

# STATE OF CONNECTICUT

## OFFICE OF THE STATE LONG TERM CARE OMBUDSMAN

### RESIDENT ADVOCATE TRAINING AND RESOURCE MANUAL



1-866-388-1888

Resident Advocate Program  
Department of Aging and Disability Services (ADS)

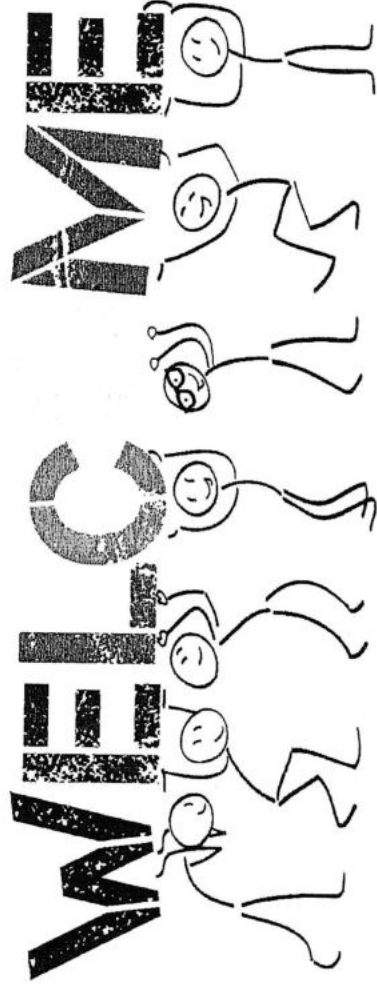
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# Welcome

- Your name
- Where you are from
- Name the “aha” moment that brought you here today
- What you hope to gain from this training



# Federal Training Requirements

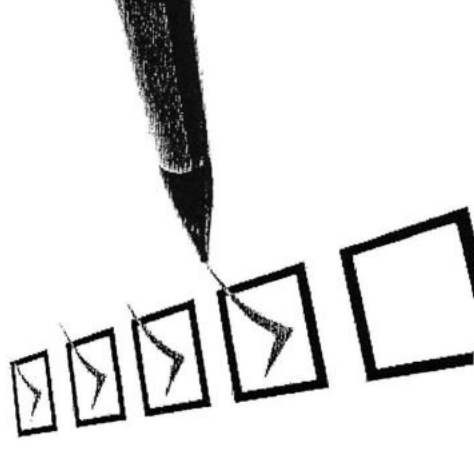
- A minimum of 36 hours of initial certification includes:

- up to 7 hours of independent study
- at least 10 hours in the field
- 16-20 hours of classroom style training

Annual In-Service Training hours required for maintaining designation of a minimum 18 hours per year is required

Methods include:

- Attend monthly meetings
- Attend LTCOP forums, RA Wrap-up
- Attend community presentations, or educational webinars







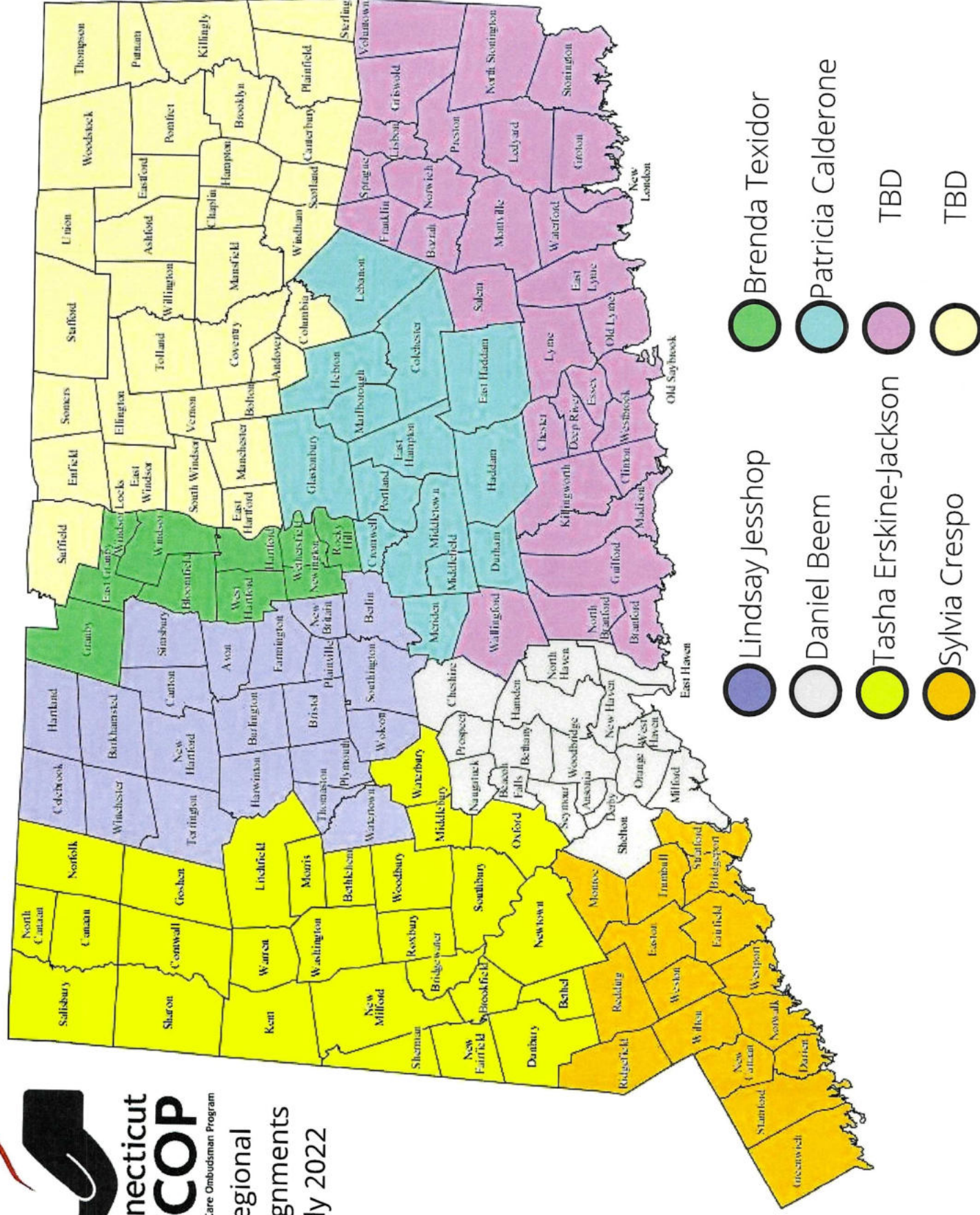
Connecticut  
**LTCOP**

### Long Term Care Ombudsman Program

## Regional

## Assignments

July 2022



## Connecticut Long-Term Care Ombudsman Program

### State Ombudsman

**Mairead Painter**

Mairead.painter@ct.gov

860-424-5238

### Regional Ombudsman

**Sylvia Crespo - South Western Region**

Phone: (866) 388-1888

Email: sylvia.crespo@ct.gov

#### **Towns Covered:**

BRIDGEPORT	DARIEN	EASTON	FAIRFIELD
GREENWICH	NEW CANAAN	NORWALK	REDDING
RIDGEFIELD	SOUTHPORT	STAMFORD	STRATFORD
TRUMBULL	WEST REDDING	WESTON	WESTPORT
WILTON			

**Tasha Erskine-Jackson - North Western Region**

Phone: (866) 388-1888

Email: tasha.erskine@ct.gov

#### **Towns Covered:**

BETHEL	BETHLEHEM	BRIDGEWATER	BROOKFIELD
CANAAN	CORNWALL	DANBURY	GOSHEN
KENT	LITCHFIELD	MIDDLEBURY	MORRIS
NAUGATUCK	NEW FAIRFIELD	NEW MILFORD	NEWTOWN
WILTON	NORFOLK	NORTH CANAAN	OXFORD
ROXBURY	SALISBURY	SHARON	SHELTON
SOUTHBURY	WARREN	WASHINGTON	WATERBURY
WOODBURY			



## Vacant Regional Ombudsman - North Eastern Region

Phone: (866) 388-1888

Email:

### Towns Covered:

ANDOVER	ASHFORD	BOLTON	CHAPLIN
COLCHESTER	COLUMBIA	EAST HARTFORD	EAST WINDSOR
EASTFROD	ELLINGTON	ENFIELD	GLASTONBURY
HEBRON	MANCHESTER	MANSFIELD	MARLBOROUGH
ROCKVILLE	SOMERS	SOUTH WINDSOR	STAFFORD
STAFFORD SPRINGS	SUFFIELD	TOLLAND	UNION
VERNON	WILLIMANTIC	WILLINGTON	WINDHAM
WINDSOR LOCKS			

## Brenda Texidor - Northern Region

Phone: (866) 388-1888

Email: [brenda.texidor@ct.gov](mailto:brenda.texidor@ct.gov)

### Towns Covered:

BLOOMFIELD	EAST GRANBY	GRANBY	HARTFORD
NEWINGTON	ROCKY HILL,	WEST HARTFORD	WETHERSFIELD
WINDSOR			

## Dan Deem - South Central Region

Phone: (866) 388-1888

Email: [dan.Deem@ct.gov](mailto:dan.Deem@ct.gov)

### Towns Covered:

ANSONIA	BEACON FALLS	BETHANY	BRANFORD
CHESHIRE	DERBY	EAST HAVEN	HAMDEN
MILFORD	NEW HAVEN	NORTH BRANFORD	NORTH HAVEN
ORANGE	PROSPECT	SEYMOUR	WEST HAVEN
WOODBIDGE			

**Daniel Beem - Eastern Region**

Phone: (866) 388-1888

Email: [@ct.gov](mailto:dan.beem@ct.gov)**Towns Covered:**

BROOKLYN	BOZRAH	BROOKLYN	CANTERBURY
DANIELSON	DAYVILLE	EAST LYME	ESSEX
FRANKLIN	GRISWOLD	GROTON	HAMPTON
KILLINGLY	LEBANON	LEDYARD	LISBON
LYME	MONTVILLE	MYSTIC	NEW LONDON
NIANTIC	NORTH STONINGTON	NORWICH	OLD LYME
OLD SAYBROOK	PLAINFIELD	POMFRET	PRESTON
PUTNAM	SALEM	SPRAGUE	STONINGTON
STOTLAND	THOMPSON	UNCASVILLE	VOLUNTOWN
WATERFORD	WOODSTOCK		

**Patricia Calderone - Central Region**

Phone: (866) 388-1888

Email: [patricia.calderone@ct.gov](mailto:patricia.calderone@ct.gov)**Towns Covered:**

CHESHIRE	CHESTER	CLINTON	COBALT
CROMWELL	DEEP RIVER	DURHAM	EAST HADDAM
EAST HAMPTON	GUILFORD	HADDAM	KILLINGWORTH
MADISON	MERIDEN	MIDDLEFIELD	MIDDLETOWN
MOODUS	PORTLAND	WESTBROOK	WALLINGFORD

**Lindsay Jesshop - North Central Region**

Phone: (866) 388-1888

Email: [lindsay.jesshop@ct.gov](mailto:lindsay.jesshop@ct.gov)**Towns Covered:**

AVON	BARKHAMSTED	BERLIN	BRISTOL
BURLINGTON	CANTON	COLEBROOK	COLLINSVILLE
FARMINGTON	FORESTVILLE	HARTLAND	HARWINGTON
KENSINGTON	NEW BRITAIN	NEW HARTFORD	PLAINVILLE
PLANTSVILLE	PLYMOUTH	PROSPECT	SIMSBURY
SOUTHINGTON	THOMASTON	TORRINGTON	WATERTOWN
WINCHESTER	WOLCOTT		

# MODULE 1

## INTRODUCTION TO THE LONG TERM CARE OMBUDSMAN PROGRAM

### **I. HISTORY OF THE LONG TERM CARE OMBUDSMAN PROGRAM**

- A. Social Security Act of 1935 - 1965
- B. Growth of the Nursing Home Industry
- C. Questions of Quality Of Care
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- A. Introduction to the Resident Advocate Role
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- C. The Do's and Don'ts of Advocacy
- D. Services Offered by the Program

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**AM session – Video Tape: “Advocates for Residents’ Rights”**

**PM session – Video Tape: CT LTCOP VRA Program**

**Annual Report, VRA Booklet, Regional Map**



# THE LONG TERM CARE OMBUDSMAN PROGRAM

## I. HISTORY OF THE LONG TERM CARE OMBUDSMAN PROGRAM

(Source: Sections A-H Excerpted from the Virginia Ombudsman Curriculum)

### A. Social Security Act Of 1935-1965

The Social Security Act is indirectly responsible for the nursing home industry, as it exists today. Social Security's original and sole purpose was to provide a supplemental retirement for working people and their dependents. It also provided Old Age Assistance (OAA) to needy people aged 65 and older who lived in the community.<sup>1</sup>

The Social Security Act prohibited Old Age Assistance money going directly to residents in public institutions. This signaled a beginning of the end for the public poor houses and provided a need for new alternatives for the aged without families who could care for them. Between 1935-1960, private rooming houses, private institutions, church-sponsored and other nonprofit institutions, and homes flourished and were paid for by the resident's Social Security money. Many of the homes began employing nurses and physicians to care for the aged and chronically ill.<sup>2</sup>

The most important factor in the development of nursing homes today was the creation of the federal Medicare and Medicaid programs in 1965. Medicare is a federal insurance program for persons over age 65. Medicare will pay for skilled nursing home care on a limited basis. Medicaid is a medical assistance program for the poor, including individuals over age 65, the blind, the disabled and members of families with dependent children. It is financed by a federal-state partnership. The purpose of this legislation was to provide financial assistance to the poor and the aged so that they would receive adequate medical care, both in and out of an institutional setting. Due to the availability of federal funds to help pay for nursing home services, demand for these services increased dramatically.

### B. Growth of Nursing Home Industry

While the proportion of elderly residing in nursing homes increased continually throughout the first half of this century, the advent of Medicare in the 1960's followed by Medicaid brought an even greater growth to the

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<sup>1</sup> Davis, W.E., Ibid.

<sup>2</sup> Adapted from Training Materials from the State of Ohio

nursing home industry. The outlay of federal dollars to support eligible seniors in participating homes far exceeded even the most liberal projections.

A look at statistics reveals the size of this industry:

- The Bureau of Census did one of the initial inventories of the nursing home industry in 1939. It counted 1,200 facilities with 25,000 beds.
- By 1960, there were 9,600 homes with 330,000 beds.
- In 1970, there were 23,000 facilities with 1.1 million beds.
- By 1980, there were 30,000 facilities with 1.5 million beds.
- In 2000, it is estimated that there are 2.8 million nursing home beds.

### C. Questions of Quality of Care

The nursing home industry in this environment grew dramatically with little direction or regulation. Many operators were well meaning but misinformed; some unscrupulous homes did indeed fleece their residents and poor care resulted in some deaths. Unfortunately, the opportunists and some of the more aggressive, dishonest operators gave the industry a bad reputation. A climate of mistrust and misunderstanding that is still prevalent developed between industry and consumers.

In the late 1960's and early 1970's, there were many publications written about abuse, neglect and substandard conditions in nursing homes. Several Congressional committees convened to hear testimony, compile data, and propose reforms for the nursing home industry.

Excerpts of testimony presented included the following two items:

*Hearings before the United States Senate on February 26, 1970, brought out the fact that it was the carpeting in a Marietta, Ohio, nursing home that speared the flames in a fire on January 9<sup>th</sup>. That fire resulted in the deaths of 32 of 46 patients from asphyxiation from the acrid, deadly smoke.*

*After delays, by the facility, in seeking medical help, twenty-five residents of a commercial Baltimore nursing home died in a salmonella food poisoning epidemic in August 1970. When twelve patients had died, the Washington Post stated "in a telephone interview, Gould (the owner) complained about the focus of the news media on the 12 deaths over the weekend, saying "is it really that big?" " <sup>3</sup>*

Ample publicity attesting to poor care and personal profit for owners created an environment in which more rigid federal regulations for standards of care were enacted in the early 1970's.

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<sup>3</sup> Butler, R.N. Why Survive? Being Old in America, NY: Harper&Row, 1975



**D. President Nixon's Eight Point Directive**

In 1971, President Nixon formulated an eight-point nursing home program that consisted of:

1. Training of 2,000 state nursing-home inspectors
2. Complete (100 percent) federal support of state inspections under Medicaid
3. Consolidation of enforcement activities
4. Strengthening of federal enforcement of standards
5. Short-term training for 41,000 professional and paraprofessional nursing home personnel
6. Assistance for state investigative "Ombudsman" units
7. Comprehensive review of long term care
8. Crackdown on substandard nursing homes: cut-off of federal funds to them.<sup>4</sup>

In summary, the rapid growth of nursing homes and a concern for the quality of life experienced by the residents of these facilities were in part responsible for the creation of the nursing home ombudsman programs that exist today.

**E. The Ombudsman Program History**

In the Supplemental Appropriations Act of December 1971, Congress made funds available for the establishment of nursing home ombudsman demonstration projects.

In May of 1975 former Commissioner on Aging, Dr. Arthur S. Flemming, invited all State Agencies on Aging to submit proposals for grants to create Ombudsman Programs. The purpose was to enable the State Agencies to develop the capabilities of the Area Agencies on Aging to promote, coordinate, monitor and assess nursing home ombudsman activities within their service areas."

**F. The Ombudsman Program under The Older Americans Act**

The 1978 Amendments to the Older Americans Act, passed in October 1978, considerably strengthened the Ombudsman Program. Title III, Section 307(a) (12) required every State to have a program and specifically defined ombudsman functions and responsibilities. The

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<sup>4</sup> Ibid

organizational structure of each program is individual to the state in which it operates.

**G. Vision and Philosophy of The Connecticut Long Term Care Ombudsman Program**

Regardless of an ombudsman's level(s) of advocacy, effort, or the complexity of the issue/problem that is being addressed, there is a basic set of principles that guide an ombudsman's decisions.

- (1) The Ombudsman provides services with respect for human dignity and the individuality of the client unrestricted by considerations of age, social or economic status, personal characteristics, or lifestyle choices.
- (2) The Ombudsman respects and promotes the client's right to self-determination.
- (3) The Ombudsman makes every reasonable effort to ascertain and act in accordance with the client's wishes.
- (4) The Ombudsman acts to protect vulnerable individuals from abuse and neglect.
- (5) The Ombudsman safeguards the client's right to privacy by protecting confidential information.
- (6) The Ombudsman remains knowledgeable in areas relevant to the long-term care system, especially regulatory and legislative information and long-term care service options.
- (7) The Ombudsman acts in accordance with the standards and practices of the Long-Term Care Ombudsman Program, and with respect for the policies of the sponsoring (contract) organization.
- (8) The Ombudsman will provide professional advocacy services unrestricted by his/her personal belief or opinion.
- (9) The Ombudsman participates in efforts to promote a quality long-term care system.
- (10) The Ombudsman participates in efforts to maintain and promote the integrity of the Long-Term Care Ombudsman Program.
- (11) The Ombudsman supports a strict conflict of interest standard, which prohibits any financial interest in the delivery or provision of nursing home, board and care services, or other long-term care services that are within their scope of involvement.
- (12) The Ombudsman staff conduct him/herself in a manner, which will strengthen the statewide and national Ombudsman network.

The Long-Term Care Ombudsman Program is a resident-centered advocacy program. The Regional Ombudsman always considers the resident (or potential resident) the client regardless of who contacts the agency. The Ombudsman will assist, represent, and intervene on behalf of the resident only as mutually agreed upon between the Ombudsman and the client, legal representative or interested party. The Ombudsman will uphold her/his legal and professional responsibility to act in situations on behalf of vulnerable individuals. The Ombudsman acknowledges that it may not be possible to represent every client as requested if the client's desired outcome is contrary to existing law or regulation.

The Ombudsman is committed to and works to promote:

- (1) The client's right to self-determination.
- (2) The optimal level of individual and group functioning and independence.
- (3) Informed participation in decision-making by all members of the long-term care community.
- (4) The protection of vulnerable individuals.

The Ombudsman carries out her/his advocacy role through the activities of providing information, assisting in problem solving, and promoting individual and group self-advocacy skills. The Ombudsman has a responsibility to respond to all requests for assistance related to long-term care services, either through direct assistance or appropriate referral.

*Therefore, Advocacy is work that is resident focused and that resolves an issue by providing mediation and access to particular systems and leaves the door open for future action. Whereas, Regulatory Enforcement is work that is government focused and punitive. Consequently, the enforcer applies actions to issues of non-compliance based on legal interpretation.*

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## THE CONNECTICUT LONG TERM CARE OMBUDSMAN PROGRAM

The Connecticut Long-Term Care Ombudsman Program (LTCOP) protects and promotes the rights and quality of life for residents of skilled nursing facilities, residential care homes and managed residential care communities, also known as assisted living facilities. This is a program that is mandated by the Federal Older Americans Act and Connecticut General Statutes Sec. 17a-405 (Formerly Sec. 17b-400). The program consists of one State Ombudsman, eight Regional Ombudsmen, one Administrative Assistant, two Clerical/Intake Staff, and a group of volunteers known as Resident Advocates (RA's).

The State Ombudsman works with state agencies, advocacy organizations, policy makers, legislators, and stakeholders to improve systems that strengthen protections at the state and federal level.

The Regional Ombudsmen (RO's) provide a voice to residents' concerns. Equally important, RO's empower residents to exercise their rights. This is achieved through direct consultation and complaint resolution with the individual at their home. The Regional Ombudsmen respond to residents' concerns and act based on the resident's direction. Regional Ombudsmen are a highly professional, expert group of advocates who work tirelessly to assist residents to achieve their desired outcome for their complaint. Regional Ombudsmen explore all avenues to fully understand an issue and reach a satisfactory resolution. Receiving complaints and working to find a resolution is the largest part of the Regional Ombudsman's work, but they also engage in many other advocacy activities. The Regional Ombudsmen promote Resident Councils by providing support and facilitating the needs of the Resident Councils as they arise. They also support the work of the Executive Board of Presidents of Resident Councils and provide outreach to the public. Regional Ombudsmen attend senior fairs throughout the state, providing presentations to various groups. During nursing home closures, Regional Ombudsmen maintain an active role to inform and support resident choice about where they will move. During facility bankruptcy reorganizations and receiverships, the Regional Ombudsmen also increase their presence in the homes to support residents and ensure their rights are honored in what can be a difficult and anxious time.

Resident Advocates are trained by Ombudsman staff in residents' rights and problem solving. Resident Advocates spend four hours per week in one assigned nursing home and help residents solve problems or address concerns with facility administration.

In partnership with residents, resident representatives, community partners, and other support stakeholders, the LTCOP celebrates collaborative achievements of many individuals and partners. The Connecticut Long-Term Care Ombudsman Program is dedicated to providing residents with opportunities to give voice to their concerns.

The Ombudsman Program has an operating budget of \$ 1,830,896, plus an additional \$64,279.24 in CARES Act funding.

- Federal Funds: \$ 349,040 (\$ 191,271 from Title VII, Chapter 2 of the Older Americans Act, and \$ 157,769 from Title IIIB of the Older Americans Act)
- State Funds: \$ 1,481,856
- COVID-19 related funds \$64,279.24 Activities Carried Out by the Office

The Mission of the Connecticut Long-Term Care Ombudsman Program is to protect the health, safety, welfare, and rights of long-term care residents by:

In 2020 and 2021, the staff of the Ombudsman program fulfilled their mission and requirements by:

- ❖ Bringing residents to the forefront to voice their concerns directly to public officials on issues affecting their lives.

The Office of the State Ombudsman developed materials for residents that focused on recovery and the support needed as we all begin to heal after the pandemic. The theme of the Annual Voices Forum was "Connection Matters - Our Voices LOUDER than EVER" and the residents were given tools and participated in a trauma and recovery training. Doctor Sheri Gibson presented, "Trauma During COVID-19: Healing Through Relationships." Dr. Gibson received her Ph.D. in Clinical Psychology with an emphasis in Geropsychology from the University of Colorado, Colorado Springs (UCCS). She is an instructor for the Psychology Department at UCCS and a faculty affiliate with the UCCS. 4 This annual event provides an opportunity for Presidents of Resident Councils in nursing homes to speak directly to public officials and agency heads in attendance, letting them know important issues they are dealing with and how these issues impact their quality of life. This year the event was held virtually due to the pandemic, but these important connections were still made. We found that some people preferred the virtual access and were able to attend, when otherwise they would not have been able to participate.

- ❖ Supporting residents in their quest to shape their own legislative agenda and to represent the residents' interests before governmental agencies: ➤ The Executive Board of Presidents of Resident Councils, a smaller regional representation of residents who are the Presidents of the Resident Councils at their nursing home, actively engaged in legislative advocacy at the General Assembly throughout the 2021 legislative session, reaching out to legislators, meeting with them, and providing testimony at public hearings when able. Some of their areas of outreach and advocacy included the Personal Needs Allowance legislation and increased staffing. The Personal Needs allowance and increased in staffing was passed.



❖ Investigating complaints and concerns made by or on behalf of residents in a timely and prompt manner.

➤ 4,499 complaints received

➤ 3,378 cases were closed

➤ 790 consultations were provided to individuals

➤ 873 consultations were provided for information and assistance to staff

➤ LTCOP testified to the key Aging, Human Services, and Public Health Committees.



## **Complaints Received by the CT LTCOP**

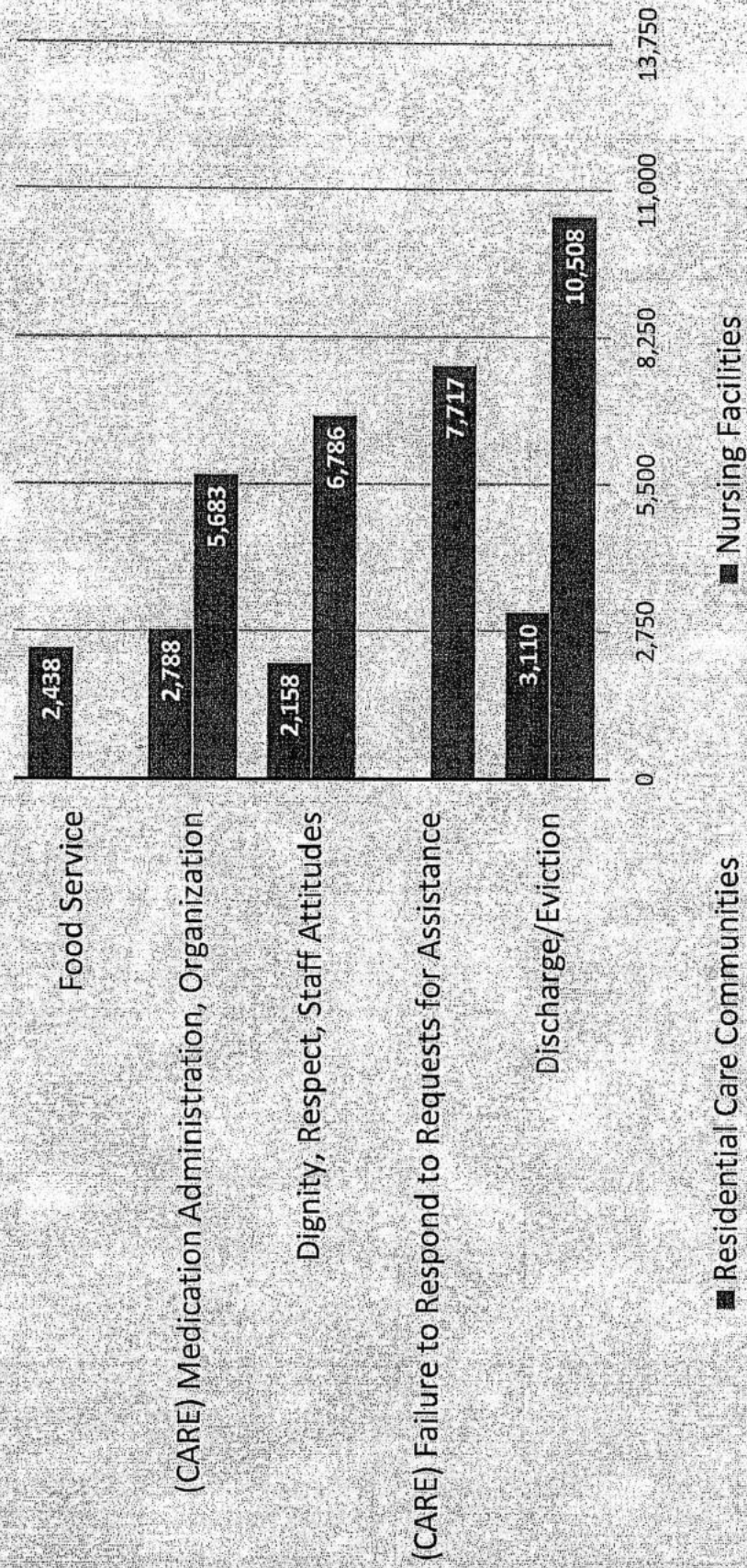
The LTCOP received a total of 4,499 Complaints in 2021

Below are the Top Five Categories of complaints in descending numerical order

- Care ( 848 Complaints)
- Residents Rights (727 Complaints)
- Admission, Transfer, and Discharge (465 Complaints)
- Environment (234 Complaints)
- Financial, property (274 Complaints)

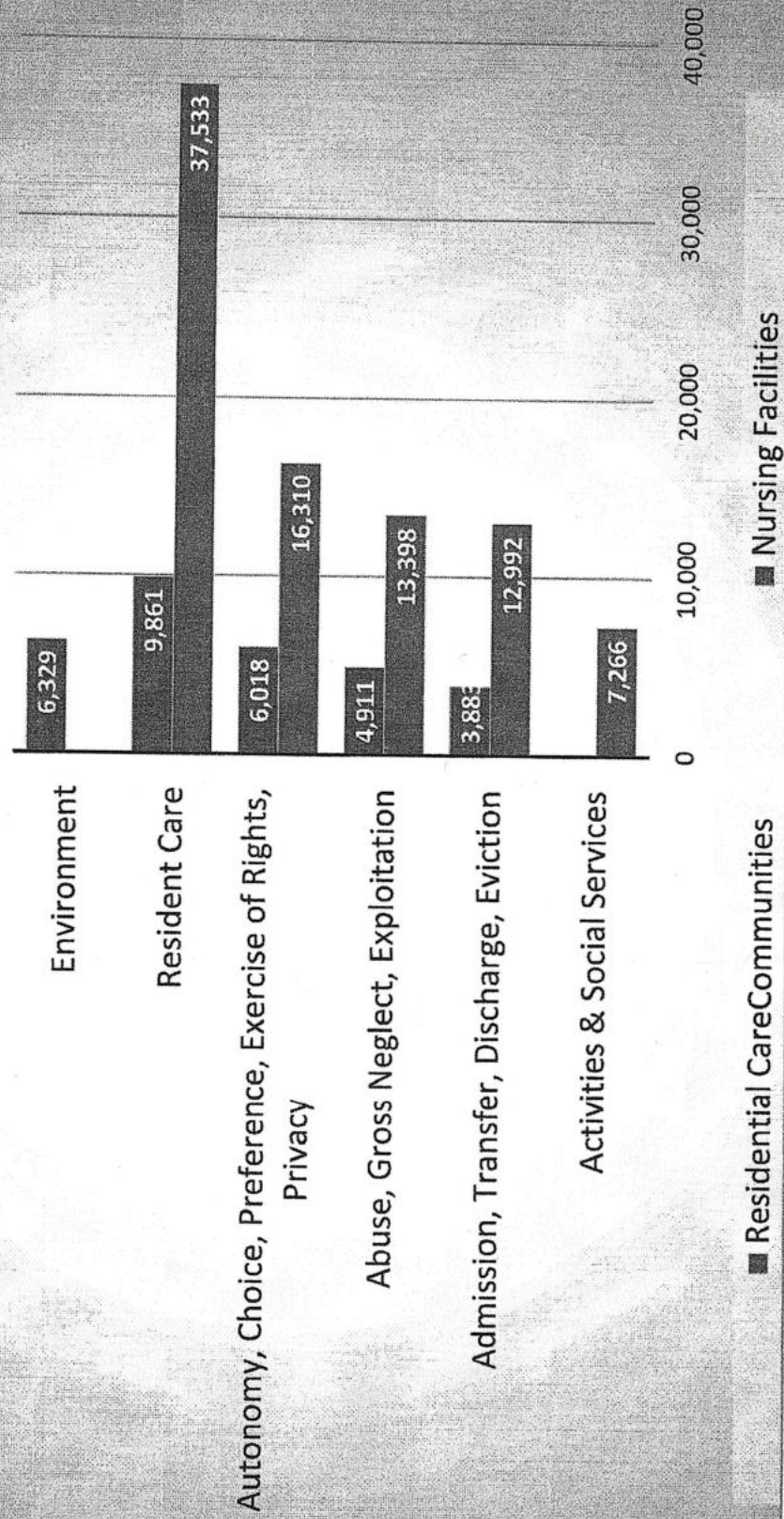


## National Top Ombudsman Program Complaints





## Top National Ombudsman Program Complaint Categories



# Fundamentals of the Long-Term Care Ombudsman Program

Empower

Ensure Confidentiality

Represent the Interests of Residents

Educate

Provide Resident-Directed Advocacy

Comply with Federal & State Laws, Regulations, and Policies

Document



## II. FUNCTIONS/ROLES OF THE RESIDENT ADVOCATE

### A. Introduction to the Resident Advocate Role

The following is an outline of different roles a Resident Advocate will use to resolve substantiated problems:

**ADVOCATE** - This is often used as a generic term for what Resident Advocates do, but in looking at roles, it has a very different meaning and function from other roles. The Resident Advocate as an advocate, works on behalf of a resident in resolving complaints that have been substantiated and need specific strategies developed to alleviate the problem that was identified. Advocacy may take the form of negotiating with an administrator or other staff; filing a complaint on behalf of the resident; working with a resident council; or getting a group of residents who have similar concerns together and working to resolve the problem as a group.

**EDUCATOR** - Resident Advocates work to educate residents, families, friends, or potential consumers about their rights and responsibilities in a facility. Resident Advocates need to have a working knowledge of current federal and state residents' rights in order to answer questions. Resident Advocates also provide information to concerned individuals who wish to advocate for themselves, but do not know how to go about it. Handouts (e.g., "How to Select a Nursing Home" or "Resident Rights Pamphlet") can be used to provide supplementary information.

**MEDIATOR** - Resident Advocates act as a mediator between resident and staff, resident and other residents, or resident and family. In this role, the Resident Advocate is a spokesperson for the resident, communicating the concerns to the appropriate staff, or family member in an effort to see the grievance or problem resolved. At times, the response may be immediate and satisfactory. The facility or individual may be unaware of the problem until it surfaces through the efforts of the Resident Advocate, and the resolution may be relatively simple. A large percent of problems result from misunderstandings or breakdowns in communication. Clarification by the Resident Advocate may be all that is necessary.

**BROKER** – Resident Advocates, in their role as brokers, investigate problems and find other agencies that could better resolve them or are essential to the problem solving process. A referral by the Resident Advocate is made to the Regional Ombudsman for further action.

**B. Advocacy Issues**

Advocacy has been described as:

- Acting on behalf of another;
- Assisting another to represent himself/herself;
- A willingness to study, to learn, to gather information necessary to support a cause;<sup>5</sup>
- Advocacy is pleading the cause of another.<sup>6</sup>

**C. The Do's and Don'ts Of Advocacy**

The **DO'S** of Advocacy

1. Respect the confidentiality of all complaints made to you.
2. Be a good listener.
3. Assure the residents that you are there to listen to their problems.
4. Speak clearly and slowly so the resident can understand you.
5. Try to talk to the resident in a quiet, private area.
6. Explain things in a few words, rather than in long paragraphs.
7. Be objective, yet understanding.
8. Try to provide an accurate picture to the residents of what they can expect.
9. Attempt to make the residents feel you care and are there to help them.
10. Work with residents, the staff and the administration in solving problems.
11. Keep accurate records of problems as requested for evaluation of the program.
12. Remember that it may take some questions and perseverance to get to the real problem.
13. Attempt to understand the total situation or problem by seeking out as many sources of information as possible.

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<sup>5</sup> Adapted from training materials from the State of Florida

<sup>6</sup> Adapted from training materials from the State of Vermont



14. Remember that the resident may tire easily, have a short attention span, digress during conversations, or simply become confused.

The **DON'TS** of Advocacy

1. Do not provide physical or nursing care. This is the responsibility of the trained nursing staff in the facility and is for the residents' protection as well as the advocate's.
2. Do not bring unauthorized articles into the home such as food, drugs, prescriptions, tobacco, matches, alcoholic beverages, or gifts.
3. Do not make promises that may be impossible to keep.
4. Do not advise residents on business or legal matters.
5. Do not be critical of the residents or the nursing home.
6. Do not engage in arguments, but rather, stick to the question or problem at hand.
7. You are not an inspector of the facility. You are there to listen to individual complaints and try to resolve them.

**D. Services Offered by the Program**

**DIRECT SERVICES** The program receives, investigates, and resolves complaints made by or on behalf of persons who are residents of long term care facilities. The complaints are limited to those relating to action, inaction or decisions of providers, or their representatives, of long term care services, of public agencies, or of social services agencies, which may adversely affect the health, safety, welfare or rights of such residents. A complaint is defined as a problem, concern or issue reported to or observed by an Ombudsman or Resident Advocate on which action is taken on behalf of the resident(s) to intervene in or alter the outcome of the situation or solve the problem.

**SYSTEMS ADVOCACY** The Ombudsman Program provides information and public education to assist individual residents, or individuals requesting the information on behalf of a resident, concerning the long term care system, the rights of residents of long term care facilities, and services available to residents including the activities of the Ombudsman Program. Public education activities include public speaking engagements, sponsoring or conducting workshops, participation in community elderly networks, developing and distributing written materials, and promoting media coverage of long term care issues.

**SYSTEMIC ADVOCACY** In accordance with federal law, the Long Term Care Ombudsman Program monitors the development and

# → History of the Program



## • 1970s

- The program officially began in 1972 with implementation of President Nixon's 1971 Eight Point Initiative to improve nursing home care.
- The program started as a demonstration program to test its effectiveness. By the late 1970s, all states were required to have an Ombudsman program as a requirement of the Older Americans Act (OAA).

## • 1980s

- The program expanded to include board and care as well as other similar adult care facilities.
- Clarifying language was added to the OAA to ensure the program's access to long-term care facilities, residents, and records.

- **1990s**

- Title VII, the Vulnerable Elder Rights Protection Program, was created in the 1992 amendments to the OAA.
- The 1992 OAA amendments also included the creation of an Office of the State Long-Term Care Ombudsman and clarified some conflicts of interest.

- **2000s**

- The 2000 OAA amendments included specific language that prohibited Ombudsmen entities and representatives of the Office from financial gain through an action or potential action brought on behalf of individuals they served.



## • **2006**

- Reauthorization added “Assisted Living Facilities” to the definition of “Long-term Care Facility” thereby requiring the LTCOP to provide services to residents of Assisted Living Facilities.

## • **2015**

- The State Long-Term Care Ombudsman Programs Rule was published in February 2015 with an effective date of July 1, 2016. The LTCOP Rule adds clarity to many of the program responsibilities and provisions in the OAA.

## • **2016**

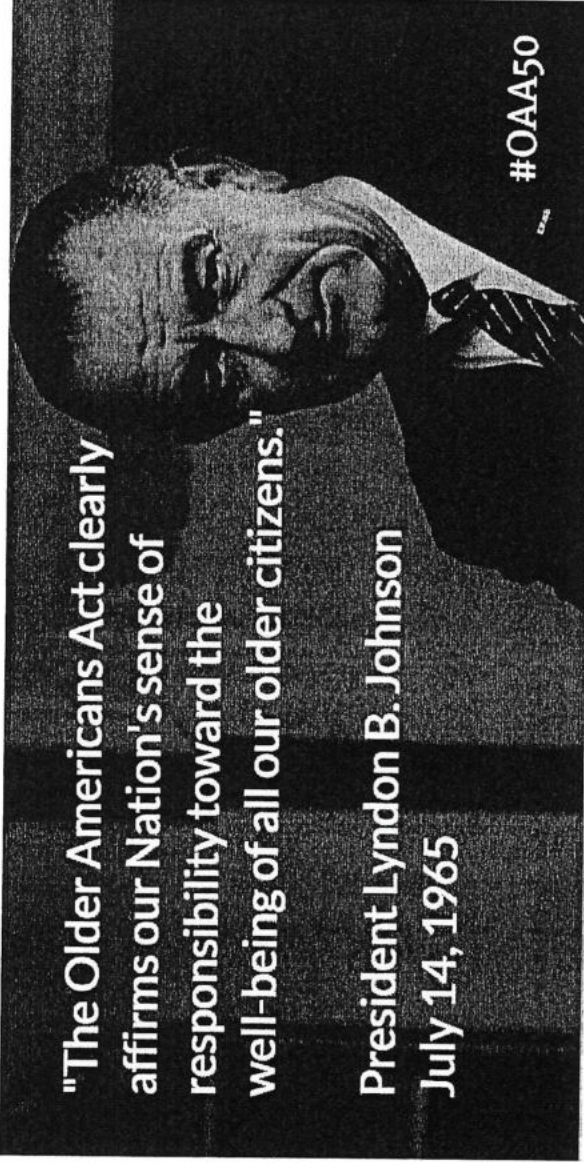
- The 2016 OAA amendments added clarity and additional authority to the LTCOP in several areas.

## • 2020

- OAA reauthorization clarified that the LTCOP is allowed to provide, and financially support, recognition for individuals designated as volunteer representatives.

"The Older Americans Act clearly affirms our Nation's sense of responsibility toward the well-being of all our older citizens."

President Lyndon B. Johnson  
July 14, 1965



#OAA50

## Ombudsman and Volunteer Resident Advocate (VRA)

### Selected Background Information

Sec. 17b-400. (Formerly Sec. 17a-405). Office of the Long-Term Care Ombudsman. Regional ombudsmen. Appointments. Inclusion in classified service. Definitions. (a) As used in this chapter:

(5) "Representative" includes a regional ombudsman, a residents' advocate or an employee of the Office of the Long-Term Care Ombudsman who is individually designated by the ombudsman.

Sec. 17b-401. (Formerly Sec. 17a-406). Residents' advocates. Appointment, expenses, removal. Use of trained volunteers. (a) Residents' advocates shall be appointed by the State Ombudsman, in consultation with the regional ombudsmen, for each region in sufficient number to serve the long-term care facilities within such region. Such residents' advocates shall, if possible, be residents of the region in which they will serve, and shall have demonstrated an interest in the care of the elderly.

Sec. 17b-402. (Formerly Sec. 17a-407). Residents' advocates. Training. Regulations. No person may perform any functions as a residents' advocate until the person has successfully completed a course of training required by the State Ombudsman.

Sec. 17b-406. (Formerly Sec. 17a-411). Duties of residents' advocates. Posting by nursing home facilities. Funding. (a) Residents' advocates, under supervision of the regional ombudsmen, shall assist the regional ombudsmen in the performance of all duties and responsibilities of the regional ombudsmen as described in section 17b-405.

(b) All long-term care facilities shall post or cause to be posted in a conspicuous place therein a list of the names of the appropriate residents' advocates and the names, addresses, and telephone numbers of the appropriate ombudsmen.

## Advocates for Residents' Rights:

### *The Older Americans Act Long Term Care Ombudsman Program*

After watching the video, Advocates for Residents' Rights: The Older Americans Act Long Term Care Ombudsman Program, use your own words to briefly describe what you learned regarding the following points.

1. The role of the Long Term Care Ombudsman (LTCO)
2. The purpose of the Long Term Care Ombudsman Program (LTCOP)
3. Five skills ombudsman need
  - 1.
  - 2.
  - 3.
  - 4.
  - 5
4. Characteristics of LTCO
5. Your questions about being an advocate



# What Makes the LTCOP Unique?



## Unique Elements of the LTCOP

While many types of ombudsman programs wrestle with ethical issues, confidentiality issues and other issues similar to those of the LTCOP, this program has a few unique elements.

- **Jurisdiction:** The jurisdiction of the LTCOP is the interest of the resident.
- **Resolution Standard:** At the end of the investigation and resolution process, the key question for a LTCO is, Has this complaint/issue been resolved to the satisfaction of the resident?
- **Works on Issues Apart from Specific Complaint:** The LTCOP has a mandate to advocate on behalf of the needs of a resident, or residents, separate from individual complaints. Therefore, the LTCOP is to be involved in broader long-term care issues. The LTCOP is expected to be involved in public policy work affecting residents in general.
- **Promotes Development of Groups:** The LTCOP promotes the development of citizen organizations to participate in the program and provides technical support for the development of resident and family councils to protect the well-being and rights of residents.

## Conflict of Interest

Many agencies, particularly governmental agencies, have conflict of interest provisions. Some also have ethical guidelines that extend to post-employment services for a period of time. In its early days, the conflict of interest provisions of the LTCOP were typically defined as having a financial or spousal conflict of interest. These concepts are commonly accepted among other programs and agencies. With the growth in long-term care services and the maturing of the LTCOP, *conflict of interest* has encompassed some additional dimensions.

The Institute of Medicine's study of the program devoted Chapter 4 to this topic.<sup>9</sup> It identifies three dimensions of conflict of interest: loyalty, commitment, and control.

- **Loyalty:** These involve issues of judgment and objectivity. These are the typical situations almost everyone understands—financial and employment considerations. An ombudsman's ability to be fair and a resident advocate might be questioned if the ombudsman also is a consultant to a facility, a board member of a facility or management company, or works as a case manager with responsibility for assisting individuals with moving into long-term care facilities. Loyalty might also be an issue if the individual is an ombudsman in a facility which was the ombudsman's previous employer.
- **Commitment:** These are issues of time and attention. Which goals are being addressed? Who establishes the goals and work priorities of the "full-time" State Ombudsman? If local ombudsmen are part time, where is their greater commitment in terms of time and loyalty?

The LTCO, whether state or local, is required to be a voice for residents. This mandate takes precedence over being a voice for the positions of the employer. As ombudsmen fulfill their role to be loyal to carrying the *resident's* message, their loyalty to their employer may be questioned. Thus, the commitment called for in the LTCOP is not the typical view of commitment expected by most employers.

- **Control:** These are issues of independence. Do other interests, priorities, or obligations of the agency that houses the ombudsman materially interfere with the LTCOP's advocacy on behalf of residents? Do administrative or political forces materially interfere with the professional judgment of the ombudsman? Is the ombudsman able to act responsibly without fear of retaliation by superiors?

The credibility of the LTCOP rests upon fulfilling its primary responsibility—acting on behalf of residents. If the program acts without being grounded in what residents want, its credibility and effectiveness will be lost.

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<sup>9</sup> Institute of Medicine. op. cit.



## **V. CONFLICTS OF INTEREST**

### **A. Conflicts of Interest Prohibited**

**Policy:** The State Agency Head and the Office will monitor and take appropriate steps to adequately remove or remedy the identified conflict of interest as defined in federal and state regulation.

**Purpose:** To ensure the Office is free from organizational and individual conflict of interest.

**Goal:** The Office will be free from conflict of interest at both the organizational level and the individual level.

#### **Procedure:**

- (1) The employment or appointment of an Ombudsman or representative of the Office with a conflict of interest that cannot be adequately removed or remedied is prohibited.
- (2) The Ombudsman will take steps to refuse, suspend or remove designation of an individual who has a conflict of interest, or who has a member of the immediate family with a conflict of interest, which cannot be adequately removed or remedied.
- (3) The Ombudsman shall consider both the organizational and the individual conflicts of interest that may impact the effectiveness and credibility of the work of the Office. In so doing, the Ombudsman shall identify actual and potential conflicts and, where a conflict has been identified, will take action to remove or remedy that conflict. Where a conflict cannot otherwise be removed or remedied, the Ombudsman and/or the State Agency, and their respective and independent legal counsel, shall identify another arrangement with a public agency or non-profit organization with which to carry out the responsibilities of the Office.

### **B. Identification of Organizational Conflicts**

- (1) In identifying conflicts of interest, the Ombudsman shall consider the organizational conflicts that may impact the effectiveness and credibility of the work of the Office. Organizational conflicts of interest include, but are not limited to, placement of the Office, or requiring that an Ombudsman or representative of the Office perform conflicting activities, in an organization that:
  - (a) Is responsible for licensing, surveying, or certifying long-term care facilities;
  - (b) Is an association (or an affiliate of such an association) of long-term care facilities, or of any other residential facilities for older individuals or individuals with disabilities;
  - (c) Has any ownership or investment interest (represented by equity, debt, or other financial relationship) in, or receives grants or donations from, a long-term care facility;
  - (d) Has governing board members with any ownership, investment or employment interest in long-term care facilities;
  - (e) Provides long-term care to residents of long-term care facilities, including the provision of personnel for long-term care facilities or the operation of programs which control access to or services for long-term care facilities;

- (f) Provides long-term care coordination or case management for residents of long-term care facilities;
  - (g) Sets reimbursement rates for long-term care facilities;
  - (h) Provides adult protective services; (i) Is responsible for eligibility determinations regarding Medicaid or other public benefits for residents of long-term care facilities;
  - (j) Conducts preadmission screening for long-term care facility placements;
  - (k) Makes decisions regarding admission or discharge of individuals to or from long-term care facilities;
  - or (l) Provides guardianship, conservatorship or other fiduciary or surrogate decision-making services for residents of long-term care facilities
- (2) The Ombudsman will evaluate the Office for organizational conflicts on an annual basis.

### **C. Removing or Remediating Organizational Conflicts**

- (1) The Ombudsman shall identify organizational conflicts of interest in the Ombudsman program and describe steps taken to remove or remedy conflicts in the annual report submitted to the Assistant Secretary through the National Ombudsman Reporting System.
- (2) In most cases, the removal or remediating of organizational conflicts will require changes to the organizational structure of the Office so that conflicts no longer exist.

### **D. Identifying Individual Conflicts of Interest.**

- (1) In identifying conflicts of interest, the Ombudsman shall consider individual conflicts that may impact the effectiveness and credibility of the work of the Office.
- (2) Individual conflicts of interest for an Ombudsman, representatives of the Office, and members of their immediate families include, but are not limited to:
- (a) Direct involvement in the licensing or certification of a long-term care facility;
  - (b) Ownership, operational, or investment interest (represented by equity, debt, or other financial relationship) in an existing or proposed long-term care facility;
  - (c) Employment of an individual by, or participation in the management of, a long-term care facility in the service area or by the owner or operator of any long-term care facility in the service area;
  - (d) Receipt of, or right to receive, directly or indirectly, remuneration (in cash or in kind) under a compensation arrangement with an owner or operator of a long-term care facility;
  - (e) Accepting gifts or gratuities of significant value from a long-term care facility or its management, a resident or a resident representative of a long-term care facility in which the Ombudsman or representative of the Office provides services (except where there is a personal relationship with a resident or resident representative which is separate from the individual's role as Ombudsman or representative of the Office);

(f) Accepting money or any other consideration from anyone other than the Office, or an entity approved by the Ombudsman, for the performance of an act in the regular course of the duties of the Ombudsman or the representatives of the Office without Ombudsman approval;

(g) Serving as guardian, conservator or in another fiduciary or surrogate decision-making capacity for a resident of a long-term care facility in which the Ombudsman or representative of the Office provides services; and

(h) Serving residents of a facility in which an immediate family member resides.

(3) To be eligible for appointment or continued employment, an Ombudsman or representative of the Office cannot have been employed by, or participated in the management of, a long-term care facility within the previous twelve months.

### **E. Removing or Remediating Individual Conflicts**

(1) The Ombudsman will:

(a) Decline to employ or appoint an individual who has an unremedied conflict of interest or who has a member of the immediate family with an unremedied conflict of interest;

(b) Avoid assigning an individual to perform duties that would constitute an unremedied conflict of interest.

(2) The Ombudsman and the State Agency will use a screening tool to identify and remedy individual conflicts of interest. The screening tool will be used when an individual is initially designated an Ombudsman, a Regional Ombudsman, or a RA, and at least annually thereafter. The screening tool shall be used by:

(a) The State Agency to screen the Ombudsman or any applicant for appointment as Ombudsman for potential conflicts of interest.

(b) The Ombudsman to screen for potential conflicts of interest for any acting or prospective Regional Ombudsman or RA.

(3) Whenever a conflict of interest involving an Ombudsman is identified by or reported to the Commissioner of the State Agency, the following rules shall apply:

(a) An Ombudsman who has knowledge of a conflict of interest shall immediately disclose the conflict of interest to the Commissioner of the State Agency.

(b) The Commissioner and the Ombudsman shall determine and agree, in writing, on the method and deadline for removing or otherwise resolving the conflict of interest.

(c) Failure of the Ombudsman and the Commissioner to arrive at a written agreement shall be a reason to terminate the appointment of the Ombudsman.

(d) Failure of the Ombudsman to comply with the terms of the written agreement shall result in termination of the appointment of the State Ombudsman.



(e) An applicant for appointment as Ombudsman who fails to comply with the terms of the written agreement shall not be appointed.

(4) Whenever a conflict of interest involving a Regional Ombudsman or a RA is identified by or reported to the Ombudsman, the following rules shall apply:

(a) A Regional Ombudsman or a RA who has knowledge of a conflict of interest shall immediately disclose the conflict of interest to the State Ombudsman.

(b) The State Ombudsman, Regional Ombudsman, or RA shall agree, in writing, on the method and deadline for resolving the conflict of interest.

(c) Failure to arrive at a written agreement shall be grounds for the State Ombudsman to deny designation or re-designation as a Regional Ombudsman or RA.

(d) A Regional Ombudsman or RA shall lose their designation if the individual fails to comply with the terms of the agreement within the timeframe specified in the agreement. An applicant for designation as a Regional Ombudsman or RA who fails to comply with the agreed upon terms before the anticipated date of designation shall not be designated.

(e) Any individual applying for designation has the duty to disclose any known conflicts of interest at the time of application for designation

Name:  
Address: 55 Farmington Avenue HTFD,CT  
Email Address:

Date:  
Phone

### Employment and Responsibilities

Have you or any members of your immediate family or household ever been employed by a long-term care provider (facility or by the owner or operator of a facility)? *Note: Immediate family member is defined as "a member of the household or a relative with whom there is a close personal or significant financial relationship" (§712 of the Older Americans Act, §1324.1, Definitions, LTCOP Rule.* ☐ Yes ☐ No

Do you, or any members of your immediate family or household, receive or have the right to receive, directly or indirectly remuneration (in cash or in kind) under a compensation arrangement with an owner or operator of a long-term care facility? ☐ Yes ☐ No

If Yes to either question, please list the following.

Start/End dates of employment (MM/YY)	Name of person employed or compensated	Your relationship	Employer	Position/duties or Compensation Arrangement

Are you currently performing any of the responsibilities listed below? *Check all that apply.*

- ☐ Surveying or participating in the licensing or certification of long-term care facilities.
- ☐ Working for an association (or an affiliate of an association) of long-term care facilities or of any other residential facilities for older individuals or individuals with disabilities.
- ☐ Providing care to residents of long-term care facilities or involved in the provision of personnel for long-term care facilities.
- ☐ Providing long-term care coordination or case management for residents of long-term care facilities.
- ☐ Providing adult protective services.
- ☐ Participating in eligibility determinations regarding Medicaid or other public benefits for residents of long-term care facilities.
- ☐ Conducting pre-admission screening for long-term care facility placements.
- ☐ Making decisions regarding admission or discharge of individuals to or from long-term care facilities.
- ☐ Providing guardianship, conservatorship, or other fiduciary or surrogate decision-making services for residents of long-term care facilities.

For all responsibilities that were checked, describe your role and provide additional information.


Are you, or a member of your immediate family, serving as an officer or board member of a long-term care facility or service provider? ☐ Yes ☐ No

If Yes, please provide additional information, e.g. position, length of service, responsibilities.


### Financial Interest

Do you or any member of your immediate family or household have an ownership or investment interest (represented by equity, debt, or other financial relationship) in an existing or proposed long-term care facility or service? ☐ Yes ☐ No

If Yes, please provide information regarding the financial interest including as applicable, the location of the facility and/or the area covered by the service.


### Relationships

Do you, or a member of your immediate family or household, have an immediate family member residing in a long-term care facility? ☐ Yes ☐ No

Do you or have you resided in a long-term care facility? ☐ Yes ☐ No

If Yes, to either of the questions, please list the following.

Name of Facility	Location of Facility	Your relationship or Length of Time

Are you serving individuals who live in long-term care facilities in any capacity, such as a volunteer visitor, conducting pet therapy, providing entertainment, or any other services, paid or volunteer? ☐ Yes ☐ No

If Yes, provide additional information.

Name of Facility	Location of Facility	Your Role	Frequency



### Additional Considerations

Do you, or a member of your immediate family or household, have any other relationships, activities, or responsibilities that may impact the effectiveness and credibility of the work of the Office of Long-Term Care Ombudsman (e.g., personal injury attorney, works for a pharmaceutical company or medical supply company)? ☐ Yes ☐ No

If Yes, please list them. If you are not sure about the potential impact on the Office, please list the relationship, activity, or responsibility, for discussion with a staff Ombudsman program representative.


### Agreements

As a representative of the Office of the State Ombudsman, I understand that I, and members of my immediate family and household, cannot:

- accept gifts or gratuities of significant value from a long-term care facility or its management, a resident or a resident representative of a long-term care facility in which I serve;
- accept money or any other consideration from anyone other than the Office, or an entity approved by the Ombudsman, for the performance of an act in the regular course of my duties as a representative of the Ombudsman program without Ombudsman approval.

If any circumstances in this document change or if I have questions or concerns regarding an actual or potential conflict of interest with my duties as a representative of the Ombudsman program, I will notify my direct Ombudsman program supervisor immediately.

If any circumstances or opportunities arise and I have questions or concerns regarding the potential impact on the effectiveness or credibility of the Ombudsman program, I will notify my direct Ombudsman program supervisor immediately.

I understand and agree with the preceding statements and verify that all the information I have provided is accurate.

Signature

Date

#### For Program use only

After reviewing this document and speaking with the applicant, it has been determined that the following conflict of interests can and will be remedied and supporting documentation is included with this application.

It has been determined (through conversation with the applicant) that the following conflicts of interests cannot be remedied, and the applicant has been notified (or will be notified). ☐ Yes ☐ No

Per our state policies and procedures, the pertinent information for designation by the State Ombudsman was forwarded to the State Office.

Off name and signature: \_\_\_\_\_

Date: \_\_\_\_\_

I worked in the facility where I am assigned for only 2 months and it was 2 years ago. I left on good terms, so I don't see a conflict of interest.

My step-mother resides in the facility where I am assigned, but we haven't talked in years, so I don't think it is a conflict of interest.

I own a licensed group home  
and would like to become a  
representative of the Office.

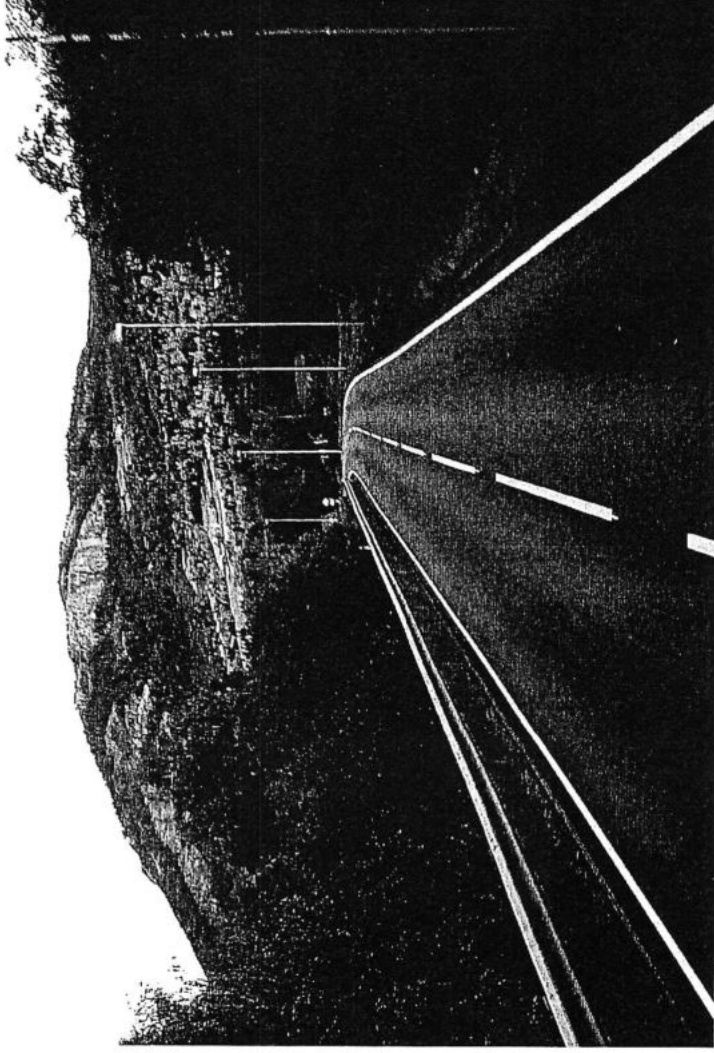
I license and inspect assisted  
living facilities, but would like to  
volunteer as a representative of  
the Office in my spare time.



# Stay in Your Lane

## LTCOP Lane

- ☐ Getting help
- ☐ Coordinating
- ☐ Facilitating
- ☐ Changing laws
- ☐ Changing policies
- ☐ Providing training
- ☐ Pointing out problems



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## Not Your Lane

- ☐ Providing care
- ☐ Feeding residents
- ☐ Pushing residents in their wheelchairs
- ☐ Telling facility staff how to do their jobs
- ☐ Policing

# Ethical Dilemmas

- June

- Jack

- Billie

# June

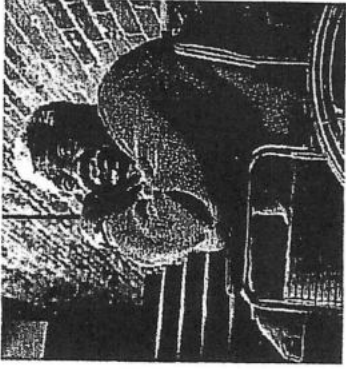


June asks you to pour her a glass of water because her throat is dry. The water pitcher and cup are on her bed-side table, but out of her reach.

She's thirsty and can't reach her water but who is responsible to get the water for her? Does she have fluid restrictions? Does she have difficulty swallowing?



# Jack



You are talking to Jack in a public area, but he wants to talk in private. He uses a wheelchair and cannot push himself down to his room. He asks you to do so.

He needs help with his wheelchair and wants to talk privately with a representative, which is his right to do so. Who is responsible for taking him to his room?

# Billie



During a visit in Billie's room, she tells you she's chilly and asks you to get her sweater out of her closet and help her put it on.

She is uncomfortable and wants her sweater but is it okay for the representative go through her closet even at her request? Who is responsible for assisting her with dressing?

Determine if the following requests to the LTCOP are appropriate or inappropriate:

A. Mr. Lopez has uncontrolled diabetes and is morbidly obese. Against the doctor's recommended diet, he wants to eat the desserts that the other residents without diabetes are served. He asks you to talk to the dietary manager about getting the same desserts as everyone else.

B. The facility social worker contacts the LTCOP and asks for help finding a facility for a resident who is causing "problems."



C. Mrs. Thompson complains that she is lonely and asks you to stay longer to keep her company and look through her photo albums with her.

D. Mrs. Cohen tells the LTCOP she would like to go to Temple every week. Mrs. Cohen states that she heard "The Ride" program takes two fellow residents, but she needs assistance to fill out the application and submit it. With Mrs. Cohen's permission, the LTCOP asks the social worker to help the resident complete the application.

E. Mr. Clark wants your help to convince the facility staff that he should be allowed to take a shower every morning. The facility says they are concerned they don't have enough staff to allow for Mr. Clark or anyone else to shower daily and asked "what would happen if all of the residents wanted to take a shower every morning?" The staff member asks you to talk Mr. Clark out of his request.

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# The National Long-Term Care Ombudsman Resource Center

## The National Long-Term Care Ombudsman Resource Center (NORC)

[www.ltombudsman.org](http://www.ltombudsman.org)

*This project was supported, in part, by grant number 90OMRC0001-01-00, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.*



# MODULE 2

## RESIDENT RIGHTS

- I. THE AGING PROCESS
- II. WHY RESIDENTS NEED ADVOCACY  
Fear of Retaliation Video and Exercise
- III. NURSING HOME RESIDENTS' RIGHTS
  - A. Purpose
  - B. Reasons Why Residents Do Not Routinely Exercise Their Rights
- IV. EMPOWERMENT
  - A. The Role of the Resident Advocate
  - B. Resident Participation
- V. NURSING HOME REFORM ACT OF 1987
  - A. Provisions of the Law
  - B. Specific Rights
  - C. Care Planning
  - D. Use of Restraints
- VI. CONNECTICUT PATIENT BILL OF RIGHTS
- VII. RIGHTS AND LEGAL MATTERS

MODULE 2 Appendix and Topics  
Video "Look At Me", Fear of Retaliation Video  
Connecticut General Statutes, Chapter 319aa  
Older Americans Act, Ombudsman Program

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## PREFACE

### OBJECTIVE

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

### INTENDED USE

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

### SUGGESTIONS FOR USING WITH THE CURRICULUM

There are several ways to use these materials.

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

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



# I. The Aging Process

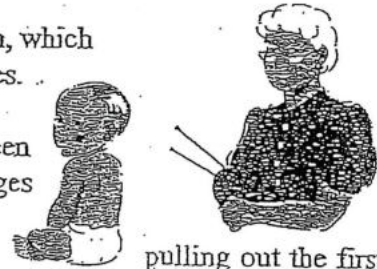
## A. What is Aging

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

Although aging is an ongoing process, the value of aging is seen differently at different points in the process. Some of the changes are anticipated with joy, such as a baby's first tooth or first step.

Other changes are greeted with a less positive response, such as pulling out the first gray hairs that appear. Youth is valued in American culture; while signs of aging are masked with face-lifts, wrinkle creams, and hair dyes. The process of physical maturation that is so eagerly anticipated in the first stages of life is viewed very negatively when the youthful attractiveness begins to change.



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

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

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

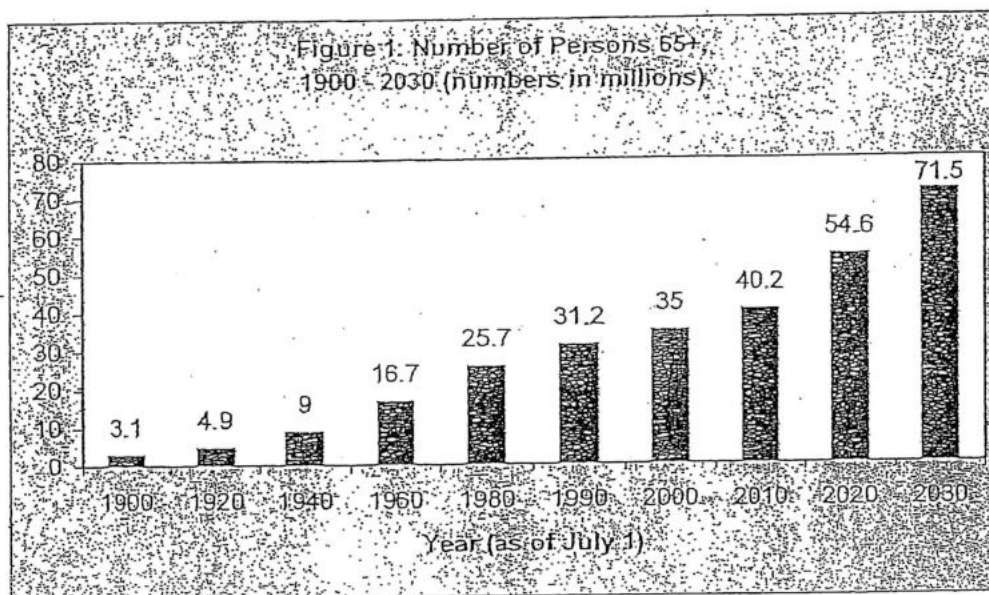
## B. Profile of Older People

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

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

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



### Numbers and Growth

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

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

### Minority Populations

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

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



### Age

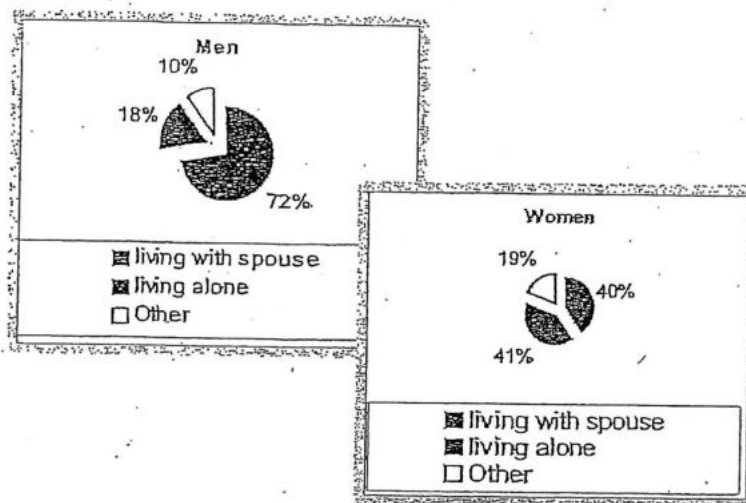
The older population itself is getting older. In 2002, the 65-74 age group (18.3 million) was eight times larger than in 1900, but the 75-84 group (12.7 million) was more than 16 times larger and the 85+ group (4.6 million) was almost 38 times larger.

### Living Arrangements

Over half of noninstitutionalized older persons lived with their spouse in 2002 (Figure 2). The proportion of individuals living with their spouse decreased with age, especially for women.

\*\*\*\* About 30% of all older persons lived alone. The proportion living alone increases with advanced age. Among women aged 75 and over, for example, half lived alone (in 2000).

Figure 2: Living Arrangements of Persons 65+: 2002



### Health and Health Care

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

### Nursing Homes

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



## II. Biological Aspects of Aging<sup>2</sup>

### A. Introduction

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

### B. Structural

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MUSCLES	Muscles lose mass and tone. While exercise helps to maintain strength and tone, it does not prevent some loss. This change is observable in the looseness of underarm skin, sagging breast, and thinner legs and arms reflecting the changes in musculature.
SKELETON	Another change affecting appearance is the flattening of the spongy "cushion" between the vertebrae. Over the years, this material loses its resiliency. Older people may be shorter than they were in younger years and have a stooped posture.
SKIN	<p>There are several changes that affect the skin.</p> <ul style="list-style-type: none"> <li>• The skin loses some elasticity, which results in wrinkles. The skin does not stretch and conform to its original shape as it once did.</li> <li>• There is a loss in the natural oils in the skin, which may lead to dryness and scratchiness. Individuals may need to use moisturizer to replace the loss in oils.</li> <li>• The skin becomes thinner and thus more susceptible to being broken or cut.</li> <li>• Older people may become more sensitive to temperature changes.</li> <li>• Some individuals may develop "aging" spots, which are dark areas of pigmentation. The presence of such spots does not indicate a problem with the function of the liver. The spots are simple changes in the pigmentation of the skin. Creams do not remove the spots although they may temporarily camouflage them. Spots on the skin of older people should be closely observed for sudden growth or changes in appearance. Such changes should be reported to a physician.</li> </ul>

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<sup>2</sup> Excerpted from The New Mexico Ombudsman Curriculum developed by Sara S. Hunt.

## C. Sensory

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

<sup>3</sup> Stuenkel, C., & Faye, E.E. "Vision Loss: Normal and Not Normal Changes among Older Adults." *Generations*, XXVIII(1), p. 8.



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distinguish distances and surface areas.

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

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

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

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

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

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

There are three major types of hearing loss.

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

### CIRCULATORY SYSTEM

The heart, like other muscles, weakens and loses pumping capacity. Arteries or veins may become rigid or blocked, which restricts blood flow and circulation. Under routine circumstances, these changes do not greatly alter the daily functioning of an individual. These changes may be observed when an aged person who has been sitting for a while suddenly stands and walks across the room. Unless a few extra seconds are allowed for the heart to supply sufficient blood to all the body extremities, the person may stumble, fall, or seem confused. After the heart has had sufficient time to pump the blood throughout the body, the unsteadiness or confusion disappears.

### DIGESTIVE SYSTEM

One of the systems least affected by aging is the digestive system. As in earlier years, diet and exercise are extremely important to maintain proper functioning. Teeth become more brittle. Saliva, necessary to swallow food, decreases; the thirst response decreases. Peristalsis (the movement of the intestines) is slower, decreasing speed and effectiveness of digestion and elimination. Choking on food is a greater risk because of a decreased gag reflex.

### URINARY SYSTEM

The urinary system experiences several changes.

- A general weakening of the bladder muscles means that the impulse to urinate cannot be delayed as long as in earlier years. When an older person says, "I have to go to the bathroom," that usually means now.
- The bladder doesn't stretch to hold as much as it used to, so urination may be more frequent.
- With weakened muscles the bladder may not empty completely which increases susceptibility to urinary infections.
- The kidneys filter the blood more slowly than in younger years. As a result, medications remain in the bloodstream longer than they do in younger people. That change in functioning compounds the danger of over-medication. Dosages of medicine need to be closely and continuously monitored. Interaction effects between prescribed medicine and over-the-counter drugs, even aspirin or Bufferin, are more likely to occur.

### REPRODUCTIVE SYSTEM

In the reproductive system there is little change. Vaginal secretions diminish; erections may require more stimulation. In men, the prostate may become enlarged. Regular check-ups are particularly important for men. Prostate trouble may go untreated until it requires radical treatment.

## E. Summary

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

### III. Psychological Aspects of Aging

#### A. Memory

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

#### B. Adaptation To Change

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

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

#### C. Reminiscence

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

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



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

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

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

#### D. Intelligence

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



## IV. Sociological Aspects of Aging

### A. Introduction

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

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

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

### B. Role Reversal

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

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

An individual may need transportation and assistance in completing forms. That does not mean that person needs someone to make financial decisions for him/her. An aged individual may require temporary assistance in managing personal affairs until that person recovers from an illness or stress and is able to resume total

responsibility. Sometimes families decide an elderly person is incapable of independence because the person makes a decision that disregards their advice.

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

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<sup>4</sup> Profile of Older Americans 2003, op.cit.

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

### C. Crisis

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

### D. Limitations

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

### E. Guilt

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

### F. Losses

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*Anger and grief are two primary reactions to loss.*

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

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

### G. Death

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



## Ombudsman Visits With Residents Who Are Dying<sup>6</sup>

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

<sup>6</sup> Adapted from Elisabeth Kubler-Ross

## V. Myths and Stereotypes

### A. Myths and Stereotypes about Senior Adults

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

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

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



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



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

## B. Myths and Stereotypes about Care

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



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

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

Since your job will be working with individuals in long term care facilities, this section will focus on applications in that environment.

The same principles are applicable to individuals in home settings or other residences.

### The Imperative for Good Care

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

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

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

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

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

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

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



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

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

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

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

## LOSS OF MOBILITY

### MYTH OR STEREOTYPE

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

### REALITY

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

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

<sup>9</sup> Tempkin, T., *Mobility: A Basic Human Need, Quality Care Advocate Special Section*, National Citizens' Coalition for Nursing Home Reform, Washington DC, 1993, p.i.

<sup>10</sup> Ibid.



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

## PRESSURE ULCERS

### MYTH OR STEREOTYPE

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

### REALITY<sup>12</sup>

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

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

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

All of the major causes can be addressed by facility staff and relate to basic, daily care routines.<sup>16</sup>

<sup>11</sup> Giveldner, S. H., and Spradler, J., "Outdoor Walking Lowers Fatigue," *Journal of Gerontological Nursing*, Vol. 14, No. 10, pp. 6-12.

<sup>12</sup> Most of this section is from: *Clinical Practice Guidelines No. 3: Pressure Ulcers in Adults: Prediction and Prevention*, US Department of Health and Human Services, Public Health Service, Agency for Health Care Policy and Research, Rockville, MD, May 1992.

<sup>13</sup> Harrington C., Carillo, H., Wellin, C., et al, *Nursing Facilities, Staffing, Residents and Facility Deficiencies*. University of California, San Francisco, August 2003.

<sup>14</sup> Resident Assessment Protocol: Pressure Ulcers, Appendix C: HCFA's RAI Version 2.0 Manual. US Department of Health and Human Services, Health Care Financing Administration, Baltimore, MD, August 1999.

<sup>15</sup> DiDomenico, D.L., and Ziegler, W.Z., *Positioning and Skin Care, Practical Rehabilitation Techniques for Geriatric Aides*, Aspen Publishers, 1989, p. 73.

<sup>16</sup> *Ombudsman Guide to the Nursing Home Reform Law*, op.cit.

## URINARY INCONTINENCE

### MYTH OR STEREOTYPE

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

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

### REALITY

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

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

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

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

<sup>17</sup> Siegal, D.L., “The Nursing Home Incontinence Project,” prepared for *Living is for the Elderly*, January 1992.

<sup>18</sup> Harrington, C., op.cit.

<sup>19</sup> “Urinary Incontinence in Adults: Acute and Chronic Management,” Agency for Health Care Policy and Research, Public Health Service, Department of Health and Human Services Clinical Practice Guideline #2, 1996 Update.

<sup>20</sup> Harrington, op.cit. 2003.

<sup>21</sup> Burger, S. G., National Citizens’ Coalition for Nursing Home Reform, in a telephone conversation, January 14, 1994.

<sup>22</sup> *Long Term Care Letter: Special Report: Incontinence*, Vol. 3, No. 9, Brown University, May 8, 1991.



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

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

## DEPRESSION

### MYTH OR STEREOTYPE

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

### REALITY

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

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

<sup>23</sup> Resident Assessment Protocol: Urinary Incontinence and Indwelling Catheter, Appendix C. HCFS's RAI Version 2.0 Manual. US Department of Health and Human Services, Health Care Financing Administration, Baltimore, MD, August 1999.

<sup>24</sup> *Diagnosis and Treatment of Depression in Late Life, Consensus Statement*, Vol. 9, No. 3, National Institutes of Health, Bethesda, MD, November 4-6, 1991.

<sup>25</sup> Levenson, S., *Psychoactive Medications, Politics, The Unconventional "Wisdom" of LTC*, Caring for the Ages, February 2002. In fact, Dr. Levenson says antidepressants are being overused without regard to the adverse effects that may accrue.

<sup>26</sup> Haight, B. and Hendrix, S., (1999) *Suicidal Intent/Life Satisfaction: Comparing Life Stories of Older Women*, Suicide and Life Threatening Behavior, 28(3) 272-284.

<sup>27</sup> Golman, D., "High Death Risk is Found in Depressed Nursing Home Patients." New York Times, February 27, 1991.

<sup>28</sup> Cromwell, Y., *Suicide in the Elderly*, in Schneider, L.S., Reynolds, B.D., Leowitz, B.D., et al *Diagnosis and Treatment of Depression in Late Life: Results of a NIH Consensus Conference*, American Psychiatric Association Press 1994.



## SAFETY CONCERNS

### MYTH OR STEREOTYPE

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

### REALITY

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

*Physical restraints do not make people safer.*

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

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

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

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

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

## VI. Common Illnesses and Conditions Associated with Aging<sup>31</sup>

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

### A. Hiatus Hernia

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

*Hiatus hernias:*

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

### B. Constipation

---

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

*Constipation can be caused by:*

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

*Residents may complain about or have:*

- Abdominal pain
- Distention of stomach
- Cramping

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

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<sup>31</sup> Excerpted and adapted from the Illinois Ombudsman Curriculum.



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

### C. Osteoporosis

---

*Osteoporosis is:*

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

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

### D. Dementia

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

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

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

<sup>32</sup> Alzheimer's Disease and Related Dementias Fact Sheet. The Alzheimer's Association. February 2004. (800)272-3900, [www.alz.org](http://www.alz.org)



pressure is to blame. One of the most important reasons for controlling high blood pressure is to prevent strokes.<sup>23</sup>

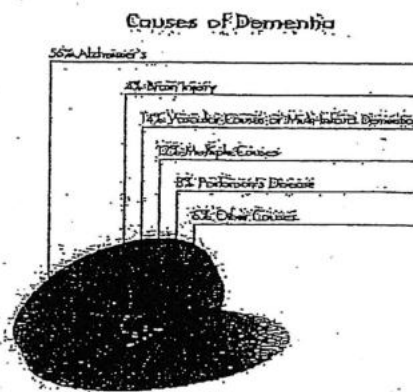
Before *dementia* became a common part of our vocabulary, the term *senility* was used. Senility and pre-senile dementia are still used as medical diagnoses. Regardless of the specific diagnosis, ombudsman approaches to residents with conditions that impair cognitive functioning are the same as described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

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

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

*Diseases that can cause irreversible dementia are:*

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



From *What is Alzheimer's Disease*<sup>24</sup>

<sup>23</sup> *Forgetfulness: It's Not Always What You Think*. Age Page, Alzheimer's Disease Education and Referral Center, National Institute on Aging, US Department of Health and Human Services. <http://www.alzheimers.org/pubs/forgetfulness.html>

<sup>24</sup> *What is Alzheimer's*, The Alzheimer's Association, November 2003. op. cit.

## E. Alzheimer's Disease<sup>35</sup>

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### *Alzheimer's is:*

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

### *Residents have:*

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

### *Progression of Alzheimer's*

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

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

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

### *Statistics/Prevalence<sup>36</sup>*

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

<sup>35</sup> *Facts: About Understanding Alzheimer's Disease*. The Alzheimer's Association, January 2004, op.cit.

<sup>36</sup> *Fact Sheet Alzheimer's Disease Statistics*. The Alzheimer's Association, April 2004, op.cit.

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

#### Understanding Behavioral Symptoms

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

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

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

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

#### Non-Drug Treatments

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

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

<sup>37</sup> *Ombudsman Guide to the Nursing Home Reform Law*, 2004, op.cit.



- **Modifying the environment.** Environmental factors such as lighting, color, and noise can greatly affect behavior. Dim lighting, for example, makes some individuals uneasy, while loud or erratic noise may cause confusion and frustration. The noise of a television set may be frightening. Modify the environment to reduce confusion, disorientation, and agitation. Keep familiar personal possessions visible to ensure comfort and feelings of warmth in your loved one's surroundings.
- **Planning activities.** The key to planning activities is in "knowing the details of a person's life."<sup>38</sup> Help individuals with Alzheimer's organize their time and know what to expect each day. Planned activities help individuals feel independent and needed by focusing their attention on pleasurable or useful tasks. Daily routines such as bathing, dressing, cooking, cleaning, and laundry can be turned into productive activities and may be pleasurable for a housewife. Working on a motor for a mechanic, walking and gardening for a farmer are other examples. Other more creative leisure activities can include singing, playing a musical instrument, painting, walking, playing with a pet, or reading. Planned activities may relieve depression, agitation, and wandering, as well as help affected loved ones enjoy the best quality of life.

### Drug Treatments

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

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

#### *Anti-psychotics (neuroleptics)*

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

#### *Anti-anxiety drugs*

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

<sup>38</sup> *Nursing Homes: Getting Good Care There*, 2002, op.cit.

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

### *Antidepressants*

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

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

### **Resources**

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

#### The Alzheimer's Association

919 N. Michigan Avenue, Suite 1000  
Chicago, IL 60611-1676  
800-272-3900  
[www.alz.org](http://www.alz.org)

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

#### Alzheimer's Disease Education and Referral (ADEAR) Center

PO Box 8250  
Silver Spring, MD 20907-8250  
800-438-4380  
[www.alzheimers.org/adear](http://www.alzheimers.org/adear)

<sup>40</sup> Sarah G. Burger, consultant, April 2004.

## F. Parkinson's Disease

*Parkinson's is:*

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

*Residents have:*

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

### Tips For Ombudsmen

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

<sup>41</sup> Movement Disorder: Old Age or a Treatable Disease? *Board & Care Quality FORUM*, Titus, S. Vol2, No. 1. Reisacher Petro and Associates, Pittsburgh, PA, Jan/Feb 1999.



## VII. Drugs and Their Side Effects in the Elderly<sup>42</sup>

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

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

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

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

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

- F329: "Unnecessary drugs." Guidance to Surveyors. State Operations Manual, Appendix P, Survey Protocol for Long Term Care Facilities. Health Care Financing Administration, Baltimore, MD. PP-114+. Also available online: <http://www.cms.hhs.gov/manuals>
- "Psychotropic Drug Use," Resident Assessment Protocol. Resident Assessment Instrument Training Manual and Resource Guide. Health Care Financing Administration, Baltimore, MD.

<sup>42</sup> Adapted from the Illinois Ombudsman Program Curriculum

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

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

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

<sup>46</sup> *Ombudsman Guide to The Nursing Home Reform Law*, 2004, op. cit.

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

SUMMARY OF DATA ON MAJOR PSYCHOTROPIC MEDICATIONS<sup>48</sup>A. Neuroleptics (Major Tranquilizers, Anti-psychotics)

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

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

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

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

**DEPRESSION WITH HALLUCINATIONS****TOXIC PSYCHOSIS—LSD, PCP**

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

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

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

*Most common drugs used with these conditions:*

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

<sup>48</sup> From the Louisiana Ombudsman Program Manual.

<sup>49</sup> Resident Assessment Instrument for Long Term Care, Psychotropic /Drug RAP, op.cit.

*Common side effects (stopping the medication will clear up symptoms in few days):*

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

#### *Summary*

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

### B. Minor Tranquilizers (Anti-Anxiety Agents)

#### *Used for:*

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

ALCOHOL WITHDRAWAL

STATUS EPILEPTICS

MUSCULAR SPASMS

*Most common drugs used with these conditions are all listed as potentially inappropriate according to the Beers Criteria. Older persons are very sensitive to them. Avoid using the long acting ones. The drugs are grouped according to length of time it remains in a person's system:*

- Long Life (18-36 Hr.), Valium, Paxipain, Xanax (avoid these)
- Medium Life (10-12 Hr.), Tranxine, Ativan, Serax
- Short Life (4-12 Hr.), Librium, Centrax

#### *Side effects:*

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

#### *Summary*

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



### C. Antidepressants

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

NOREPINEPHRINE TYPE DEPRESSION — characterized by:

- Sleepiness
- Overeating
- Weight gain

SEROTONIN TYPE DEPRESSION — characterized by:

- Restlessness
- Anxiety
- Loss of appetite/weight

#### PANIC ATTACKS

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

Most common drugs used with these conditions:

- |           |              |           |             |            |
|-----------|--------------|-----------|-------------|------------|
| — Asendin | — Imipramine | — Pamelor | — Sinequan  | — Vivactil |
| — Desyrel | — Ludiomil   | — Prozac  | — Surmontil | — Zoloft   |
| — Elavil  | — Norpramin  | — Paxil   | — Tofranil  |            |

Common side effects:

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

#### Summary

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

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

### D. Lithium Therapy

---

*Used for:*

BIPOLAR DISORDERS: Manic/depressive, manic, depression

ALCOHOLISM

*Medication used:*

- Lithium

*Side effects:*

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

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

*Summary*

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

### E. Miscellaneous

---

NASAL DECONGESTANT SPRAYS

- Used for the relief of nasal congestion

*Adverse Effects*

- "Rebound congestion"
- Burning/stinging
- Sneezing

*Examples:*

- Dristan      - Neo-Synephrine      - Sinex

**CAFFEINE**

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

*Adverse Effects of Caffeine*

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



## The Aging Process

\* Required

Enter your name (last name first; for example: Smith, John) \*

Your answer

1. Depression in the elderly is under diagnosed and under treated. \*

☐ True

☐ False

2. Medications prescribed for a medical problem may have an unintended effect on behavior. \*

☐ True

☐ False

3. It is possible for bones to break spontaneously. \*

☐ True

☐ False

4. Chronological age is an accurate indicator of an individual's feelings and abilities. \*

☐ True

☐ False

5. There are a range of non-drug interventions and treatments that may be effective in meeting a resident's needs when behavioral symptoms occur. \*

☐ True

☐ False



5/8/2019

6. The possibility that a person will live in a nursing home increases with age until age 78 when it remains the same no matter how long the person lives. \*

☐ True

☐ False

7. It is important to allow older people the extra seconds needed for their eyes to accommodate to changes in light or distance. \*

☐ True

☐ False

8. Individuals who have some degree of hearing loss may not realize that they have a loss. \*

☐ True

☐ False

9. One method of coping with change is through reminiscence. \*

☐ True

☐ False

10. Intelligence declines with the normal aging process. \*

☐ True

☐ False

11. "Once a man, twice a child," remains one of the great truths about the elderly. \*

☐ True

☐ False

12. Sensitivity to smells decreases with aging. \*

☐ True

☐ False

13. Sexual desire ceases in old age. \*

☐ True

☐ False

14. Movement is not important for individuals who are confined to bed. \*

☐ True

☐ False

15. Pressure sores are an unfortunate part of normal aging for frail, elderly persons. \*

☐ True

☐ False

16. Physical restraints prevent falls and injuries for individuals who are confused or have balance problems. \*

☐ True

☐ False

17. In spite of age related changes, individuals living in nursing homes are to be assisted in maintaining or improving their abilities unless a decline is unavoidable. \*

☐ True

☐ False

18. Inactivity increases calcium depletion which may contribute to osteoporosis. \*

☐ True

☐ False

19. Alzheimer's Disease affects areas of the brain that control long term memory first. \*

☐ True

☐ False



5/8/2019

20. Incontinence is a normal part of aging. \*

☐ True

☐ False

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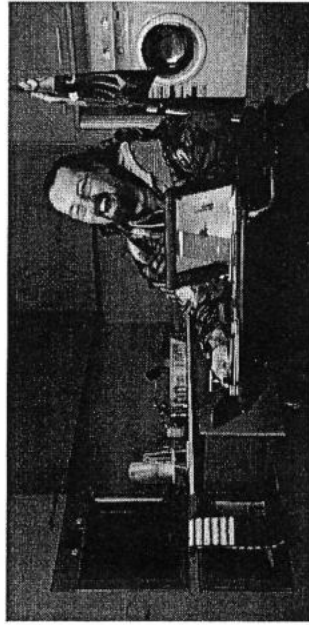
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# Who Lives in Nursing Facilities and Why?



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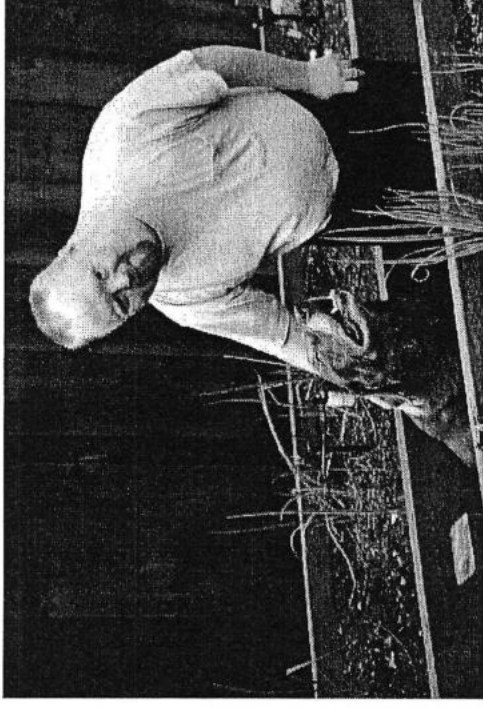


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## → **Where do persons with disabilities live?**

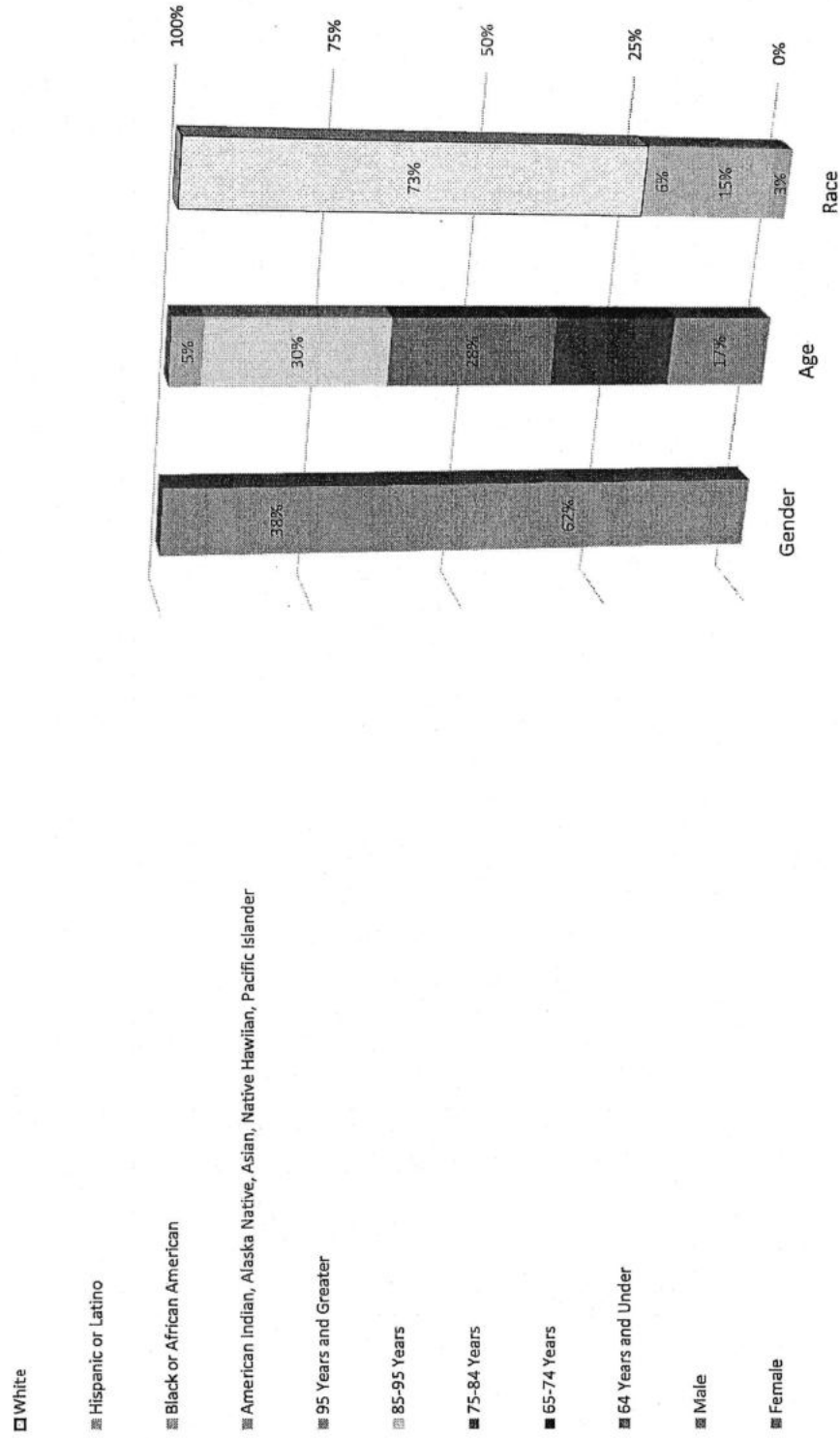
- With their families in the community
- Group homes
- Intermediate Care Facilities for the Intellectually Disabled (ICF/IID)
- Residential care communities (RCCs)
- Nursing facilities



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## 2021 National Nursing Facility Population



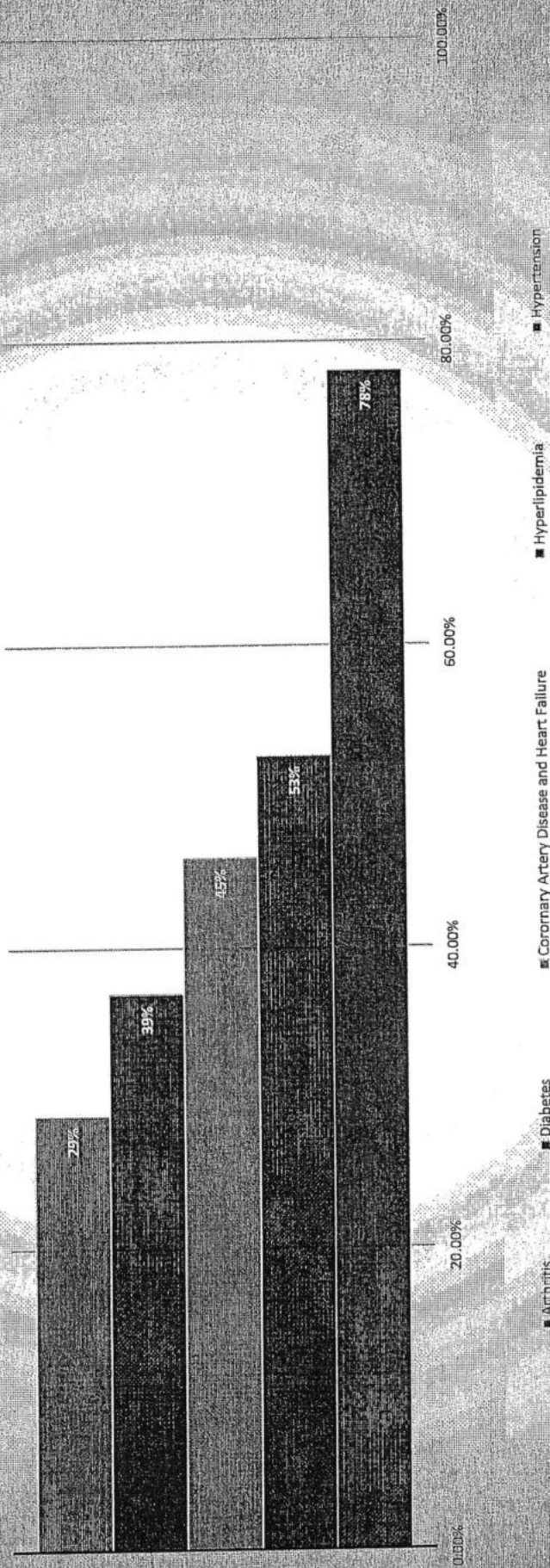
# Common Physical Diagnoses and Their Importance to the Ombudsman Program



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# 2021 National Residents' Common Health Diagnoses





# Hypertension

- Why is this important information for the LTCOP?
- Residents may have concerns related to:
  - Medication
  - Diet
  - Exercise
  - Stress
- Residents may want to go against doctor's orders and ask the LTCOP to advocate on their behalf.

# Heart Disease & High Cholesterol

- Why is this important information for the LTCOP?
- Residents may have concerns such as:
  - Fear
  - Anxiety
  - Medication distribution
  - Diet



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# Diabetes

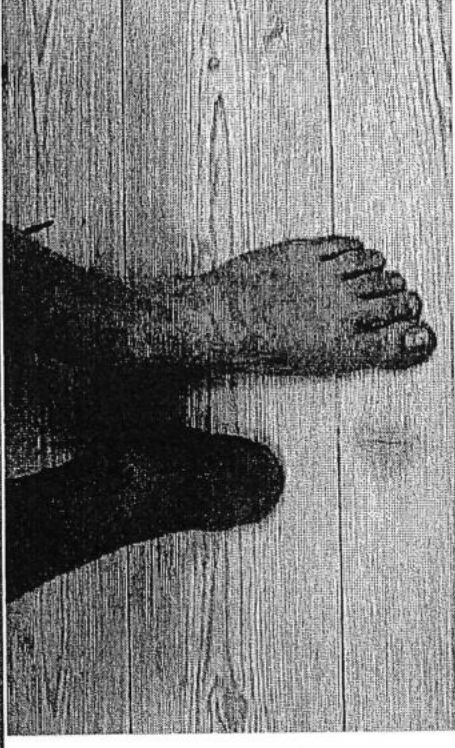
- Type 1 diabetes occurs when the body does not make insulin.
- Type 2 diabetes is more common and occurs when the body does not make or use insulin well.
- The term “brittle diabetes” may be used to describe uncontrolled diabetes with drastic swings between too high or too low blood sugar.



# Diabetes

• Why is this important information for the LTCOP?

- Residents may have concerns such as:
  - Uncontrolled blood sugar levels
  - Insulin not being checked per doctor's order
  - A diet served that is not appropriate for people with diabetes
  - The facility not allowing the resident's right to decline dietary restrictions set by the physician or the facility
  - Possible amputation



# Arthritis

- Why is this important information for the LTCOP?
- Residents may have concerns related to:
  - Pain
  - Quality of life
  - Anxiety
  - Depression



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Cogn

***Important:***

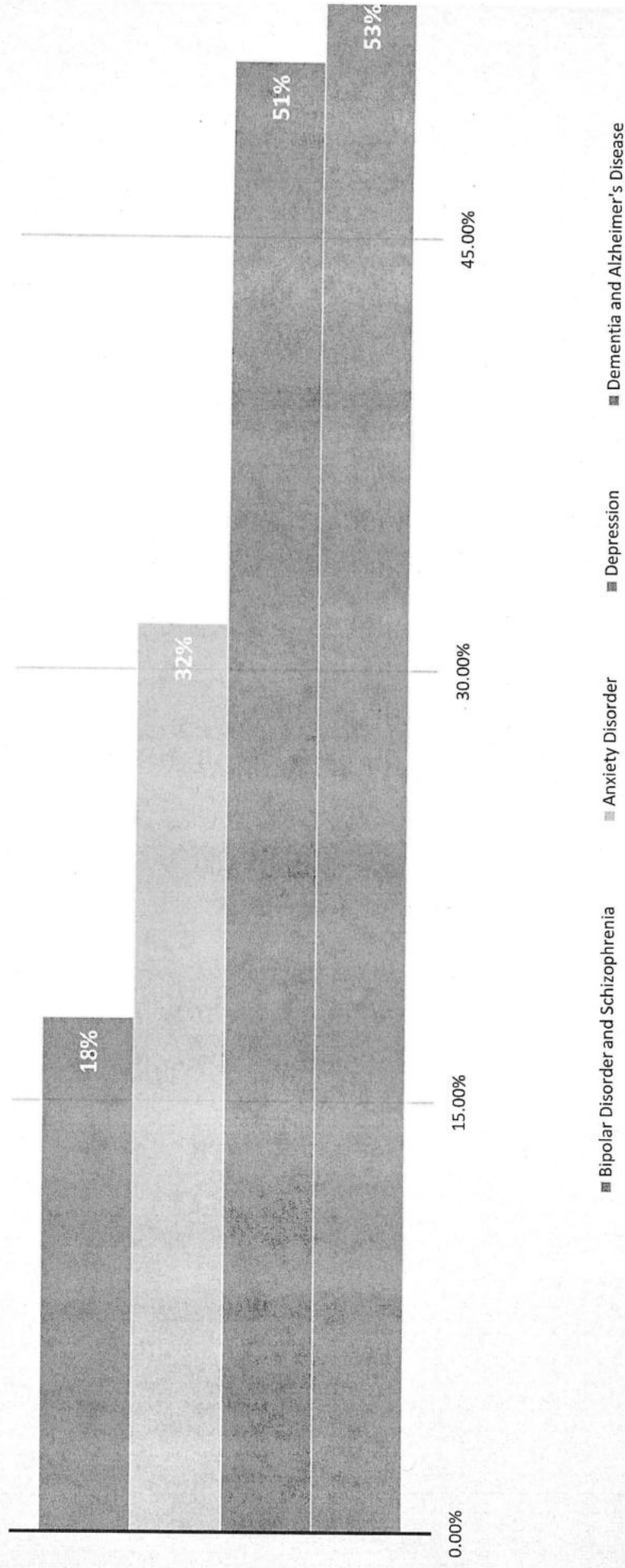
*The Ombudsman program does not serve as a source of medical advice or expertise (even if a representative has such expertise) but serves to represent resident concerns and ensure that the resident has access to medical information and their health care providers.*



# **Serious Mental Illness (SMI)**

- Why is this information important for the LTCOP?
- Working with individuals who have a diagnosis of a serious mental illness may be challenging due to barriers in communication
- Facility staff are often not properly trained
- Residents with SMI are at greater risk for facility-initiated discharge

# 2021 National Cognitive Disorders & Mental Health Diagnoses in Nursing Facilities



# Bipolar Disorder

Causes dramatic shifts in a person's:

- Mood
- Energy
- Ability to think clearly

Individuals with this disorder experience extreme high and low mood as mania and depression.



# Anxiety Disorders

Emotional Symptoms		Physical Symptom
Feelings of apprehension or dread		Pounding or racing heart and shortness of breath
Feeling tense or jumpy		Sweating, tremors and twitches
Restlessness or irritability		Headaches, fatigue and insomnia
Anticipating the worst and being watchful for signs of danger		Upset stomach, frequent urination or diarrhea

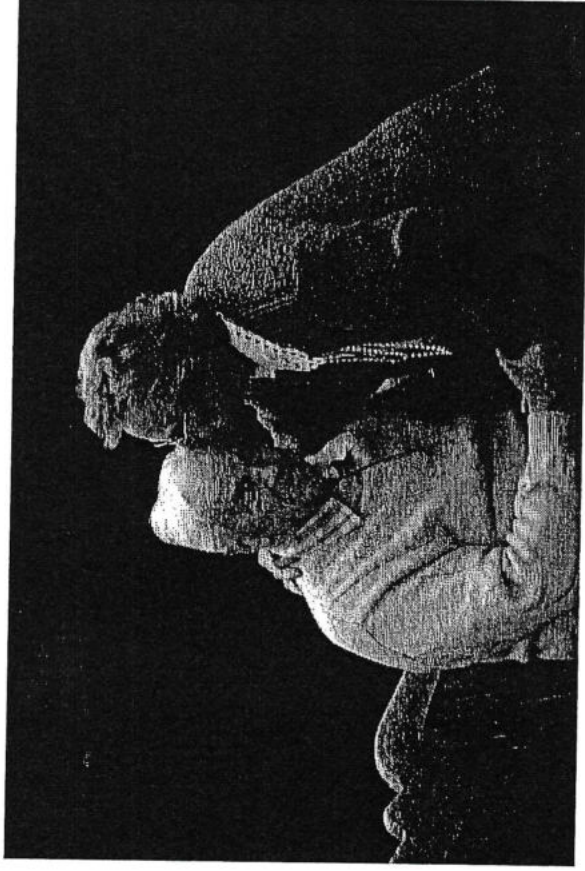
# **Major Depressive Disorder (MDD)**

- One of the most common mental disorders
- Symptoms vary, but may include:
  - Sadness
  - Hopelessness
  - Anxiety
  - Pessimism
  - Irritability
  - Worthlessness
  - Fatigue

---

# Dementia

- Decline in memory, reasoning or other thinking skills that interferes with daily life. Affects the ability to:
  - Communicate
  - Remember
  - Reason
  - Think





# Dementia

- Why is this information important to the LTCOP?

- Residents may have concerns about:

- Anxiety
    - Medication
    - Others respecting their rights
    - Their care plan

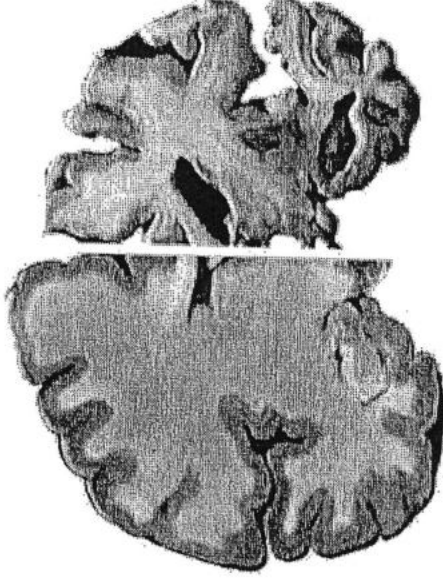
- Facilities and other residents may have concerns about:

- Wandering
    - Combativeness
    - Anxiety

# Alzheimer's Disease

- Memory loss
- Disorientation
- Confusion
- Behavior changes
- Weight loss
- Incontinence
- Delusions or hallucinations
- Difficulty:
  - Speaking
  - Eating or swallowing

Healthy Brain      Severe Alzheimer's



# Why do People Stay in Long-Term Care?

- Nursing facilities:

- The resident's health did not improve enough to go home
- The resident does not have available supports and services in order to successfully live home alone
- The resident does not have a home to go to

- RCCs

- Their needs are being met
- Socialization
- Fills the gap between living independently and living in a nursing home



# Experiences of Loss

When you get rid of  
your house, everything,  
it is a horrible thing and  
hard to get adjusted to.  
They have given me  
kind words. - Bobby


Loss	New Circumstances	Possible Effects
Health	Coming to terms with managing a new or worsening illness and/or disability	Feeling anxiety, fear, frustration, anger, despair
Home	Removed (voluntarily or involuntarily) from a familiar home or setting to an unknown, unfamiliar place	Having a sense of uneasiness, anxiousness, uncomfortableness, confusion as to whereabouts
Family, Friends, Neighbors	Separated from loved ones with whom you lived or visited often - perhaps the resident's partner or caregiver passed away.	Feeling sad, lonely, forgotten, isolated, missing loved ones



# Experiences of Loss

My greatest loss was not mobility but losing the ability to give and receive affection.  
- Lee

Loss	New Circumstances	Possible Effects
<b>Freedom</b>	Adjusting to new routines, scheduled activities, and the confines of the facility; understanding a new system with rules and guidelines	Feeling frustrated, angry, hopeless, loss of control over daily life; having no autonomy, feeling like a child again
<b>Privacy</b>	Sharing a room with a stranger, staff walking in and out, people asking personal questions, people washing and dressing you and taking you to the bathroom	Feeling humiliated, embarrassed, loss of dignity, frustration, anger
<b>Personal Property</b>	Loss of personal belongings with special meaning or memories	Feeling disconnected

- 
2. Name some reasons people enter long-term care facilities.
  3. Name some of the losses that residents may experience when they enter a long-term care facility and how those losses affect residents?
  4. Name some of the common diagnoses and other health concerns of residents.
  5. Why is it important for representatives to understand resident experiences?



# RESIDENTS RIGHTS

## II. WHY RESIDENTS NEED ADVOCACY

In any group situation differences of opinion and preference occur. In an institutional setting, certain methods of operation develop for convenience and efficiency, which may conflict with the needs of individual residents. Yet, residents may be unable to express their particular needs without assistance from others. Barriers to self-advocacy are manifold.

### *Individual Problems Which May Surface in Nursing Homes*

- Loneliness - need of someone to talk with
- Boredom - not enough social or personal activities
- Problem with roommate(s)
- Lack of privacy
- Poor food service or quality
- Inability to get services, care or attention because of physical or communication problems
- Physical or drug restraints
- Use, accounting and safe keeping of personal funds and personal possessions
- Desire to go outside the facility for community activities
- Insufficient medical or nursing care
- No rehabilitative care
- Neglect
- Resident abused physically or mentally
- Loss of dignity and feeling of respect based on general treatment in facility
- Additional or high charges for "extra" services
- Transfer from one room to another without notice
- Transfer to another facility because of change from private pay to Medicaid

### III. NURSING HOME RESIDENTS' RIGHTS

#### A. Purpose

The purpose of residents' rights is to safeguard and promote dignity, choice and self-determination of residents in nursing homes and to protect civil, personal and privacy rights, the right to information, rights related to health care, due process and life in the nursing home, transfer and discharge rights, the handling of personal finances and the right to be free from abuse and restraints.

#### B. Reasons Why Residents Do Not Routinely Exercise Their Rights

- Residents are intimidated by the idea of appearing in any way to criticize the nursing home.
- Most residents do not know that they have specified rights and do not know what their rights are in a nursing home.
- Even residents who are aware of their rights must choose their "battles" and often put up with daily violations of their individuality and dignity because; a) it requires too much strength to challenge each encounter; b) they are easily labeled troublemakers; c) they are dependent for their care on those very people and they are, therefore, hesitant to criticize, and often d) they experience a sense of defeatism.
- Residents' autonomy is undermined from the start by the very fact that most residents would rather not be in a nursing home; many did not have much of a role or choice in the decision to be there, and most have no other options.
- Residents face physical, emotional, psychological, social and mental disabilities that make it difficult for them to voice their concerns.

### IV. EMPOWERMENT

Empower means to give power to another or to take it for oneself. The dictionary definition is "to give authority to, to authorize". This concept includes an advocate's conscious decision to enable a disadvantaged person or group to become capable of self-advocacy.

#### A. The Role of the Resident Advocate

As a Resident Advocate, you will be an advocate acting on behalf of residents. In some cases, you will be able to educate, support, and encourage residents to



engage in self-advocacy, to represent themselves. In other situations, you will be representing the resident(s). There is a basic complaint process, a problem solving process that Ombudsmen use to analyze and resolve problems.

Resident Advocates are in a unique position to empower residents to exercise their rights. They can help residents and facilities overcome the obstacles to the exercising of residents' rights by:

- Educating residents, facility personnel, and family members about residents' rights
- Encouraging residents to exercise their rights in very specific ways
- Supporting residents in the exercising of their rights
- Modeling/demonstrating a respect for residents' rights; and
- Maintaining a continuous awareness of, and sensitivity to, residents' rights

Resident Advocates can serve as a counterbalance to some of the barriers that inhibit the implementation of residents' rights. They have an obligation not only to provide information about residents' rights, but also to assist residents in exercising those rights: resident empowerment.

## **B. Resident Participation**

The 1987 Nursing Home Reform Amendments (OBRA '87) provide the following to support resident self-determination:

**FREE CHOICE:** The right to choose a personal attending physician, to be fully informed in advance about care and treatment, to be fully informed in advance of any changes in care or treatment that may affect the resident's well-being, and (except with respect to a resident adjudged incompetent) to participate in planning care and treatment or changes in care and treatment.

**ACCOMMODATION OF NEEDS:** The right to reside and receive services with reasonable accommodations of individual needs and preferences, except where the health or safety of the individual or other residents would be endangered. The right to receive notice before the room or roommate of the resident in the facility is changed.

**GRIEVANCES:** The right to voice grievances with respect to treatment or care that, is or fails to be, furnished, without discrimination or reprisal for voicing the grievances and the right to prompt efforts by the facility to resolve grievances the resident may have, including those with respect to the behavior of other residents.



**PARTICIPATION IN RESIDENT AND FAMILY GROUPS:** The right of the resident to organize and participate in residents groups in the facility and the right of the resident's family to meet in the facility with the families of other residents in the facility.

## V. THE NURSING HOME REFORM ACT OF 1987

### A. Provisions of the Law

The Nursing Home Reform Amendments of OBRA '87 require that nursing facilities "promote and protect the rights of each resident..." Several important provisions of the law set the stage for protection of these rights.

1. **Quality of Life:** The new law requires each nursing facility to "care for its residents in such a manner and in such an environment as will promote maintenance or enhancement of the quality of life of each resident". A new emphasis is placed on dignity, choice, and self-determination for nursing home residents.
2. **Provision of Services and Activities:** The new law requires each nursing facility to "provide services and activities to attain or maintain the highest practicable physical, mental and psychosocial well-being of each resident in accordance with a written plan of care which is initially prepared, with the participation to the extent practicable of the resident or the resident's family or legal representative."
3. **Participation in Facility Administration:** The new law makes "resident and advocate participation" a criteria for assessing a facility's compliance with administration requirements.
4. **Assuring Access to the Ombudsman Program:** The new law; (a) grants immediate access by Ombudsmen to residents and reasonable access, in accordance to state law, by the Ombudsmen to records; (b) requires facilities to inform residents how to contact Regional Ombudsman to voice complaints or in the event of a transfer or discharge from the facility; (c) requires state agencies to share inspection results with the Ombudsman Program.

Before the enactment of The Nursing Home Reform Act of '87, several residents' rights could be limited or denied because the resident's physician documented that the exercise of that right was "medically contra-indicated".

This provision gave the physician the power to restrict a resident's rights. The Nursing Home Reform Act of '87 removed this provision.

## **B. Specific Rights**

Under the law (The Nursing Home Reform Act of '87), each nursing facility must "protect and promote the rights of each resident" including:

1. **Rights to self-determination:** Nursing home residents have the right:
  - To choose their personal physician;
  - To full information, in advance, and participation in planning and making any changes in their care and treatment;
  - To reside and receive services with reasonable accommodation by the facility of individual needs and preferences;
  - To voice grievances about care or treatment they do or do not receive without discrimination or reprisal, and to receive prompt response from the facility; and
  - To organize and participate in resident groups (and their families have the right to organize family groups) in the facility
2. **Personal and Privacy Rights:** Nursing home residents have the right:
  - To participate in social, religious, and community activities as they choose;
  - To privacy in medical treatment, accommodations, personal visits, written and telephone communications, and meetings of resident and family groups; and
  - To confidentiality of personal and clinical records.
3. **Rights Regarding Abuse and Restraints:** Residents have the right:
  - To be free from physical or mental abuse, corporal punishment, involuntary seclusion, or disciplinary use of restraints
  - To be free of restraints used for the convenience of staff rather than the well-being of residents;
  - To have restraints used only under written physician's orders to treat a resident's medical symptoms and ensure the resident's safety and the safety of others; and
  - To be given psychopharmacologic medication only as ordered by a physician as part of a written plan of care for a specific medical



symptom, with annual review for appropriateness by an independent, external expert.

4. **Rights to Information:** Nursing homes must:

- Upon request provide residents with the latest inspection results and any plan of correction submitted by the facility
- Notify residents in advance of any plans to change their room or roommate;
- Inform residents of their rights upon admission and provide a written copy of the rights, including their rights regarding personal funds and their right to file a complaint with the state survey agency;
- Inform residents in writing, at admission and throughout their stay, of the services available under the basic rate and any extra charges for extra services including, for Medicaid residents, a list of services covered by Medicaid and those for which there is an extra charge; and
- Prominently display and provide written and oral information for residents about how to apply for and use Medicaid benefits and how to receive a refund for previous private payments that Medicaid will pay retroactively.

5. **Rights to Visits:** The nursing home must:

- Permit immediate visits by a resident's personal physician and by representatives from the licensing agency and the Ombudsman Program;
- Permit immediate visits by a resident's relatives, with the resident's consent;
- Permit visits "subject to reasonable restriction" for others who visit with the resident's consent; and
- Permit Ombudsmen to review resident's clinical records if a resident grants permission.

6. **Transfer and Discharge Rights:** Nursing homes "must permit each resident to remain in the facility and must not transfer or discharge the resident unless":

- The transfer or discharge is necessary to meet the resident's welfare and the resident's needs which cannot be met by the facility;



- Resident's health has improved such that the resident no longer needs nursing home care;
- The health or safety of other residents is endangered; or
- The resident is more than 15 days in arrears of payment, when privately paying for care;
- The facility ceases to operate.
  - **Notice:** must be given to residents and their representatives before transfer:
  - **Timing:** at least 30 days in advance, or as soon as possible if more immediate changes in health require more immediate transfer:
  - **Content:** reason for transfer, the resident's right to appeal the transfer, and the name address and phone number of the ombudsman program and protection and advocacy programs for mentally ill and developmentally disabled; and
  - **Returning to the Facility:** the right to request that a resident's bed be held, including information about how many days Medicaid will pay for the bed to be held and the facility's bed-hold policies, and the right to return to the next available bed if Medicaid bed-holding coverage lapses.
  - **Orientation:** A facility must prepare and orient residents to ensure safe and orderly transfer or discharge from the facility.

7. **Protection of Personal Funds:** A nursing facility must:

- Not require residents to deposit their personal funds with the facility; and
- If it accepts written responsibility for resident's funds;
- Keep funds over \$50 in an interest bearing account, separate from the facility account;
- Keep other funds available in a separate account or petty cash fund;
- Keep a complete and separate accounting of each resident's funds, with a written record of all transactions, available for review by residents and their representatives;
- Notify Medicaid residents when their balance comes within \$200 of the Medicaid limit and the effect of this on their eligibility;

- Upon a resident's death, turn funds over to the resident's trustee;
- Purchase a surety bond to secure resident's funds in its keeping; and
- Do not charge a resident for any item or service covered by Medicaid, specifically including routine personal hygiene items and services.

8. **Protection Against Medicaid Discrimination:** Nursing homes must:

- Establish and maintain identical policies and practices regarding transfer, discharge and the provision of services required under Medicaid for all individuals regardless of source of payment;
- Not require residents to waive their rights to Medicaid, and must provide information about how to apply for Medicaid;
- Not require a third party to guarantee payment as a condition of admission or continued stay; and
- Not "charge, solicit, accept or receive" gifts, money, donations, or "other consideration" as a precondition for admission or for continued stay for persons eligible for Medicaid.

***RESIDENTS' RIGHTS  
PERTAINING TO FEAR  
OF RETALIATION***

***&***

***THE BEST PRACTICES  
THAT SUPPORT THEM***



## Resident Rights

## Best Practices that Support Resident Rights

**The resident has a right to a dignified existence, self determination, and communication with and access to persons and services inside and outside the facility. A facility must protect the rights of each resident**

- Facilities are encouraged to have discussions of resident rights more frequently.
- Have your roommate advocate for you.
- A designated resident on each wing to advocate at the Resident council meeting on their behalf.
- Review a section of the Residents Rights each month in the resident council meeting and conduct a Q & A.

**The resident has the right to exercise his or her rights as a resident of the facility and as a citizen or resident of the United States.**

- The Registrar of voters [Democrat, Republican & Independent] assists this process by coming in to assist one-on-one with our residents who need help filling out the absentee ballot.
- The Residents watch the elections on TV and it is discussed the next day at a coffee/newspaper hour.
- Facility will educate residents on admission of rights within the facility. Residents will also be provided with opportunities to participate in current events through discussions, newspapers, internet access, voting, and correspondence as a citizen of the United States.

**The resident has the right to be free of interference, coercion, discrimination, and reprisal from the facility in exercising his or her rights.**

- If staff members are present at the resident council meeting, the residents have the right to ask the staff members to step out of the meeting in order for them to meet privately.

## Resident Rights

## Best Practices that Support Resident Rights

**The resident or his or her legal representative has the right** upon an oral or written request, to access all records pertaining to himself or herself including current clinical records within 24 hours excluding weekends and holidays; and after receipt of his or her records for inspection, to purchase at a cost not to exceed the community standard photocopies of the records or any portions of them upon request and 2 working days advance notice to the facility.

- Include the residents COP & COE if applicable.
- Rate is not to exceed the going rate of .65 per page or free to residents who qualify for Medicaid - Title 19.

**The resident has the right** to be fully informed in language that he or she can understand of his or her total health status, including but not limited to, his or her medical condition.

- Residents Rights are available in English & Spanish, are posted on the bulletin boards in the hallways and are available in the resident council minutes to any resident. If the resident speaks in another language interpreters are used, including the Language Bank.
- *Web site also available: [www.babelfish.yahoo.com](http://www.babelfish.yahoo.com) and [www.translate.google.com](http://www.translate.google.com)*

**The resident has the right** to be fully informed in advance about care and treatment and of any changes in that care or treatment that may affect the resident's well being.

- Care plan meetings, when appropriate should be arranged at the bedside of the resident for their inclusion, with the full team.
- Offer information in advance to residents and family members on frequent Q. & A.
- Have the C.N.A. present
- Whole team needs to be present; nurse, S.W., T.R.D., C.N.A., Dietician, P.T., O.T., S.T., MDS coordinator.
- Offer phone conference for families unable to be present with the whole team; or offer alternate time for the whole team to meet with family & resident.
- Written notice should be given to residents as well as reminding them the morning of the meeting.
- Ambassador [staff member] to guard and assist with concerns or issues during the residents stay.
- Copy of the care plan given to the resident or their responsible party member.



## Resident Rights

## Best Practices that Support Resident Rights

**The resident has the right** to refuse treatments, to refuse to participate in experimental research, and to formulate an advance directive. The facility must inform the resident both orally and in writing in a language that the resident understands of his or her rights and all rules and regulations governing resident conduct and responsibilities during their stay in the facility.

- Advanced Directives and consents are explained and signed upon admission.
- Don't start the conversation with Advanced Directives but instead offer the resident and family time to make choices and to be fully informed of medical outcomes.
- Residents Rights are available in English & Spanish, are posted on the bulletin boards in the hallways and are available in the resident council minutes to any resident. If the resident speaks in another language interpreters are used, including the Language Bank.
- Residents should have access to a communication board

**The resident has the right** to voice grievances without discrimination or reprisal.

- Facilities are encouraged to adopt policies regarding fear of retaliation, including a "no tolerance" policy.
- Form an internal committee to provide meaningful and an interactive in-service to staff and residents specific to this issue.

**The resident has the right** to prompt efforts by the facility to resolve grievances the resident may have, including those with respect to the behaviors of other residents.

- Contact trusted staff members, ombudsman, resident council president, etc. to voice your concerns anonymously.
- Establish a "concerns box" so residents can submit a concern anonymously. Facilities should check this box on a regular basis to address the concerns.
- All management including upper management and the administrator can be invited as needed to resident council meetings so residents can voice concerns.

**The resident has the right** to refuse to perform services for the facility.

- Residents will be educated on their rights pertaining to freedom of choice on admission and semi-annually thereafter. Residents who perform services for the facility are acknowledged through their care plan.



<b>Resident Rights</b>	<b>Best Practices that Support Resident Rights</b>
<p><b>The resident has the right</b> to have reasonable access to the use of a telephone where calls can be made without being overheard.</p>	<ul style="list-style-type: none"> <li>• Cordless phones are available on each resident's unit. If the resident wants to make a private call the Social Services Office phone may be used which is located in a secluded office.</li> </ul>

**Note: These rights cannot be violated by a conservator unless the conservator is given specific written authority to do so after a hearing in the Probate Court conducted according to the conservatorship statute.**

**This product was developed by the Fear of Retaliation Committee Members Membership included residents, the Connecticut Long Term Care Ombudsman and individuals from public agencies and industries affiliated with long term care.**

**2010**

# Resident Experiences

Video: Voices Speak out Against Retaliation

1. What reasons are given for not reporting poor treatment or problems within the facility?
2. What concerns or fears are brought up by the residents?
3. What examples of retaliation did you hear from the video?
4. What examples to overcome the fear of retaliation are discussed in the video?





## RESIDENTS' RIGHTS: AN OVERVIEW

**Residents' Rights** are guaranteed by the federal 1987 Nursing Home Reform Law. The law requires nursing homes to "promote and protect the rights of each resident" and places a strong emphasis on individual dignity and self-determination. Nursing homes must meet federal residents' rights requirements if they participate in Medicare or Medicaid. Some states have residents' rights in state law or regulation for nursing homes, licensed assisted living, adult care homes, and other board and care facilities. A person living in a long-term care facility maintains the same rights as an individual in the larger community.

### RESIDENTS' RIGHTS GUARANTEE QUALITY OF LIFE

The 1987 Nursing Home Reform Law requires each nursing home to care for its residents in a manner that promotes and enhances the quality of life of each resident, ensuring **dignity, choice, and self-determination**.

All nursing homes are required "to provide services and activities to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident in accordance with a written plan of care that... is initially prepared, with participation, to the extent practicable, of the resident, the resident's family, or legal representative." ***This means a resident should not decline in health or well-being as a result of the way a nursing facility provides care on a regular basis.***

**The 1987 Nursing Home Reform Law protects the following rights of nursing home residents:**

#### The Right to Be Fully Informed of

- Available services and the charges for each service
- Facility rules and regulations, including a written copy of resident rights
- Address and telephone number of the State Ombudsman and state survey agency
- State survey reports and the nursing home's plan of correction
- Advance plans of a change in rooms or roommates
- Assistance if a sensory impairment exists
- Residents have a right to receive information in a language they understand (Spanish, Braille, etc.)

#### Right to Complain

- 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 ombudsman program
- To file a complaint with the state survey and certification agency

#### Right to Participate in One's Own Care

- 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
- Refuse chemical and physical restraints
- Review one's medical record
- Be free from charge for services covered by Medicaid or Medicare

#### Right to Privacy and Confidentiality

- Private and unrestricted communication with a person of their choice
- During treatment and care of one's personal needs
- Regarding medical, personal, or financial affairs

#### Rights During Transfers and Discharges

- Remain in the nursing facility unless a transfer or discharge:
  - is necessary to meet the resident's welfare;
  - is appropriate because the resident's health has improved and s/he no longer requires nursing home care;
  - is needed to protect the health and safety of other residents or staff;
  - 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 thirty-day notice of transfer or discharge which includes the reason, effective date, location to which the resident is transferred or discharged, the right to appeal, and the name, address, and telephone number of the state long-term care ombudsman
- Safe transfer or discharge through sufficient preparation by the nursing home

### **Right to Dignity, Respect, and Freedom**

- To be treated with consideration, respect, and dignity
- To be free from mental and physical abuse, corporal punishment, involuntary seclusion, and physical and chemical restraints
- To self-determination
- Security of possessions

### **Right to Visits**

- By a resident's personal physician and representatives from the state survey agency and 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

### **Right to Make Independent Choices**

- 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 nursing home
- Organize and participate in a Resident Council
- Manage one's own financial affairs

## **Advocates for Residents Rights**

Where do you go for help if you're concerned a facility is not guaranteeing the rights of residents? Contact your local or state long-term care ombudsman or, if one exists, your state's citizen advocacy group. The Long-Term Care Ombudsman Program is required by federal law to promote and protect the rights of residents in licensed long-term care facilities. The Consumer Voice can help you locate advocates and ombudsmen in your area. Visit our website:

**[www.theconsumervoice.org](http://www.theconsumervoice.org)** to view a map listing ombudsmen and citizen advocacy groups nationwide.

**For more information and resources on residents' rights  
go to, [www.theconsumervoice.org](http://www.theconsumervoice.org).**

*National Consumer Voice for Quality Long-Term Care (formerly NCCNHR) is a nonprofit organization founded in 1975 by Elma L. Holder to protect the rights, safety and dignity of American's long-term care residents.*





# NURSING HOME RESIDENTS' RIGHTS<sup>1</sup>

<sup>1</sup>See 42 CFR §483 for a full listing of Residents' Rights

Residents of nursing homes have rights that are guaranteed by the federal Nursing Home Reform Law. The law requires nursing homes to “promote and protect the rights of each resident” and stresses individual dignity and self-determination. Many states also include residents’ rights in state law or regulation.



## Right to a Dignified Existence

- Be treated with consideration, respect, and dignity, recognizing each resident’s individuality
- Freedom from abuse, neglect, exploitation, and misappropriation of property
- Freedom from physical or chemical restraints
- Quality of life is maintained or improved
- Exercise rights without interference, coercion, discrimination, or reprisal
- A homelike environment, and use of personal belongings when possible
- Equal access to quality care
- Security of possessions



## Right to Self-Determination

- Choice of activities, schedules, health care, and providers, including attending physician
- Reasonable accommodation of needs and preferences
- Participate in developing and implementing a person-centered plan of care that incorporates personal and cultural preferences
- Choice about designating a representative to exercise his or her rights
- Organize and participate in resident and family groups
- Request, refuse, and/or discontinue treatment



## Right to be Fully Informed of

- The type of care to be provided, and risks and benefits of proposed treatments
- Changes to the plan of care, or in medical or health status
- Rules and regulations, including a written copy of residents’ rights
- Contact information for the long-term care ombudsman program and the state survey agency
- State survey reports and the nursing facility’s plan of correction
- Written notice before a change in room or roommate
- Notices and information in a language or manner he or she understands (Spanish, Braille, etc.)

## Right to Raise Grievances

- Present grievances without discrimination or retaliation, or the fear of it
- Prompt efforts by the facility to resolve grievances, and provide a written decision upon request
- To file a complaint with the long-term care ombudsman program or the state survey agency

## Right of Access to

- Individuals, services, community members, and activities inside and outside the facility
- Visitors of his or her choosing, at any time, and the right to refuse visitors
- Personal and medical records
- His or her personal physician and representatives from the state survey agency and long-term care ombudsman program
- Assistance if sensory impairments exist
- Participate in social, religious, and community activities

## Rights Regarding Financial Affairs

- Manage his or her financial affairs
- Information about available services and the charges for each service
- Personal funds of more than \$100 (\$50 for residents whose care is funded by Medicaid) deposited by the facility in a separate interest-bearing account, and financial statements quarterly or upon request
- Not be charged for services covered by Medicaid or Medicare

## Right to Privacy

- Regarding personal, financial, and medical affairs
- Private and unrestricted communication with any person of their choice
- During treatment and care of personal needs

## Rights During Discharge/Transfer

- Right to appeal the proposed transfer or discharge and not be discharged while an appeal is pending
- Receive 30-day written notice of discharge or transfer that includes: the reason; the effective date; the location going to; appeal rights and process for filing an appeal; and the name and contact information for the long-term care ombudsman
- Preparation and orientation to ensure safe and orderly transfer or discharge
- Notice of the right to return to the facility after hospitalization or therapeutic leave

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## GET HELP

For more information about Residents' Rights, or questions or concerns, contact your Long-Term Care Ombudsman Program. The Long-Term Care Ombudsman Program promotes and protects the rights of residents in licensed long-term care facilities. Visit **[www.theconsumervoice.org](http://www.theconsumervoice.org)** for more information.





## The Ombudsman Program Under The Older Americans Act

The 1978 Amendments to the Older Americans Act, passed in October 1978, considerably strengthened the Ombudsman Program. Title III, Section 307(a)(12) required all state agencies on aging to establish an Ombudsman program that would carry out the following activities:

- Investigate and resolve long term care facility residents' complaints;
- Promote the development of citizens' organizations and train volunteers;
- Identify significant problems by establishing a statewide reporting system for complaints, and work to resolve these problems by bringing them to the attention of appropriate public agencies;
- Monitor the development and implementation of federal, state, and local long term care laws and policies;
- Gain access to long term care facilities and to residents' records;
- Protect the confidentiality of residents' records, complainants' identities, and Ombudsman files.

These regulatory provisions set the framework for development of State programs that encompassed both the sub-state program focus of the early nationwide program and the complaint investigation focus of the demonstration projects. Thus, States were able to build on their early Ombudsman initiatives as they began implementing the legislative requirements. Many States developed and worked for enactment of State Ombudsman legislation. Such legislation is sometimes necessary to comply with the requirement in the Act to secure access to facilities and to residents' records.

The 1981 reauthorization of the Older Americans Act resulted in a further expansion of Ombudsman duties. In addition to nursing homes, board and care homes were included in the Ombudsman realm of responsibilities. The name was changed from Nursing Home Ombudsman Program to Long Term Care Ombudsman Program (LTCOP) to reflect this change. Other duties remained substantially the same.

No major changes were made to the LTCOP's duties in the 1984 reauthorization of the OAA.

The 1987 Amendments to the OAA made substantial changes related to the Long Term Care Ombudsman Program resulting in a significant improvement in the ability of program to advocate on behalf of residents of Long Term Care facilities. The changes required States to provide for:

- Ombudsman access to residents and residents' records.
- Immunity to Ombudsman for the good faith performance of their duties.
- Prohibitions against willful interference with the official duties of an Ombudsman and/ or retaliation against an Ombudsman, resident, or other individual for assisting the Ombudsman program in the performance of their duties.

The 1992 reauthorization made other changes to the OAA and to the Long Term Care Ombudsman Program. These changes included:

- The establishment of the Office of Long Term Care Ombudsman Programs in the Administration on Aging;
- The Office to be headed by an Associate Commissioner for the Ombudsman Programs.

During 2000, the Older Americans Act was re-authorized, with no changes made to the Titles pertaining to the Long Term Care Ombudsman Program.

During January of 2001, a final report prepared by the Administration on Aging evaluating the Long Term Care Ombudsman Program was released. "Residents of nursing homes, board and care homes, and adult care facilities and their families have strong advocates in the nation's long-term care ombudsmen", according to the report. The evaluation confirms that Ombudsman Programs under the Older Americans Act are empowering long-term care residents and their families to be informed long-term care consumers and to facilitating the resolution of problems regarding care and conditions in long-term care facilities.

In Connecticut, PUBLIC ACT 99-176 further strengthens the independence and mandate of the Office of the State Long Term Care Ombudsman.



residents of a nursing home facility;

(3) "Transfer trauma" means the medical and psychological reactions to physical transfer that increase the risk of death, or grave illness, or both, in elderly persons; and

(4) "Substantial violation" means a violation of law which presents a reasonable likelihood of serious physical or mental harm to residents of a nursing home facility.

§ Sec. 19a-550. (Formerly Sec. 19-622). Patients' bill of rights. (a)(1) As used in this section, (A) "nursing home facility" shall have the same meaning as provided in section 19a-521, and (B) "chronic disease hospital" means a long-term hospital having facilities, medical staff and all necessary personnel for the diagnosis, care and treatment of chronic diseases; and (2) for the purposes of subsections (c) and (d) of this section, and subsection (b) of section 19a-537, "medically contraindicated" means a comprehensive evaluation of the impact of a potential room transfer on the patient's physical, mental and psychosocial well-being, which determines that the transfer would cause new symptoms or exacerbate present symptoms beyond a reasonable adjustment period resulting in a prolonged or significant negative outcome that could not be ameliorated through care plan intervention, as documented by a physician in a patient's medical record.

(b) There is established a patients' bill of rights for any person admitted as a patient to any nursing home facility or chronic disease hospital. The patients' bill of rights shall be implemented in accordance with the provisions of Sections 1919(b), 1919(c), 1919(c)(2), 1919(c)(2)(D) and 1919(c)(2)(E) of the Social Security Act. The patients' bill of rights shall provide that each such patient: (1) Is fully informed, as evidenced by the patient's written acknowledgment, prior to or at the time of admission and during the patient's stay, of the rights set forth in this section and of all rules and regulations governing patient conduct and responsibilities; (2) is fully informed, prior to or at the time of admission and during the patient's stay, of services available in the facility, and of related charges including any charges for services not covered under Titles XVIII or XIX of the Social Security Act, or not covered by basic per diem rate; (3) is entitled to choose the patient's own physician and is fully informed, by a physician, of the patient's medical condition unless medically contraindicated, as documented by the physician in the patient's medical record, and is afforded the opportunity to participate in the planning of the patient's medical treatment and to refuse to participate in experimental research; (4) in a residential care home or a chronic disease hospital is transferred from one room to another within the facility only for medical reasons, or for the patient's welfare or that of other patients, as documented in the patient's medical record and such record shall include documentation of action taken to minimize any disruptive effects of such transfer, except a patient who is a Medicaid recipient may be transferred from a private room to a nonprivate room, provided no patient may be involuntarily transferred from one room to another within the facility if (A) it is medically established that the move will subject the patient to a reasonable likelihood of serious physical injury or harm, or (B) the patient has a prior established medical history of psychiatric problems and there is psychiatric testimony that as a consequence of the proposed move there will be exacerbation of the psychiatric problem which would last over a significant period of time and require psychiatric intervention; and in the case of an involuntary transfer



from one room to another within the facility, the patient and, if known, the patient's legally liable relative, guardian or conservator or a person designated by the patient in accordance with section 1-56r, is given at least thirty days' and no more than sixty days' written notice to ensure orderly transfer from one room to another within the facility, except where the health, safety or welfare of other patients is endangered or where immediate transfer from one room to another within the facility is necessitated by urgent medical need of the patient or where a patient has resided in the facility for less than thirty days, in which case notice shall be given as many days before the transfer as practicable; (5) is encouraged and assisted, throughout the patient's period of stay, to exercise the patient's rights as a patient and as a citizen, and to this end, has the right to be fully informed about patients' rights by state or federally funded patient advocacy programs, and may voice grievances and recommend changes in policies and services to facility staff or to outside representatives of the patient's choice, free from restraint, interference, coercion, discrimination or reprisal; (6) shall have prompt efforts made by the facility to resolve grievances the patient may have, including those with respect to the behavior of other patients; (7) may manage the patient's personal financial affairs, and is given a quarterly accounting of financial transactions made on the patient's behalf; (8) is free from mental and physical abuse, corporal punishment, involuntary seclusion and any physical or chemical restraints imposed for purposes of discipline or convenience and not required to treat the patient's medical symptoms. Physical or chemical restraints may be imposed only to ensure the physical safety of the patient or other patients and only upon the written order of a physician that specifies the type of restraint and the duration and circumstances under which the restraints are to be used, except in emergencies until a specific order can be obtained; (9) is assured confidential treatment of the patient's personal and medical records, and may approve or refuse their release to any individual outside the facility, except in case of the patient's transfer to another health care institution or as required by law or third-party payment contract; (10) receives quality care and services with reasonable accommodation of individual needs and preferences, except where the health or safety of the individual would be endangered, and is treated with consideration, respect, and full recognition of the patient's dignity and individuality, including privacy in treatment and in care for the patient's personal needs; (11) is not required to perform services for the facility that are not included for therapeutic purposes in the patient's plan of care; (12) may associate and communicate privately with persons of the patient's choice, including other patients, send and receive the patient's personal mail unopened and make and receive telephone calls privately, unless medically contraindicated, as documented by the patient's physician in the patient's medical record, and receives adequate notice before the patient's room or roommate in the facility is changed; (13) is entitled to organize and participate in patient groups in the facility and to participate in social, religious and community activities that do not interfere with the rights of other patients, unless medically contraindicated, as documented by the patient's physician in the patient's medical records; (14) may retain and use the patient's personal clothing and possessions unless to do so would infringe upon rights of other patients or unless medically contraindicated, as documented by the patient's physician in the patient's medical record; (15) is assured privacy for visits by the patient's spouse or a person designated by the patient in accordance with section 1-56r and, if the patient is married and both the patient and the patient's spouse are inpatients in the facility, they are permitted to share a room, unless medically contraindicated, as documented by the attending physician in the medical record; (16) is fully informed of the availability of and may examine all current state, local and federal inspection reports and plans of correction; (17) may organize, maintain and participate in a patient-run resident council, as a means of fostering communication

among residents and between residents and staff, encouraging resident independence and addressing the basic rights of nursing home and chronic disease hospital patients and residents, free from administrative interference or reprisal; (18) is entitled to the opinion of two physicians concerning the need for surgery, except in an emergency situation, prior to such surgery being performed; (19) is entitled to have the patient's family or a person designated by the patient in accordance with section 1-56r meet in the facility with the families of other patients in the facility to the extent the facility has existing meeting space available which meets applicable building and fire codes; (20) is entitled to file a complaint with the Department of Social Services and the Department of Public Health regarding patient abuse, neglect or misappropriation of patient property; (21) is entitled to have psychopharmacologic drugs administered only on orders of a physician and only as part of a written plan of care developed in accordance with Section 1919(b)(2) of the Social Security Act and designed to eliminate or modify the symptoms for which the drugs are prescribed and only if, at least annually, an independent external consultant reviews the appropriateness of the drug plan; (22) is entitled to be transferred or discharged from the facility only pursuant to section 19a-535 or section 19a-535b, as applicable; (23) is entitled to be treated equally with other patients with regard to transfer, discharge and the provision of all services regardless of the source of payment; (24) shall not be required to waive any rights to benefits under Medicare or Medicaid or to give oral or written assurance that the patient is not eligible for, or will not apply for benefits under Medicare or Medicaid; (25) is entitled to be provided information by the facility as to how to apply for Medicare or Medicaid benefits and how to receive refunds for previous payments covered by such benefits; (26) on or after October 1, 1990, shall not be required to give a third party guarantee of payment to the facility as a condition of admission to, or continued stay in, the facility; (27) in the case of an individual who is entitled to medical assistance, is entitled to have the facility not charge, solicit, accept or receive, in addition to any amount otherwise required to be paid under Medicaid, any gift, money, donation or other consideration as a precondition of admission or expediting the admission of the individual to the facility or as a requirement for the individual's continued stay in the facility; and (28) shall not be required to deposit the patient's personal funds in the facility.

(c) The patients' bill of rights shall provide that a patient in a rest home with nursing supervision or a chronic and convalescent nursing home may be transferred from one room to another within a facility only for the purpose of promoting the patient's well-being, except as provided pursuant to subparagraph (C) or (D) of this subsection or subsection (d) of this section. Whenever a patient is to be transferred, the facility shall effect the transfer with the least disruption to the patient and shall assess, monitor and adjust care as needed subsequent to the transfer in accordance with subdivision (10) of subsection (b) of this section. When a transfer is initiated by the facility and the patient does not consent to the transfer, the facility shall establish a consultative process that includes the participation of the attending physician, a registered nurse with responsibility for the patient and other appropriate staff in disciplines as determined by the patient's needs, and the participation of the patient, the patient's family, a person designated by the patient in accordance with section 1-56r or other representative. The consultative process shall determine: (1) What caused consideration of the transfer; (2) whether the cause can be removed; and (3) if not, whether the facility has attempted alternatives to transfer. The patient shall be informed of the risks and benefits of the transfer and of any alternatives. If subsequent to the completion of the consultative process a patient still does not wish to be transferred, the



# Person-Centered Care Based in Law

- Nursing Home Reform Act (OBRA) *Omnibus Budget Reconciliation Act of 1987*
- Federal Requirements for States and Long-Term Care Facilities

Who decides?  
**The resident!**



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# NCCNHR

The National Consumer Voice For Quality Long-Term Care

**Federal Nursing Home Reform Act  
from the  
Omnibus Budget Reconciliation Act of 1987 or simply  
OBRA '87 SUMMARY**

Developed by Hollis Turnham, Esquire

In 1987, President Ronald Reagan signed into law the first major revision of the federal standards for nursing home care since the 1965 creation of both Medicare and Medicaid 42 U.S.C.1396r, 42 U.S.C. 1395i-3, 42 CFR 483. The landmark legislation changed forever society's legal expectations of nursing homes and their care. Long term care facilities wanting Medicare or Medicaid funding are to provide services so that each resident can "attain and maintain her highest practicable physical, mental, and psycho-social well-being."

Medicaid Provision: 42 U.S.C. 1396r(b)(4)  
<http://www4.law.cornell.edu/uscode/42/1396r.html>

Medicare Provision: 42 U.S.C. 1395i-3(b)(4)  
<http://www4.law.cornell.edu/uscode/42/1395i-3.html>

Federal Regulations: 42 CFR 483.25  
[http://www.access.gpo.gov/nara/cfr/waisidx\\_02/42cfr483\\_02.html](http://www.access.gpo.gov/nara/cfr/waisidx_02/42cfr483_02.html)  
(Scroll down to retrieve a specific title part and section as text or pdf file.)

## **WHAT IS OBRA '87?**

The Federal Nursing Home Reform Act or OBRA '87 creates a set of national minimum set of standards of care and rights for people living in certified nursing facilities. This landmark federal legislation comes by its common name "OBRA" through the legislative process. Congress, then and now, usually completes a huge measure of its budgetary and substantive work in one large bill. The bill accomplishing that function in 1987 was entitled the Omnibus Budget Reconciliation Act of 1987 or "OBRA '87." The separate Federal Nursing

Home Reform Act along with many other separate bills was "rolled into" one bill to insure final passage of all the elements.

These minimum federal health and care requirements for nursing homes are to be delivered through variety of established protocols within nursing homes and regulatory agencies. And as minimum standards, Long-Term Care Ombudsmen should view OBRA as a baseline that should be built upon to reach not only resident "well-being" but also happiness and fulfillment.

OBRA also recognized the unique and important role performed by the LTCOP for nursing home residents. The federal Medicaid and Medicaid legislation included those distinct advocacy roles and subsequent regulations and other guidance has given LTCOPs additional tools to serve resident interests.

The changes OBRA brought to nursing home care are enormous. Some of the most important resident provisions include:

- Emphasis on a resident's quality of life as well as the quality of care;
- New expectations that each resident's ability to walk, bathe, and perform other activities of daily living will be maintained or improved absent medical reasons;
- A resident assessment process leading to development of an individualized care plan 75 hours of training and testing of paraprofessional staff;
- Rights to remain in the nursing home absent non-payment, dangerous resident behaviors, or significant changes in a resident's medical condition;
- New opportunities for potential and current residents with mental retardation or mental illnesses for services inside and outside a nursing home;
- A right to safely maintain or bank personal funds with the nursing home; Rights to return to the nursing home after a hospital stay or an overnight visit with family and friends The right to choose a personal physician and to access medical records;
- The right to organize and participate in a resident or family council;
- The right to be free of unnecessary and inappropriate physical and chemical restraints;
- Uniform certification standards for Medicare and Medicaid homes;
- Prohibitions on turning to family members to pay for Medicare and Medicaid services;



- and New remedies to be applied to certified nursing homes that fail to meet minimum federal standards.

OBRA set in motion forces that changed the way state inspectors approached all their visits to nursing homes. Inspectors no longer spend their time exclusively with staff or with facility records. Conversations with residents and families are a prime time survey event. Observing dining and medications administration are a focal point of every annual inspection.

Under OBRA, Long Term Care Ombudsman Programs have defined roles to fulfill and tools to use in the annual inspection process to nurture the conversations between residents/families and inspectors and life in the nursing home.

### **HOW DID OBRA '87 COME ABOUT?**

The federal Nursing Home Reform Act became law with growing public concern with the poor quality of care in too many nursing homes and the concerted advocacy of advocates, consumers, provider associations, and health care professionals. Congress asked the Institute of Medicine (IoM) to study how to better regulate the quality of care in the nation's Medicaid and Medicare certified nursing homes.

In its 1986 report Improving the Quality of Care in Nursing Homes, the expert panel recommended:

- A stronger federal role in improving quality;
- Revisions in performance standards, the inspection process, and the remedies to improve nursing home services;
- Better training of nursing home staff;
- Improved assessment of resident needs; and
- A dynamic and evolutionary regulatory process.
- Information can be found at:  
[http://www.nap.edu/catalog.php?record\\_id=646](http://www.nap.edu/catalog.php?record_id=646)

In order to assure implementation of the IoM recommendations from the "blue ribbon panel," the National Citizens' Coalition for Nursing Home Reform organized the "Campaign for Quality Care" to support the federal reforms. National organizations representing consumers, nursing homes, and health care professionals worked together, and continue to work, to create consensus positions on major nursing home issues. Their consensus positions on the IoM report laid the foundation for the federal law.

OBRA has changed the care and lives of nursing home residents across America. There have been significant improvements in the



comprehensiveness of care planning. Anti-psychotic drug use declined by 28-36% and physical restraint use was reduced by approximately 40%.

Several states have taken all or parts of OBRA '87 and made them state law for their licensed nursing homes or other kinds of long term care facilities. For example, the state of Washington has extended the rights that nursing home residents have to residents of all Washington long term care facilities.

And, Michigan has incorporated many of the OBRA prohibitions on Medicaid discrimination into state law.

Online Research: *The links to federal laws and regulations in this document have been made to the most reliable sources known to the Ombudsman Resource Center. Links to the Medicaid and Medicare laws are made to the Legal Information Institute maintained by Cornell University. The federal code of regulations is accessed here through the United States Government Printing Office.* If these resources do not meet your needs or you find better resources for federal legal research, please contact Center staff at [ombudcenter@nccnhr.org](mailto:ombudcenter@nccnhr.org)

## **Resident Assessments and Care Plans**



## ASSESSMENT AND CARE PLANNING: THE KEY TO QUALITY CARE

Every person in a nursing home has a right to good care, under the law. The law says the home must help people "attain or maintain" their highest level of well-being - physically, mentally and emotionally. To give good care staff must assess each resident and plan care to support each person's life-long patterns, and current interests, strengths and needs. Resident and family involvement in care planning gives staff information they need to make sure residents get good care and the care they deserve.

### WHAT IS A RESIDENT ASSESSMENT?

Assessments gather information about how well residents can take care of yourselves and when you need help in "functional abilities" -- how well you can walk, talk, eat, dress, bathe, see, hear, communicate, understand and remember. Staff also ask about residents' habits, activities and relationships so they can help residents live more comfortably and feel more at home. The assessment helps staff look for what is causing a problem. For instance, poor balance could be caused by medications, sitting too much, weak muscles, poor-fitting shoes, a urinary infection or an ear ache. Staff must know the cause in order to give treatment.

### WHAT IS A PLAN OF CARE?

A plan of care is a strategy for how the staff will help a resident. It says what each staff person will do and when it will happen (for instance—The nursing assistant will help Mrs. Jones walk to each meal to build her strength). Care plans must be reviewed regularly to make sure they work and must be revised as needed. For care plans to work, residents must feel like they meet your needs and must be comfortable with them. Care plans can address any medical or non-medical problem (example: incompatibility with a roommate).

### WHAT IS A CARE PLANNING CONFERENCE?

A care planning conference is a meeting where staff and residents/families talk about life in the facility-- meals, activities, therapies, personal schedule, medical and nursing care, and emotional needs. Residents/families can bring up problems, ask questions, or offer information to help staff provide care. All staff who work with a resident should be involved--nursing assistants, nurse, physician, social worker, activities staff, dietician, occupational and physical therapists.

### WHEN ARE CARE PLANNING CONFERENCES HELD?

Care planning meetings must occur every three months, and whenever there is a big change in a resident's physical or mental health that might require a change in care. The care plan must be completed within 7 days after an assessment. Assessments must be completed within 14 days of admission and at least once a year, with reviews every three months and when a resident's condition changes.

### WHAT SHOULD YOU TALK ABOUT AT THE MEETING?

Talk about what you need, how you feel; ask questions about care and the daily routine, about food, activities, interests, staff, personal care, medications, and how well you get around. Staff must talk to you about treatment decisions, such as medications and restraints, and can only do what you agree to. You may have to be persistent about your concerns and choices. For help with problems, contact your local ombudsman, advocacy group or others listed on the next page.



## **HOW RESIDENTS AND THEIR FAMILIES CAN PARTICIPATE IN CARE PLANNING**

Residents have the right to make choices about care, services, daily schedule and life in the facility, and to be involved in the care planning meeting. Participating is the only way to be heard.

### **Before the meeting:**

- Tell staff how you feel, your concerns, what help you need or questions you have; plan your agenda of questions, needs, problems and goals for yourself and your care.
- Know, or ask your doctor or the staff, about your condition, care and treatment.
- Ask staff to hold the meeting when your family can come, if you want them there.

### **During the meeting:**

- Discuss options for treatment and for meeting your needs and preferences. Ask questions if you need terms or procedures explained to you.
- Be sure you understand and agree with the care plan and feel it meets your needs. Ask for a copy of your care plan.
- Ask with whom to talk if you need changes in it.

### **After the meeting:**

See how your care plan is followed; talk with nurse aides, other staff or the doctor about it.

### **Families:**

- Support your relative's agenda, choices and participation in the meeting.
- Even if your relative has dementia, involve her/him in care planning as much as possible. Always assume that s/he may understand and communicate at some level. Help the staff find ways to communicate with and work with your relative.
- Help watch how the care plan is working and talk with staff if questions arise.

### **A Good Plan Should:**

- Be specific, individualized and written in common language that everyone can understand;
- Reflect residents' concerns and support residents' well-being, functioning and rights; Not label residents' choices or needs as "problem behaviors;"
- Use a multi-disciplinary team approach and use outside referrals as needed;
- Be re-evaluated and revised routinely - Watch for care plans that never change.

**For more information and resources on assessment and care planning,  
go to [www.theconsumervoice.org](http://www.theconsumervoice.org)**

*National Consumer Voice for Quality Long-Term Care (formerly NCCNHR) is a nonprofit organization founded in 1975 by Elma E. Holder to protect the rights, safety and dignity of American's long-term care residents.*

## Assessments

All nursing facilities are required by federal regulations to provide supports and services necessary to help residents reach or maintain their highest practicable level of well-being. Nursing facilities are required to conduct initial and periodic comprehensive and accurate assessments. An initial assessment evaluates functional capacity and helps staff learn about the resident and their needs. The Resident Assessment Instrument-Minimum Data Set, often referred to as the "MDS" is the required assessment tool used in nursing facilities. It is designed to collect the minimum amount of data to guide care planning and monitoring for residents. It is from this assessment that care plans are developed.

The most important tools for assuring that residents receive adequate care are through resident assessment, care plan development, and the care plan meeting.

### **When Does the Nursing Facility Assess the Resident?**

- At the time of admission (details below)
- When readmitted following hospitalization
- Quarterly
- Annually
- After a significant change in condition
- When a significant change to a prior assessment needs to be made
- At the time of discharge

*When Medicare is paying for the resident's stay, the facility must complete an assessment at the following specific intervals, different from the list above: 5-day, 14-day, 30-day, and 90-day mark.*

### **What is the Ombudsman Program's Role in an Assessment?**

The Ombudsman program can help residents participate in the assessment process to the greatest extent possible by:

- Suggesting that residents prepare for the assessment by thinking about daily routines, activity preferences, and goals before staff begin interviews
- Reminding residents that they can request activities or daily routines that are not included in the list provided on the MDS assessment
- Helping residents work with facility staff to resolve any issues related to assessment interview procedures

## Baseline Care Plan

Within 48 hours of admission, nursing facilities are required to develop a baseline care plan for each resident. It must include the instructions needed to provide effective and person-centered care of the resident and meet professional standards of quality care.

The nursing facility is required to provide the resident and their decision maker with a summary of the baseline care plan including but not limited to the following information:

- The initial goals of the resident
- A summary of the resident's medications and dietary instructions
- Any services and treatments to be administered by the facility

## The Care Plan

The care plan must include resident-specific, measurable objectives, and timeframes to meet the resident's medical, physical, mental, and psychosocial needs identified in their MDS. The care plan must also describe services that will be used to help the resident attain or maintain their highest practicable physical, mental, and psychosocial well-being. Care plans must include the resident's preferences, including the right to refuse treatment, and potential for discharge.

A thorough care plan is:

- Individualized
- Specific
- Comprehensive
- Written in a language everyone can understand
- Reflective of the resident's concerns, preferences, and goals
- Supportive of the resident's well-being, abilities, and rights

Federal regulations require facilities to develop and implement a comprehensive person-centered care plan within seven days after completion of the MDS assessment, but not more than 21 days after admission.

Residents' rights to participate in the development and implementation of their person-centered care plan are clear. The mere existence of the regulations, however, does not guarantee that these planning processes will operate in a person-centered way. Some nursing facilities may be inclined to treat the planning regulations as a bothersome requirement, which makes it essential that residents effectively assert both their right to participate and their preferences for care and discharge. This is where the Ombudsman program can provide an extra voice of knowledge and support to help the resident achieve their goals.



## **Residents' Rights Related to Care Planning<sup>44</sup>**

- ✓ The right to participate in the planning process, including the right to identify individuals or roles to be included in the planning process, the right to request meetings, and the right to request revisions to the person-centered plan of care.
- ✓ The right to participate in establishing the expected goals and outcomes of care, the type, amount, frequency, and duration of care, and any other factors related to the effectiveness of the plan of care.
- ✓ The right to be informed, in advance, of changes to the plan of care.
- ✓ The right to receive the services and/or items included in the plan of care.
- ✓ The right to see the care plan, including the right to sign it after significant changes to the plan of care are made.

The nursing facility is required to inform the resident of their right to participate in their treatment plan and support them in doing so. The planning process is required to include the resident and/or the resident's representative, an assessment of the resident's strengths and needs, and to incorporate the resident's personal and cultural preferences in developing goals of care.

Once the MDS assessment is complete and a care plan is written, a care plan meeting is held no later than 21 days after admission, every three months, or after a significant change in condition. The care plan meeting is supposed to be scheduled to accommodate the resident and/or the resident's representative.

### **The Care Plan Meeting**

The care plan meeting is a conference where staff, the resident, and persons of the resident's choice go over the care plan. Care plans are a great tool to use when resolving a complaint. Representatives of the Office can participate in a care plan meeting with permission of the resident. It is a good idea to request a copy of the current care plan as well as the proposed care plan (if available) prior to the meeting. Review both care plans with the resident and talk about the resident's concerns and goals and expectations of the representative's role during the care plan meeting.

While an effective care plan requires the involvement of several individuals, all members of the care plan team may not actually attend the meeting.

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<sup>44</sup> 42 CFR Part 483 Requirements for Long-Term Care Facilities, § 483.21 Comprehensive person-centered care planning. <https://www.govinfo.gov/content/pkg/FR-2016-10-04/pdf/2016-23503.pdf>



The National

**CONSUMER VOICE**

for Quality Long-Term Care  
formerly NCCNHR

# FACT SHEET

## BASICS OF INDIVIDUALIZED QUALITY CARE

Individualized care is the right of every nursing home resident. The Nursing Home Reform Law of 1987 requires that residents receive services and activities to "attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident in accordance with a written plan of care..." Quality of care means what care is provided. The law also requires nursing facilities to "care for its residents in such a manner and in such an environment as will promote maintenance or enhancement of the quality of life of each resident." An emphasis is placed on dignity, choice, and self determination for residents. Quality of life means how care is provided.

The law requires nursing facilities to provide quality of care in a way that supports quality of life for each resident. When facilities do this, they achieve individualized care for each resident. Residents and family members should expect the facility to provide individualized care based on Quality of Care Basics.

Read a real resident's experience in one nursing home and follow how an Individualized Plan of Care should be developed. For this example, four areas of care will be used: (1) the assessment and care plan process (the basis for individualized care), (2) toileting, (3) hydration, and (4) mobility. (For more information, see Burger et al "Nursing Homes: Getting Good Care There," Chapters 4 and 5, available from the Consumer Voice).

### HOW ONE NURSING HOME RESIDENT AND HER DAUGHTER CAN ACHIEVE THE BASICS OF INDIVIDUALIZED CARE

Your mother lived independently until she suffered a stroke two months ago. Your need to work prevents you from bringing her to your home for care. Together you made the decision that she would go to a nursing home for rehabilitation. The stroke left her with right-sided weakness (she is also right-handed) and some inability to make herself understood. Based on your mother's excellent response to rehab in the hospital, her physician thinks she should continue to make progress and return home in eight to twelve weeks.

The nursing home staff welcomed your mom. You both felt confident about your decision. Your mom's roommate was glad for the company and was patient with her slow speech. Your mom asked you to attend the first care planning conference with her.

The staff said your mom would receive physical therapy three times a week, and speech and occupational therapy once a week.

You're both pleased with the therapy program, but your mother complained that the nursing staff will not take her to the toilet except as part of the therapy sessions. A fastidious woman, your mother knows when she has to go the bathroom and was determined to use the toilet, not a brief (diaper), bedpan, or commode. At the end of her second month in the facility, you noticed that you had difficulty opening your mother's right hand for the manicure she loved to get. Her skin looked very dry and flaky. Your mom's spirits seemed to be sinking. In fact, recently she seemed to be getting worse, not better.

When you mentioned these concerns to the staff, you were told that this happens to all frail, old people. The nursing staff then suggested speaking with the doctor to obtain an order for an antidepressant. You became really concerned.

### ASSESSMENT AND CARE PLANNING

**The Resident Assessment and Care Plan Process:** In order to know what care and services to provide and how to provide them, the law requires a careful and thorough assessment of your mom. Staff need to learn your mom's strengths and needs. A list of assessment items relating to your mom includes:

- Her life history, daily routines, strengths, interests, food likes and dislikes, and other personal information. (Think of this information as the important details about your mother that reflects who she is as an individual, and which will form the basis for planning her care.)
- Her ability to function including walking, dressing, using the toilet, and eating. (The stroke has affected your mom's right and dominant side, so she will need assistance to regain independence.)



- Physical or mental conditions that may affect her ability to recover. (Except for the stroke, she is quite healthy mentally and physically.)
- Her potential for improvement. (Her physician expects her to recover and go home.)
- • Communication abilities. (Her speech is slowed.)
- Nutritional status and medications. (She must relearn to feed herself and manage her own medications.)

The assessment is completed by day 7 in a skilled unit (your mother's situation at first); by the 14th day in a nursing facility (long term chronic care); and once a year thereafter, or whenever a resident's condition changes. The assessment is done by the interdisciplinary team (IDT) that includes: the resident, direct caregiver(s), nurse, physician, physical therapist, occupational therapist, speech therapist, activity therapist, dietitian, and social worker. The assessment information is the foundation for the care planning process.

## DEVELOPING AN INDIVIDUALIZED CARE PLAN

The Care Plan, by law, is initially prepared with participation to the extent practicable of the resident or the resident's family or legal representative. The initial care plan must be complete by the 21st day of her stay, and subsequent care plan reviews are repeated quarterly, or whenever there is a major change in a resident's condition. The initial care plan process begins during the assessment. It is called an Individualized Care Plan because each resident's conditions, abilities, needs, routines, and goals are unique, requiring a plan of care (road map for care) that reflects who this individual is. The overarching goal is for your mother to return home and live as independently as possible. There are many little goals along the way. Care plan goals are all measurable, time limited, and the team member responsible for each is identified. This simply means that each goal will be clearly identified and stated. Each goal will also list an estimated time for accomplishment, as well as the specific team member(s) responsible in assisting to achieve that goal.

Physical Therapy will help your mother to regain the ability to walk. Occupational Therapy will assist her in attaining independence in dressing, eating, and toileting. Speech Therapy will help to improve her slow speech pattern. But therapy only takes up a few hours each day. The IDT must plan what happens for the rest of the 24-hour period. This plan must support your mother's goal for independence

and prevent any harm from occurring. The Plan of Care must then be relayed to each staff member, including the Certified Nursing Assistants (CNAs), so that everyone is consistent in helping your mom reach her stated goals.

Traditionally, nursing homes have used nursing/medical model care plans. That type of plan is not suited to individualized nursing home care. It is written from the staff perspective rather than each resident's perspective.

**Here is an example of what you may find:**

Problem  
Incontinence

Goal  
Will become independent in toileting

Approaches  
Assist to bedpan at 6 am, 9am, 12 noon, 4pm, 9pm (or when requests) (CNA). Assess ability to stand and pivot on left leg in one week to transfer to commode or toilet, 2/14/16 (N/PT\*).

**Here is an example of an individualized care plan written from a resident's perspective:**

Need  
I need assistance with using the bathroom.

Goal  
I want to regain my independence in using the toilet so that I may go home.

Approaches  
I know when I have to go to the bathroom and will tell you. Please assist me to the bed pan on my usual schedule from home at 6am, 9am, 12 noon, 4pm, 9pm (and when I request) (CNA). Assess my ability to stand and pivot on left leg in one week. Then help me to the commode or toilet, 2/14/16 (N/PT\*).

\*CNA=Certified Nursing Assistant, N=Nursing;  
PT=Physical Therapy; OT=Occupational Therapy;  
ST=Speech Therapy; D=Dietary





## PHYSICAL RESTRAINT-FREE CARE

### EVERYONE DESERVES DIGNITY AND FREEDOM

Restraint-free individuals can eat, dress and move independently, maintain their muscle and strength, interact with others, and maintain their freedom and dignity.

#### Physical Restraints

##### What are Physical Restraints?

A physical restraint is any object or device that the individual cannot remove easily which restricts freedom of movement or normal access to one's body. Examples include vest restraints, waist belts, geri-chairs, hand mitts, lap trays, and side rails.

##### Poor outcomes of restraints:

- Accidents involving restraints which may cause serious injury: bruises, cuts, entrapment, side rail deaths by strangulation, and suffocation.
- Changes in body systems which may include: poor circulation, constipation, incontinence, weak muscles and bone structure, pressure sores, agitation, depressed appetite, infections, or death.
- Changes in quality of life which may include: reduced social contact, withdrawal, loss of autonomy, depression, disrupted sleep, agitation, or loss of mobility.

Physical restraints are used in place of good care because:

- Facilities or family members mistakenly believe that they ensure safety;
- Facilities fear liability;
- Facilities may use them in place of adequate staff.

Restraints are most often used on:

- Frail elderly residents who have fallen or may fall.
- Residents with a dementing illness who wander unsafely or have severe behavioral symptoms

#### PHYSICAL RESTRAINT USE IN THE U.S.

Nationally, over 6% of nursing home residents are restrained. The Advancing Excellence in America's Nursing Homes Campaign has set a goal of 5% or less for all nursing homes in the country. In many nursing homes across the country, residents are restraint-free without any increase in serious injuries. It is unrealistic to expect that all falls and injuries can be prevented.

#### Federal Law and Regulations

The Nursing Home Reform Act of 1987 (OBRA '87) states the resident has the right to be free from physical or chemical restraints imposed for purposes of discipline or convenience and if restraint is not required to treat the resident's medical symptoms.

This law also includes provisions requiring:

- quality of care—to prevent poor outcomes;
- assessment and care planning—for each resident to attain and maintain her/his highest level of functioning;
- residents be treated in such a manner and environment to enhance quality of life.

#### RESTRAINT REDUCTION STRATEGIES

Twenty years of experience provide many strategies for safe restraint reduction and elimination. Restraint reduction involves the whole facility, including administrators, nursing directors, physical and recreational therapists, nursing assistants, and housekeeping personnel. Family members and advocates can encourage the facility's efforts, and expect and insist that the facility:



- Complete a **comprehensive resident assessment** that identifies strengths and weaknesses, self care abilities and help needed, plus lifelong habits and daily routines.
- Develop an **individualized care plan** for how staff will meet a resident's assessed needs. It describes the care goals (e.g. safe walking), and when and what each staff person will do to reach the goal. The care team includes staff, residents and families (if the resident wants), and devises the plan at the quality care plan conference. The resident may also invite an ombudsman to attend. Care plans change as the resident's needs change.
- Train staff to assess and meet an individual resident's needs—hunger, toileting, sleep, thirst, exercise, etc.—according to the **resident's routine rather than the facility's routine.**
- Make permanent and consistent staff assignments and promote staff flexibility to meet residents' individualized needs.
- Treat medical conditions, such as **pain**, that may cause residents to be restless or agitated.
- Support and encourage care giving staff to **think creatively** of new ways to identify and meet residents' needs. For example, a "night owl" resident could visit the day room and watch TV if unable to sleep at night.
- Provide a **program of activities** such as exercise, outdoor time, or small jobs agreed to and enjoyed by the resident.
- Provide **companionship**, including volunteers, family, and friends by making the facility welcoming.
- Create a **safe environment** with good lighting, pads on the floor to cushion falls out of bed, a variety of individualized comfortable seats, beds and mattresses, door alarms, and clear and safe walking paths inside and outside the building.

### **NURSING HOMES CAN IMPLEMENT SPECIFIC PROGRAMS FOR REDUCING PHYSICAL RESTRAINTS, INCLUDING:**

Restorative care, including walking, dressing, independent eating, and bathing programs, as well as:

- Wheelchair management program—including correct size and good condition for seat cushions.
- Individualized seating program—chairs, wheelchairs, tailored to individual needs.
- Specialized programs for residents with dementia, designed to increase their quality of life.
- Videotaped family visits for distant families.
- Wandering program—to promote safe wandering while preserving the rights of others.
- Preventive program based on knowing the resident—to prevent triggering of behavioral symptoms of distress.
- Toileting of residents based on their schedules rather than on staff schedules.

**For more information and resources on physical restraint free care, go to [www.theconsumervoice.org](http://www.theconsumervoice.org).**

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# ADVANCED PLANNING AND THIRD- PARTY DECISION-MAKERS

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Section 4



# Third-Party Decision-Makers

## Assigned *by* the Resident

- Power of Attorney (POA)
  - Appointed by the individual
  - Does not remove rights
  - Different types of POAs

## Assigned *for* the Resident

- Guardianship
- Conservatorship
  - Appointed by the court
  - Removes the individual's rights
  - Deems the individual incapable of administering their own affairs

# Power of Attorney (POA)

“Power of Attorney” is the document.

“Principal” is the person appointing the decision-maker (agent).

“Agent” is the person who is appointed by the principal.

Agents are required to act with the highest degree of good faith.

An agent's authority can be revoked by the principle.

# Your Rights To Make Health Care Decisions

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A Summary of Connecticut Law



prepared by the Office of the Attorney General  
for the Department of Social Services and  
Department of Public Health

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# **Your Rights to Make Health Care Decisions**

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You have the right to make health care decisions about the medical care you receive. If you do not want certain treatments, you have the right to tell your physician you do not want them and have your wishes followed.

You also have the right to receive information from your physician to assist you in reaching a decision about what medical care is to be provided to you.

There may come a time when you are unable to actively participate in determining your treatment due to serious illness, injury or other disability.

This booklet discusses the options available in Connecticut to help you to provide written instructions to guide your physician, family and others as to what treatment choices you desire to be made if you can not express your wishes. It also shows you how to appoint someone to make decisions on your behalf.

## **Frequently Asked Questions**

### **Do I have the right to make health care decisions?**

Yes. Adult patients in Connecticut have the right to determine what, if any, medical treatment they will receive. If you can understand the nature and consequences of the health care decisions that you are being asked to make, you may agree to treatment that may help you or you may refuse treatment even if the treatment might keep you alive longer.

### **Do I have the right to information needed to make a health care decision?**

Yes. Physicians have the responsibility to provide patients with information that can help them to make a decision. Your physician will explain:

- what treatments may help you;
- how each treatment may affect you, that is, how it can help you and what, if any, serious problems or side effects the treatment is likely to cause;
- what may happen if you decide not to receive treatment.

Your physician may also recommend what, if any, treatment is medically appropriate, but the final decision is yours to make. All of this information is provided so you can exercise your right to decide your treatment wisely.

## **What is an advance directive?**

An advance directive is a legal document through which you may provide your directions or express your preferences concerning your medical care and/or to appoint someone to act on your behalf. Physicians and others use them when you are unable to make or communicate your decisions about your medical treatment.

Advance directives are prepared before any condition or circumstance occurs that causes you to be unable to actively make a decision about your medical care.

In Connecticut, there are two types of advance directives:

- the living will or health care instructions
- the appointment of a health care representative

## **Must I have an advance directive?**

No. You do not have to make a living will or other type of advance directive to receive medical care or to be admitted to a hospital, nursing home or other health care facility. No person can be denied medical care or admission based on whether they have signed a living will or other type of advance directive.

If someone refuses to provide you medical care or admit you unless you sign a living will or other type of advance directive, contact the Department of Public Health in Hartford, Connecticut at 860-509-7400.

## **What is a living will?**

A living will is a document that states your wishes regarding any kind of health care you may receive. Should you be in a terminal condition or permanently unconscious, the living will can also tell your physician whether you want "life support systems" to keep you alive or whether you do not want to receive such treatment, even if the result is your death. A living will goes into effect only when you are unable to make or communicate your decisions about your medical care.

## **What does terminal condition and permanently unconscious mean?**

A patient is in a "terminal condition" when the physician finds that the patient has a condition which is (1) incurable or irreversible and (2) will result in death within a relatively short time if life support systems are not provided.

"Permanently unconscious" means a permanent coma or persistent vegetative state where the patient is not aware of himself or his surroundings and is unresponsive.

## **What is a life support system?**

A "life support system" is a form of treatment that only delays the time of your death or maintains you in a state of permanent unconsciousness. Life support systems may include among other things:

- devices such as respirators and dialysis;
- cardiopulmonary resuscitation (CPR);
- food and fluids supplied by artificial means, such as feeding tubes and intravenous fluids.

It does not include

- normal means of eating and drinking, such as eating with assistance of another person or through a straw;
- medications that help manage pain;

## **Will I receive medication for pain if I have a living will?**

Yes. A living will does not affect the requirement that your doctor provide you with pain medication or care designed solely to maintain your physical comfort (for example, care designed to maintain your circulation or the health of your skin and muscles). This type of care must be provided whenever appropriate.

## **What is a health care representative?**

A health care representative is a person whom you authorize in writing to make any and all health care decisions on your behalf including the decision whether to withhold or withdraw life support systems. A health care representative does not act unless you are unable to make or communicate your decisions about your medical care. The health care representative will make decisions on your behalf based on your wishes, as stated in a living will or as otherwise known to your health care representative. In the event your wishes are not clear or a situation arises that you did not anticipate, your health care representative will make a decision in your best interests, based upon what is known of your wishes.

## **What kind of treatment decisions can be made by a health care representative?**

A health care representative can make any and all health care decisions for you, including the decision to accept or refuse any treatment, service or procedure used to diagnose or treat any physical or mental condition. The health care representative can also make the decision to provide, withhold or withdraw life support systems. The health care representative cannot make decisions for certain specific treatments which by law have special requirements.



### **How will my health care representative know when to get involved in making decisions for me?**

At any time after you appoint your health care representative, your health care representative can ask your attending physician to provide written notice if your physician finds that you are unable to make or communicate your decisions about your medical care. Even if your health care representative does not do so, your health care providers will usually seek out your health care representative once they determine that you are unable to make or communicate your decisions about your medical care.

### **What is a conservator?**

A "conservator of the person" is someone appointed by the Probate Court when the Court finds that a person is incapable of caring for himself/herself including the inability to make decisions about his or her medical care. A person who is conserved by a court is known as a "ward".

The conservator of the person is responsible for making sure that the ward's health and safety needs are taken care of and generally also has the power to give consent for the ward's medical care, treatment and services.

You can name in advance the person you want the Court to appoint as your conservator if you become incapable of making your own decisions. If you have a conservator, he or she will be consulted in all medical care decisions. If you have a living will, however, the conservator's consent is not required to carry out your wishes as expressed in the living will.

If a conservator is later appointed for you, he or she must follow your health care instructions, either as expressed in a living will, or as otherwise known to your conservator made while you were able to make and communicate health care decisions. Further, a conservator cannot revoke your advance directives without a probate court order.

### **How are decisions made if I have both a health care representative and a conservator?**

Generally, the decision of a health care representative will be followed if the conservator and health care representative disagree unless the probate court orders otherwise. This rule may not apply when the conservator has been appointed in some particular situations.

### **What advance directives should I have?**

If you want to be sure that your wishes about your medical care are known if you cannot express them yourself, you should have a living will and you should

also appoint a health care representative. Each of these advance directives has a special importance.

If you are unable to make or communicate your preferences as to your medical care, your physician will likely look first to your living will as the source of your wishes. Your health care representative can make decisions on your behalf according to what is stated in your living will. In situations that are not addressed by your living will, your health care representative can make a decision in your best interests consistent with what is known of your wishes.

### **Who can I name as my health care representative or as my conservator?**

If you wish to you can name the same person to be your health care representative and to be your conservator. The following persons cannot be named your health care representative:

- your physician;
- if you are a patient at a hospital or nursing home or if you have applied for admission, the operators, administrators, and employees of the facility;
- an administrator or employee of a government agency responsible for paying for your medical care.

Other than these restrictions, you can name anyone you feel is appropriate to serve as your health care representative. Of course, you should speak to the person whom you intend to name and be sure of his or her willingness to serve and to act on your wishes.

### **Do I need a lawyer to create an advance directive?**

No. You do not need a lawyer to create an advance directive. You can use the forms in this booklet.

### **Do I need a notary to create an advance directive?**

Except for optional forms, the forms do not require the use of a notary. An additional optional form called a witnesses' affidavit that is included among the forms in this booklet requires a notary public or a lawyer to verify the signature of the witnesses. This form is discussed in more detail in the next section. If you have legal questions, you should consult a lawyer.

### **Do I have to sign my advance directives in front of witnesses?**

Yes. You must sign the document in the presence of two witnesses in order for the advance directives to be valid. The witnesses then sign the form.



For the living will and the appointment of health care representative, an optional form is provided in this booklet. It is called a witnesses' affidavit. It is the witnesses' sworn statement that they saw you sign the living will or appointment form, that you were of sound mind and it was your free choice to do so. In the event that there is a dispute regarding your living will or appointment of a health care representative, the witnesses' affidavits support its validity. This affidavit requires the use of an attorney or notary public. No other form requires the use of a notary or an attorney.

### **Who can witness my signature on an advance directive?**

In general, Connecticut law does not state who may or may not be a witness to your advance directive. An important exception is that the person who you appoint to be your health care representative or as your conservator cannot be a witness to your signature of the appointment form.

### **Once I complete an advance directive what should I do?**

You should tell the following persons that you have completed an advance directive and give them copies of the directives you have made:

- your physician;
- the person(s) you have named as a health care representative;
- anyone who will make the existence of your advance directives known if you cannot do so yourself, such as family members, close friends, your clergy or lawyer.

You should also bring copies with you when you are admitted to a hospital, nursing home or other health care facility. The copies will be made part of your medical record.

### **After I complete an advance directive, can I revoke it?**

Yes. You can revoke your living will or appointment of a health care representative at any time. A living will can be revoked either orally or in writing. If you sign a new living will, it may revoke any prior living will you made.

However, to revoke your appointment of a health care representative, you must do so in writing that is observed and signed by two witnesses in order for the revocation to be valid.

Remember whenever you revoke an advance directive to tell your physician and others who have copies of your advance directive.



To revoke your designation of a conservator, you can do so either in writing or by making a new designation which states that earlier designations are revoked. It is advisable to put any revocation in writing. However, once a court has appointed a conservator, it cannot be revoked without a court order.

**If I already have a living will or appointed someone to make health care decisions, do I need a new one?**

No. Connecticut's living will statutes were revised effective October 1, 2006. If your living will and other advance directives, such as a health care agent or power of attorney for health care, were completed prior to this date, they are still valid, although they are slightly different than the new advance directives.

On October 1, 2006, the health care representative replaced the appointment of a health care agent and power of attorney for health care. The health care representative is, in effect, a combination of these two types of advance directives. The new living will makes clear that the living will can be used to provide your instructions regarding any type of health care, not just life support systems.

**If I don't have an advance directive, how will my wishes be considered if I am unable to speak for myself?**

If you are unable to make and communicate your decision concerning your medical care and you do not have a living will, your physician can consult with other persons to determine what your wishes are regarding the withholding or withdrawal of life support systems. If you have discussed your wishes with your physician, he or she will, of course, know your stated wishes. Your physician may also ask your health care representative, your next of kin or close relatives and your conservator, if one has been appointed, what you have told them about your wishes regarding withholding or withdrawing life support systems. If your wishes are unknown, then decisions will be made based upon what is in your best interests.

It is not recommended that you rely on oral instructions to these individuals to make your wishes known. If there is no living will, such instructions are required to be specific and may need to be proven in a court. You are better advised to complete a living will or appoint a health care representative if you want to be sure that your wishes will be understood and known in the event you are unable to state them yourself.

**What is a document of anatomical gift?**

It is a document in which you make a gift of all or any part of your body to take effect upon death. Any adult may make an anatomical gift in writing, including through a will, a donor card or by a statement imprinted or attached to a motor

vehicle operator's license. An anatomical gift may be made for the purpose of transplants, therapy, research, medical or dental education, or the advancement of medical or dental science. If you do not limit the gift's purpose to one or some of these uses, the gift can be used for any of these purposes. You may select who receives the gift - a hospital, physician, college, or an organ procurement group. You may also specify that the gift be used for transplant or therapy for a particular person. If no one is named to receive the gift, any hospital may do so.

### **Can I revoke an anatomical gift?**

Yes. An anatomical gift may be revoked or changed only by (1) a signed statement; (2) an oral statement in the presence of two witnesses; (3) or by informing your physician if you are in a terminal condition. An anatomical gift may not be revoked after the donor's death.

### **What if I have more questions?**

If you have additional questions about advance directives, discuss them with your physician and family. A social worker, patient representative or chaplain may be able to assist you, but they cannot provide legal advice. If you have legal questions, you should speak with a lawyer.

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## ADVANCE DIRECTIVE FORMS

Three sets of forms are contained in this booklet.

1. A **combined advance directive** form includes all of the advance directives- appointment of health care representative, living will, appointment of conservator and organ donation into one form. In the combined form, there is a place where you can choose to not make or use each kind of directive by signing your initials.
2. An **appointment of health care representative** form if you wish to only appoint a health care representative.
3. A **living will or health care instructions** if you wish to only make your wishes known but not appoint anyone to act on your behalf.

Each form includes the optional witness affidavit form.



**COMBINED ADVANCE  
DIRECTIVES  
FORM**

## ADVANCE DIRECTIVES OF \_\_\_\_\_

To Any Physician Who Is Treating Me, this document contains the following:

1. My Appointment of A Health Care Representative
2. My Living Will or Health Care Instructions
3. My Document of Anatomical Gift
4. The Designation of My Conservator Of The Person For My Future Incapacity

As my physician, you may rely on these health care instructions and decisions made by my health care representative or conservator of my person, if I am unable to make a decision for myself.

I choose not to appoint a health care representative, please go to the next page. \_\_\_\_\_ (Initial here)

### APPOINTMENT OF HEALTH CARE REPRESENTATIVE

I appoint \_\_\_\_\_ to be my health care representative. If my attending physician determines that I am unable to understand and appreciate the nature and consequences of health care decisions and unable to reach and communicate an informed decision regarding treatment, **my health care representative is authorized to (1) accept or refuse any treatment, service or procedure used to diagnose or treat my physical or mental condition, except as otherwise provided by law, such as psychosurgery or shock therapy as defined in Conn. Gen. Stat. § 17a-540, and (2) make the decision to provide, withhold or withdraw life support systems.**

I direct my health care representative to make decisions on my behalf in accordance with my wishes, as stated in this document or as otherwise known to my health care representative. In the event my wishes are not clear or a situation arises that I did not anticipate, my health care representative may make a decision in my best interests, based upon what is known of my wishes.

If \_\_\_\_\_ is unwilling or unable to serve as my health care representative, I appoint \_\_\_\_\_ to be my alternative health care representative.

I further instruct that as required by law my attending physician disclose to my health care representative protected health information regarding my ability to understand and appreciate the nature and consequences of health care decisions and to reach and communicate an informed decision regarding treatment at the representative's request made at anytime after I sign this form.

I choose not to provide Health Care Instructions, please go to the next page. \_\_\_\_\_ (Initial here)

## LIVING WILL or HEALTH CARE INSTRUCTIONS

If the time comes when I am incapacitated to the point when I can no longer actively take part in decisions for my own life, and am unable to direct my physician as to my own medical care, I wish this statement to stand as a statement of my wishes.

I, \_\_\_\_\_, the author of this document, request that, if my condition is deemed terminal or if I am determined to be permanently unconscious, I be allowed to die and not be kept alive through life support systems.

By terminal condition, I mean that I have an incurable or irreversible medical condition which, without the administration of life support systems, will, in the opinion of my attending physician, result in death within a relatively short time. By permanently unconscious I mean that I am in a permanent coma or persistent vegetative state which is an irreversible condition in which I am at no time aware of myself or the environment and show no behavioral response to the environment.

### *Specific Instructions*

Listed below are my instructions regarding particular types of life support systems. This list is not all-inclusive. My general statement that I not be kept alive through life support systems provided to me is limited only where I have indicated that I desire a particular treatment to be provided.

	<u>Provide</u>	<u>Withhold</u>
Cardiopulmonary Resuscitation	_____	_____
Artificial Respiration (including a respirator)	_____	_____
Artificial means of providing nutrition and hydration	_____	_____
_____	_____	_____
_____	_____	_____

Other specific requests: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**I do want sufficient pain medication to maintain my physical comfort. I do not intend any direct taking of my life, but only that my dying not be unreasonably prolonged.**



## DOCUMENT OF ANATOMICAL GIFT

I make no anatomical gift at this time.

\_\_\_\_\_ (Initial here)

I hereby make this anatomical gift, if medically acceptable,  
to take effect upon my death

\_\_\_\_\_ (Initial here)

I give: (check one) \_\_\_\_\_ (1) any needed organs or parts  
\_\_\_\_\_ (2) only the following organs or parts:

\_\_\_\_\_

to be donated for: (check one)

\_\_\_\_\_ (1) any of the purposes stated in subsection (a) of section 19a-279f of the general statutes

\_\_\_\_\_ (2) these limited purposes \_\_\_\_\_.

## DESIGNATION OF A CONSERVATOR OF THE PERSON

I choose not to designate a person to be appointed as my conservator. \_\_\_\_\_ (Initial here)

If a conservator of my person should need to be appointed, I designate  
\_\_\_\_\_, be appointed my conservator.

If this person is unwilling or unable to serve as my conservator of my person, I designate  
\_\_\_\_\_ be appointed my conservator.

No bond shall be required of either of them in any jurisdiction.

**These requests, appointments, and designations are made after careful reflection, while I am of sound mind. Any party receiving a duly executed copy or facsimile of this document may rely upon it unless such party has received actual notice of my revocation of it.**

X \_\_\_\_\_ L.S. Date \_\_\_\_\_, 20\_\_\_\_

## WITNESSES' STATEMENTS

This document was signed in our presence by \_\_\_\_\_ the author of this document, who appeared to be eighteen years of age or older, of sound mind and able to understand the nature and consequences of health care decisions at the time this document was signed. The author appeared to be under no improper influence. We have subscribed this document in the author's presence and at the author's request and in the presence of each other.

X \_\_\_\_\_  
(Witness)

X \_\_\_\_\_  
(Number and Street)

X \_\_\_\_\_  
(City, State and Zip Code)

X \_\_\_\_\_  
(Witness)

X \_\_\_\_\_  
(Number and Street)

X \_\_\_\_\_  
(City, State and Zip Code)

OPTIONAL FORM

**WITNESSES' AFFIDAVITS**

STATE OF CONNECTICUT

COUNTY OF \_\_\_\_\_

)  
)  
) :ss. \_\_\_\_\_  
) (Town)  
)

We, the subscribing witnesses, being duly sworn, say that we witnessed the execution of these health care instructions, the appointment of a health care representative, the designation of a conservator for future incapacity and a document of anatomical gift by the author of this document; that the author subscribed, published and declared the same to be the author's instructions, appointments and designation in our presence; that we thereafter subscribed the document as witnesses in the author's presence, at the author's request and in the presence of each other; that at the time of the execution of said document the author appeared to us to be eighteen years of age or older, of sound mind, able to understand the nature and consequences of said document, and under no improper influence, and we make this affidavit at the author's request this \_\_\_\_\_ day of \_\_\_\_\_, 20\_\_\_\_.

x \_\_\_\_\_  
(Witness)  
x \_\_\_\_\_  
(Number and Street)  
x \_\_\_\_\_  
(City, State and Zip Code)

x \_\_\_\_\_  
(Witness)  
x \_\_\_\_\_  
(Number and Street)  
x \_\_\_\_\_  
(City, State and Zip Code)

Subscribed and sworn to before me by \_\_\_\_\_ and \_\_\_\_\_,  
the signing witnesses to the foregoing affidavit this \_\_\_\_\_ day of \_\_\_\_\_,  
20\_\_\_\_.

\_\_\_\_\_  
Commissioner of the Superior Court  
Notary Public  
My Commission expires: \_\_\_\_\_

(Print or type name of all persons signing under all signatures)

**APPOINTMENT OF  
HEALTH CARE  
REPRESENTATIVE  
FORM**



## APPOINTMENT OF HEALTH CARE REPRESENTATIVE

I understand that, as a competent adult, I have the right to make decisions about my health care. There may come a time when I am unable, due to incapacity, to make my own health care decisions. In these circumstances, those caring for me will need direction and will turn to someone who knows my values and health care wishes. By signing this appointment of health care representative, I appoint a health care representative with legal authority to make health care decisions on my behalf in such case or at such time.

I appoint \_\_\_\_\_ to be my health care representative. If my attending physician determines that I am unable to understand and appreciate the nature and consequences of health care decisions and to reach and communicate an informed decision regarding treatment **my health care representative is authorized to (1) accept or refuse any treatment, service or procedure used to diagnose or treat my physical or mental condition, except as otherwise provided by law, such as psychosurgery or shock therapy as defined in Conn. Gen. Stat. § 17a-540, and (2) make the decision to provide, withhold or withdraw life support systems.**

I direct my health care representative to make decisions on my behalf in accordance with my wishes as stated in a living will, or as otherwise known to my health care representative. In the event my wishes are not clear or a situation arises that I did not anticipate, my health care representative may make a decision in my best interests, based upon what is known of my wishes.

If \_\_\_\_\_ is unwilling or unable to serve as my health care representative, I appoint \_\_\_\_\_ to be my alternative health care representative.

This request is made, after careful reflection, while I am of sound mind.

\_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_ (Date)      X \_\_\_\_\_

### WITNESSES' STATEMENTS

This document was signed in our presence by \_\_\_\_\_ the author of this document, who appeared to be eighteen years of age or older, of sound mind and able to understand the nature and consequences of health care decisions at the time this document was signed. The author appeared to be under no improper influence. We have subscribed this document in the author's presence and at the author's request and in the presence of each other.

X \_\_\_\_\_  
(Witness)

X \_\_\_\_\_  
(Number and Street)

X \_\_\_\_\_  
(City, State and Zip Code)

X \_\_\_\_\_  
(Witness)

X \_\_\_\_\_  
(Number and Street)

X \_\_\_\_\_  
(City, State and Zip Code)

OPTIONAL FORM

**WITNESSES' AFFIDAVITS**

STATE OF CONNECTICUT

COUNTY OF \_\_\_\_\_

)  
)  
) :ss. \_\_\_\_\_  
) (Town)  
)

We, the subscribing witnesses, being duly sworn, say that we witnessed the execution of this appointment of a health care representative by the author of this document; that the author subscribed, published and declared the same to be the author's instructions, appointments and designation in our presence; that we thereafter subscribed the document as witnesses in the author's presence, at the author's request and in the presence of each other; that at the time of the execution of said document the author appeared to us to be eighteen years of age or older, of sound mind, able to understand the nature and consequences of said document, and under no improper influence, and we make this affidavit at the author's request this \_\_\_\_ day of \_\_\_\_\_, 20\_\_\_\_.

x \_\_\_\_\_  
(Witness)  
x \_\_\_\_\_  
(Number and Street)  
x \_\_\_\_\_  
(City, State and Zip Code)

x \_\_\_\_\_  
(Witness)  
x \_\_\_\_\_  
(Number and Street)  
x \_\_\_\_\_  
(City, State and Zip Code)

Subscribed and sworn to before me by \_\_\_\_\_ and \_\_\_\_\_,  
the signing witnesses to the foregoing affidavit this \_\_\_\_ day of \_\_\_\_\_,  
20\_\_\_\_.

\_\_\_\_\_  
Commissioner of the Superior Court  
Notary Public  
My Commission expires: \_\_\_\_\_

(Print or type name of all persons signing under all signatures)

**LIVING WILL OR  
HEALTH CARE  
INSTRUCTIONS  
FORM**



## LIVING WILL or HEALTH CARE INSTRUCTIONS

If the time comes when I am incapacitated to the point when I can no longer actively take part in decisions for my own life, and am unable to direct my physician as to my own medical care, I wish this statement to stand as a statement of my wishes.

I, \_\_\_\_\_, the author of this document, request that, if my condition is deemed terminal or if I am determined to be permanently unconscious, I be allowed to die and not be kept alive through life support systems.

By terminal condition, I mean that I have an incurable or irreversible medical condition which, without the administration of life support systems, will, in the opinion of my attending physician, result in death within a relatively short time. By permanently unconscious I mean that I am in a permanent coma or persistent vegetative state which is an irreversible condition in which I am at no time aware of myself or the environment and show no behavioral response to the environment.

### *Specific Instructions*

Listed below are my instructions regarding particular types of life support systems. This list is not all-inclusive. My general statement that I not be kept alive through life support systems provided to me is limited only where I have indicated that I desire a particular treatment to be provided.

	<u>Provide</u>	<u>Withhold</u>
Cardiopulmonary Resuscitation	_____	_____
Artificial Respiration (including a respirator)	_____	_____
Artificial means of providing nutrition and hydration	_____	_____
_____	_____	_____
_____	_____	_____

Other specific requests: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**I do want sufficient pain medication to maintain my physical comfort. I do not intend any direct taking of my life, but only that my dying not be unreasonably prolonged.**

This request is made, after careful reflection, while I am of sound mind.

\_\_\_\_\_ / \_\_\_\_\_ / \_\_\_\_\_ (Date)      X \_\_\_\_\_

## WITNESSES' STATEMENTS

This document was signed in our presence by \_\_\_\_\_ the author of this document, who appeared to be eighteen years of age or older, of sound mind and able to understand the nature and consequences of health care decisions at the time this document was signed. The author appeared to be under no improper influence. We have subscribed this document in the author's presence and at the author's request and in the presence of each other.

x \_\_\_\_\_  
(Witness)

x \_\_\_\_\_  
(Number and Street)

x \_\_\_\_\_  
(City, State and Zip Code)

x \_\_\_\_\_  
(Witness)

x \_\_\_\_\_  
(Number and Street)

x \_\_\_\_\_  
(City, State and Zip Code)

OPTIONAL FORM

**WITNESSES' AFFIDAVITS**

STATE OF CONNECTICUT

COUNTY OF \_\_\_\_\_

)  
)  
) :ss. \_\_\_\_\_  
) (Town)  
)

We, the subscribing witnesses, being duly sworn, say that we witnessed the execution of this living will or health care instructions by the author of this document; that the author subscribed, published and declared the same to be the author's instructions, appointments and designation in our presence; that we thereafter subscribed the document as witnesses in the author's presence, at the author's request and in the presence of each other; that at the time of the execution of said document the author appeared to us to be eighteen years of age or older, of sound mind, able to understand the nature and consequences of said document, and under no improper influence, and we make this affidavit at the author's request this \_\_\_\_\_ day of \_\_\_\_\_, 20\_\_\_\_.

x \_\_\_\_\_  
(Witness)  
x \_\_\_\_\_  
(Number and Street)  
x \_\_\_\_\_  
(City, State and Zip Code)

x \_\_\_\_\_  
(Witness)  
x \_\_\_\_\_  
(Number and Street)  
x \_\_\_\_\_  
(City, State and Zip Code)

Subscribed and sworn to before me by \_\_\_\_\_ and \_\_\_\_\_,  
the signing witnesses to the foregoing affidavit this \_\_\_\_\_ day of \_\_\_\_\_,  
20\_\_\_\_.

\_\_\_\_\_  
Commissioner of the Superior Court  
Notary Public  
My Commission expires: \_\_\_\_\_

(Print or type name of all persons signing under all signatures)



# Connecticut Long Term Care Ombudsman Program

[CT.gov Home](#) / [Long Term Care Ombudsman Program](#) / Your Legal Rights

## Your Legal Rights As an Individual Receiving Long Term Services and Supports

We are all protected by certain legal rights that seek to provide each of us with fair treatment and quality care, safe from discrimination, fear or abuse. Understanding your legal rights, benefits and obligations is crucial to maximizing the use of the long term services and supports you receive.

The Connecticut Long Term Care Ombudsman Program has created this page to provide you with links and pertinent information to help you to do just that.

### Learning About Your Legal Rights

One centralized resource that the state of Connecticut offers regarding your legal rights is [My Place CT](#). My Place CT is a free web based resource center created specifically for individuals in Connecticut. Once on the [My Place CT Legal Rights Web Page](#), you can use the menus to find subjects that best match your needs.

- The Legal Matters section addresses issues, such as living wills, powers of attorney, conservators and other legal matters that are important to understand when planning for your future.
- The Consumer Rights section will help you recognize and understand your rights within the system of services and supports for older adults and persons with disabilities.
- The Legal Resources section will point you to organizations that can provide additional information and help.

Another General Resource for Connecticut Residents is [CT Law Help](#). [CTLawHelp.org](#) was created by several nonprofit legal services organizations whose shared mission is to improve the lives of Connecticut's poorest citizens by providing free legal services to people with low income. The website is funded by the [Connecticut Bar Foundation](#) and the [Legal Services Corporation](#), and seeks to further the goal of equal access to justice by providing information and self-help materials on legal issues affecting people with low income.

## Legal Resources - Where to Get Help

- For concerns over your care, or if you feel your rights have been violated, you should contact the nursing home administrator or a staff member in charge.
- You can also [contact us](#) at the CT Long-Term Care Ombudsman Program by calling us at [1-866-388-1888](#) (Toll-Free) or by Email at [LTCOP@CT.GOV](mailto:LTCOP@CT.GOV).
- You can also file a complaint with the [Department of Public Health](#).

For additional information on the legal rights and benefits available to older adults and people with disabilities, review the resources below:

### Obtaining Legal Assistance

#### Connecticut Network for Legal Aid

This network of several nonprofit legal services organizations has a shared mission to improve the lives of Connecticut's low-income residents by providing free legal services. Their goal is to offer equal access to justice by providing information and self-help materials on a variety of legal issues.

Explore the [Connecticut Network for Legal Aid](#) website for contact and eligibility information as well as extensive legal self-help information and tools. Services are free.

### Consumer Law Project for Elders (CLPE)

The CLPE Hotline provides free legal assistance, including advice, representation and referrals to people aged 60 and over who have consumer problems or questions about their rights as consumers. Call [1-800-296-1467](#) (Toll-Free) to be connected with a legal specialist.

### Need a Lawyer?

Local and county bar associations offer lawyer referral services to help you find a private attorney in your county. There may be a fee for the referral and for services from private attorneys.

#### Area | Telephone

Hartford, Litchfield, Middlesex, Tolland and Windham

[1-860-525-6052](#)

Fairfield

[1-203-335-4116](#)

New Haven

[1-203-562-5750](#)

New London

[1-860-889-9384](#)

### Other Legal Service Resources

There are also a number of legal services organizations that provide free legal help to those who qualify. One of the organizations listed below may be able to help. Contact them directly for information about their services and eligibility requirements.

- **[Connecticut Legal Services](#):** A nonprofit law firm dedicated to representing, advising and educating low-income individuals and families in matters relating principally to civil law and thereby helping them secure the protections, privileges, benefits, rights and opportunities these laws provides.
- **[Greater Hartford Legal Aid](#):** A not-for-profit law firm whose staff helps clients with civil (not criminal) legal issues. They are advocates, primarily lawyers and paralegals, who know how to serve people who have little money.
- **[New Haven Legal Assistance](#):** Provides high-quality legal services to individuals, families and groups in the greater New Haven area, including the lower Naugatuck Valley, who are unable to obtain legal services because of limited income, age, disability, discrimination, and other barriers.
- **[Statewide Legal Services of Connecticut \(SLS\)](#):** A private, nonprofit corporation dedicated to helping as many low-income people possible to understand their civil (non-criminal) legal problems. They cooperate with other nonprofit law firms and volunteer attorneys to provide a broad range of legal services to Connecticut's poor.

- **Disability Rights Connecticut (DRCT)**: In addition to conducting investigations, educating policy makers, and challenging discriminatory barriers in court, we can help individuals with disabilities understand and exercise their rights. When you contact DRCT, you will be given information about disability rights, referred to experts and resources, empowered in your advocacy efforts and provided representation consistent with DRCT's mandates, priorities and resources. The agency also provides public education and training and informs policymakers about issues affecting people with disabilities.

[\(DRCT Programs and Services English\)](#)

[\(DRCT Programs and Services Spanish\)](#)

[\(DRCT Poster English\)](#)

[\(DRCT Poster Spanish\)](#)

## National Law Advocacy Groups

**The National Center on Law & Elder Rights (NCLER)**: The National Center on Law and Elder Rights (NCLER) provides the legal services and aging and disability communities with the tools and resources they need to serve older adults with the greatest economic and social needs. A centralized, one-stop shop for legal assistance, NCLER provides Legal Training, Case Consultations, and Technical Assistance on Legal Systems Development. Justice in Aging administers NCLER through a contract with the Administration for Community Living's Administration on Aging.

**The National Academy of Elder Law Attorneys (NAELA)**: Members of the NAELA are attorneys who are experienced and trained in working with the legal problems of older Americans with disabilities. Elder and special needs law includes helping such persons and their families with planning for incapacity and long-term care, Medicaid and Medicare coverage (including coverage of nursing home and home care), health and long-term care insurance, and healthcare decision making. It also includes drafting of supplemental needs and other trusts, the selection of long-term care providers, home care and nursing home problems solving, retiree health and income benefits, retirement housing, and fiduciary services or representation. Established in 1987, NAELA is a non-profit association that assists lawyers, bar organizations, and others. NAELA's mission is to educate, inspire, serve and provide community to attorneys with practices in elder and special needs law. NAELA currently has members across the United States, Canada, Australia and the United Kingdom.

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# Frequently Asked Questions About Powers of Attorney

April 2019 by CLS

## What is a Power of Attorney?

A Power of Attorney is a legal document you use to allow another person to act for you. You create a legal relationship in which you are the principal and the person you appoint is the agent. A Power of Attorney specifies the powers you give to your agent. The powers can be limited or broad. For example, if you are selling your house, but unable to attend the closing, you can give someone the power just to sign the deed in your absence. Most durable powers of attorney, however, give your agent the power to do almost anything you could do.

Banks, brokerage firms, and other financial institutions may require you to sign one of their own forms. The CT law requires that these third parties accept the power of attorney if it's acknowledged. The law provides for a process for verification if there are still questions.

## What does "durable" mean?

All Powers of Attorney executed in Connecticut are presumed to be 'durable' unless stated otherwise. The word 'durable' means the Power of Attorney will still be effective if the principal becomes mentally incapacitated. A Power of Attorney in Connecticut no longer needs to state that "this Power of Attorney shall not be affected by the subsequent disability or incompetence of the principal" or similar words. The powers you give to your agent will remain effective when you are unable to give your agent instructions. Older power of attorneys and out of state powers of attorney may still have these words, and remain effective. You or your attorney may still choose to include those words, or the word 'durable' in the new Connecticut powers of attorney. But if not, your power of attorney is durable unless otherwise stated.

## When does the Power of Attorney take effect?

The Power of Attorney is effective as soon as you sign it before two witnesses and have it notarized. You may give the Power of Attorney to your agent(s) and tell the person(s) not to use it unless you are unconscious or unable to act for yourself. However, the agent could use the Power of Attorney as soon as he or she receives it.

Some people may choose to use a "springing" Power of Attorney. A springing Power of Attorney is one that only becomes effective if a specific triggering event happens, such as your incapacity. There are two types of springing Powers of Attorney. First, the agent needs an affidavit showing that the agent can use the Power of Attorney. Then, even though the agent has the Power of Attorney, the agent cannot use it until the agent has accepted the document with the affidavit. In other states, the agent's power under a springing Power of Attorney is not accepted in other states.

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If I give someone a Power of Attorney, does that risk my money any more?

**No.** When you give someone a Power of Attorney, you still have the right to control your money and property. However, you are giving your agent the ability to access your money. Your agent is not supposed to take or use your money without your permission, but there is a risk that a dishonest or unscrupulous agent might steal your money. It is therefore very important to choose an agent you trust. You should go over the agent's duties before you sign your power of attorney.

## Can the Power of Attorney be used by the agent to take my money or property without my permission?

There is a risk that the agent you choose to give your Power of Attorney may abuse the power by taking or spending your money without your knowledge or permission. Because the agent can use the Power of Attorney to access your bank account and sell your property, do not give your Power of Attorney to anyone you do not trust with your money or property. It can be very difficult to get back money or property taken by the agent, because the agent usually has no money left to return. The agent may also sell your property, or mortgage it, making it worth less.

## If I think someone is using my Power of Attorney to steal from me, what can I do?

First, you should **revoke the Power of Attorney**.

Second, notify all banks or other financial institutions in which you have money that you have revoked the Power of Attorney

Third, you can go to the probate court (by yourself or through an attorney) and demand that the agent you suspect of stealing from you **file an accounting** showing how the money was spent. You will need to pay a filing fee and possibly pay the agent for the cost of preparing the accounting. The court will hold a hearing at which time you can challenge the information given in the accounting. Ultimately, if the court finds the agent took your money without your permission, you can sue the agent or possibly press criminal charges.

## How can I revoke my Power of Attorney?

If you have not given the Power of Attorney to anyone, you can revoke it by destroying the document. The Power of Attorney cannot be used unless the agent has it or it (or a copy) has already been given to banks, financial institutions or others so that they think you want the agent to act on your behalf.

If the Power of Attorney has been given to the agent, an institution, or has already been recorded, you should execute a document revoking the Power of Attorney that is witnessed and acknowledged in the same manner as the first Power of Attorney. A **revocation** is included on this website. Then you will need to give a copy of the Revocation to the banks or others so that they know the Power of Attorney is no longer good.

Connecticut law does *not* provide that a new Power of Attorney is possible to have more than one agent with your Power of Attorney with an attorney.

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What is the difference between a "short form" and

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The "statutory short form" Power of Attorney is the most common Power of Attorney form available on line and sold in Connecticut stores. The document lists only the powers given to the agent. It is "short" because it does not include the paragraph that describes each power in detail NOR DOES IT PROVIDE FOR ESTATE PLANNING POWERS. **IMPORTANT:** In the statutory short form, ALL the powers listed are included; you should initial the boxes only to DELETE certain powers. The SAMPLE short form Power of Attorney can be found here. The statute that describes the powers can be found here.

A "statutory long form" Power of Attorney is available if you wish to give your agent additional "hot powers" or ESTATE PLANNING POWERS. **IMPORTANT:** *In the long form the hot powers must be initialed IF YOU GRANT THEM TO YOUR AGENT. These powers are broad and sweeping and should only be granted after consultation with an attorney.* If you execute either a "statutory short form" or "statutory long form" Power of Attorney, it would be wise to keep a copy of the statute handy. You can read the statute here: **Power of Attorney Statute.**

## I have a Power of Attorney I signed in another state. Can I use it in Connecticut?

Most Powers of Attorney signed in other states will be recognized in Connecticut. In general, a Power of Attorney used to convey title to real estate, must be signed, dated, witnessed by two people, and "acknowledged" or notarized by a notary public or court official. (State laws govern who is authorized to take "acknowledgments.") The practical question is not whether the Power of Attorney is valid, but whether a financial institution will honor it. Also, if the document refers to statutes from another state, you may have to provide a copy of those statutes.

The law may be different in the state where you signed your Power of Attorney. Even if the document lists the same or similar powers, they may have a different meaning when used in Connecticut. Also, many states have different statutory protections for people signing a Power of Attorney.

## Do I need to get a new Power of Attorney if I move to a different state?

When you move to a different state, you should always consult a local attorney to see whether your Power of Attorney will be effective the way you intended.

In some states, a Power of Attorney is not "durable" unless it is "*recorded*," that is, filed with local government. In addition, there may be special rules about how it is revoked. Check with a local attorney.

## Why do I need a Power of Attorney?

A Power of Attorney can be very helpful to you and your family. If you were unable to handle your own affairs as a result of illness, accident, or even absence, the Power of Attorney gives your agent the power to handle your affairs as you would handle them yourself. You might not be able to execute a Power of Attorney at a time when you are disabled due to an accident. If you are unable to handle your own affairs and have no Power of Attorney, your spouse or family member can ask the Court to appoint a Conservator of the Estate (COE) for you. The Court will then require the COE to file an inventory, and prepare accountings. Sometimes this is a lot of expense. We prefer to avoid the expense of probate court by naming their Attorney.

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## Where should I keep my Power of Attorney?

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Your Power of Attorney is an important legal document. Keep it in a safe and secure place. You may wish to give a copy to your agent(s) or inform them of a place where it can be easily found. Your agent may keep a copy in case yours is lost. Make sure your family knows where to find your Power of Attorney, or whom to ask when it is needed.

### **Do I need to update my Power of Attorney if nothing has changed?**

Some banks and financial institutions will try to reject a Power of Attorney that is several years old because of the possibility that the Power of Attorney has been revoked. There are several options to prepare for this. If you remain competent, it is prudent to re-execute your Power of Attorney every five years or so.

It is always a good idea to review your Power of Attorney periodically to make sure you still agree with your choices.

If you are no longer competent, your agent can sign an affidavit that your power of attorney is in full force and affect and provide that to the financial institution.

CT law requires banks and other third parties to accept your power of attorney if it's properly acknowledged. If the bank has remaining questions there is a written procedure that they must follow before they can reject the power of attorney.

### **Do I need the original power of attorney?**

CT law states, "unless a power of attorney otherwise provides, a photocopy or electronically transmitted copy of an original power of attorney has the same effect as the original."

### **Do powers of attorney cover digital assets?**

A digital asset is defined by the CT Revised Uniform Fiduciary Access to Digital Assets Act, effective 1 OCT 2016, as "...an electronic record in which an individual has a right or interest." such as electronic records, emails, social media accounts, digital files, and virtual currency. The statutory SHORT FORM power of attorney forms do not automatically give this power to your agent. You must add this power in the statutory SHORT FORM power of attorney forms if you want your agent to have it.

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# Connecticut Judicial Branch Law Libraries



 [Ask a Librarian](#)

## Connecticut Law About Powers of Attorney

These links connect to resources available and are provided with the understanding that they represent only a starting point for research.

 This web page has many external links to valuable resources. Please view our [Linkage Policy](#) for more information.

See Also: [Law About Living Wills](#)

### Research Guides and Information

#### Information from the Connecticut Probate Courts:

- [New Power of Attorney Law Takes Effect October 1st, 2016](#)

#### Information from CTLawHelp.Org

- [Powers of Attorney](#)
  - [Frequently Asked Questions about Powers of Attorney in Connecticut](#)
  - [Durable Statutory Power of Attorney - Short Form](#)
  - [Revocation of Power of Attorney Form](#)

#### OLR Research Reports - Office of Legislative Research:

*Office of Legislative Research reports summarize and analyze the law in effect on the date of each report's publication. Current law may be different from what is discussed in the reports.*

- [Power of Attorney "Hot Powers" - 2020-R-0285](#)  
*Summarize Connecticut's power of attorney "hot powers" statute.*
- [Durable Power of Attorney - 2007-R-0372](#)  
*You asked (1) whether there is any state oversight of people granted durable power of attorney and (2) what sanctions might apply if a person granted this power took advantage of the grantor, for example by misappropriating his property.*
- [Power of Attorney - Revocative - 2005-R-0669](#)  
*You asked how a person might revoke a power of attorney? Our office is not authorized to give legal opinions and*

### Recent Public Acts

- [Public Act 17-91](#) - *An Act Adopting The Connecticut Uniform Recognition of Substitute Decision-Making Documents Act and Revising The Connecticut Uniform Power of Attorney Act*
  - [Summary](#)
- [Public Act 16-40](#) - *An Act Concerning Revisions to the Connecticut Uniform Power of Attorney Act*
  - [Summary](#)
- [Public Act No. 15-240](#) - *An Act Concerning Adoption of the Connecticut Uniform Power of Attorney Act*
  - [Summary](#)

### Connecticut General Statutes

#### Selected statutes:

- [Chapter 15C - Connecticut Uniform Power of Attorney Act](#)
  - [Sec. 1-350 et seq.](#)

[Sec. 1-352](#) *Power of attorney short form, long form and optional information form.*

Click on the link below to search the full-text of the statutes:

[https://search.cga.state.ct.us/r/statute/dtsearch\\_form.asp](https://search.cga.state.ct.us/r/statute/dtsearch_form.asp)

### Recent Case Law

#### Connecticut Appellate Court:

- [Kindred Nursing Centers East, LLC v. Morin](#), 125 Conn. App. 165, 7 A. 3d 919 (2010). "Under our common law, a power of attorney creates a formal contract of agency between the grantor and his attorney in fact. *Long v. Schull*, 184 Conn. 252, 256, 439 A.2d 975 (1981). Under our statutory law, this agency relationship encompasses a variety of transactions that the grantor presumptively has authorized his attorney in fact

*this report should not be considered one.*

- Joint Power of Attorney - 2002-R-0758  
*You asked if someone gives a power of attorney to two people in the same document, do both have to sign a deed on the principal's behalf.*
- Power of Attorney - Mental Capacity - 2002-R-0094  
*You asked about the mental capacity requirements for someone who wishes to execute a power of attorney.*

to undertake on his behalf. General Statutes Sec. 1-42 et seq. The central issue in this case is whether, pursuant to these established legal principles, a person to whom a resident of a nursing home has given a power of attorney has a duty to assist the nursing home in securing the continuation of the resident's eligibility for medicaid financing."

### Library Materials

- Connecticut Estates Practice: Incapacity, Powers of Attorney and Adoption in Connecticut, 4th edition, by Ralph H. Folsom, Laura Weintraub Beck & Daniel P. Fitzgerald
  - *Chapter 6: Powers of Attorney*
- Connecticut Estate Planning, Wills and Trusts Library, by Robert F. Cohn.
  - *Chapter 30: Durable Powers of Attorney for Financial Matters*
- Durable Powers of Attorney and Health Care Directives, by Michael L. M. Jordan

Search the [online catalog](#) for availability and locations.

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