered. They also have the right to participate in decisions about any treatment, including the right to refuse treatment.

Residents have the right to:

- Be fully aware of available services and the charges for each service
 - Knowledge of facility rules and regulations, including a written copy of resident rights
 - The address and telephone number of the State Long-Term Care Ombudsman and state survey agency
 - Review state survey reports and the facility's plan of correction
 - Receive advance notice of a change in rooms or roommates
 - Assistance if a sensory impairment exists
 - Receive information in a language they understand (Spanish, Braille, etc.)
- **The right to freedom.** Long-term care residents have the right to be free from mental or physical abuse and from physical and chemical restraint unless ordered by their physician. Residents have the right to make independent choices.

Residents have the right to:

- Make personal decisions, such as what to wear and how to spend free time
 - Reasonable accommodation of one's needs and preferences
 - Choose a physician
 - Participate in community activities, both inside and outside the facility
 - Organize and participate in a Resident Council
- **The right to care.** Residents have the right to equal care, treatment, and services provided by the facility without discrimination.

Residents have the right to:

- Receive adequate and appropriate care
- Be informed of all changes in medical condition
- Participate in their own assessment, care-planning, treatment, and discharge
- Refuse medication and treatment
- Review one's own medical record and receive copies at a reasonable cost
- Be free from charge for services covered by Medicaid or Medicare

- **The right of residence.** Long-term care residents have the right to live at the facility unless they violate publicized regulations. They may not be discharged without timely and proper notification to both the resident and the family or guardian.

Residents have the right to:

- Remain in the facility unless a transfer or discharge
 - (a) is necessary to meet the resident's welfare
 - (b) is appropriate because the resident's health has improved and s/he no longer requires the facility's level of care
 - (c) is needed to protect the health and safety of other residents or staff
 - (d) is required because the resident has failed, after reasonable notice, to pay the facility charge for an item or service provided at the resident's request
 - Receive 30 day notice of transfer or discharge which includes the reason, effective date, location to which the resident is to be transferred or discharged, the right to appeal, and the name/address/phone number of the Long-Term Care Ombudsman.
 - Safe transfer or discharge through sufficient preparation by the facility
- **The right of expression.** Residents have the right to exercise their rights, including the right to file complaints/grievances without fear of reprisal.

Residents have the right to:

- Present grievances to staff or any other person, without fear of reprisal and with prompt efforts by the facility to resolve those grievances
- To complain to the Long-Term Care Ombudsman program
- To file a complaint with the state survey and certification agency

Obstacles to Implementing Residents' Rights

Each October, nursing homes and other long-term care facility residents, along with family members, long-term care ombudsmen, citizen advocates, and facility staff promote Nursing Home Residents' Rights Month by honoring individual rights of long-term care residents. Certain rights, specific to individuals who live in long-term care facilities, are set forth under state and federal laws. The Office of the State Long-Term Care Ombudsman, as well as other concerned advocates, work throughout the year to ensure residents rights are understood and protected. Despite these efforts, long-term care residents often face obstacles which impede their ability to exercise these rights.

Most long-term care facilities inform residents of their rights upon moving into a facility; however, with the stresses and anxieties of moving into a new home, many residents do not fully understand these rights. Residents do benefit from continual reminders of their rights through regular conversation with staff and consistent and respectful treatment in routine care. In addition, residents do have the right to establish and participate in resident councils in which rights and concerns may be discussed.

Resident's family members and friends may also be unaware of residents' rights or may be uncertain how to empower their relative to maintain self-determination. Providing education and information to family and friends is necessary to ensure the ongoing support of all residents' rights. In fact, family and friends may establish and participate in family councils. These councils allow family and friends to discuss issues of importance to them while ensuring the health, safety, welfare and rights of their loved ones.

Residents and families who understand and choose to assert their rights sometimes face resistance. This implies that asserting one's rights is a negative thing to do and discourages residents from voicing concerns in the future. It is up to all of us who work with or interact with individuals residing within long-term care facilities to acknowledge the rights that are bestowed upon all residents and empower those residents to speak up for those rights to be honored. Residents benefit where staff and others see their abilities instead of disabilities and actively pursue the rights of all residents.

What Staff Can Do

Educate residents and their families about their rights.

Facilities can foster dignity for their residents by encouraging residents and families to have knowledge of resident rights. Iowa law states that each resident shall be encouraged and assisted throughout the resident's stay to exercise their rights as a resident and as a citizen. Residents may voice grievances as well as recommend changes in policies and service to administrative staff or to outside representatives of the resident's choice. These rights are to be exercised free from interference, coercion, discrimination, or reprisal. Facilities are also required to post, in a prominent area, the contact information for several agencies including the Long-Term Care Ombudsman's Office. Long-term care ombudsmen are advocates for residents and supporters of resident rights but can often assist facilities in finding resolution for resident concerns.

Educate and sensitize every level of staff about residents' rights.

All staff members are representatives of a facility and can make a big difference in a resident's life. Having sufficient ratios of trained staff who themselves have dignified working conditions can provide a sense of community that is good for all.

Incorporate resident participation and self-determination into every aspect of nursing home services.

Assist staff, residents, and families to overcome the tension between dependence and empowerment by encouraging and promoting an open exchange of ideas, recommendations, and concerns throughout the facility. Establish an effective grievance process, support resident council meetings and follow up on resident concerns brought forward. Utilize the information and wisdom of residents and their representatives to make the facility feel like a home and not an institution.

Residents' Rights Frequently Asked Questions (FAQ)

How are residents made aware of their rights?

Residents can be made aware of their rights through several methods including admission paperwork, prominently posted signs, Resident Council meetings, or contact with their Long-Term Care or Volunteer Ombudsman.

How can a facility allow residents to exercise their rights?

- Ask what the resident wants to do, rather than telling them what to do
- Honor resident choices such as when and how to bathe, when and what to eat, and times they prefer to get up and go to bed
- Knock and wait for a response before entering a resident's room
- Respect a resident's privacy and maintain confidential information
- Treat the resident with dignity and respect at all times
- Encourage contact with a Long-Term Care Ombudsman or Volunteer Ombudsman

Where are the phone numbers listed for the Department of Inspections and Appeals and for the Long-Term Care Ombudsman's Office?

This information should be posted in a prominent/conspicuous place in the facility.

Can any resident leave the building to go shopping or out to dinner?

Yes. There may be instances where it is unwise or unsafe for the resident to leave such as agitation or confusion when taken out of a familiar environment, very high risk of fall, or combative behavior without a known cause.

How should a facility handle incoming and out-going mail?

Mail should be delivered unopened. Mail and parcels should be sent without question.

Is a resident allowed to see his/her medical record? Who else can see it?

A resident is allowed to see his or her medical record. A legal guardian and an attorney-in-fact for health care decisions, if the power of attorney is in effect, have access as well. Others may view the record with the permission of the resident.

Does a resident have the right to make private, personal phone calls? Do residents in a facility have the right to privacy when using a facility phone?

Absolutely.

When a resident receives a phone call on the facility phone, can the staff ask who is calling?

Not unless there is a good reason that the resident defines.

Can a resident vote?

Yes, they can vote. If a resident is aware of the election and can make a choice independently, he/she should be allowed to vote and the facility should facilitate this process (i.e., providing an absentee ballot or transportation to a voting station).

Does a resident have the right to have total privacy during visits with spouses or friends?

Absolutely.

Can a resident refuse care? Treatment? Medications? Prescribed diet?

Yes for all. Staff may provide information and education about the consequences of refusal of treatment and care.

Can a facility force a resident to do something they don't want to do, like take a shower?

No.

Can a staff member enter a resident's room at any time?

No. He or she should be invited in or should knock and wait for a reply to enter.

Is it okay for staff to borrow a resident's personal item if they ask first?

This is never okay.

Should facility staff tell a resident what they're going to do during treatment, care, and assistance?

Yes, and they should explain the process as they go.

Can a facility restrict visiting hours or visitors?

The facility cannot restrict visiting hours. Visitors could be restricted only in extreme circumstances such as the resident refusing to see the visitor, the visitor causing unreasonable disruption or hazard to residents and staff, or if there is a doctor order in place to restrict the visitor(s).

Rights for Residents with Alzheimer's Disease/Dementia

Residents with dementia or Alzheimer's Disease still have the same rights as others who live in long-term care. Staff must be able to balance resident rights with the safety of each individual person. Personal history plays a vital role in developing an individualized plan of care for each person. Consistent staffing is also important to develop relationships and stability in the lives of people with dementia.

- **Right to Privacy and Confidentiality**
 - Private and unrestricted communication with friends and family of their choice
 - During treatment and care
 - Regarding medical, personal, financial affairs
- **Right to Dignity and Respect**
 - To be treated with consideration, respect and dignity
 - To be free from any type of abuse
 - To Self Determination
 - Security of Possessions
- **Right to Make Independent Choices**
 - Make personal decisions
 - What to wear
 - What they would like to eat
 - What activities they want to participate in
- **Right to Visits**
 - By family, friends and others of the resident's choosing
 - By a physician, Long-Term Care or Volunteer Ombudsman, or Department of Inspections and Appeals
 - Have the right to refuse visitors

Communication Tips for Residents with Alzheimer's/Dementia

***Dignity is not about what others are doing,
but how we treat them no matter what they are doing.***

- Approach from the front.
- Identify yourself.
- Face the person before you speak and make sure you have eye contact. Speak at a naturally lower tone of voice. Speak clearly, concisely, and at a calm pace.
- Converse at the resident's eye-level.
- Listening is very important in communicating. Use your eyes to observe, your ears to hear, your mind to reflect and your heart to feel what the resident is communicating to you.
- Be aware of every aspect of how to present yourself; voice, tone, posture, facial expression, body language.
- Eliminate background noise and confusion.
- Emphasize recognition, not recall.
- Do not argue or disagree.
- “Ground” the person by touching a hand and saying his/her name.
- Use short, simple (adult) sentences.
- Use full names and action words.
- Allow ample time for a response. If repeating is necessary, use exactly the same words. The third time, try other words.
- For those that are difficult to understand, try to catch one or two words that can clue you in on what they are trying to tell you.
- Supply words the person is trying to recall only after ample time has been given for him/her to try.
- If you don’t understand, say so.
- Provide reassurance by confirming the emotional message even if you cannot understand what the person is saying.
- Ask a staff member if there is a best way to communicate with particular individuals.

Investigating Concerns for People with Alzheimer's/Dementia

- If the resident is making the complaint:
 - A person with mild or moderate dementia can probably still think clearly enough to report concerns.
 - Attempt to get permission to speak with family and/or staff so that you can acquire more details.
 - Find out how the resident would like the complaint resolved and try to act on that.
 - Ask questions to make sure you understand.

- If the family/friend initiate the complaint:
 - Try to get as many details as possible
 - What is the resident's opinion of what happened?
 - Who was involved?
 - What happened exactly?
 - Where did it happen/When did the problem occur?
 - Have they talked to anyone about this problem?
 - Who?
 - What was the response?
 - Was an action plan created?
 - If so, was the action plan followed?
 - Did the complainant receive any follow up information?
 - What does the care plan say that the staff will do?
 - Does the resident appear to be distressed by this problem?
 - These complaints may need to be referred to the local ombudsman as many times the chart and/or care plan needs to be reviewed.

- If the resident is unable to communicate:
 - Observe the situation and the resident
 - Does the resident appear content?
 - Does the staff appear to understand how to communicate with this person?

Personality/Behavior Challenges in Residents with Alzheimer's/Dementia

When working with people diagnosed with dementia it is very important to remember that ALL BEHAVIOR HAS MEANING.

When visiting a facility and observing people with dementia, keep in mind research shows that 96% of all “behavior” challenges occur late in the afternoon.

Before labeling behavior/personality challenges as a problem, many things should be considered, like medication side effects, acute or chronic illness, boredom, depression, frustration or even the personality of the person prior to diagnosis of this disease.

The first question you should consider when thinking about people with dementia is:

Whose problem is it? As well as:

- Does the resident understand what he/she is supposed to do?
- Does the staff take the time to get to know each resident on a personal level so that needs, wants and desires can be anticipated?
- Is the staff able to make adaptations in their words, rate and pattern of speech, body language and tone of voice to help each person understand?
- Could changes in the environment make a difference? Is it too loud? Are there enough signs/cues so the resident can find his/her way around?
- Do residents appear to be active and engaged in daily life?
- Is the staff engaged at all times with the residents?
- Does there appear to be enough staff to meet the needs of the residents?
- Is this a calm and happy place to call home?

Stages of Alzheimer's Disease

Early Stage

Some forgetfulness may be noticed by others but still able to function almost normally
Begins to make small mistakes, but can cover-up and fix
Attribute forgetfulness to age

Early Middle Stage

Staff may begin to notice small difficulties in daily life skills
May be unable to locate possessions
Occasional slight confusion over people, time, chronology of events
May appear to be socially inappropriate which can lead family/friends to be concerned that care is not being provided
May have problems following more than 3-step commands
Frustration, depression, denial, withdrawal

Middle Stage

Short term memory problems apparent to others
May have word finding difficulties
May need assistance with Activities of Daily Living but adept at hiding problems
May be depressed, may be in denial
Probably still reading, has difficulties retaining information
Confusion when introduced to new people, can't remember names
Distracted by noise or multiple speakers, unable to process rapid speech, may be unable to concentrate
Needs simplified instructions
Objects may be found in odd locations
Sometimes confused about time and place

Late Middle Stage

Short term memory loss very apparent
Will have trouble remembering new information
May withdraw from activities due to inability to understand directions, inability to concentrate
Sometimes disoriented as to time, place, people
May not understand word meanings—needs slower pace
Current/recent events lose meaning
May be confused about personal history
Concentration continues to worsen
At risk for financial fraud
May need to be reminded to use the bathroom

Early Late Stage

Short term memory continues to fade, long term memory also impaired; confusion
Needs constant supervision for safety purposes
Needs continual assistance with Activities of Daily Living
No longer understands diagnosis
Probably unable to recall personal information: address, phone number
Frequent confusion as to day, time, place, season, people
Can remember own name, name of spouse and possibly children
May be incontinent or may be able to use toilet with reminders and assistance

Middle Late Stage

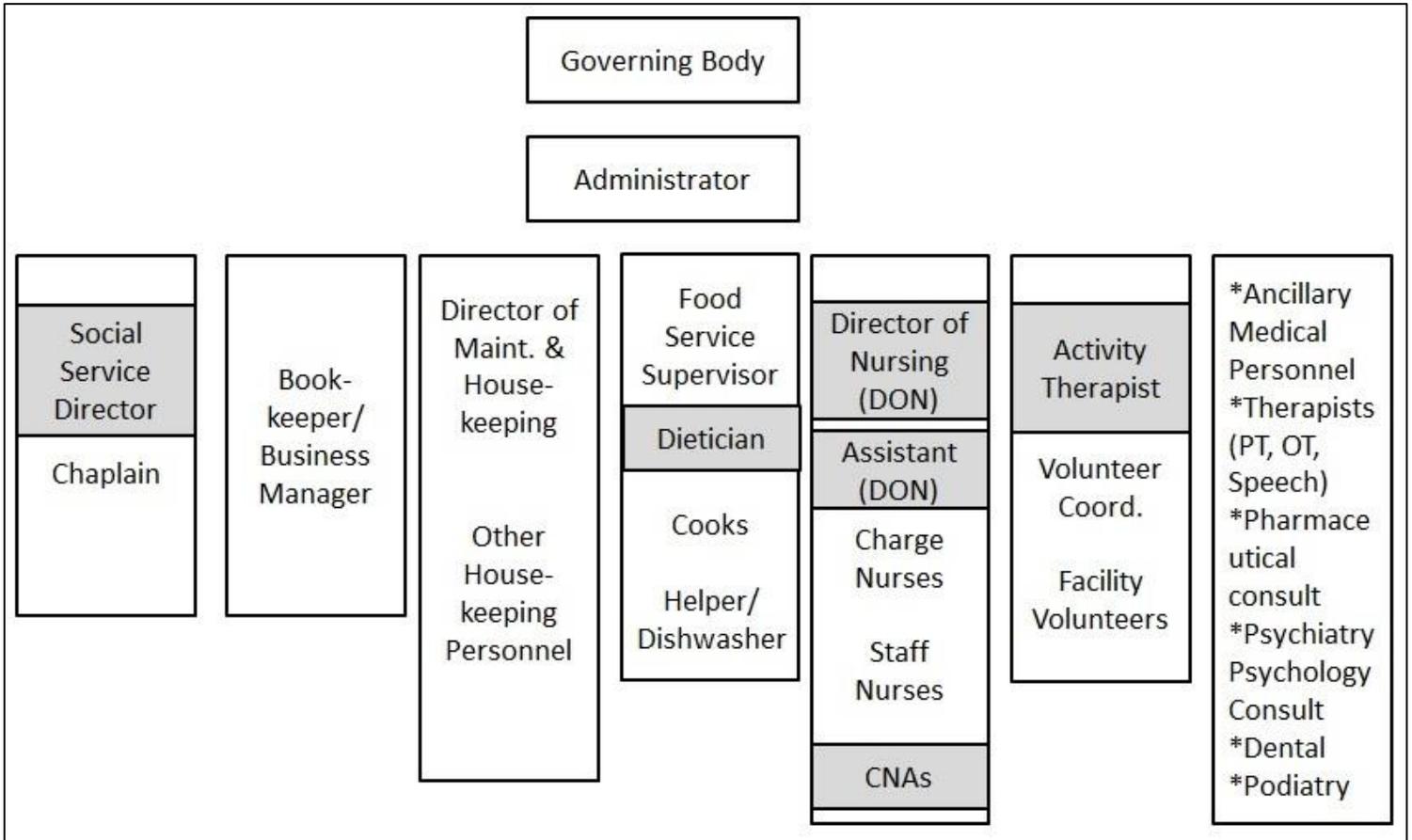
Little apparent short term memory, long term memory appears to be very impaired
Verbal communication consists of a few words or phrases
Not aware of disease, events, experiences, day, date, time, season, year
Needs routine and stable environment
Requires complete assistance with Activities of Daily Living
May not distinguish between familiar and unfamiliar people
Cannot carry a thought long enough to complete a task

Late Stage

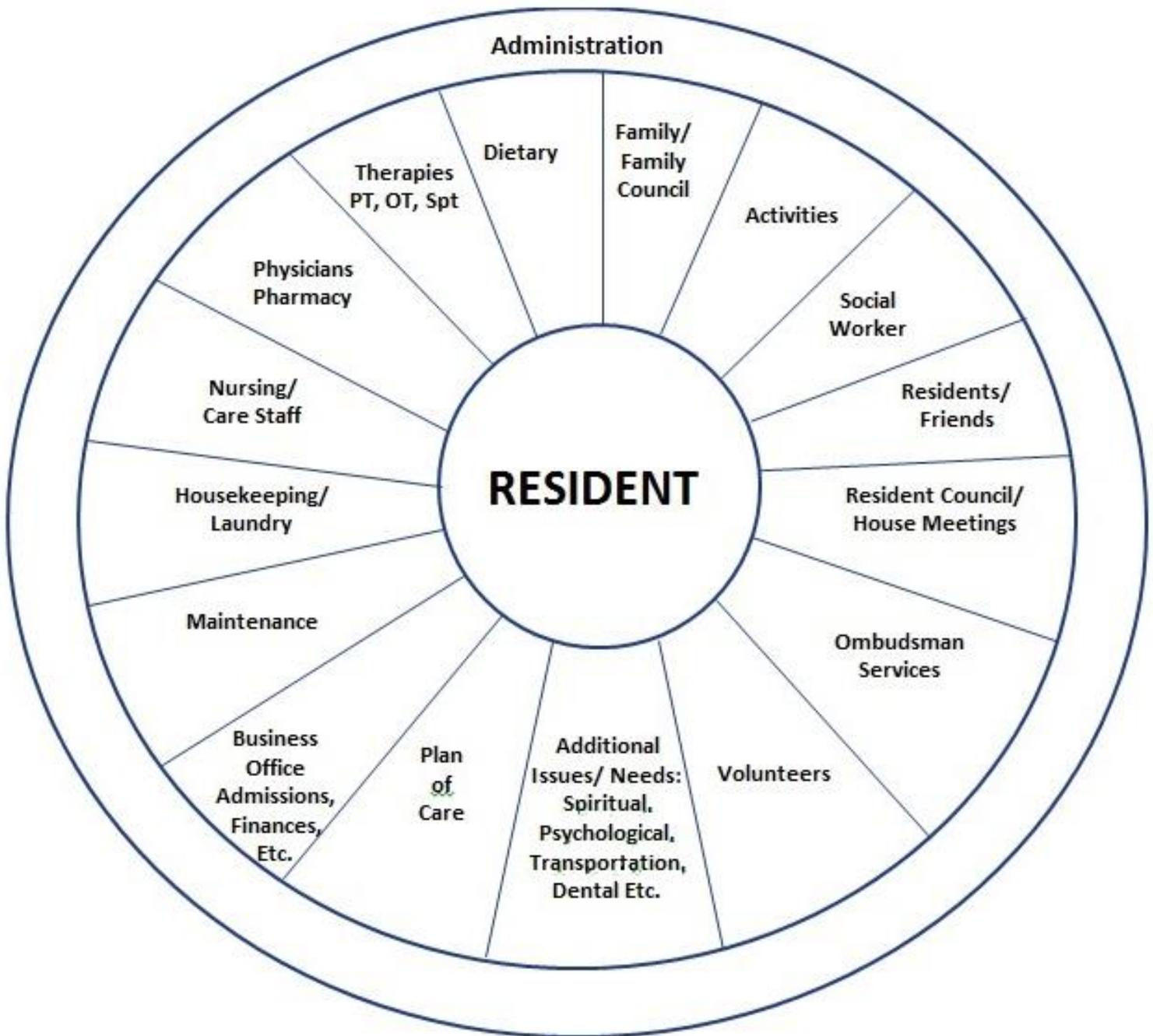
No apparent short term or long term memory
Needs full time, constant care
Return of primitive reflexes
Unable to communicate verbally, unable to walk
Spends majority of time in bed
Unable to attend to any personal needs
Incontinent
Eventually unable to swallow
It appears that the brain can no longer tell the body what to do
Emotions and feelings still intact: love, shame, pain

Reisberg, Ferris, Leon, and Crook. The global deterioration scale for assessment of primary degenerative dementia. *American Journal of Psychiatry*, 1982, 139:1136-1139

Typical Nursing Facility Organization Chart



Resident Centered Model



Examples of Poor Infection Control Practices In Long-Term Care Facilities

- A. Poor hand washing practices of residents, exhibited by one or more of the following:
 - Residents are not given the opportunity to wash hands frequently
 - Dirty fingernails
 - Hands not washed prior to eating
 - Hands and/or face being washed anytime by staff using the same cloth on multiple people

- B. Poor hand washing practices of staff, exhibited by one or more of the following:
 - Hands not washed after contact with body fluids
 - Hands not washed after removing gloves
 - Hands not washed after being soiled
 - Hands not washed as necessary with soap or antibacterial hand sanitizer

- C. Use of items for more than one resident:
 - Towel, washcloth, disposable wipes
 - Staff wearing the same pair of disposable gloves and performing tasks for more than one resident
 - Use of same drinking or eating equipment for more than one resident

- D. Unclean equipment:
 - Lift equipment that have slings/straps, base soiled with urine, feces or other substances
 - Tables in dining room that are not cleaned prior to the meal time
 - Bedside tray tables that are not clean, particularly when residents eat meals/snacks there and/or they appear to be a resting place for a urinal.

What Volunteers Can Do

- If you are ill, don't visit the facility.
- Wash your hands before and after visits.
- Use and check hand sanitizers.
- Advocate for residents to be able to wash their hands and have clean clothing, especially before and after meals.
- Pay close attention to any infection procedure signs on residents' room doors and follow the protocols. Check with the nurses' station if you are unsure.
- If there is a flu outbreak, a sign may be posted on the front door of the facility. During an outbreak you do not have to visit the facility but you are not restricted from visiting.
- Vaccinations (including flu shots) are not required for volunteers.
- If you regularly volunteer five hours per week or more, you should receive a TB test from your physician, and share a copy of the results with the VOP Coordinator.

Glossary of Long-Term Care Terminology

Activities of Daily Living (ADLs): Basic personal activities which include bathing, eating, dressing, mobility, transferring from bed to chair, and using the toilet. ADLs are used to measure how dependent a person may be on requiring assistance in performing any or all of these activities.

Administrator: In the context of a nursing facility, a person who administers, manages, supervises, or is in general administrative charge.

Admission: Date at which an individual was reported to have been admitted to a nursing home.

Advance Directive: Also known as a "living will" or a "durable power of attorney for health care" it is a written instructional health care directives and/or appointment of an agent.

Aging and Disability Resource Centers (ADRCs): ADRCs serve as single points of entry into the long-term supports and services system for older adults and people with disabilities. Through integration or coordination of existing aging and disability service systems, ADRC programs raise visibility about the full range of options that are available, provide objective information, advice, counseling and assistance, empower people to make informed decisions about their long term supports, and help people more easily access public and private long term supports and services programs.

Ambulate: To move from place to place; walk.

Assisted Living Program (ALP): An entity that provides housing with services which may include but are not limited to health-related care, personal care, and assistance with instrumental activities of daily living to three or more tenants in a physical structure which provides a homelike environment. Includes 24-hour response staff to meet scheduled and unscheduled or unpredictable needs in a manner that promotes maximum dignity and independence and provides supervision, safety, and security.

Attorney-in-fact: An individual who is designated by a power of attorney as an agent to make decisions on behalf of a principal and has consented to act in that capacity.

Call Light/Call Button: A bedside button tethered to the wall in a resident's room, which directs signals to the nursing station; a call light usually indicates that the resident has a need requiring attention from an aid or nurse on duty. In nursing facilities, a light above the resident's door is illuminated to indicate that the call button has been pushed.



Capacity: An individual's ability to understand the significant benefits, risks, and alternatives to proposed health care and to make and communicate a health care decision. The term is frequently used interchangeably with competency but is not the same. Competency is a legal status imposed by the court through guardianship and/or conservatorship.

Care Plan: Written document which outlines the types and frequency of the long-term care services that a consumer receives. It may include treatment goals for him or her for a specified time period.

Caretaker: A related or nonrelated person who has the responsibility for the protection, care, or custody of a dependent adult as a result of assuming the responsibility voluntarily, by contract, through employment, or by order of the court.

Certified Nurse Assistant (CNA): A nurse assistant that has completed required state training and competency testing in the skills required to work as a nurse assistant.

Charge Nurse: The charge nurse is the nurse, usually assigned for a shift, who is responsible for the immediate functioning of the unit. The charge nurse is responsible for making sure nursing care is delivered safely and that all the residents on the unit are receiving adequate care.

Chronic Confusion and Dementing Illness (CCDI): A special license classification for nursing facilities which designate and dedicate the facility of a special unit within the facility to provide care for persons who suffer from chronic confusion or a dementing illness.

Cognitive Impairment: Deterioration or loss of intellectual capacity which requires continual supervision to protect the resident or others, as measured by clinical evidence and standardized tests that reliably measure impairment in the area of (1) short or long-term memory, (2) orientation as to person, place and time, or (3) deductive or abstract reasoning. Such loss in intellectual capacity can result from Alzheimer's disease or similar forms of irreversible Dementia.

Competency: The ability to discharge or understand either health care or financial management decisions. Competency is a legal finding. Competency proceedings (guardianship and conservatorship hearings) are conducted to the allow court to determine mental capacity.

Conservator: A person appointed by the court to have the custody and control of the property of a ward.

Continuing Care Retirement Community (CCRC): communities which offer multiple levels of care (independent living, assisted living, skilled nursing care) housed in different areas of the same community or campus and which give residents the opportunity to remain in the same community if their needs change. Provides residential services (meals, housekeeping, laundry), social and recreational services, health care services, personal care, and nursing care. Requires payment of a monthly fee and possibly a large lump-sum entrance fee.

Dependent Adult: A person eighteen years of age or older who is unable to protect the person's own interests or unable to adequately perform or obtain services necessary to meet essential human needs, as a result of a physical or mental condition which requires assistance from another, or as defined by departmental rule.

Director of Nursing (DON): A registered nurse who supervises the care of all the residents at a long-term care facility. In some facilities, there is also an Assistant Director of Nursing (ADON) who backs up the Director of Nursing, especially in the DON's absence or off-hours.

Discharge: The release of a resident from a provider's care, usually referring to the date at which a resident leaves the facility.

Elder Group Home: A single-family residence that is operated by a person who is providing room, board, and personal care and may provide health-related services to three through five elders who are not related to the person providing the services, and which is staffed by an on-site manager 24-hours per day.

Elopement: In the context of long-term care, a term where a resident leaves the facility without the knowledge of staff.

Fiduciary: Relating to, or founded upon, a trust or confidence. A fiduciary relationship exists where an individual has an explicit or implicit obligation to act on behalf of another person's interests in matters that affect the other person (i.e. guardian, conservator, attorney-in-fact or agent under power of attorney).

Gait Belt: A device used to transfer people from one position to another, from one thing to another or while ambulating people that have problems with balance.



Geriatrician: Physician who is certified in the care of older people.

Geriatrics: Medical specialty focusing on treatment of health problems of the elderly.

Gerontology: Study of the biological, psychological and social processes of aging.

Guardian: The person appointed by the court to have custody of the person of the ward.

Hospice Care: Services for the terminally ill provided in the home, a hospital, or a long-term care facility. Includes home health services, volunteer support, grief counseling, and pain management.

Hoyer Lift: A Hoyer Lift is a brand name for a device that allows caregivers to lift people who are unable to stand without assistance. A Hoyer lift is used to transfer a person any time the person needs to be moved. Residents are lifted by a sling device, and then transferred to the toilet or shower, wheelchair, stretcher or back to bed. Hoyer Lifts may be electric or manual.



Incompetency: The lack of ability to implement or understand either health care or financial management decisions. Incompetence is declared by the court when an individual is in need of a guardian or conservator. This determination is made only after the individual meets the proper “standards” under Iowa law.

Independent Living Facility: Rental units in which services are not included as part of the rent, although services may be available on site and may be purchased by residents for an additional fee.

Instrumental Activities of Daily Living (IADLs): The activities often performed by a person who is living independently in a community setting during the course of a normal day, such as managing money, shopping, telephone use, travel in community, housekeeping, preparing meals, and taking medications correctly.

Intermediate Care Facility (ICF): A nursing home, recognized under the Medicaid program, which provides health-related care and services to individuals who do not require acute or skilled nursing care, but who, because of their mental or physical condition, require care and services above the level of room and board available only through facility placement.

Involuntary Discharge: If a resident does not wish to leave a facility and the facility provides them with a written, valid notification of discharge, it is considered involuntary. Involuntary discharges may only be given under limited circumstances, and the facility is responsible for providing the resident with a safe and orderly discharge to an appropriate location.

Iowa Department of Inspections and Appeals (DIA): A multifaceted regulatory agency charged with protecting the health and safety of Iowans. The agency is responsible for inspecting, licensing and/or certifying health care providers and suppliers, restaurants and grocery stores, social and charitable gambling operations, hotels and motels, and barber and beauty shops. In addition, DIA staff investigates alleged fraud in the State's public assistance programs and conducts contested case hearings through independent administrative law judges to settle disputes between Iowans and various state government agencies.

Level of Care: Amount of assistance required by consumers which may determine their eligibility for programs and services. Levels may include: nursing, intermediate, and skilled.

License/Licensure: Permission granted to an individual or organization by a competent authority, usually public, to engage lawfully in a practice, occupation, or activity.

Licensed Practical Nurse (LPN): A person who has completed a program in nursing and is licensed to provide basic care under the supervision of a physician or registered nurse.

Long-Term Care (LTC): Range of medical and/or social services designed to help people who have disabilities or chronic care needs. Services may be short or long-term and may be provided in a person's home, in the community, or in facilities (e.g., nursing homes or assisted living facilities).

Long-Term Care Ombudsman (LTCO): An individual designated by a state ombudsman who is responsible for investigating and resolving complaints made by or for residents in long-term care facilities. Also responsible for monitoring federal and state policies that relate to long-term care facilities, for providing information to the public about the problems of older people in facilities, and for training volunteers to help in the ombudsman program. The long-term care ombudsman program is authorized by the Older Americans Act.

Look Back Period: Five-year period prior to a person's application for Medicaid payment of long-term care services. The Medicaid agency determines if any transfers of assets have taken place during that period that would disqualify the applicant from receiving Medicaid benefits for a period of time called the penalty period.

Mandatory Reporter: A staff member or employee of a facility or program who, in the course of employment, examines, attends, counsels, or treats a dependent adult in a facility or program and reasonably believes the dependent adult has suffered dependent adult abuse, shall report the suspected dependent adult abuse to the department.

Medicaid: Federal and state-funded program of medical assistance to low-income individuals of all ages. There are income eligibility requirements for Medicaid. Sometimes referred to as Title XIX.

Medicare: Federal health insurance program for persons age 65 and over (and certain disabled persons under age 65).

Merry Walker: A framed ambulation device that is a walker/chair combination.



Nursing Facility: Facility licensed by the state to offer residents personal care as well as skilled nursing care on a 24 hour a day basis. Provides nursing care, personal care, room and board, supervision, medication, therapies and rehabilitation.

Occupational Therapy (OT): Designed to help patients improve their independence with activities of daily living through rehabilitation, exercises, and the use of assistive devices.

Physical Therapy (PT): Designed to restore/improve movement and strength in people whose mobility has been impaired by injury and disease. May include exercise, massage, water therapy, and assistive devices.

Power of Attorney: Legal document authorizing one to act as the attorney in fact or agency of the principal (individual signing the document).

- A durable power of attorney for health care authorizes the attorney-in-fact to make health care decisions for the principal if the principal is unable, in the judgment of an attending physician.
- A financial power of attorney gives an attorney-in-fact the authority to act on the principal's behalf in financial matters. Also known as a General Power of Attorney.

Pre-Admission Screening and Resident Review (PASRR): For a state to have its Medicaid plan approved by the Centers for Medicare and Medicaid Services (CMS), it must maintain a Preadmission Screening and Resident Review (PASRR) program that complies with the relevant federal laws and regulations. Everyone who applies for admission to a nursing facility (NF) must be “screened” for evidence of serious mental illness (MI) and/or intellectual disabilities (ID), developmental disabilities (DD), or related conditions. Generally speaking, the intent of PASRR is to ensure that all NF applicants are thoroughly evaluated, that they are placed in nursing facilities only when appropriate, and that they receive all necessary services while they are there.

Principal: An individual who authorizes a person to act on his or her behalf through a power of attorney document.

Quality of Care: A measure of the degree to which delivered health services meet established professional standards and judgments of value to the consumer.

Registered Nurse (RN): A nurse who has graduated from a formal program of nursing education and has been licensed by an appropriate state authority.

Rehabilitation: The combined and coordinated use of medical, social, educational, and vocational measures for training or retaining individuals disabled by disease or injury to the highest possible level of functional ability.

Representative Payee: The term “Representative Payee” is unique to the Social Security Administration (SSA); however the role of representative payee is simply one of agency, that is, the representative payee is the designated agent for a recipient of Social Security benefits whom the SSA has determined to be incapable of managing his or her SSA benefits.

Residential Care Facility (RCF): A facility that provides room, board and personal care, and 24-hour supervision of individuals who need assistance with the activities of daily living.

Skilled Nursing Care: Daily nursing and rehabilitative care that can be performed only by or under the supervision of, skilled medical personnel. "Higher level" of care (such as injections, catheterizations, and dressing changes) is provided by trained medical professionals.

Speech Therapy (SPT): Designed to help restore speech through exercises.

Spousal Impoverishment: Federal regulations preserve some income and assets for the spouse of a nursing home resident whose stay is covered by Medicaid.

Substitute Decision Maker: Is defined as a guardian, conservator, representative payee, attorney-in-fact under a power of attorney, or a personal representative.

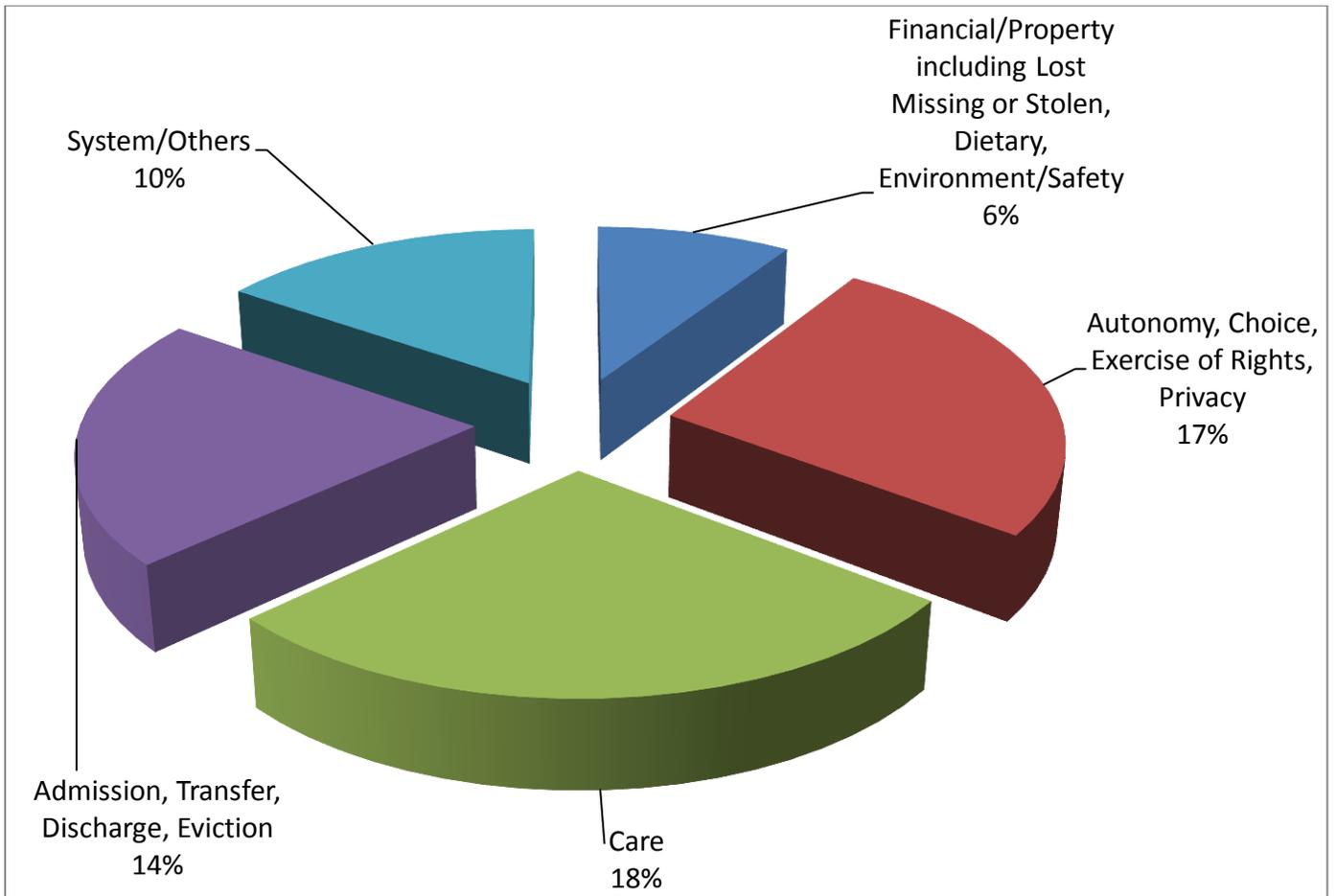
Sundowners Syndrome: Sundowner's Syndrome is the name given to an ailment that causes symptoms of confusion after "sundown." These symptoms appear in people who suffer from Alzheimer's disease or other forms of dementia. Not all patients who suffer from dementia or Alzheimer's exhibit Sundowner's symptoms, however. Conversely, some people exhibit symptoms of dementia all day which grow worse in the late afternoon and evening, while others may exhibit no symptoms at all until the sun goes down.

Transfer: 1) Moving a resident into and out of a bed, chair, wheelchair, etc. This is considered an Activity of Daily Living (ADL). 2) The relocation of a resident to another facility.

Office of the State Long-Term Ombudsman 2014 Cases and Complaints

Category	FFY14	FFY14	Issues addressed through this category
Number of New Cases Opened	731		
Number of New Complaints	1,106		
Abuse, Gross Neglect, Exploitation	23	2%	Physical, sexual, verbal, seclusion, financial and resident to resident willful deprivation
Access to Information	35	3%	Access to records, to visitors, information on services/benefits/medical/advance directives/rights
Admission, Transfer, Discharge, Eviction	157	14%	Admission contract & procedure, appeal process, bed hold, discharge/eviction notice & procedure, discrimination due to disability, Medicaid status, room assignment
Autonomy, Choice, Exercise of Rights, Privacy	185	17%	Physician, pharmacy, hospice, other health care provider, confinement, treated with dignity & respect, smoking, refuse care, language barrier, participate in care plan, privacy to visitors/telephone/mail/couples/treatment/confidentiality, response to complaints/retaliation
Financial, Property Lost, Missing or Stolen	67	6%	Billing/charges, personal funds, personal property
Resident and Tenant Care	205	18%	Injuries, response to requests for assistance, care plan/resident assessment, contracture, medications, personal hygiene, physician services, pressure sores, symptoms unattended, incontinent care, tubes, wandering
Rehabilitation or Maintenance of Function	50	5%	Assistive devices, bowel/bladder training, dental & mental health services, ambulation, therapies, vision & hearing
Restraints-Chemical and Physical	8	1%	Physical restraint and psychoactive drugs-assessment use, monitoring, evaluation
Activities and Social Services	36	3%	Choice, community interaction, resident conflict, social services availability/ appropriateness
Dietary	64	6%	Assistance in eating, hydration, food service, snacks, temperature, therapeutic diet, weight loss
Environment/Safety	66	6%	Air temperature/quality, noise, housekeeping, equipment/buildings, furnishings, infection control, laundry, odors, space for activities/dining, supplies, ADA accessibility
Policies, Procedures, Attitudes, Resources	20	2%	Abuse investigation/reporting, administrator unresponsive, grievance procedure, inappropriate or illegal policies, insufficient funds to operate, operator inadequately trained, offering inappropriate level of care, resident or family council interfered with
Staffing	47	4%	Communication barrier, shortage of staff, staff training/turn-over/unresponsive, supervision, eating assistants
Certification/Licensing Agency	7	1%	Access to information including survey, response to complaint, decertification/closure, sanction, survey process/ombudsman participation, transfer/eviction hearing
State Medicaid Agency	19	2%	Access to information application, denial of eligibility, non-covered services, personal needs allowance, services
System/Others	113	10%	Abuse by family member/friend/guardian, bed shortage, facilities operating without a license, family conflict, legal, Medicare, mental health/developmental disabilities/PASRR, physician/assistant, protective service agency, SSA/SSI/VA/other health benefits/agencies, request for less restrictive placement
Services Other than NF/RCF/ALP	4	0%	Home care, hospital/hospice, congregate housing not providing care, services from outside provider

Top Five Complaints by Major Reporting Category 2014



MY WORLD NOW

Life in a nursing home, from the inside

By ANNA MAE HALGRIM SEAVER

THIS IS MY WORLD NOW. IT'S ALL I HAVE LEFT, YOU SEE, I'M OLD. And, I am not as healthy as I used to be. I'm not necessarily happy with it but I accept it. Occasionally, a member of my family will stop in to see me. He or she will bring me flowers or little present, maybe a set of slippers- I've got 8 pair. We'll visit for a while and they will return to the outside world and I'll be alone again.

Oh, there are other people here in the nursing home. Residents, we're called. The majority are about my age. I'm 84. Many are in wheelchairs. The lucky ones are passing through-a broken hip, a diseased heart, something has brought them here for rehabilitation. When they're well they'll be going home.

Most of us are aware of our plight. Some are not. Varying stages of Alzheimer's have robbed several of their mental capacities. We listen to endlessly repeated stories and questions. We meet them anew daily, hourly or more often. We smile and nod gracefully each time we hear a retelling. They seldom listen to my stories, so I've stopped trying.

The help here is basically pretty good, although there's a large turnover. Just when I get comfortable with someone he or she moves on to another job. I understand that. This is not the best job to have.

I don't like some of the physical things that happen to us. I don't care much for a diaper. I seem to have lost the control acquired so diligently as a child. The difference is that I'm aware and embarrassed but I can't do anything about it. I've had 3 children and I know it isn't pleasant to clean another's diaper. My husband used to wear a gas mask when he changed the kids. I wish I had one now.

Why do you think the staff insists on talking baby talk when speaking to me? I understand English. I have a degree in music and am a certified teacher. Now I hear a lot of words that end in "y." Is this how my kids felt? My hearing aid works fine. There is little need for anyone to position their face directly in front of mine and raise their voice with those "Y" words. Sometimes it takes longer for a meaning to sink in; sometimes my mind wanders when I am bored. But there's no need to shout.

I tried once or twice to make my feelings known. I even shouted once. That gained me a reputation of being "crotchety." Imagine me, crotchety. My children never heard me raised my voice. I surprised myself. After I've asked for help more than a dozen times and received nothing more than a dozen condescending smiles and a "Yes, deary, I am working on it," something begins to break. That time I wanted to be taken to a bathroom.

I'd love to go out for a meal, to travel again. I'd love to go to my own church, sing in my own choir. I'd love to visit my friends. Most of them are gone now or else they are in different "homes" of their children's choosing. I'd love to play a good game of bridge but no one here seems to concentrate very well.

My children put me here for my own good. They said they would be able to visit me frequently. But they have their own lives to lead. That sounds normal. I don't want to be a burden. They know that. But I would to see them more. One of them is here in town. He visits as much as he can.

Something else I've learned to accept is a loss of privacy. Imagine having a roommate at my age. I do appreciate some time to myself and believe that I have earned at least that courtesy. As I sit think or writing, one of the aides invariably opens the door unannounced and walks in as if I'm not there. Sometimes she even opens my drawers and begins rummaging around. Am I invisible? Have I lost my right to respect and dignity? What would happen if the roles were reversed? I am still a human being; I would like to be treated as one.

The meals are not what I would choose for myself. We get variety but we don't get a choice. I am one of the fortunate ones who can still handle utensils. I remember eating off such cheap utensils in the Great Depression. I worked hard so I would not have to ever use them again. But here I am.

Did you ever sit in a wheelchair over an extended period of time? It is not comfortable. The seat squeezes you in the middle and applies constant pressure on your hips. The armrests are too narrow and my arms slip off. I am luckier than some. Others are strapped into their chairs and abandoned in front of the TV. Captive prisoners of daytime television: soap operas, talk shows and commercials.

One of the residents died today. He was a loner who, at one time, started his own business and developed a multimillion-dollar company. His children moved him here when he could no longer control his bowels. He didn't talk to most of us. He often snapped at the aides as though they were his employees. But he just gave up; willed his own demise. The staff has made up his room and another man has moved in.

A typical day. Awakened by the woman in the next bed wheezing-a former chain smoker with asthma. Call an aide to wash me and place me in my wheelchair to wait for breakfast. Only 67 minutes until breakfast. I'll wait. Breakfast in the dining area. Most of the residents are in wheelchairs. Others use canes or walkers. Some sit and wonder what they are waiting for. First meal of the day. Only 3 hours and 26 minutes until lunch. Maybe I'll sit around and wait for it. What is today? One day blends into the next until day and date mean nothing.

Let's watch a little TV. Oprah and Phil and Geraldo and who cares if some transvestite is having trouble picking a color-coordinated wardrobe from his husband's girlfriend's mother's collection. Lunch. Can't wait. Dried something with pureed peas and coconut pudding. No wonder I'm losing weight.

Back to my semiprivate room for a little semiprivacy or a nap. I do need a beauty rest, company may come today. What is today, again? The afternoon drags into early evening. This used to be my favorite time of the day. Things would wind down. I would kick off my shoes. Put my feet up on the coffee table. Pop open a bottle of Chablis and enjoy the fruits of my day's labor with my husband. He's gone. So is my health. *This* is my world.

SEAVER, who lived in Wauwatosa, Wis., died in March. Her son found these notes in her room after her death. Article from NEWSWEEK; June 27, 1994