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The National Long-Term Care Ombudsman Resource Center

# **MODULE THREE**

## **Putting the Resident First**

## **TRAINEE MANUAL**

January 2022

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## Section 1:

## **Welcome and Introduction**

## Welcome

Welcome to Module 3 of certification training, *Putting the Resident First*. Thank you for being here to learn more about the Long-Term Care Ombudsman program and resident-centered advocacy.

## Module 3 Agenda

- Section 1: Welcome and Introduction
- Section 2: Person-Centered Care
- Section 3: Decision Making
- Section 4: Advance Planning and Third-Party Decision Makers
- Section 5: Empowerment
- Section 6: Resident Assessments and Care Plans
- Section 7: Resident Councils and Family Councils
- Section 8: Conclusion

## **Module 3 Learning Objectives**

After completion of Module 3 you will understand:

- Person-centered care
- Advance planning and decision-making authority
- The importance of empowerment
- Assessment and care plans
- Resident Councils and Family Councils

## Module 3 Key Words and Terms

The key words and terms are defined relative to Ombudsman program practices and are found throughout this Module. Take a moment to familiarize yourself with this important information.

**Centers for Medicare & Medicaid Services (CMS)** – A division within the U.S. Department of Health and Human Services. CMS administers the nation's major healthcare programs, including Medicare and Medicaid.

**Culture Change** – The common name given to the national movement based on persondirected values and practices to ensure long-term services and supports are "directed by and centered on" the person receiving care.<sup>1</sup>

**Empowerment** – This is a primary role of the Long-Term Care Ombudsman program in which representatives provide the tools (e.g., information about residents' rights, facility responsibilities), encouragement, and assistance to promote resident self-advocacy.

**Family Council** – A group of residents' family members that meets regularly to discuss and offer suggestions about facility policies and procedures affecting residents' care, treatment, and quality of life; support each other; plan resident and family activities; participate in educational activities; or for any other purpose.<sup>2</sup>

**Fiduciary** – A person or organization with a legal or ethical relationship with an individual who is required to act in the individual's best interest.

**Highest Practicable Level of Well-Being** – The highest possible level of physical, mental, and psychosocial function a resident can maintain or achieve.

**Hospice** – An agency or organization that provides care to terminally ill individuals and has a valid Medicare provider agreement. Some hospices are located within a hospital, nursing facility, or a home health agency.<sup>3</sup>

**Informed Consent** – The permission from a resident or a resident representative after a full explanation has been given of the facts, options, and possible outcomes of such options in the manner and language in which the resident or resident representative understands.

**Long-Term Care Ombudsman Programs Final Rule (LTCOP Rule)** – The Federal Rule that governs the Long-Term Care Ombudsman program (45 CFR Part 1324).<sup>4</sup>

<sup>&</sup>lt;sup>1</sup> What Is Culture Change? Pioneer Network. <u>https://www.pioneernetwork.net/elders-families/what-is-culture-change/</u>

<sup>&</sup>lt;sup>2</sup> State Operations Manual Appendix PP Guidance to Surveyors DEFINITIONS §483.10(f)(5)-(7)

<sup>&</sup>lt;sup>3</sup> <u>https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandComplianc/Hospices</u>

<sup>&</sup>lt;sup>4</sup> https://www.govinfo.gov/content/pkg/CFR-2017-title45-vol4/xml/CFR-2017-title45-vol4-part1324.xml

**Medicaid** – A state and federal assistance program that serves low-income people of every age. It is run by state and local governments following federal guidelines.<sup>5</sup>

**Medicare** – A federal insurance program run by CMS for those who have paid into the program. It serves people over 65 years of age, regardless of their income, younger individuals with disabilities, and persons on dialysis.<sup>6</sup>

**Minimum Data Set 3.0 (MDS, MDS 3.0)** – A federally mandated assessment of all residents in Medicare and Medicaid certified nursing facilities. MDS assessments are conducted upon admission, throughout the resident's stay and upon discharge. The data from the assessments is transmitted electronically using the MDS national database at CMS.<sup>7</sup>

**Office of the State Long-Term Care Ombudsman (Office, OSLTCO)** – As used in sections 711 and 712 of the Act, means the organizational unit in a State or territory which is headed by a State Long-Term Care Ombudsman.<sup>8</sup>

**Ombudsman** – A Swedish word meaning agent, representative, or someone who speaks on behalf of another. For the purposes of this manual, the word "Ombudsman" means the State Long-Term Care Ombudsman.

**Omnibus Budget Reconciliation Act of 1987 (OBRA '87)** – Also known as the "Federal Nursing Home Reform Act."

**Preadmission Screening and Resident Review (PASRR)** – A federally required assessment tool to help ensure that persons with mental illness or developmental disabilities are not inappropriately admitted to nursing facilities.

**Representatives of the Office of the State Long-Term Care Ombudsman** (**Representatives**) – As used in sections 711 and 712 of the Act, means the employees or volunteers designated by the Ombudsman to fulfill the duties set forth in \$1324.19(a), whether personnel supervision is provided by the Ombudsman or his or her designees or by an agency hosting a local Ombudsman entity designated by the Ombudsman pursuant to section 712(a)(5) of the Act.<sup>9</sup>

**Resident Council** – A group of residents that meets regularly to discuss and offer suggestions about facility policies and procedures affecting residents' care, treatment, and quality of life; support each other; plan resident and family activities; participate in educational activities; or for any other purpose.<sup>10</sup>

<sup>8</sup> 45 CFR Part 1324 Subpart A §1324.1 Definitions

<sup>&</sup>lt;sup>5</sup> <u>https://www.hhs.gov/answers/medicare-and-medicaid/what-is-the-difference-between-medicare-medicaid/index.html</u>
<sup>6</sup> <u>http://www.medicare.gov</u>

<sup>&</sup>lt;sup>7</sup> Centers for Medicare & Medicaid Services retrieved from <u>https://www.cms.gov/Research-Statistics-Data-and-Systems/Computer-Data-and-Systems/Minimum-Data-Set-3-0-Public-Reports</u>

<sup>&</sup>lt;sup>9</sup> 45 CFR Part 1324 Subpart A §1324.1 Definitions

<sup>&</sup>lt;sup>10</sup> State Operations Manual Appendix PP Guidance to Surveyors DEFINITIONS §483.10(f)(5)-(7)

**Resident Representative** – An individual chosen by the resident to act on their behalf, or a person authorized by federal or state law (e.g., agent under a Power of Attorney, representative payee, and other fiduciaries) to act on behalf of a resident in order to support the resident in decision-making; access medical, social, or other personal information of the resident; manage financial matters; or receive notifications; legal representative (as used in Section 712 of the Act), or a court-appointed guardian or conservator of a resident.<sup>11</sup>

**Residential Care Community (RCC)** – A type of long-term care facility as described in the Older Americans Act (Act) that, regardless of setting, provides, at a minimum, room and board, around-the-clock on-site supervision, and help with personal care such as bathing and dressing or health-related services such as medication management. Facility types include but are not limited to: assisted living; board and care homes; congregate care; enriched housing programs; homes for the aged; personal care homes; adult foster/ family homes; and shared housing establishments that are licensed, registered, listed, certified, or otherwise regulated by a state.<sup>12</sup>

**Skilled Nursing Facility or Nursing Facility** – Also known as a "nursing home," is a certified facility that provides skilled nursing care for residents who require medical or nursing care rehabilitation or provides health-related care and services to individuals who, because of their mental or physical condition, require care and services (above the level of room and board) which can be made available to them only through institutional facilities.<sup>13</sup> For the purposes of this training and to be consistent with the National Ombudsman Reporting System (NORS), we use the term "nursing facility" for both skilled nursing facilities and nursing facilities.<sup>14</sup>

**Social Security Administration (SSA)** – A government agency that administers Social Security, a social insurance program with retirement, disability, and survivor benefits.<sup>15</sup>

State Long-Term Care Ombudsman (Ombudsman, State Ombudsman) – As used in sections 711 and 712 of the Act, means the individual who heads the Office and is responsible personally, or through representatives of the Office, to fulfill the functions, responsibilities, and duties set forth in §1324.13 and §1324.19.

<sup>&</sup>lt;sup>11</sup> LTCOP Final Rule §1324.1 Definitions <u>https://www.govinfo.gov/content/pkg/CFR-2017-title45-vol4/xml/CFR-2017-title45-vol4-part1324.xml</u>

<sup>&</sup>lt;sup>12</sup> CA-04 02 Residential Care Community Table 1 Part C Case and Complaint Definitions https://ltcombudsman.org/uploads/files/support/NORS\_Table\_1\_Case\_Level\_10-31-2024.pdf

<sup>&</sup>lt;sup>13</sup> This definition is a combination of Requirements for, and assuring Quality of Care in, Skilled Nursing Facilities, Section 1819(a) of the Social Security Act [42 U.S.C. 1395i–3(a)]

https://www.ssa.gov/OP\_Home/ssact/title18/1819.htm and Requirements for Nursing Facilities, Section 1919(a) of the Social Security Act [42 U.S.C. 1396r(a)] https://www.ssa.gov/OP\_Home/ssact/title19/1919.htm

<sup>&</sup>lt;sup>14</sup> NORS Table 1 https://ltcombudsman.org/uploads/files/support/NORS\_Table\_1\_Case\_Level\_10-31-2024.pdf

<sup>&</sup>lt;sup>15</sup> Social Security Administration <u>https://www.ssa.gov/</u>

**State Long-Term Care Ombudsman program (Ombudsman program, the program, LTCOP)** – As used in sections 711 and 712 of the Act, means the program through which the functions and duties of the Office are carried out, consisting of the Ombudsman, the Office headed by the Ombudsman, and the representatives of the Office.<sup>16</sup>

**State Survey Agency** – The state agency responsible for certifying and/or licensing longterm care facilities and conducting inspections and investigations to ensure federal and state compliance.

**State Surveyor** – An individual who works for the State Survey Agency to conduct indepth surveys, inspections, and investigations of long-term care facilities.

**Subsection Symbol (§)** – The subsection symbol is used to denote an individual numeric statute or regulation (rule).

<sup>&</sup>lt;sup>16</sup> 45 CFR Part 1324 Subpart A §1324.1 Definitions

## Section 2:

## **Person-Centered Care**

## **Person-Centered Care**

Person-centered care<sup>17</sup> is a process for selecting and organizing the services and supports that an older adult or person with a disability may need to live to their fullest potential. Most importantly, the person who receives the services and supports directs and makes decisions about how they receive care.

Person-centered care places decision-making and self-determination in the hands of individual residents to express choices and preferences about their care and day-to-day activities to the maximum extent possible.

Areas in which person-centered, individualized care can be implemented include, but are not limited to:

- Activities
- Bathing
- Care
- Death and dying
- Dining
- Dressing
- Engagement in community
- Medication administration
- Relationships
- Staff assignments
- Work

Person-centered practices:

- Put residents at the center of decision-making
- Recognize residents are experts about their lives
- Acknowledge residents have individual interests, needs, and abilities
- Emphasize person-first language to eliminate stereotypes and labeling

### **Person-First Language**

Part of person-centered care is using appropriate language that puts the resident before the diagnosis or disability and is sensitive and respectful to the resident. This type of language is called "person-first."



<sup>&</sup>lt;sup>17</sup> The terms "person-centered" and "person-directed" are often used interchangeably. Since "person-centered" care and planning is used in federal law, we are using "person-centered" care in these training materials.

Person-First Language:

- Refers to the person first and the diagnosis or disability second.
   Appropriate: "A resident living with dementia."
   Not appropriate: "A confused resident."
- Uses neutral language that does not describe the resident as lacking or deficient. Appropriate: "June had a stroke." "June uses a wheelchair." Not appropriate: "June is a victim of a stroke." "June is confined to a wheelchair."
- Does not use a label to describe someone instead of using their name. Appropriate: Bill, Jack, Doris, Mr. Davis, Ms. Combs Not appropriate: "feeders," "honey," "sweetie," "confused."



Watch the video titled <u>Person-Centered Care: Person-Centered Language.</u><sup>18</sup>

1. What are your takeaways from the video?

## **Person-Centered Care Based in Law**

Awareness of and requirements to provide person-centered care or planning are growing. Federal regulations for nursing facilities<sup>19</sup> and for Medicaid-funded long-term services and supports require person-centered care and planning.<sup>20</sup> Brief examples from federal requirements are below. Person-centered care and residents' rights will be discussed more in the next module.

Omnibus Budget Reconciliation Act of 1987 - The first federal law to refer to person-

"When staff put residents first in their language, they recognize the whole person and don't let disabilities define a resident."

Person-Centered Care: Person-Centered Language centered care is the Omnibus Budget Reconciliation Act of 1987 (OBRA '87), also known as the Nursing Home Reform Act.<sup>21</sup>

While the primary goals of OBRA '87 were to improve the quality of care provided to residents and establish uniform standards for nursing facilities, OBRA '87 also required **nursing facilities** to:

• Promote the "physical, mental, and psychosocial well-being of each resident"

• Promote the quality of life, choice, self-determination, and rights of each resident

<sup>&</sup>lt;sup>18</sup> This video series was developed by the Texas Department of Aging and Disability Services in coordination with the Texas Long-Term Care Ombudsman Program. <u>https://www.youtube.com/watch?v=zP2FfqHD6Lc</u>

<sup>&</sup>lt;sup>19</sup> 42 Code of Federal Regulations. Part § 483. <u>https://www.federalregister.gov/documents/2016/10/04/2016-</u>

<sup>23503/</sup>medicare-and-medicaid-programs-reform-of-requirements-for-long-term-care-facilities#h-203 <sup>20</sup> Home and Community-Based Services Final Regulation. <u>https://www.medicaid.gov/medicaid/home-community-based-services-final-regulation/index.html</u>

<sup>&</sup>lt;sup>21</sup> OBRA '87 Subtitle C: Nursing Home Reform – Part 1 and 2 <u>https://www.congress.gov/bill/100th-congress/house-bill/3545</u>

Additionally, OBRA '87 required state and federal governments to:

- Evaluate whether each resident is receiving care which promotes the highest practicable well-being
- Ensure facility compliance with residents' rights and quality of life

**Federal Requirements for States and Long-Term Care Facilities**<sup>22</sup> – Person-centered care is a requirement of the federal nursing facility regulations. The regulations define resident-centered care as follows:

"...person-centered care means to focus on the resident as the locus of control and support the resident in making their own choices and having control over their daily lives."

#### Home and Community-Based Services Final Regulation

For many years, there have been efforts on the national and state levels to give individuals needing long-term services and supports more choices as to where and how they receive those services, offering options to receive services in their home or community setting rather than an institutional setting (such as a nursing facility).

On January 10, 2014, the Centers for Medicare & Medicaid Services (CMS) issued the Medicaid Home and Community-Based Services (HCBS) settings final rule. The final rule addresses several sections of Medicaid law under which states may use federal Medicaid funds to pay for HCBS, meaning some residential care communities may accept Medicaid under an HCBS waiver. Nearly all states and DC offer services through HCBS waivers.

In addition to how states may use waivers, the final rule specifies that service planning for participants in Medicaid HCBS programs under section 1915(c) and 1915(i) of the Act must be developed through a person-centered planning process that addresses health and long-term services and support needs in a manner that reflects individual preferences and goals. Person-centered planning will be discussed more in a future section, but the rule clearly states the importance of person-centered care.

"The individual will lead the person-centered planning process where possible."<sup>23</sup>

## What Does Resident-Centered Care Look Like?

The following activity uses a tool designed for individuals who are entering long-term care. To help understand the basics of resident-centered care, complete the answers in *My Personal Directions for Quality of Life*.

 <sup>&</sup>lt;sup>22</sup> 42 Code of Federal Regulations. Part § 483. <u>https://www.federalregister.gov/documents/2016/10/04/2016-23503/medicare-and-medicaid-programs-reform-of-requirements-for-long-term-care-facilities#h-203</u>
 <sup>23</sup> 42 C.F.R. §441.540(a) and 42 C.F.R. §441.725(a).



- 1. Complete the My Personal Directions for Quality of Life document.<sup>24</sup>
- 2. Review your answers as instructed during training (by yourself, with someone else, or through group discussion).
- 3. Should you ever need long-term services and supports, how do you think sharing this information will impact your relationship with a caregiver and the care you receive?

Facilities that operate using a more institutional care model usually focus on what works best for the facility. Management makes most of the decisions, and daily schedules accommodate staff preferences and facility routines. Facilities that truly practice personcentered care make decisions based on the residents' preferences, care needs, and routines. The chart below illustrates some of the differences between a traditional, institutional model of care and person-centered care.

### EXAMPLES OF TRADITIONAL VS. PERSON-CENTERED CARE MODELS<sup>25</sup>

Figure 1

Traditional Care	Person-Centered Care	
Residents are told when to wake up, go to bed, eat, and bathe based upon facility schedules and set routines.	Residents wake up, go to bed, eat, and bathe when they choose. Staff alters their work routines to honor residents' preferences.	
Residents frequently have different care staff. Therefore, the staff do not know the residents well and are not familiar with their preferences or routines. Residents often feel unknown, insecure, scared, and they don't always get their needs met.	The same staff takes care of the same residents. They know each other, and caring relationships develop. Research indicates that consistent staffing results in better care and can help residents feel more secure, content, and happy.	
There is a structured activity schedule with little input from residents.	There are daily activities, whether individual or in a group, planned or spontaneous, which consider residents' interests.	
Residents may feel as if they have reached the end of the road and see the facility as a place to die.	Rituals and celebrations acknowledge life and establish an environment where everyone is recognized.	

<sup>&</sup>lt;sup>24</sup> The National Consumer Voice for Quality Long-Term Care <u>https://theconsumervoice.org/uploads/files/long-term-care-recipient/my-personal-directions-blank-revised-fillable.pdf</u>

<sup>&</sup>lt;sup>25</sup> The information in the Figure 1 and the paragraph introducing the chart was adapted from The Pioneer Network, *Moving to Person-Directed Care*, <u>https://www.pioneernetwork.net/elders-families/care-changing/</u>.

## How the Ombudsman Program Promotes Resident-Centered Care

It is the role of the Ombudsman program to advocate for residents' rights and personcentered care empowering residents to direct their care and life. How does the LTCOP promote resident-centered care? This is accomplished though educating and empowering residents, modeling person-centered communication, and promoting resident participation in the care plan process.

### **Educate and Empower**

A key responsibility of the Ombudsman program is to inform individuals about residents' rights. Representatives continually educate residents, family members, staff members, and the public. By providing information about residents' rights and person-centered care representatives empower residents to voice their concerns and be part of the complaint resolution process to the extent possible or desired.

The Ombudsman program also serves as a resource to staff by sharing promising practices and providing training on residents' rights and person-centered care. Many Ombudsman programs are involved in local coalitions and initiatives in support of culture change<sup>26</sup> and person-centered care.

### **Model Person-Centered Behavior**

Representatives model how to work and communicate with residents. Representatives always treat residents with dignity and respect. For example, by following the direction of the resident and involving the resident throughout the problem-solving process (to the extent possible or desired), the Ombudsman program models person-centered care to facility staff, family members, and others.

# Promote Resident Involvement in the Care Plan Process

Representatives support resident participation during the care plan process to ensure the resident's needs and preferences are heard, incorporated, and implemented. The care plan process is discussed in more detail later in this Module.



Learn more by visiting the NORC website on person-centered care.27

 <sup>&</sup>lt;sup>26</sup> To learn about culture change, visit the Pioneer Network website: <u>https://www.pioneernetwork.net/</u>
 <sup>27</sup> The National Long-Term Care Ombudsman Resource Center *Person-Centered Care* <u>https://ltcombudsman.org/issues/person-centered-care</u>

## **Section 3:**

## **Decision-Making**

### Decision-Making Capacity Understanding Capacity<sup>28</sup>

Capacity is the ability to make and communicate an informed choice. There is no simple test for capacity. Often, understanding the person's personal values, preferences, or goals can assist in understanding their capacity to make decisions.

Capacity is issue-specific, a spectrum, and transient. The first question is: "capacity to decide what?" Different types of decisions require varying levels of memory and distinct cognitive skills. The memory needed depends on how relevant past information is to the choice at hand. For example, very little memory is needed to decide what to wear or eat today. Different decisions require different cognitive skills, such as calculation, comparison, or organizing data.

Capacity is a spectrum. The ability to understand and make choices is not an on-off function. Capacity varies in subtle degrees, from no or very low levels of understanding, to the ability to understand and make decisions on very sophisticated and complex issues. Capacity is affected by health, pain, medication, illness, or injury. Capacity can be developed by learning and experience, and it can decrease with illness or injury. As these factors change, capacity can increase, decease, and return.

<sup>28</sup> Adapted from Issues in Capacity: Balancing Empowerment and Protection. Chapter Summary. July 2020. Godfrey, David. ABA Commission on Law and Aging. National Center on Elder Law and Rights. <u>https://ncler.acl.gov/getattachment/ElderJustice-Toolkit/Navigating-Ethical-Issues-Complex-Situations/Capacity-Ch-Summary.pdf.aspx?lang=en-US</u>

Decision-making capacity applies to all areas, including health, legal, financial, daily life, visitors, etc. Regardless of capacity, residents make decisions every day about how they want to spend their time. For example, a resident may not know what year it is, but may be able to communicate whether they want a specific family member or friend to visit them and what activities and food they prefer. Or a resident may not be able to manage their finances but can determine who they want to manage their affairs.

Decision-making capacity is not a one-time determination; rather it is on a spectrum and can change from hour to hour or day to day. Like someone coming out of anesthesia or experiencing mind-altering effects of some medication, a resident may have decision-making capacity in some areas of their life, but not others.

The goal of the Ombudsman program is to focus on the resident and their wishes even if the resident is not able to make all their decisions. For example, a resident may determine their daily routine, go out and visit with friends, or spend "pocket money," but leave major financial and complex medical decisions up to an individual acting as their representative (e.g., the

# Why is this important information for the LTCOP?

Knowing the resident and their ability to make decisions is important because the Ombudsman program seeks direction from the resident when resolving a complaint. The LTCOP Rule uses the term "informed consent" with regard to taking action on a complaint, access or sharing their records and other information. Informed consent is permission granted with the understanding of all possible options and outcomes, and risks and benefits associated with such options and outcomes.

agent on a Durable Power of Attorney). Communicate with residents and assume they can make their own decisions. The next section will discuss third-party decision makers (also known as resident representatives) and documentation to review in order to determine if a resident has an assigned decision-maker and which decisions they can make on behalf of a resident.

## When Decision-Making Capacity is Unclear

As resident advocates, it is a core program responsibility to empower residents and encourage others to realize the extent of the resident's decision-making abilities.

When you are unsure of a resident's decision-making capacity, some questions to consider include:

- Does the resident understand the information?
- Can the resident relate the information to their situation?
- Does the resident understand the possible outcomes of their decision?

- Can the resident retain the information long enough to make a decision?
- Can the resident communicate their decision in some way?

If the resident's ability to make decisions is still not clear, or the status of the resident's capacity is uncertain, you may consider the following:

- Ask the resident for permission to speak with their representative (i.e., decisionmaker)
- Follow state program policies and procedures for working with residents when capacity is unclear
- Consult your supervisor for guidance

To empower residents to exercise their right to choose and participate in their care (to the greatest extent possible), ensure that:

- Information presented to the resident is in a language and manner in which the resident understands
- Choices and outcomes are discussed fairly and evenly and without other people influencing the resident
- The resident is given the opportunity to talk to anyone they rely upon to make important decisions
- The resident is given enough time to consider their options

## **Section 4:**

## Advance Planning and Third-Party Decision Makers

### **Advance Planning**

The Patient Self-Determination Act (PSDA) requires most hospitals, nursing facilities, home health agencies, hospice programs, and HMOs (health management organizations) to provide information on advance directives at the time of admission.<sup>29</sup> The PSDA strengthened residents' rights to be informed of, and establish, advance directives.<sup>30</sup>

Advance care planning involves learning about the types of decisions that might need to be made, considering those decisions ahead of time, and then letting others know (e.g., family members and health care providers) about their preferences. These preferences are often put into an *advance directive*, a legal document that goes into effect only if an individual is incapacitated and unable to speak for themself.<sup>31</sup>

## **Health Care Advance Directives**

Per the American Bar Association,<sup>32</sup> a health care advance directive is the primary legal tool for any health care decision made on behalf of an individual should the individual become unable to speak for themself. "Health care advance directive" is the general term for any written statement someone makes while competent concerning their future health care wishes. Formal advance directives include the Living Will and the Healthcare Power of Attorney. Other types of advance care directives involve discussions with a person's doctor, and these are written in the form of a medical order.

<sup>&</sup>lt;sup>29</sup> Adapted from Law for Older Americans. March 2013. Health Care Advance Directives. What is the Patient Self-Determination Act? American Bar Association.

https://www.americanbar.org/groups/public education/resources/law issues for consumers/patient self determinati on\_act/

 <sup>&</sup>lt;sup>30</sup> H.R. 4449 – Patient Self-Determination Act of 1990. <u>https://www.congress.gov/bill/101st-congress/house-bill/4449</u>
 <sup>31</sup> Advance Care Planning: Health Care Directives. National Institute on Aging.

https://www.nia.nih.gov/health/advance-care-planning-health-care-directives

<sup>&</sup>lt;sup>32</sup> This paragraph was adapted from the Law for Older Americans. Health Care Advance Directives. April 2012. American Bar Association.

https://www.americanbar.org/groups/public\_education/resources/law\_issues\_for\_consumers/directive\_whatis/

#### CPR Directive and POLST: Why is this important information for the LTCOP?

The CPR Directive and the POLST are documents that explain the resident's wishes. When a resident is unable to communicate their wishes and there is a question about endof-life decisions, these directives to medical professionals help determine what actions the resident wants or does not want taken. These are one type of medical records a representative of the Office may need to review during complaint investigation\* (following relevant policies and procedures).

\*Complaint handling will be discussed in future modules.

**Cardiopulmonary Resuscitation (CPR) Directive** Health care advance directives may also have other terms like, "Cardiopulmonary Resuscitation (CPR) Directive" or "Do Not Resuscitate (DNR) Order." This type of medical order is signed by the doctor and patient and instructs providers on the patient's desire about resuscitation if the person's heart or breathing stops. Some states call this directive an "Out-of-the-Hospital DNR." The form for this, and who must sign it, varies from state to state.

#### Portable Medical Orders<sup>33</sup>

Portable medical orders are often referred to as POLST. However, states use other names or different definitions POLST acronym [e.g., (Practitioner/Provider/Physician Orders for Life-Sustaining Treatment), POST (Physician Orders for Scope of Treatment), MOLST (Medical Orders for Life-Sustaining Treatment), MOST (Medical Orders for Scope of Treatment)]. A POLST form tells health care providers what treatments the individual wants and the individual's goals of care, even if transferring from the hospital to a nursing facility, or to hospice or another setting. Points to remember about this type of order:

- POLST is for people who are seriously ill or have advanced frailty.
- It is a form that is signed by both the patient, or in many states by the health care representative if the patient is unable to do so, and the doctor.
- Most important is that it involves a discussion between the doctor and the patient.



Learn more about portable medical order forms in your state.34

### **Third-Party Decision Makers**

The advance directives discussed include information about specific documents and physician's orders that express an individual's preferences for health care treatment. Some advance directives allow for individuals to name someone else to make decisions on their behalf.

<sup>&</sup>lt;sup>33</sup> Information adapted from POLST Basics. National POLST. <u>https://polst.org/about/</u>

<sup>&</sup>lt;sup>34</sup> <u>https://polst.org/programs-in-your-state/</u>

The Ombudsman program follows the direction of the resident. However, there are residents who lack the ability to communicate their wishes, needs, or preferences. Then whose direction does the program follow? It depends. Some residents have chosen a decision maker, and some have been assigned a decision maker by the courts. Other residents rely upon someone who helps them make medical and financial decisions. In this section, we will explore the different types of decision makers and their authority to make decisions with or on behalf of residents.

There are two types of decision makers. Those that are assigned **by** the resident and those that are assigned **for** the resident. Decision makers may only act within the guidelines granted by or for the resident.

### Decision Makers Assigned by the Resident

#### Power of Attorney (POA)

A power of attorney is a legal document in which a person appoints another individual(s) to be their decision maker if/when they are no longer able to do so or earlier in some situations.

Power of Attorney Facts

- "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 principal.

There are different types of POAs. For example, a durable power of attorney comes into effect as soon as the document is signed. A springing power of attorney "springs" into effect if the principal becomes unable to communicate informed consent. There are POAs

#### Power of Attorney: Why is this important information for the LTCOP?

For a representative to take direction from an agent under a power of attorney, the type of POA and the powers, or authority, granted to the agent must be identified. It is necessary for the Ombudsman program to obtain or review the POA to determine the extent of the authority granted.

specific to health care decisions and some that are specific to finances and property. Every state has their own specific power of attorney terminology, forms, and laws.



Learn more about POAs here.35

<sup>&</sup>lt;sup>35</sup> https://www.americanbar.org/groups/real\_property\_trust\_estate/resources/estate\_planning/power\_of\_attorney/

### Decision Makers Assigned for the Resident

#### **Guardianship and Conservatorship**

The definitions of guardianship and conservatorship vary from state to state. In most states, when a guardian or conservator is appointed, the court removes some or all the individual's rights and deems the individual incapable of administering their own affairs. Those affairs may be financial, personal, day-to-day, or other. Guardianships and conservatorships may be limited in scope and in length of time.

Some guardians or conservators are family or friends of residents who know their values and goals, and others are court-appointed professionals who do not know or may have never met the resident.

The Ombudsman program advocates that the resident choose who their decision maker is and what authority they are giving to the person, as opposed to having the court make these decisions. Because guardianships and conservatorships remove individuals' rights, they should be considered as a last resort.



Learn more about guardianship.36

#### **Representative Payee**

A representative payee<sup>37</sup> is a person or an organization appointed to receive Social Security or Supplemental Security Income (SSI)<sup>38</sup> benefits for anyone who can't manage or direct the management of their benefits for themself. SSI is designed to help people who are aged, blind, or have disabilities and who have little or no income. SSI provides cash to meet basic needs for food, clothing, and shelter.

#### **Default Health Care Decision Makers**

Most, but not all, states have a statute that provides guidance for who can make health care decisions for a patient who is unable to make or communicate a health care decision, has not named someone to help with health care decisions, and does not have a court-appointed representative. The statutes vary from state to state, but most commonly the statutes empower immediate family; some include other persons in a close relationship to the patient.<sup>39</sup> These default decision makers are limited to health care decisions only as allowed in the statute in that state.

<sup>&</sup>lt;sup>36</sup> American Bar Association <u>https://www.americanbar.org/groups/law\_aging/resources/guardianship\_law\_practice/</u> <sup>37</sup>Social Security Administration *Representative Payee* <u>https://www.ssa.gov/payee/</u>

<sup>&</sup>lt;sup>38</sup> Social Security Administration *Supplemental Security Income* <u>https://www.ssa.gov/ssi/</u>

<sup>&</sup>lt;sup>39</sup> "Default Surrogate Consent Statutes" American Bar Association

https://www.americanbar.org/content/dam/aba/administrative/law\_aging/2019-sept-default-surrogate-consentstatutes.pdf

### **Role of a Resident Representative**

The LTCOP Rule defines "resident representative" as "an individual chosen by the resident to act on their behalf, or a person authorized by federal or state law (e.g., agent under a Power of Attorney, representative payee, and other fiduciaries) to act on behalf of a resident in order to support the resident in decision-making; access medical, social,

or other personal information of the resident; manage financial matters; or receive notifications; legal representative (as used in Section 712 of the Act), or a court-appointed guardian or conservator of a resident."<sup>40</sup> When working with or on behalf of a resident, there are times when the Ombudsman program takes direction from the resident's representative.

Once the LTCOP has determined the resident is not able to communicate informed consent and before the LTCOP takes direction from someone other than the resident, consider the following questions:

- Does the resident have an advance planning directive? If so, what kind of directive?
- Does the resident have a supported decision maker?
- Does the resident have a guardian or conservator?
- Is there evidence of the resident representative's authority?

#### **Fiduciary Definition**

A fiduciary is a person or organization with a legal or ethical relationship with a resident who is required to act in the resident's best interests (e.g., guardian to resident, agent under a POA to a principal, trustee to beneficiary, executor of a will to the will beneficiaries, etc.).

When it comes to investigating complaints, the LTCOP Rule is clear, requiring the Ombudsman program to determine and verify the authority of a decision maker. The Rule states that the Ombudsman program:

"...shall ascertain the extent of the authority that has been granted to the resident representative under court order (in the case of a guardian or conservator), by power of attorney or other document by which the resident has granted authority to the representative, or under other applicable State or Federal law."<sup>41</sup>

In other words, the Ombudsman program reviews the relevant documentation to determine in what circumstances they are to follow the direction of the resident representative. The resident representative can only act within the scope of the authority

<sup>&</sup>lt;sup>40</sup> LTCOP Final Rule §1324.1 Definitions <u>https://www.govinfo.gov/content/pkg/CFR-2017-title45-vol4/xml/CFR-2017-title45-vol4/xml/CFR-2017-title45-vol4/xml/CFR-2017-title45-vol4/xml/CFR-2017-title45-vol4/xml/CFR-2017-title45-vol4/xml/CFR-2017-title45-vol4/xml/CFR-2017-title45-vol4/xml/CFR-2017-title45-vol4/xml/CFR-2017-title45-vol4/xml/CFR-2017-title45-vol4/xml/CFR-2017-title45-vol4/xml/CFR-2017-title45-vol4/xml/CFR-2017-title45-vol4/xml/CFR-2017-title45-vol4-part1324.xml</u>

<sup>&</sup>lt;sup>41</sup> Published in the Federal Register, 02/11/2015, Vol. 80, No. 28. LTCOP Final Rule. 1324.19 (b)(2)(iv) Duties of the representatives of the Office. <u>https://ltcombudsman.org/uploads/files/library/2015-01914.pdf</u>

granted. For example, a daughter may say that she has power of attorney to make health care decisions. The Ombudsman program must ask for proof and verify the accuracy and details of decision-making authority. This may also require the Ombudsman program to consult with the program's legal counsel or local legal services if there are questions or concerns about the form.

## **Section 5:**

## Empowerment

### Empowerment

Empowerment is a primary role of the Long-Term Care Ombudsman program in which representatives provide the tools (e.g., information about residents' rights, facility responsibilities), encouragement, and assistance to promote resident self-advocacy. Empowering residents helps them to become stronger and more confident. In an ideal world, when a resident has a concern, they feel assured to approach staff or others for help. However, there are factors that may affect a resident's sense of empowerment.

The Ombudsman program was created to help restore the balance of power between residents and staff, as well as between residents and their family members. The LTCOP ensures residents have someone on their side who helps empower them and, if necessary, be their advocate.

## **Barriers to Empowerment**

Barriers that may influence a resident's sense of empowerment are numerous.

Residents may...

- Feel hopeless
- Experience physical, emotional, psychological, social, and/or mental challenges that make it difficult to voice concerns
- Accept ongoing rights violations as a regular part of living in a nursing facility
- Express not wanting to "rock the boat"
- Fear getting someone in trouble
- Feel isolated
- Not want to be labeled as "a troublemaker" or "difficult"
- Experience side-effects of medication that interfere with a resident's ability to voice concerns
- Feel as though complaining won't help
- Not have been educated about their rights or how to assert their rights
- Be treated differently for complaining
- Fear retaliation

Staff may...

- Run resident council meetings resulting in residents not speaking out about concerns
- Not have been trained on residents' rights
- Be ambivalent or negative when responding to residents
- Ignore residents completely

## **Fear of Retaliation**

Watch this video titled <u>Voices Speak out Against</u> <u>Retaliation</u><sup>42</sup>

- 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?

"Because when people speak their mind, they become confident and empowered. And when they're empowered their quality of life improves."

Ronnie – Voices Speak Out Against Retaliation

- 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?

Retaliation is one of the most common reasons expressed by residents for not seeking resolution to their concern. It may be real or perceived, but in either situation, it is frightening to residents. When instances of retaliation occur, they can range from subtle to obvious.

Subtle instances of retaliation include but are not limited to:

- Call lights not answered or are delayed in being answered
- Staff ignoring resident requests for help
- Nurses withholding pain medication or late when distributing medication

Obvious instances of retaliation include but are not limited to:

- Rough care
- Abusive treatment
- Eviction or attempted eviction
- Withholding food and water

## Partnering with Residents for Self-Advocacy

Representatives all have one thing in common: they want to help residents. Often the first thought that comes to mind is to *take action for them*, but that is not empowering. The Ombudsmen program plays an important role in helping people restore their own sense of self and regain their personal power and voice. Residents who have always found it easy to speak up may merely need to be pointed in the right direction and be given a little assurance that they are within their rights. Others may need a lot more encouragement; they may need you to go for them or with them.

<sup>&</sup>lt;sup>42</sup>Connecticut Long-Term Care Ombudsman Program <u>https://www.youtube.com/watch?v=feoQjlW3\_bc</u>

The first step in this process of empowering residents is simply to have genuine, meaningful connection with residents, to get to know them as individuals. Start by listening to the resident's concerns, their ideas about resolving their concerns, and the actions they have already taken to address the problem. Listening to the resident shows them that their thoughts and feelings are important.

Some steps to take to encourage empowerment for self-advocacy include but are not limited to:

- Educating residents about their rights, including their right to present grievances without fear of retaliation
- Educating staff about residents' rights
- Encouraging residents to participate and address their concern in the care plan meeting (discussed later in this Module)
- Encouraging residents to participate and address their concern in the Resident Council meetings (discussed later in this Module)
- Talking about which staff member may most effectively address the problem
- Explaining how to file a complaint with the state agency responsible for investigations in long-term care facilities, and the pros and cons of doing so

When talking to a resident about their concerns, suggest the resident meet with the staff person whom you both have identified as the person most likely to help resolve the problem. When you make this suggestion, it may be helpful to offer to attend the meeting with the resident. The Ombudsman program's presence may increase the resident's confidence that their concern will be heard and resolved.

If you attend a meeting with the resident and the staff member, make sure you and the resident have a clear understanding of what will be discussed and who will take the lead in the discussion. Always go with the resident's preference. Talk to the resident about their desired outcome of the discussion so you understand their goal of the meeting. Remember you are there to promote resident empowerment and advocate for resident rights, not to bring the resident in line with the facility's preferences.

Encourage family members and friends of residents to speak out when they have concerns. Often, the Ombudsman program works with the resident representative when the resident is unable to communicate informed consent. When working with the resident representative, it is equally important to use empowerment strategies as a tool to resolve concerns.



Watch the video titled <u>Residents' Rights Month</u> which summarizes the information discussed on empowerment and retaliation.<sup>43</sup>

<sup>&</sup>lt;sup>43</sup> Weld County, Texas Area Agency on Aging <u>https://www.youtube.com/watch?v=B9mm9EBkUMw</u>

## **Section 6:**

## **Resident Assessments and Care Plans**

### 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

#### 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 personcentered 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 personcentered 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.
- $\checkmark$  The right to be informed, in advance, of changes to the plan of care.

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

- ✓ 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.

## Person-Centered Planning in Home and Community-Based Services (HCBS)

As mentioned earlier, CMS published a rule in 2014 that defined "home and communitybased services" for services states provide under HCBS waivers. The rule explains what states must do in their Medicaid HCBS programs by establishing rights for HCBS recipients and requirements for service providers. The HCBS Rule applies to all settings in which an HCBS recipient lives or receives the HCBS services, including residential care communities that accept Medicaid coverage for services.

The rule describes the minimum requirements for person-centered plans developed through this process, including that the process results in a person-centered plan with individually identified goals and preferences.<sup>45</sup>

<sup>&</sup>lt;sup>45</sup> Centers for Medicare & Medicaid Services. Home and Community Based Services. Fact Sheet. January 2014. <u>https://www.medicaid.gov/sites/default/files/2019-12/final-rule-fact-sheet.pdf</u>

Similar to federal nursing facility requirements for assessment and care planning, the HCBS Rule requires the development of a person-centered service plan that is developed using a person-centered planning process driven by the individual receiving services.

The Rule includes four main steps for the person-centered plan process:46

#### 1. Assessment

An assessment, in consultation with the individual and/or their representative, is required to identify the individual's functional needs; physical, cognitive, and behavioral health care and support needs; strengths and preferences; available service and housing options; and a caregiver assessment (if needed), to develop a person-centered service plan.

#### 2. Person-Centered Planning Meetings

Based on the assessment, a written service plan is developed with the individual (and/or their representative). According to the rule, "the person-centered planning process is driven by the individual." This means that the individual chooses who participates in the meetings; meeting times and locations are convenient to the individual; choices for services and living options are discussed, and the individual can request meetings to update/change their choices. Additionally, the information provided should be in plain language that is accessible to the individual.

#### 3. Writing the Plan

The plan should be written in a language and manner the individual understands and at a minimum should include the following:

- Where the individual chooses to live and receive other services, like supported employment
- Strengths, preferences, and need
- Supports needed, both paid and unpaid
- The individual's goals and how the individual will know the goal is accomplished
- Potential risks and plans to deal with them
- The name of the person responsible for making sure the plan is followed
- After the individual agrees with the plan, everyone that participated in the planning meeting signs the plan and receives a copy

### 4. Reviewing the Plan

The plan should be reviewed at least every 12 months, but the individual can request a meeting to review and update or change the plan at any time.

<sup>&</sup>lt;sup>46</sup> Steps below adapted from the HCBS Rule §441,720 and §441.725(a) and the Person-Centered Planning and Home and Community-Based Services fact sheet <a href="https://prod.nmhealth.org/publication/view/help/3792/">https://prod.nmhealth.org/publication/view/help/3792/</a>



Learn more about the HCBS Final Rule and Person-Centered Planning.47



Watch the video called <u>*Person-Centered Care: Care Plans*</u><sup>48</sup> as an introduction to care plans and the care plan process. While watching the video consider:

- 1. What key points does the video explain?
- 2. Have you participated in a care plan meeting?

#### **Key Care Plan Meeting Participants**

- Resident
- Resident's legal representative
- Care Plan Coordinator
- Physician(s)
- Nursing staff, including Certified Nursing Assistants (CNAs)
- Dietary staff
- Therapy staff
- Social services staff
- Activities staff
- Anyone else invited by the resident (e.g., family members, representative of the Office)

#### What is Discussed at the Care Plan Meeting?

- Resident needs and preferences
- Supports and services to be provided
- The staff responsible for providing the supports and services
- Resident's preferred daily routines
- Dietary preferences, concerns, and needs
- Resident's preferred activities and interests
- Medication
- Desire to leave the nursing facility/return to the community



<sup>&</sup>lt;sup>47</sup> HCBS Final Rule <u>https://www.medicaid.gov/medicaid/home-community-based-services/guidance/home-community-based-services-final-regulation/index.html</u>, ACL Person-Centered Planning <u>https://acl.gov/programs/consumer-control/person-centered-planning</u>

<sup>&</sup>lt;sup>48</sup> Texas Health and Human Services in coordination with the Texas Long-Term Care Ombudsman Program https://www.youtube.com/watch?v=JGgCJp2XQpY

### Ombudsman Program Advocacy Before, During, and After the Care Plan Meeting

#### Preparing for the Care Plan Meeting

Nursing facilities are required to hold care plan meetings at the time of day that works best for the resident and accommodates a resident's representative. This may include conducting the meeting in-person, via a conference call, or video conferencing. The meeting should be held in a location of the resident's choosing that ensures privacy. The facility must provide sufficient advance notice of the meeting and plan enough time for discussion and decision-making.

The Ombudsman program can empower the resident and/or their representative to speak up if they would like the meeting to be longer than the scheduled timeframe or prefer/need the meeting to be scheduled differently. The representative can offer to attend the meeting. If the resident would like for you to attend, talk with them about their expectations about everyone's role in the care plan meeting as well as the resident's concerns and goals.

You can further empower the resident by suggesting they prepare a list of the assistance, activities, or other preferences that they want to have included in their care plan. Ask the resident to think of how to explain those preferences and how to present them to the nursing facility staff. Residents and their families are likely to be unfamiliar with the care planning process, at least at first, so good preparation is an important way to ensure that the care plan meeting is properly focused on the resident's needs, goals, and preferences.

#### **During the Care Plan Meeting**

Ombudsman program advocacy during the care plan meeting includes ensuring:

- The resident has an opportunity to speak
- The resident's questions are answered
- The resident's preferences are addressed
- · Supports and services options are discussed
- The resident understands and agrees with the care plan
- The resident receives a copy of the plan if requested
- The resident knows who to talk to if there are changes to be made to the care plan
- The resident understands there are options to leave the nursing facility and receive long-term services and supports in the community and how to seek assistance, if applicable (transitioning to the community is discussed more in future modules)

#### After the Care Plan Meeting

LTCOP actions may include but are not limited to:

- Following up with the resident to find out if their care plan is being followed and asking if they are satisfied with the supports and services received
- Asking them if changes need to be made to the care plan
- Explaining their right to request another care plan meeting at any time to make modifications, advising them that if something is not included in their care plan, it will likely not happen



Learn more about <u>assessments and care plans</u>.<sup>49</sup> For additional training on person-centered care, go to the Texas Long-Term Care Ombudsman <u>Person-Centered Care Video Series</u> Teaching Guide.<sup>50</sup>

 <sup>49</sup> The National Consumer Voice for Quality Long-Term Care A Closer Look at the Revised Nursing Facility Regulations Assessment, Care Planning, and Discharge Planning <u>https://theconsumervoice.org/uploads/files/issues/A Guide to the Revised Nursing Facility Regulations.pdf</u>
 <sup>50</sup> Texas Long-Term Care Ombudsman Person-Centered Care Video Series Teaching Guide <u>https://ltcombudsman.org/uploads/files/support/Person-Centered-Care-Video-Series-Teaching-Guide.pdf</u>

## Section 7:

## **Resident Councils and Family Councils**

## **Resident Councils**

A Resident Council is an independent group of residents that meets regularly to discuss and seek resolution to concerns; offer suggestions about facility policies and procedures affecting residents' care, treatment, and quality of life; support each other; plan resident and family activities; participate in educational activities; or for any other purpose.

Some states have regulations pertaining to Resident Councils in both nursing facilities and RCCs. These state regulations often mirror the federal regulations below.

### **Federal Regulations**

Federal nursing facility regulations include the following requirements for Resident Councils:

- The facility must provide a Resident Council, if one exists, with a private space for meetings.
- The facility must take reasonable steps, with the approval of the Resident Council, to make residents aware of upcoming meetings in a timely manner.
- The facility must provide a designated staff person who is approved by the Resident Council and the facility to provide assistance and respond to written requests from the Resident Council.
- The facility must consider the views of a Resident Council and act promptly upon grievances and recommendations of the Resident Council concerning issues of resident care and life in the facility.
  - The facility must be able to demonstrate their response and rationale for their response.
  - The right to a response does not mean facilities are required to implement every request of the Resident Council.
- The Resident Council meetings are closed to staff, visitors, and other guests. For staff, visitors, or other guests to attend, the Resident Council must invite them.

### The Ombudsman Program and the Resident Council

The Ombudsman program is required to assist with the development of Resident Councils when asked. Representatives often encourage residents to share their concerns during the Resident Council meeting to address concerns that may affect all or some residents, such as call lights not being answered in a timely manner or cold food.

Representatives of the Office must have the approval of the Council Members to attend the meetings. Often, representatives are welcome to attend and do so on a regular basis. There are great benefits in attending the Resident Council meetings, such as getting to know residents, being a familiar support to residents, and getting a sense of how the residents are treated and how the facility is managed. It is a good idea to check in with the Resident Council President or another Council Member during regular visits to get a sense of what is going on in the facility.

## **Family Councils**

A Family Council is a group of residents' family members that meets regularly to discuss and offer suggestions about facility policies and procedures affecting residents' care, treatment, and quality of life; support each other; plan resident and family activities; participate in educational activities; or, for any other purpose.<sup>51</sup>

Members form a united consumer voice which can play a crucial role in voicing concerns, requesting improvements, supporting new family members and residents, and supporting facility efforts to make care and life in the facility the best it can be.

Similar to how parents' associations work with schools, Family Councils provide a way for concerned persons to actively participate in helping the facility to be the best it can be, through combining and prioritizing shared concerns and then communicating them to facility administrators, making recommendations, and suggesting solutions, sharing answers and information when replies are received, and supplementing staff services via additional actions which enhance residential life.

A Family Council meets regularly and promotes communication, action, support, and education. The specific activities of the Council depend upon the needs of the residents and the choices made by Council members.

Family Councils operate on the premises that:

- There is strength in numbers and that combined voices garner more attention than just one
- Increased family involvement fosters greater staff accountability, which in turn decreases possible neglect and abuse
- Streamlining concerns is more efficient and reduces the time staff ultimately spends addressing repeat issues

### **Federal Law**

The 1987 Nursing Home Reform Act guarantees the families of nursing facility residents a number of important rights to enhance a loved one's nursing facility experience and improve facility-wide services and conditions. Key among these rights is the right to form a Family Council and hold regular private meetings.

Nursing facilities must provide a meeting space, cooperate with the Council's activities, and respond to the group's concerns. Nursing facilities must appoint a staff advisor or liaison to the Family Council, but staff and administrators have access to Council meetings only by invitation. While the federal law specifically references "families" of

<sup>&</sup>lt;sup>51</sup> State Operations Manual Appendix PP Guidance to Surveyors DEFINITIONS §483.10(f)(5)-(7)

residents, close friends of residents are encouraged to play an active role in Family Councils, too.

Specifically, the federal law includes the following requirements on Family Councils:

- A resident's family has the right to meet in the facility with the families of other residents in the facility.
- The facility must provide a family group, if one exists, with private space.
- Staff or visitors may attend meetings at the group's invitation.
- The facility must provide a designated staff person responsible for providing assistance and responding to written requests that result from group meetings.
- When a family group exists, the facility must listen to the views and act upon the grievances and recommendations of residents and families concerning proposed policy and operational decisions affecting resident care and life in the facility.

These federal requirements are often supplemented by State Statutes.

### The Ombudsman Program and the Family Council

In addition to acting as an advocate for residents, the Ombudsman program can educate residents, families, and friends about residents' rights, state surveys, and federal and state laws that are applicable to nursing facilities and other long-term care facilities. The LTCOP also provides support and advocacy to Family Councils when asked by the Council.

Successful Family Councils maintain open communications with the LTCOP which is mutually beneficial: the program is kept informed of concerns which reflect multiple residents' experiences (which often reflect the facility culture) and the Council has a human resource which can help to differentiate fact from fiction when members seek to clarify and correct problematic situations.

Even if a state does not have regulations for residential care communities regarding Resident Councils and/or Family Councils, there are no requirements restricting the councils and the Ombudsman program providing support to councils in RCCs.



Learn more about Resident and Family Councils.52

<sup>&</sup>lt;sup>52</sup> The National Long-Term Care Ombudsman Resource Center *Family and Resident Councils* <u>https://ltcombudsman.org/issues/family-and-resident-councils</u>

## **Section 8:**

## Conclusion

## Module 3 Questions

- 1. Why is it important for a representative to know about advance planning and thirdparty decision makers?
- 2. Explain what "empowerment" means to you.
- 3. When a resident is hesitant to speak up about a concern, what can you do to help? Hint: Look at Section 3.
- 4. Name four residents' rights that are related to care planning.
- 5. Name two things a facility must do to assist Resident Councils and Family Councils.

#### True or False

a. The charge nurse is responsible for assuring the nursing care provided by other nurses and nursing aides meets federal and state requirements.

b. The care plan coordinator is a social worker who works with other facility staff, residents, and residents' family members to conduct assessments and to coordinate individual nursing care.

## **Module 3 Additional Resources**

#### **Centers for Medicare & Medicaid Services**

Long-Term Care Facilities
 <u>https://www.cms.gov/Regulations-and-Guidance/Legislation/CFCsAndCoPs/LTC</u>

#### Residents' Rights

- Bingo Game
   <u>https://mightyrightspress.org/product/residents-rights-bingo/</u>
- Card Game https://theconsumervoice.org/product/residents-rights-playing-cards

#### Person-Centered Care

NORC Resource <u>https://ltcombudsman.org/issues/person-centered-care</u>

Person-centered language suggestions https://ltcombudsman.org/uploads/files/support/word-of-the-week-summary.pdf

Nursing Facility Staffing Levels in your State

- Long-Term Care Community Coalition
   <u>https://nursinghome411.org/data/staffing/</u>
- CMS Payroll-Based Journal (PBJ) staffing data submitted by long-term care facilities <u>https://data.cms.gov/quality-of-care/payroll-based-journal-dailynurse-staffing</u>

LTC Informational Series Video 6 Effective Advocacy & Complaint Management for Residents

Southwestern Commission AAA, LTCOP, Sylva, North Carolina <u>https://www.youtube.com/watch?v=8s7d1oE8\_Q0&list=PLSu\_zY6vP6REXfvjgVf7E-F9CG2K\_9P-F&index=6</u>