



**The National Long-Term Care
Ombudsman Resource Center**

INITIAL CERTIFICATION TRAINING CURRICULUM FOR LONG-TERM CARE OMBUDSMAN PROGRAMS

Module 2: The Resident and the Resident Experience

WELCOME AND INTRODUCTION

Section 1

Welcome

- Your name
- Where are you from
- One thing you learned from Module 1
- What you hope to learn since the last module



ANY
QUESTIONS
?

Today's Agenda

Section 1: Welcome and Introduction (15 minutes)

Section 2: Resident Demographics (45 minutes)

Section 3: The Resident Experience (45 minutes)

-----Scheduled break-----

Section 4: Common Health Experiences (60 minutes)

Section 5: Conclusion (15 minutes)

Module 2 Learning Objectives

- Who lives in long-term care facilities
- Why people enter long-term care
- Why people stay in long-term care
- The impact of loss when residents enter long-term care
- Common diagnoses, the effects on residents, and the importance to the LTCOP
- Common health concerns in long-term care



WHO LIVES IN LONG-TERM CARE SETTINGS AND WHY?

Section 2

If you're a caregiver, you don't just insert a hearing aid for a hearing-deprived resident, you don't just give a shower to a manually disabled resident, you don't just wipe a totally dependent resident. In short, you do more than assist a resident with performing the Activities of Daily Living: **You become the human bridge that carries a trace of dignity to the helpless; that empathizes with their inability and uncertainty.** - David

Who Lives in Nursing Facilities and Why?



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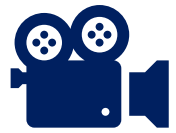
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LTC Informational Series Video 9 - Diversity in Long-Term Care Facilities

Myth/Stereotype	Reality
Residents are not connected to what is going on around them.	Residents are interested in meaningful relationships.
Residents are child-like and should be treated as such.	Residents are adults and should be treated with dignity and respect.

Myth/Stereotype	Reality
<p>Residents are dependent and want someone to take care of all their needs.</p> <p>People with disabilities always need help.</p>	<p>Most residents maintain abilities and want to care for themselves as much as possible.</p>
<p>Older people don't participate in sexual activity.</p> <p>Most people with disabilities cannot have sexual relationships.</p>	<p>Need for sexual expression and intimacy continues throughout life. Anyone can have a sexual relationship by adapting sexual activity. Sexuality is a basic human need and the choice to participate in sexual acts belongs to the resident.</p>

Myth/Stereotype	Reality
Younger people do not reside in long-term care facilities.	There are younger residents who live in long-term care facilities.
People with mental illnesses are not admitted into nursing facilities.	There are residents who live in long-term care facilities with a range of mental illness diagnoses.
Old people are unproductive and set in their ways. They have already made their contribution to society.	The need to feel a sense of purpose in life does not change once one becomes a resident.



Watch *Adorable Kittens and Seniors Come Together and Help Each Other*

Your assumptions are your
windows on the world.
Scrub them off every once
in awhile, or the light won't
come in.

- Alan Alda

2021 National Nursing Facility Population

White

Hispanic or Latino

Black or African American

American Indian, Alaska Native, Asian, Native Hawaiian, Pacific Islander

95 Years and Greater

85-95 Years

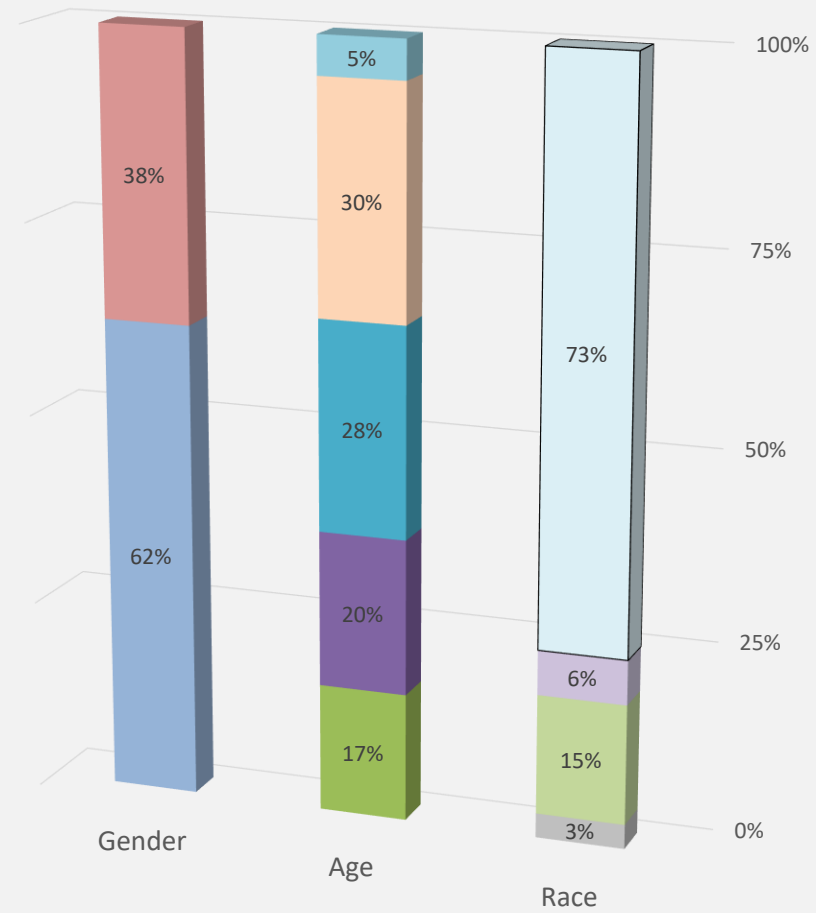
75-84 Years

65-74 Years

64 Years and Under

Male

Female



National Residential Care Communities Population

American Indian, Alaska Native, Native Hawaiian, Pacific Islander

Black or African American

Hispanic or Latino

White

85 Years and Greater

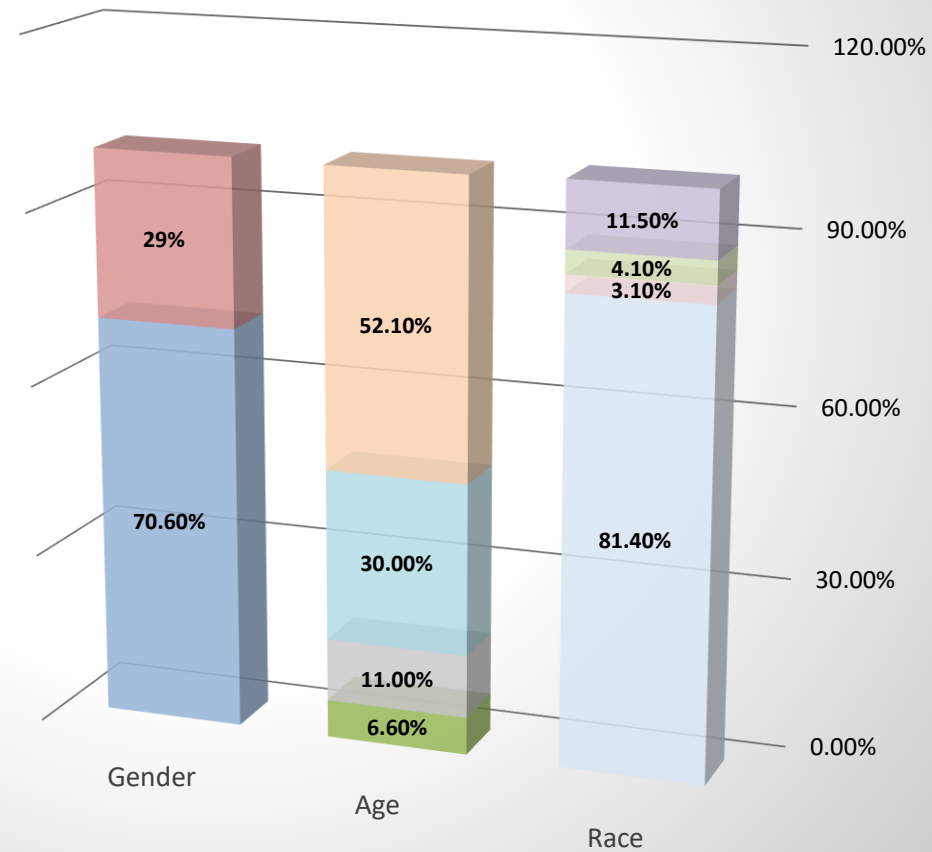
75-84 Years

65-74 Years

64 Years and Under

Male

Female



→ **Types of Residential Care Communities**

Intellectual and Developmental Disabilities

- Problems with:
 - Learning
 - Problem solving
 - Judgment
 - Communication
 - Independent living skills



→ 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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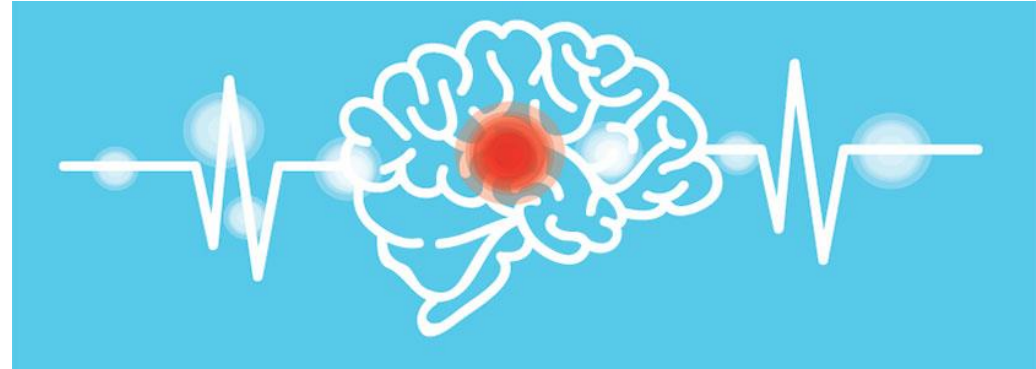
Events and Situations

- A sudden medical event
- The progression of dementia
- The progression of a chronic or terminal illness



Medical Event Examples

- Accidents
- Strokes
- Falls



Alison Parker

I am 45 years old and was in a car accident and almost died. I woke up from a coma 2 months later in the hospital and was told I have a traumatic brain injury. I was discharged from the hospital to the nursing facility for physical and speech therapies. I still struggle with my memory and speech and my right side is also affected from the brain injury; but I am working on getting stronger. I rely on others to help me with my activities of daily living, but I'm getting better. I can brush my teeth and feed myself, but I need someone to set everything up for me. I cannot completely wash myself or get dressed on my own. I am working with the facility to help me find a place to live in the community.



Alzheimer's Disease or other Dementias

- Memory loss
- Disorientation
- Confusion
- Delusions or hallucinations
- Behavior changes
- Difficulty eating or swallowing
- Difficulty speaking
- Weight loss
- Wandering
- Incontinence



Bernie Ford

My father lived at home with his wife until she passed away. After she died, it became clear that his dementia was much worse than I had thought. His wife did everything for him and tried not to worry me with the worsening symptoms of Alzheimer's. My father moved in with me and after 6 months, I knew I was in over my head. He began wandering in the middle of the night and a couple of times was brought back to my home by the neighbors. At times he would hallucinate and become combative due to fear and confusion. I knew I could no longer manage his care. I found an assisted living facility for him that specializes in memory care.



Chronic or Terminal Illnesses

- Cancer
- Congestive heart failure
- Liver disease
- Diabetes
- COPD (chronic obstructive pulmonary disease)
- ALS (Lou Gehrig's disease)
- MS (multiple sclerosis)
- Renal failure
- Others



Carolyn Dunn

I moved into the nursing facility because I have COPD and struggle with breathing. One afternoon, I had a terrible coughing episode and passed out in my home. As luck would have it, my son happened to stop by and found me laying on the floor. I went to the hospital and was told my lungs are damaged. I need help and I'm too scared to live alone so I decided to move to a nursing facility. My doctor agreed with my decision, and I know my son feels better now that I'm not alone.



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

THE RESIDENT EXPERIENCE

Section 3

Quality is about meaningful interactions and relationships. There is an extraordinary aide, Jan, who worked overnight and regularly came in to awaken me at about 6:15 a.m. She started the one cup coffee maker, reset the thermostat in the room, and smiled as she left the room telling me, “Have a good day.” It is the little things in life that matter – meaningful interactions and relationships. - Terry



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Routines and Activities



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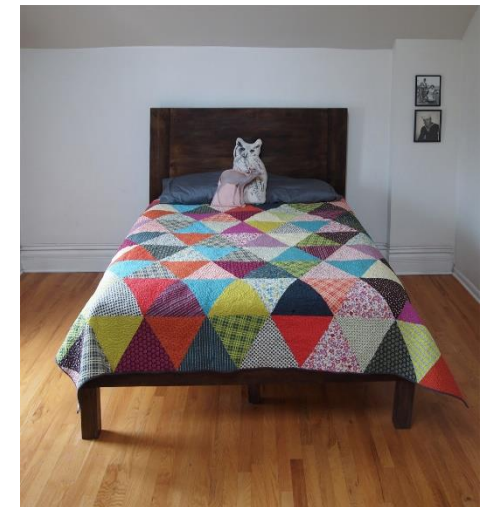


Look at all your daily routines and activities again, and the people involved and consider:

- Why are your routines important to you?
- Should you have to give up your daily routines?
- If you had to modify your routines, what would make the transition easier?



Personal Items



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Picture your personal possessions and consider:

- Why are your possessions so important to you?
- Should you have to give up all but three of them?
- What would help ease you into your new surroundings without your familiar and beloved possessions?

Experience of loss

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
Freedom	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
Privacy	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
Personal Property	Loss of personal belongings with special meaning or memories	Feeling disconnected

What's a good day?

Um, getting up early, which I've had a tough time convincing them that that's what we need. Um, having breakfast in the morning, that's good. I have time after breakfast to do some physical therapy if I could find someone to help me. Um, which is about always available most of the time. And then it's sitting outside with some friends, breathing in the good air or going upstairs and watching TV or reading, all those exciting things. Then it's lunch and then you go back to, going outside, and if you get tired of that, then you go back upstairs to your room, watch TV and read, come down for dinner and when that's done, you go outside and you go upstairs, you watch TV or read. - Jessica

When I wake up and I get my cup of caffeinated coffee. I get hot water for caffeinated coffee, I have instant coffee and that makes my day, my caffeinated coffee. I go to breakfast, a lot of people don't but I'm able to and if there is some activity going on that I especially like, like cards or bingo, or a nice amusement and then if I have a nice supper and then I usually go to bed early, I watch television, Wheel of Fortune, Jeopardy. - Fran

COMMON HEALTH EXPERIENCES

Section 4

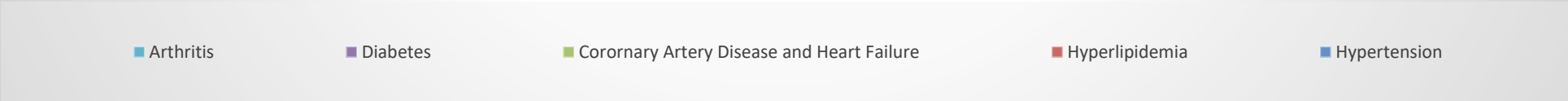
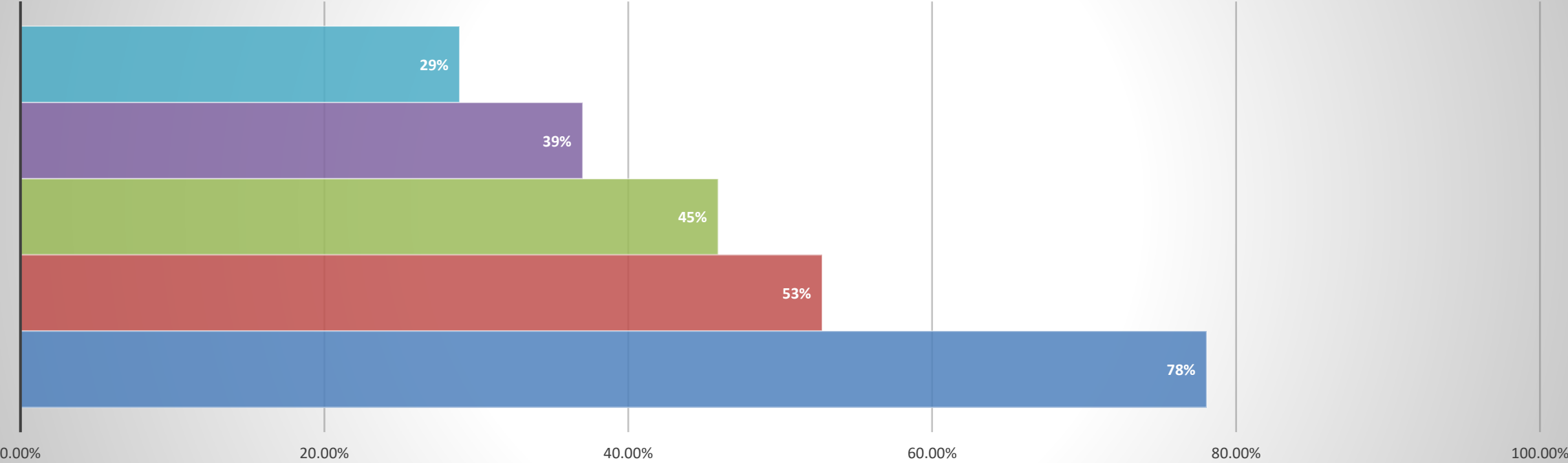
I don't ever want to be in a nursing home, I used to say. I fell and broke bones, went to the nursing home, went home, fell again, went back to the nursing home. I need to be in a nursing facility -I want to be in a nursing home. - Betty

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



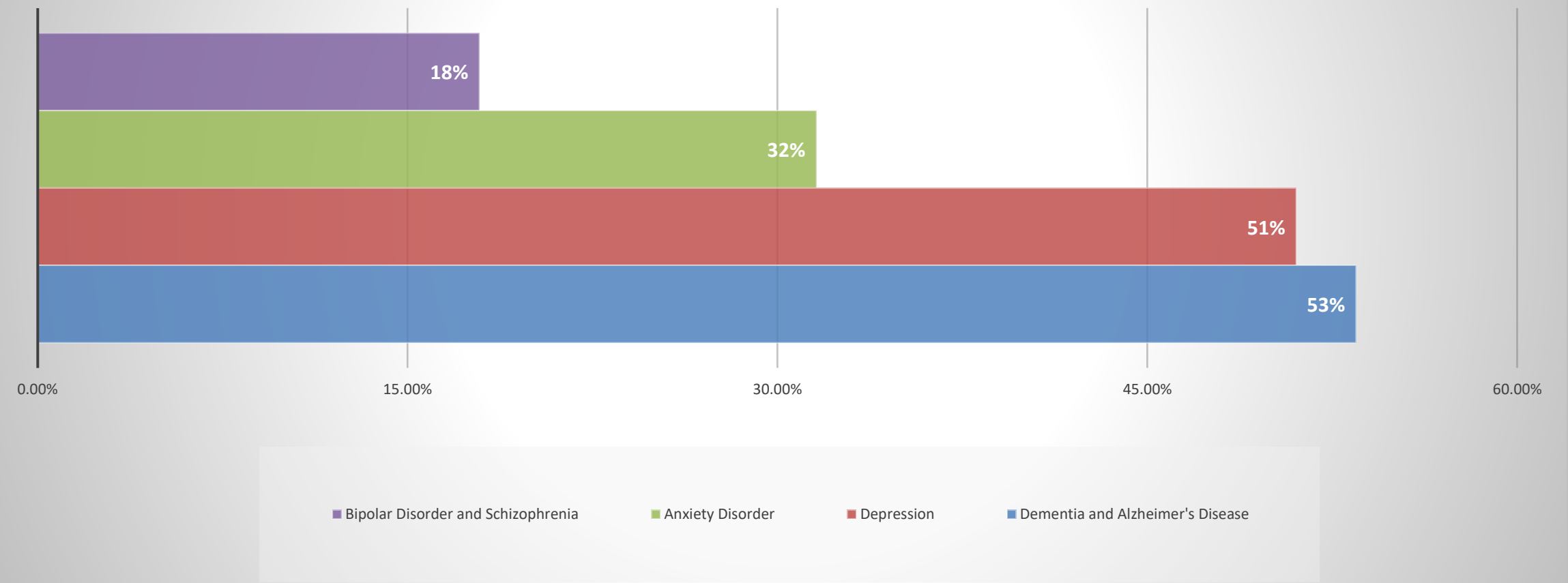
Important:

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.

Cognitive Disorders and Mental Health



2021 National Cognitive Disorders & Mental Health Diagnoses in Nursing Facilities



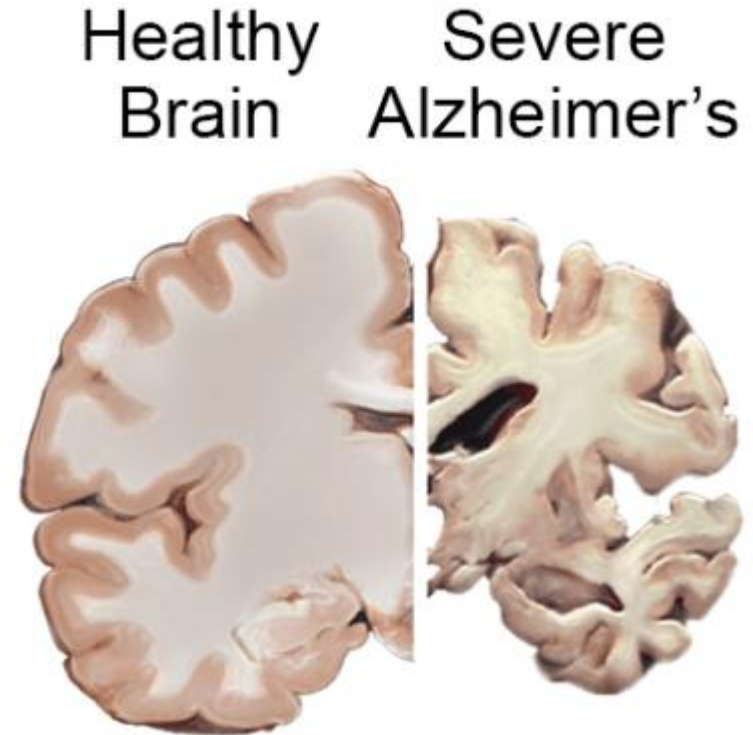
Dementia

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



Alzheimer's Disease

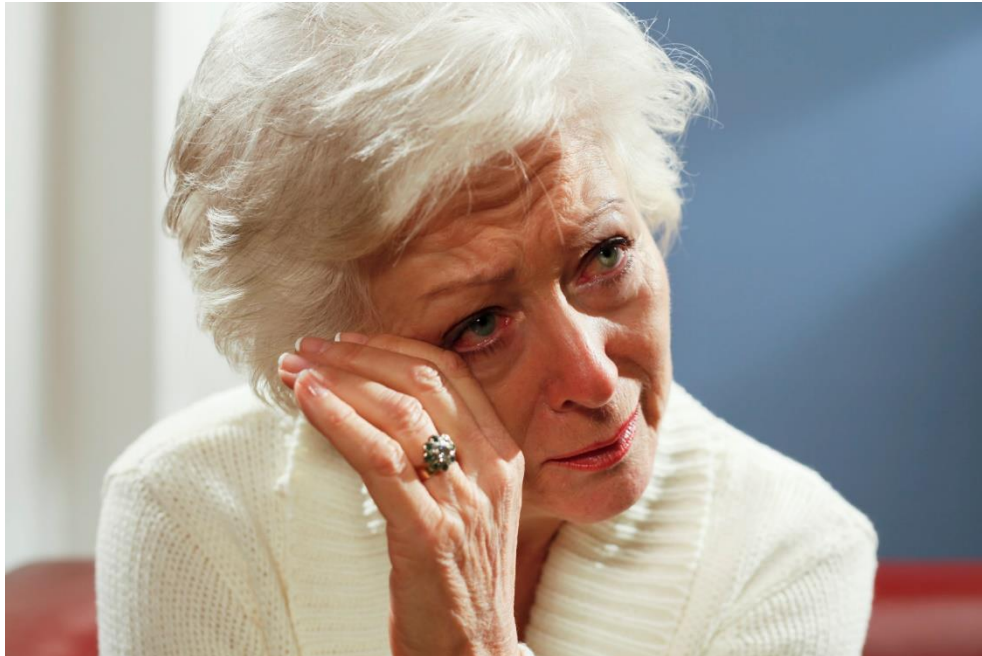
- Memory loss
- Disorientation
- Confusion
- Behavior changes
- Weight loss
- Incontinence
- Delusions or hallucinations
- Difficulty:
 - Speaking
 - Eating or swallowing



LTC Informational Series Video 7 - Addressing Dementia in Long-Term Care Facilities

Greta

Greta said she feels scared at night when they turn all the lights off in her room.



Doris

Doris complained that someone stole her purse, and she wants help with getting it back.



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

Mental Illness



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

Bipolar Disorder

Causes dramatic shifts in a person's:

- Mood
- Energy
- Ability to think clearly

Individuals with this disorder experience extreme high and low moods, known as mania and depression.

Major Depressive Disorder (MDD)

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

Schizophrenia

Interferes with a person's ability to:

- Think clearly
- Manage emotions
- Make decisions
- Relate to others
- Maintain touch with reality

Depression

- Why is this important information for the LTCOP?
 - Residents with depression may not seek assistance from the LTCOP.
 - Residents with depression may sleep often or stay in their room.



Anxiety Disorders

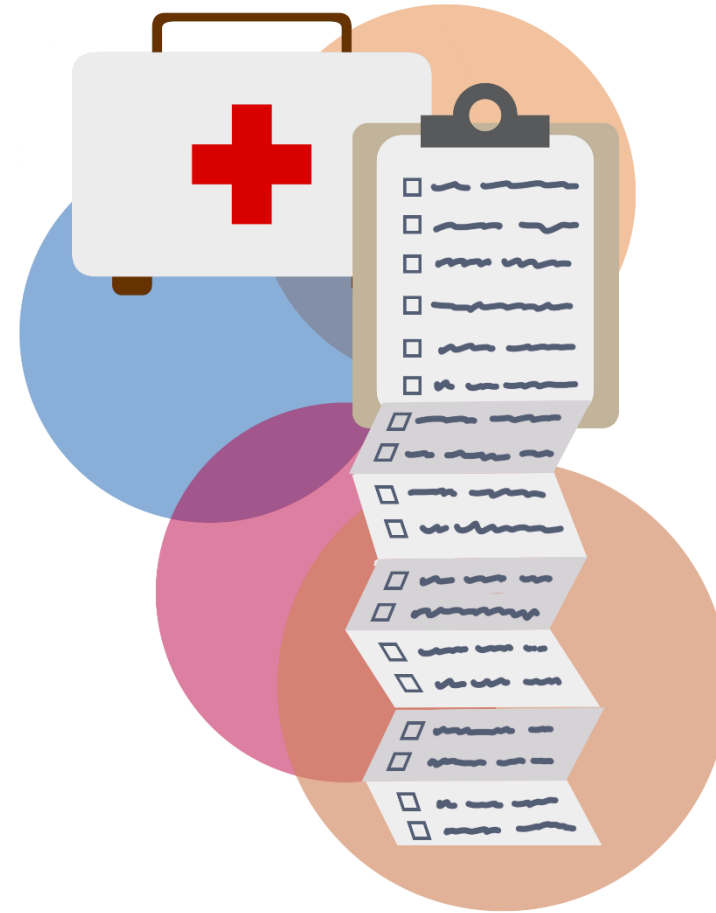
Emotional Symptoms	Physical Symptoms
Feelings of apprehension or dread	Pounding or racing heart and shortness of breath
Feeling tense or jumpy	Sweating, tremors and twitches
Restlessness or irritability	Headaches, fatigue and insomnia
Anticipating the worst and being watchful for signs of danger	Upset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

- Why is this information important to the LTCO?
- Representatives should be:
 - Honest
 - Relatable
 - Respectful



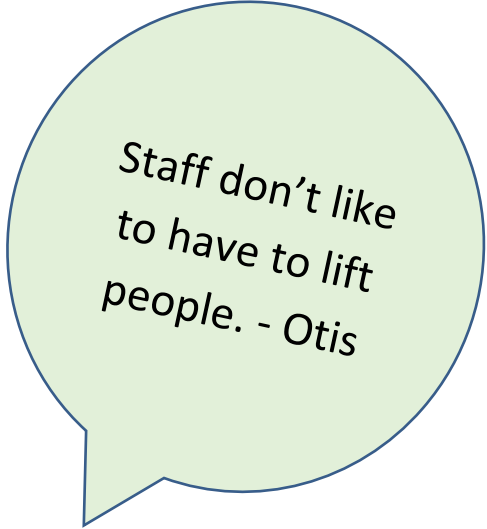
Other Health Concerns

- Falls
- Incontinence
- Pain
- Pressure Ulcers



Falls

- Common reasons residents fall
 - Medical conditions
 - Medication side-effects
 - Accidents
 - Hazards and spills on the floor
- While some falls are unavoidable, there are preventive measures facilities can take to lower the likelihood of a fall



*Staff don't like
to have to lift
people. - Otis*

Incontinence

Lack of privacy
during incontinent
care

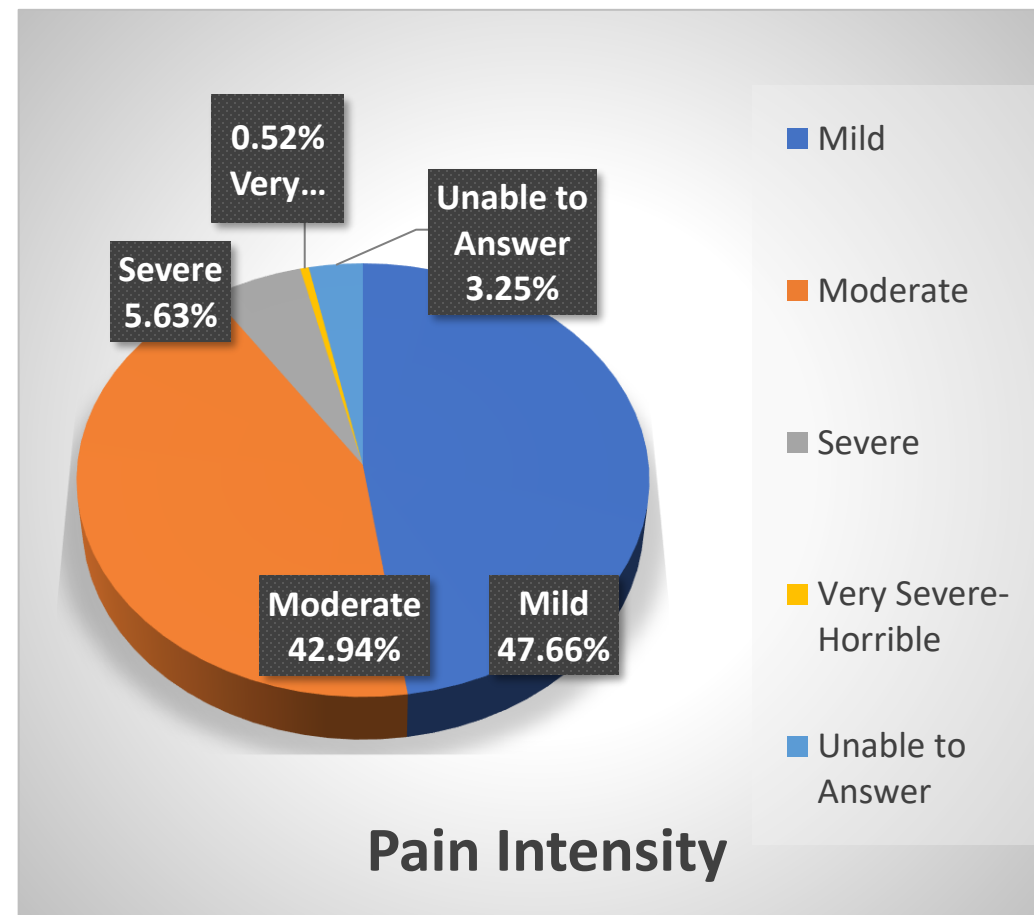
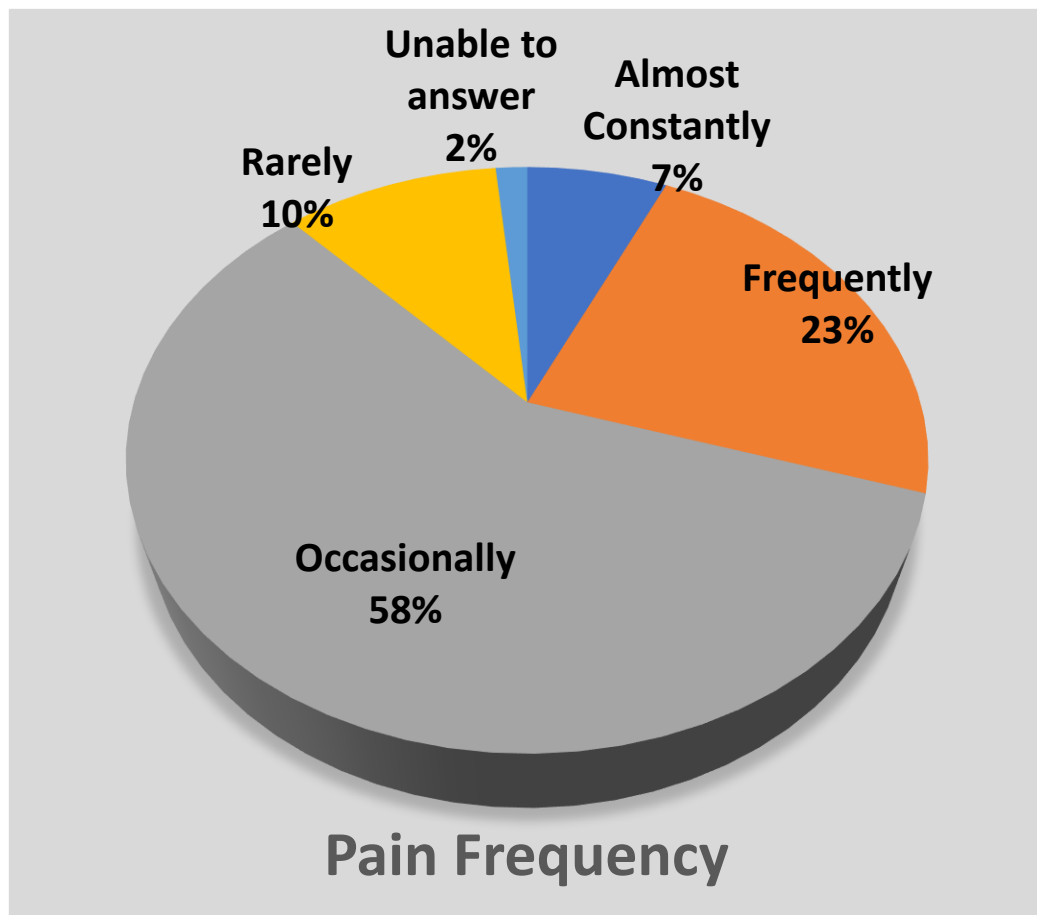
Residents being
left in their own
waste

Residents
not changed
often enough

#1 and #2

Call lights not
answered timely
which can lead to
accidents

Residents not
being taken to the
bathroom and
asked to just go
on themselves



Pain

Effects

- Loss of appetite
- Loss of interest in activities
- Difficulty sleeping
- Depression
- Stress
- Anxiety
- Anger
- Feeling misunderstood

Treatments

- Aroma therapy
- Massage
- Music therapy
- Heat or cold packs
- Over-the-counter medication
- Prescription medication
- Others

Pain Concerns Heard by the LTCOP

Residents who have used opioid pain medications for years have suddenly been told they can no longer use opioids and must switch to non-opioid pain medications that don't effectively manage their pain.

Residents have reported that they are in so much pain that they have attempted suicide due to their untreated pain. This is very disturbing.

There have been residents who complain that they don't feel they are getting their pain addressed or getting their pain medicine that helps with their pain.

Another resident reported she has to go through so many hoops just to get relief from her pain. For example, she has to go to the doctor weekly or every two weeks just to get a scrip for her chronic pain." She is in her 90's.

Resident Quotes on Pain

The pain is always there... it will never go away completely. - Joe

...only thing that works is the opioids, but it doesn't always help. Sometimes it takes 1 hour to kick in. - Charlie

Sometimes medication isn't effective for entire window of time. - Lewis

Was an instance of a nurse diverting fentanyl patches for herself. - Pat

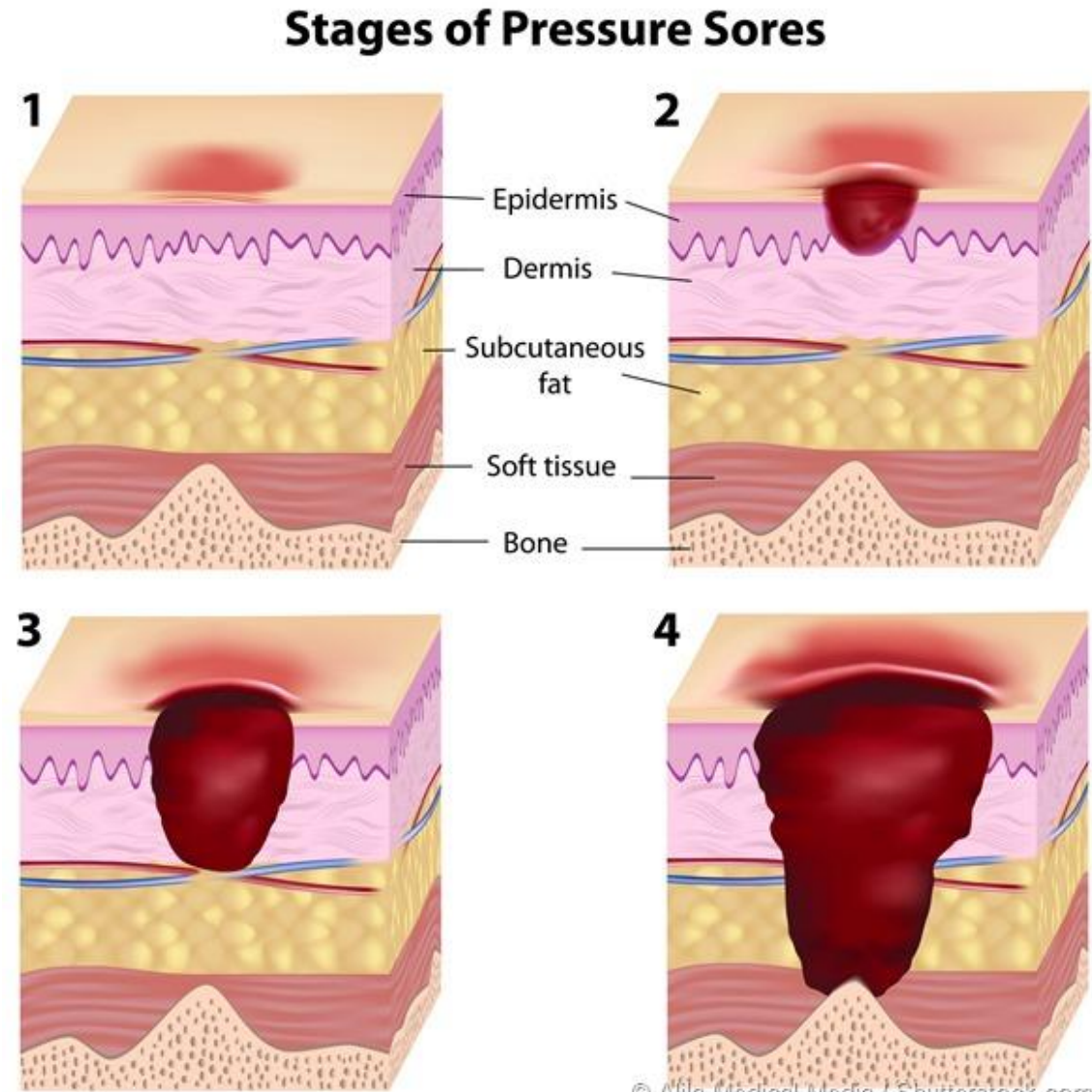
...meds were not always ordered on time from the pharmacy so may have to go one or more days without treatment. - Michael

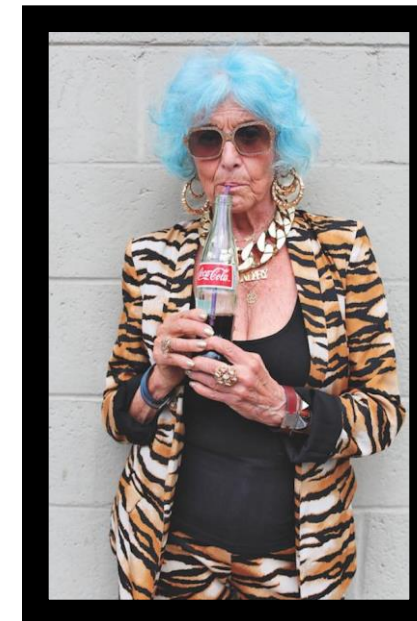
One resident said she has to be assertive to get her meds –says she “rounds up” staff to get them. - Ezra

Pressure Ulcers

Risk factors include:

- Lying in the same spot
- Incontinence
- Spinal cord injuries, neurological disorders, etc.
- Poor nutrition and hydration
- Medical conditions affecting blood flow





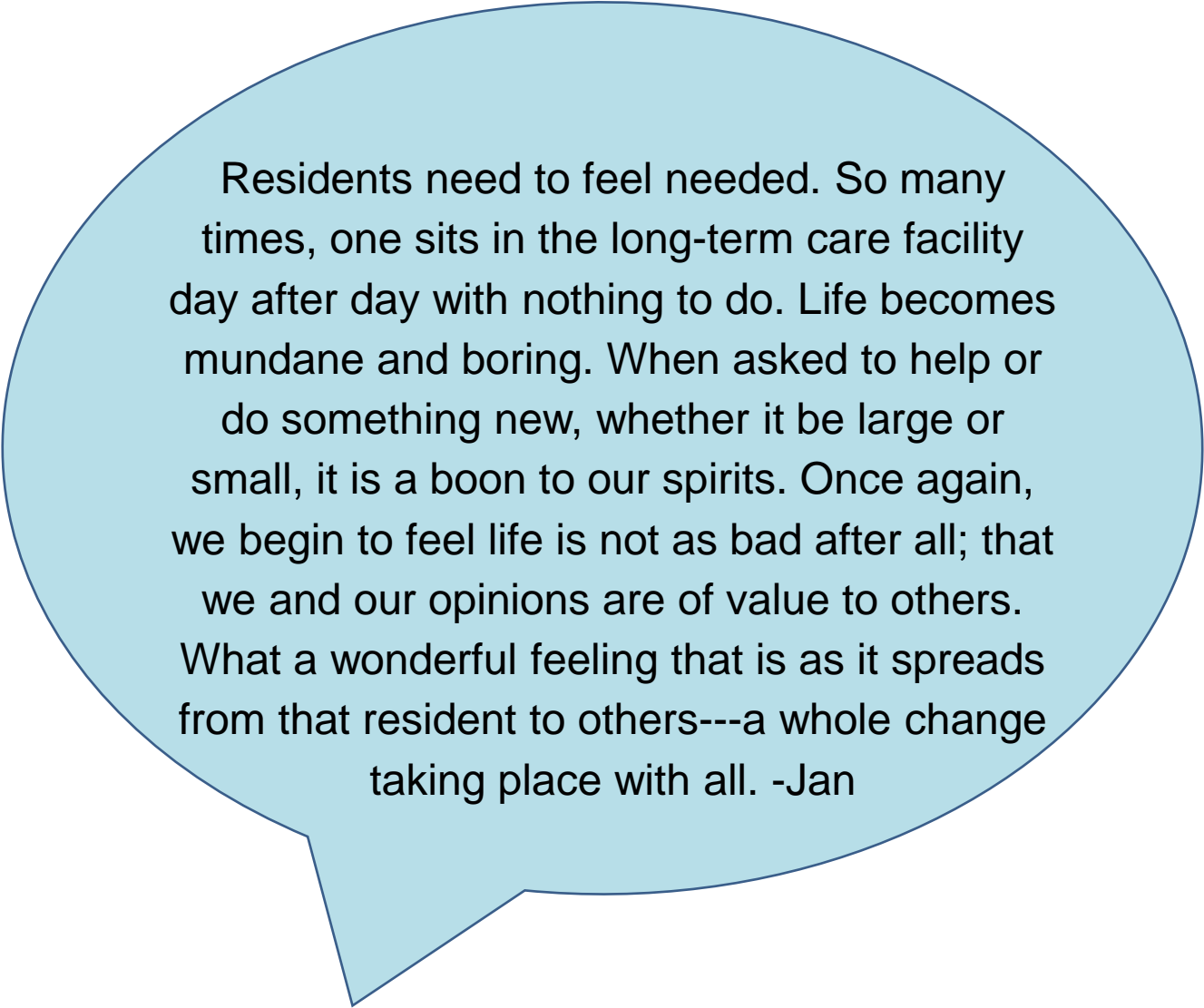
“If you’ve talked to one resident, you’ve talked to one resident.”



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CONCLUSION

Section 5



Residents need to feel needed. So many times, one sits in the long-term care facility day after day with nothing to do. Life becomes mundane and boring. When asked to help or do something new, whether it be large or small, it is a boon to our spirits. Once again, we begin to feel life is not as bad after all; that we and our opinions are of value to others. What a wonderful feeling that is as it spreads from that resident to others---a whole change taking place with all. -Jan

Module 2 Questions

1. Select the statements that are true about individuals who live in long-term care facilities. Residents
 - a. May be of any ethnicity
 - b. Are not under the age of 65 years
 - c. Are primarily men
 - d. Are primarily white
 - e. Are primarily over 85 years of age

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?

QUESTIONS?

ADDITIONAL RESOURCES

Refer to your trainee manual for other sources of information related to topics discussed in this module.

Contact Information

- INSERT PRESENTER CONTACT INFORMATION



The National Long-Term Care Ombudsman Resource Center

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

www.ltcombudsman.org

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