

Younger Adults in Long Term Care

Meeting the Challenge and Setting the
Standard

•

•

A growing concern

- Adults 18-64 are the fastest growing subpopulation in long term care.
- 20 years ago, those under age 65 were 8% of long term care, now they are 16.5%.
- Younger adults
 - longer lengths of stay,
 - Medicaid payor
 - Male, black or Hispanic
 - higher rates of anxiety, depression, and suicidal behaviors.
 - Living in for-profit nursing homes with lower star ratings.
 - Less likely considered in research and regulatory decision making

•

•

Separate populations with different needs.

- The majority of younger adults are male, whereas older adults and seniors are mostly female. White people make up the majority of older residents and black and Hispanic make up the younger group.
- Serious mental illness and psychiatric medications are far more common among younger adults.
- Younger adults also have greater rates of cerebral palsy, paralysis, traumatic brain injury, multiple sclerosis, diabetes and ventilator use.
- Nursing homes may not even be able to care for younger adults, but there are limited options.

•

•

On the Cutting Edge

- Edgemoor has a higher number of younger adults and more experience caring for them as a safety net facility.
- PALTCM gathered a group of those caring for younger adults from all over the US and found little literature, but a lot of experience and "best practices" and developed a toolkit.
- Nursing homes are highly challenged to care for many younger adults with the current financial and regulatory environment. These are often LONG TERM patients.

What are the pillars of success?

- Don't admit what you cannot care for
- Know the residents well. Invest early
- Know the regulations well.
- Know its not the best fit—expect long term stays, privacy concerns, complaints, and struggles
- Rules cannot be enforced; Influence behavior through relationships.
- Work as interdisciplinary team.
- Exercise creativity, attention to detail and documentation skills.

How do they get into nursing homes?

- Developmental disability.
- Gradual decline due to neurodegenerative disorders (MS, HD).
- Sudden change in lifestyle (accident).
- Long term mental illness and associated decline.
- Long term poor behaviors (drug addiction, poor self care, smoking, alcohol) culminating in cognitive loss, physical abilities and decline.

Different than older adults

- Psychologically, socially, developmentally, medically, and cognitively
- Activities preferred
- Foods preferred
- Ways of communicating
- Expectations
- Developmental/life stage
- Worldview
- Medical problems
- Discharge Options

Young people have unique medical problems (some of which keep them from getting too old!)

- Fertility and birth control
- Sexually transmitted diseases (though this is a growing problem in the elderly as well)
- A lack of comorbidities
- Substance abuse may be more prominent

Also more common in the young...

- Night owls
- Fashion ideas
- Social media, technology
- More physical strength
- Minor children
- Goals for the future (education)
- Ideas about privacy
- Different expectations, entitlements
- Different attitudes toward tube feeding and cognitive loss and code status

Meet Martin

Martin suffered a traumatic spinal cord injury resulting in quadriplegia. He now is developing limited use of the upper extremities, but is totally dependent. He is withdrawn, angry and irritable, and complains frequently about staff. He wants to go out daily to drink or use marijuana and sometimes brings it inside. He uses a power chair. His care needs are heavy and he is often unkind to caregivers. He is sure he doesn't belong with all these old people in the SNF.

•

•

A framework for analysis

- Understand their **individual perspective**.
- Know the **regulations**.
- Develop and nurture the **relationship** to influence behavior (relationship-based influence versus "compliance") .
- Be clear about **staff roles** and responsibilities.

Keep your eye on the situation as it evolves and repeat as needed, get to **win-win**.

•

•

INDIVIDUAL PERSPECTIVE

- Stephen Covey "Seek first to understand, then be understood"
- Know me and let me know you care for me before telling me what you need and want.



•

•

Getting to Know people

- Educate your staff on listening first. Make time for it. Monitor and watch. It saves so much time later,
- Consider teaching Nonviolent communication-- behaviors are reflection of needs and focusing on the need is better
- Put yourself on the same side of the equation—the rules are tough "for both of you"—you are on their side —you want their needs met too. You are looking for a compromise. You are an advocate.
- Find out how they like to be told bad news, rules, how they deal with conflict, what their goals are. BEFORE you need it.

4 principles of Nonviolent Communication

- Observation helps us communicate what we see and hear without judgment.
 - I'm seeing you come in slurring your speech and not as friendly as usual, and I am concerned.
- Feelings help us connect with others emotionally and build understanding.
 - I'm worried about you and want to assure you are safe. Because of your medications and condition, I am worried there are special risks you may not be aware of.
- Needs to help us identify what we value and what we need to feel satisfied.
 - Its part of my job as your nurse to learn about what is happening with you and how it impacts your body and then to see what we can do to keep you safe.
- Requests help us communicate what we need from others in a clear and non-threatening way
 - Would you talk to me about what is happening and what you need from me?

"Everything we do is in service of our needs."

"Max-Neef's model where needs may be categorized into 9 classes:

- sustenance,
- safety,
- love,
- understanding/empathy,
- creativity,
- recreation,
- sense of belonging,
- autonomy and
- meaning.

Quick practice

- There is nothing to do
- You guys are just here for the money and don't care at all for me.
- Staff are stealing my stuff.
- What's the point in talking, no one here ever listens. It's all rules, rules.
- I'm out of here.
- I hate the food here.
- It doesn't matter anyway, so leave me alone.
- sustenance,
- safety,
- love,
- understanding/empathy,
- creativity,
- recreation,
- sense of belonging,
- autonomy and
- meaning.

REGULATIONS

- Younger Adults push the limits of regulations which are not designed for them.
- But that's your problem
- Know the regulations and interpretive guidance well and speak to it in your planning and documentation.



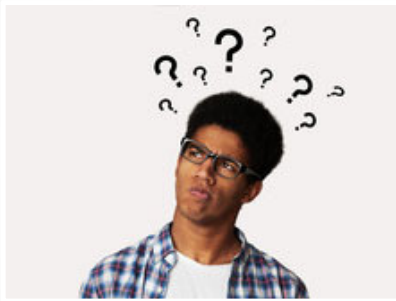
What regulations?

- **Admission**—assure we can provide care for what may be a long time
- **Resident Rights**—so many! including activities of interest, right to refuse, right to daily choices, home like, grievances,
- **Clinician responsibilities**
- **Care planning and assessment**
- **Trauma informed care/Behavioral Health care**
- **Discharge** when there are few safe options most times

Balance between autonomy and safety

- Clarify the tension between the facility need for protection and safety protect and the resident's right to exercise autonomy.
- Enhance processes of assessment, care planning for risk mitigation and documentation (and get used to doing it over and over again).

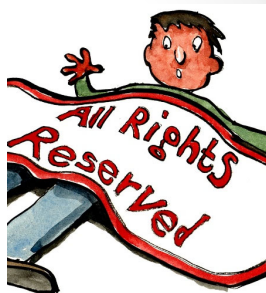
You let them do what?



Or, "do we have the authority to stop this?"

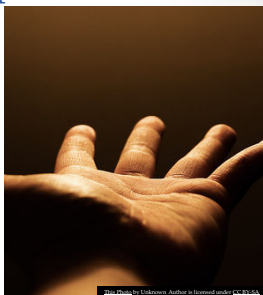
I have a right to make bad choices.

- I have the right to experience expected consequences of my choices.
- Punishment isn't ever allowed.
- Expression of my rights end where yours begin.



Concept of a need versus a want or preference

- "We are here to meet all your needs and some of your wants."



"all your needs and some of your wants"

- Identify the difference between **needs** (food, clothing, pain management, assistance) and **wants or preferences** (dilaudid 4 mg, clothing too small, transfers any time requested, help holding a cigarette).
- Re-examine resident rights:
 - "They have a right to..." gives way to "your right to ____ is limited by the other resident's right to ____."
 - Know what is a right versus a preference (or "want").

The perfect answer varies on a continuum

- Finding the right balance between safety and autonomy is highly related to decision making capacity assessment.
- The balance is situational. We need to assess, and we need to at least attempt to offer choice and make things safer. We need a plan.
- Sometimes we need to violate rights, but when we do, we need exceptional documentation that is patient centered and caring and honoring the struggle.
- Other times when we really have little we CAN do, we need to document well why we are so ineffective at changing a risky situation.

Concept of staff being important too

...
If behavior impacts staff morale, performance, well being, then this impacts other resident care and cannot be permitted.
Cannot run a facility without engaged and safe staff.

Achieving balance when...

- Patient refuses all care and examinations and is conserved.
- Patient with capacity is leaving and coming back intoxicated
- Patient is highly demanding/disruptive with their behaviors impacting the care of other residents and staff wellbeing
- Patient keeps being found vaping in bed with oxygen on
- Patient is driving even though you don't think it is safe.



Developing Relationships

Stages of relationships

- Initiating
- Sustaining
- Repairing
- Ending



Ways to enhance relationships

- **Becoming familiar with life in the LTC home to support social connection**—Orientation, aligning expectations, enhancing mobility, interesting activities.
- **Physical and virtual access beyond the LTC home as strategies to maintain contact**—e.g internet, technologies
- **Getting to know residents to deepen relationships:** benefits of using routine care and interactions as opportunities for social contact, using family and friend knowledge as a resource, and fostering resident relationships.
- **Person-centered approaches to build social connection** included considering physical, mental, cognitive, and sensory impairments, accounting for adjustment and sociability, using communal spaces well, and prioritizing psychosocial needs.

The framework we recommend

- Understand their **individual perspective**.
- Know the **regulations**.
- Develop and nurture the **relationship** to influence behavior (relationship-based influence versus "compliance") .
- Be clear about **staff roles** and responsibilities.
- Through engagement and meaning, get to **win-win**.


Staff Roles and Responsibilities



Photo credit: iStockphoto.com/Robert K. O'Neil

Facility Leaders have responsibility

- Make sure our staff are appropriately trained and supported in caring for our complex younger residents.
- Consistent staff is highly recommended. But we still need to teach staff boundaries.
- Watch out for transference—they feel like our children sometimes. But they are not
- Leadership can be the “bad guy” to protect the primary relationships.



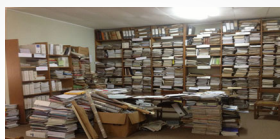
You have to develop new skills

...

Capacity assessment, documentation, setting boundaries, listening, negotiating, conflict management, technology and keeping one step ahead.

Staff responsibilities

- Follow the regulations or have a VERY GOOD reason not to
- Offer a mechanism for care plan requests and input
- Do appropriate assessments
- Have people who are very good write comprehensive summary notes with compassion notes, review care plans. Then others can learn
- Make certain all IDT members are involved
- Have a care plan that is person-centered and trauma informed.



DOCUMENTATION IS CRITICAL

...

Care planning, progress notes, why you made the decision you did and what else you considered...

Unique challenges

Younger adults bring unique challenges to the nursing home and almost all are informed by psychosocial issues.
Relationships are key to solving them.

Challenges you may face

- Manipulative, demanding, use of profanity.
- Substance abuse, drug seeking (prescription drugs more often the "drug of choice").
- Frequent complaints or demands.
- Noise, clutter, night-owl schedules.
- Operating a business in your facility?
- Non-adherence, pushing the limits.
- Challenges with technology that they know more about it than we do.
- Stronger and scarier when angry
- Driving, Sexual expression, ?pregnancy
- Poor curb appeal.

Let's practice with SCI

- **Individual perspective:** imagine paralysis, little hope, loss of autonomy
- **Regulations:** choice; rights, behavioral health, trauma informed care, assessments, input into care plan.
- **Relationships:** long term, many risks, adaptation
- **Staff roles:** understanding medical issues—spasm, autonomic instability, the need to be "straight" in lifts, pressure relieving cushions, protect power chair, capacity assessments, boundaries
- Getting to **win-win**: celebrate milestones, tell a positive story.

Power chairs	Driving	Tech challenges	Pregnancy
Substance Use	WHAT'S YOUR CHALLENGE?		Operating a business
Leaving the facility for unsafe reasons	clutter	Mental illness	Frequent complaints to the state of abuse
Verbal or Physical aggression to staff	Bad influence on others	Highly demanding	Sexual expression

Power chair

Sally's power chair broke and the company is so delayed in fixing it. She thinks staff broke it. She has an old one, but it has a battery that keeps dying and it is too big for her, but she insists on being put in that one daily. Her skin is open because the cushion got deflated. She keeps getting stranded in the community and wants you to pick her and the chair up.



Power chair safety

- Individual perspective:
- Regulations:
- Relationships:
- Staff roles:
- Finding win-win:

Power chair safety

- **Individual perspective:** chair is life, mobility, independence
- **Regulations:** privilege; assessment
- **§ 483.70 Administration.**
- A facility must be administered in a manner that enables it to use its resources effectively and efficiently to attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident.
- **Relationships:** treat chair with respect
- **Staff roles:** assessment, monitoring, cleaning, maximize safety for self and others, repairs, rescues negotiating loss of privileges
- **Finding win-win:** assessments for capacity, use, community integration; statements of understanding, ongoing monitoring for change, cleaning policies, education

FACILITY DE SNF
Use of Power Wheelchair: Resident Agreement

I understand that the use of power wheelchairs at FACILITY is only permitted if medically necessary and safe.

I understand staff cannot place me in the power wheelchair without a physician order. If the physician has concerns about the safety of my power wheelchair or my ability to operate it, my use of the power wheelchair may be further evaluated, curtailed, supervised or restricted.

I understand that the use of a power wheelchair can have risks as well as benefits and that the risks of using the power wheelchair may be greater due to my medical condition. I understand the need to work with the staff at FACILITY to assist me in making decisions about my use of the power wheelchair and its features and accessories.

I understand that when I am off the facility grounds, FACILITY has no responsibility for my use of the power wheelchair. Staff will not come to pick me up or assist me if the power wheelchair fails to work for any reason. I am responsible for making sure my power wheelchair is operating properly and battery is fully charged prior to leaving the facility. In the event that I become stranded in the community, I am responsible for making arrangements to transport me and my belongings back to FACILITY. If I am unable to make arrangements to get back or am experiencing any medical or health concern, I am notified FACILITY who may assist in arranging medical transport for me for my safety. However, I understand that most types of transport will not be able to bring my power chair back and that I am solely responsible for the personal belongings and/or power wheelchair, which may be left behind.

I understand that I must keep my chair in good condition. I understand that I am responsible for any cost of repairs, wheelchair upgrades or replacement. I understand that FACILITY will give me a manual wheelchair to use.

I assume all responsibility for my use of the power wheelchair and hereby release FACILITY, its employees and the attending physician(s) from all responsibility regarding my power wheelchair and any damage or loss that may be caused by my operation of the chair.

I understand that my power wheelchair is to be operated at slow walking speed (around 3 miles per hour maximum) within the facility with special attention to speed when I am in crowded areas or around corners. When operating on the facility grounds, speeds may be decreased to a slow walking speed of 1 mile per hour, but the power wheelchair is only

FACILITY DE SNF
Use of Power Wheelchair: Resident Agreement

to be operated on sidewalks and special care is to be taken on driveways and car thoroughfares.

I understand if I exceed this speed, the motor on the power wheelchair can be adjusted to reduce speed or I may have restrictions placed or loss of the privilege to operate a power wheelchair at FACILITY.

I will not participate in threat or unsafe activities while using a power wheelchair at FACILITY. I will not use my power wheelchair when I am intoxicated, drowsy or ill or any situation when I might have impaired judgment or coordination. I understand that I may not be permitted to take prescribed medications prior to operating the chair if those medications make me less alert, more confused or impair my judgment.

I understand the dangers to myself and others of using the wheelchair in an unsafe manner like having people ride on it or pushing or pulling others. I will not engage in these activities on grounds or within the facility.

I understand that if I loan or give my power wheelchair to another resident that I am still responsible for the rest of my repairs to the chair unless I transfer ownership of the chair and Medicare/Medicaid is notified by serial number of the wheelchair change.

I understand I may be required to undergo periodic evaluations to assure I can operate my power wheelchair safely. Staff may not be permitted to place me in the chair until safety issues are resolved.

I understand that if my health or my ability to operate a power wheelchair declines, my interdisciplinary team can recommend that my privilege to use a power wheelchair at FACILITY be withdrawn. This decision can be reversed at any time if my health or ability to operate a power wheelchair improves.

My signature below indicates that I understand what is expected of me and the potential risks.

Signature of Resident:	Date:
Signature of Staff discussing issue:	Date:
Signature of Representative:	Date:
Signature of FACILITY Staff Member:	Date:

Resources

- Sample policy on power chairs
- Sample statement of understanding
- Sample Assessment
- Sample care plan

Kevin

Kevin asks for a marijuana prescription and insists it is all that works for him. He is leaving the facility daily to smoke and you think it is both cigarettes and marijuana and at times he is intoxicated. Staff keep finding lighters, vape pens. Once another resident was high and stated Kevin gave him some. He has 10/10 pain and insists only dilaudid works and will call the state if you don't prescribe it.

Use of Drugs or Alcohol

- **Individual perspective:**
- **Regulations:**
- **Relationships:**
- **Staff roles:**
- **Finding win-win:**

Use of drugs or alcohol

- **Individual perspective:** suffering, desire for control, escape, passive aggressive
- **Regulations:** pain control program, but not dilaudid, provider ethics and standards, pain control needs to increase quality of life
- **Relationships:** need to believe you care
- **Staff roles:** assess, offer help; monitor, capacity assessment, trials, avoid punishing
- **Finding win-win:** persistence, creativity, celebrate success

Scenario: A delivery arrives for a patient. The package is from a dispensary and it's a cute little bag of candy. The delivery driver asks if they can connect with the patient directly, but you say you can help. The delivery driver then asks for you to sign for the candy.

What do you do? Discuss signs for the candy!

- The marker is **we**—you need to reject that delivery. It's marijuana!

What are some other signs of marijuana?

- The number 420 (also in a date April 20 which is celebrated for marijuana and came from a group of students in 1971 who smoked at 4:20 p.m.)
- The word Cannabis on the package
- Small packets of candy, gummies or baked goods with warning labels on them to keep out of reach of children
- The logo of a marijuana plant



As residents are learning, it is possible they are smoking or eating marijuana and we want to keep this out of our facility. We had a patient recently who had a lot of contraband in his room and purse and we noticed we didn't have him a receipt at all.

➤ We have to be at least a little bit familiar with illicit substances around here! Below are pictures of what we found in your case recognize things better in the future.

➤ If you are something, say something. We can get together and coach. [Recognize-Illicit-Contraband-1-11-Quick-Reference-Search-and-Seize-5-5-18-Don-VanDusen-MD-2018-1-11-11](https://www.cannabuse.com/2018/01/11/Recognize-Illicit-Contraband-1-11-Quick-Reference-Search-and-Seize-5-5-18-Don-VanDusen-MD-2018-1-11-11)



Prescription bottle with someone else's name on it, mints and small packets are marijuana.



These are all devices to deliver nicotine or marijuana.

How to communicate around substance use.

- Be honest about what you observe, try not to judge or preach.
- Ask questions, seek to understand.
- Develop a relationship—accepting them as they are but caring enough to tell them the hard truths.
- Talk about how much you care.
- Ask them to help you by suggesting what they want (goals) and what they plan.
- Do NOT threaten discharge.
- Tell them calmly what YOU will do if they are intoxicated.
- Explain risks—both short term and long term, to themselves and others.
- Evaluate their medication profile to see if there are any medications which interact with alcohol
- Evaluate decision making capacity Get permission to speak with family.
- Consider what interventions you can put in place to make this safer
- Educate, encourage reduction in quantity or strength or frequency of intake, encourage more positive relationships, discontinue medications that interact, try to reduce access to funds, if possible, try to meet needs in another way, search and remove contraband from rooms, offer treatment (often off campus—AA or perhaps online...<https://www.smartrecovery.org/community/>)

•

•

Brief Intervention Model: FRAMES*

- Feedback of personal risk
- Responsibility (of the patient to change)
- Advice to change (without judging)
- Menu of change options (choices)
- Empathy (“it’s tough”)
- Self-efficacy (optimism –“you can do it”)

Miller & Sanchez, 1993; World Health Organization manual for Brief Intervention

• http://apps.who.int/iris/bitstream/handle/10665/67210/WHO_MSD_MSB_01.6b.pdf;jsessionid=43A6AF05FAB1994D951C6106153E71BB12?sequence=1

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

•

DEALING WITH INTOXICATION

- First, assess the situation and make sure you know what you are dealing with.
 - Do they appear intoxicated from alcohol or illegal drugs? Signs of intoxication: smell of alcohol, poor coordination, slurred speech, nausea, vomiting, flushed face, seizures.
 - Are substances visible, e.g., cans of beer in wheelchair?
 - Could they have a medical condition that makes them appear intoxicated?
 - Ask them:
 - Did they use alcohol or drugs?
 - How much?
 - When they last used?
 - Note: they may or may not be truthful, but still ask and watch them.
- This is not a good time for confrontation, avoid yelling, berating, education or confrontation, SAFETY FIRST
- Make sure there are always two staff when interacting with the intoxicated resident. Intoxicated people are often unpredictable and may become violent without provocation.
- An intoxicated person may not recall accurately, e.g., they fall and “remember” that you pushed them (again, always two staff).
- Try to ensure the resident's safety. Move the person to a safer environment (their room) and remove all harmful objects (anything they can hurt themselves or others with). Remove power chair!
- Assess for signs of injury:
 - Head trauma or other injuries. Abrasions, bruises.
 - Low or high blood glucose.
- Watch and expect behaviors: confrontational, argumentative, irrational, uncooperative, belligerent, clumsy and emotionally unstable.
- Monitor for possible alcohol poisoning.
 - Full effect of drug or alcohol may take time. It may get worse before better.
 - Wake them up at intervals (every 20 minutes).
 - Put them on side with pillow behind them in case of vomiting.
 - When to call an ambulance (911): if they are physically abusive, if they cannot wake up, if they have seizures, if vitals become unstable (low temp, irregular breathing).
- Have medications reviewed by pharmacy in light of possible interactions before giving them to a potentially intoxicated person (for instance ask pharmacy to review and discontinue all medications that potentially interact with alcohol).

•

•

[illegible]

Sample Policy elements

I. POLICY

FACILITY will take reasonable steps to discourage or prevent residents from self-administering drugs or other medically necessary psychotropic substances (e.g., inhaler, insulin, exercise, etc.) that weigh less than 500mg and are not in a container being associated with the resident.

FACILITY will take reasonable steps to ensure no medication from them (stolen and/or not prescribed substances with restriction of resident rights) is given or justified for safety of the individual or others.

II. PROCEDURES

A. Initial history will ascertain information about substance use and related diagnoses (current or historical), treatment and current use.

B. Residents with substance use disorder diagnoses, who are amenable to treatment, will be offered treatment available at **FACILITY**, including counseling and referrals.

C. Clinical staff will offer to provide people of substance abuse disorder through observation, laboratory studies, and development of consistent relationships.

D. When substance use or a substance not described is suspected, all clinical team members including nursing, social workers, psychology, and physical medicine and assessment and implement harm reduction interventions designed to protect the person, staff, and others and ensure the community from drug use impacts on health.

E. The Physicians and Long-term/Primary Care will take reasonable steps to provide the safety of the resident and facility within the constraints of resident rights. Such steps may include:

- Assessment of risks and implementation of resident specific interventions for drug mitigation.
- Assessment with change of circumstances, held at 60 days from date of initiation or any deviation.
- Development of relationships (built-up trust and willing setting involving patient's resources).
- Education concerning the problem.
- Offering medication treatment to a suitable.
- Strongly to direct attention to harm reduction and education education case.
- Implementation of care plan for acute situations.
- Toxic screen and other inspection for continued.

III. MEDICATIONS

- 1. Hospitalized monitoring of the resident.
- 2. Observation of visitors or contacts with the sick person.
- 3. Having facility provided medication orders or treatments do not attempt to permit residents substances used outside.
- 4. Through pharmacy control and review of the resident's medication regimen for possible recurrent adjustments to maintain the risk of the resident's use of non-prescribed substances.
- 5. Notification of people of substance use disorder to reduce substance use (if appropriate).
- 6. Notification of representatives of other facilities to make their own substance use or substance use.
- 7. Observation of prisoners (e.g., operation of prisoners) to enable within the facility to prevent self and others.
- 8. Attention to medication use approach to health and behavioral concerns.
- 9. Abuse or neighborhood (damage).
- 10. Notification of other (non-facility) cases.
- 11. Care plan updates.
- 12. Transfer or discharge.

IV. OUTCOMES

The resident population includes individuals who are amenable to facility, exhibit cognitive impairment, and most of whom have significant histories of drug use and other issues under Section 502(b). Subsequent to this population group significant risk of damage to the staff and residents was observed in the literature, the facility who maintains decision-making capacity, the facility will be located at what can offer or refuse.

V. CODES OF CONDUCT, Policies, Authority

CFR: 403.10, 403.12.

A photograph of a cluttered living room. The room is filled with various items, including a large television, a wooden cabinet, a chair, a table, and a bed. The word "Clutter" is overlaid in large white text.

This is my home and I need this stuff!

Mr. G has been in LTC for 2 yrs. He has a power wheelchair and a second one that is broken, but he may want to fix it. He shops on Craigslist and has purchased a laptop, desktop, large TV, and stereo system. He has his own coffee pot (he doesn't like decaf) and a large bottled water dispenser and requests staff to purchase the water and put the five gallon bottle on the dispenser. He has a large collection of sock monkeys. He is quadriplegic and uses a Hoyer lift. He refuses to part with anything, has a big "do not enter" sign on his door, and only lets certain staff he trusts touch his things.

Clutter

- **Individual perspective:**
- **Regulations:**
- **Relationships:**
- **Staff roles:**
- **Finding win-win:**

Clutter

- **Individual perspective:** *This is all I have—limits are tight. Electronics are expensive but needed! Its not that hard to care for my stuff correctly. It is not fair!*
- **Regulations:** right to belongings, but limits. Staff must be able to do care safely
- §483.10(l);
- §483.15(e), F252 §483.15(h)
- §483.15(h)(2)) F323 §483.25(h)
- **Relationships:** sorting, sustaining together
- **Staff roles:** who manages the belongings, loss
- **Finding win-win:** pride at the appearance, involved in finding solutions, feeling of helping the nurses.

Justify clutter reduction

- There are limits to the amount of possessions that can be stored and difficult decisions must be made as to what items are the highest priorities.
- Resident items must fit in their rooms;
- Possessions require care. They need to be kept clean, moved frequently, folded, sorted and moved.
- If a resident (or family member) can be completely independently responsible for their personal possessions then more items can be accommodated. However, in situations where the resident cannot be responsible for their items due to physical or mental disability, the time spent on caring for personal possessions falls on clinical staff.
- When clinical staff spend time caring for possessions they have less time to care for residents. As a result, personal possessions that require staff time/maintenance may be limited. Clutter can be a safety hazard both for residents and staff who need extra clear side walkways and workspaces for safety. Housekeeping has to maintain a high level of cleanliness and the presence of excessive personal items may unreasonably interfere with this duty and place staff at increased risk of injury due to the need to move personal items.

Resources

- Sample facility inspection form
- Sample "clutter letter"

Tech support

- Toby uses the facility internet to access pornographic websites; he shows them to others—for a price.
- Shakira's iPod is lost again; she wants it replaced.
- Dylan is paralyzed and needs staff to help him set up the computer and to load software for him. He keeps getting scammed.
- Portia posts info about the facility on her blog and takes photos/videos of staff without their knowledge.

Rational Use of Technology

- Individual perspective:
- Regulations:
- Relationships:
- Staff roles:
- Finding win-win:

Rational use of technology

- Individual perspective: *I am not disabled on the internet.*
- Regulations: privacy, rights, needs versus wants
- Relationships: let them teach you
- Staff roles: staff have the right to be free of resident/family harassment, hostile workplace, privacy; can electronics make staff lives easier
- Finding win-win: they can teach each other, cleanup computers, clear expectations on who pays for loss. Wireless. Promote autonomy using technology (arrange appointments)

Out on the town

Martin goes out all day in his power chair and returns late at night. He has a pressure ulcer, but he doesn't want to "rot in bed." He smokes on his own, and burns his fingers or has holes in his pants. He sometimes buys food for his friends or drags them along behind him to help them get to the 7-11.

Out on the town

- Individual perspective:
- Regulations:
- Relationships:
- Staff roles:
- Finding win-win:

Out on the town

- Individual perspective: self destructive, immature coping, hopeless, depression, avoidance
- Regulations: autonomy, safety, undue influence or danger to others
- Relationships: influence behavior
- Staff roles: capacity and community assessment, making it safer, monitoring, assuring safety of peers with lower capacity
- Finding win-win: community integration and discharge, enhanced happiness, relationships with peers (altruism), cooling off

Resident Statement of Understanding for Leaving Grounds Unaccompanied

As a resident of a long-term care facility, I have the right to leave the facility without accompaniment as long as I have the capacity to understand the risks and have the physical abilities to leave.

It is not recommended that I leave unaccompanied because I require ongoing medical care and have physical and/or mental limitations. I acknowledge there are significant risks if I exercise my right to leave the grounds by myself including, but not limited to:

1. I may have a medical problem that results in injury and/or death and not be able to seek medical or nursing attention (e.g., heart attack, stroke, seizure).
2. I may need to go to the hospital or require emergency services.
3. I may get lost and/or become disoriented to change positions or help staying clean and dry and result in a higher risk of pressure sores, falls or other problems.
4. The inability of facility staff to respond to an emergency.
5. Being involved in an accident or incident that could cause serious medical injury or death through my action or that of others (cars, coast, dog attack).
6. Suffering harm related to my own behavior, for example use of substances and suffering overdose, or injury due to use of candles, matches, lighters, or exposure of other medical complications.
7. Have an injury related to heat or cold, for example, suffering frostbite, dehydration, or heatstroke/rehydration that could result in significant injury or death.
8. I may run out of batteries in the community and not have a way to get them charged again.
9. I may have to leave my wheelchair in the community if it runs out of batteries or breaks down or I am taken somewhere by ambulance and this may result in death, loss or damage to the chair if I cannot make other arrangements.
10. Loss/Change to my wheelchair power, wheelchair or other property.
11. Infectious disease exposure.

FACILITY will use reasonable measures to help prepare you to manage these risks and assess your abilities to help you make an informed decision about leaving

grounds. However, once you leave, you are responsible for your own safety and well-being. If you are not past the time you establish, please call us and let us know as we worry about you. If you do not return on time, we may try to call you and when you want out with us may even have to notify law enforcement for a welfare check.

If you are stranded, we can arrange for an ambulance to get you back here, but they will likely leave your wheelchair behind. If you suffer an emergency, you should be prepared to call 911 to obtain assistance since FACILITY does not provide transportation or other services for residents who choose to leave grounds outside of facility sponsored outings or facility ordered appointments.

Staff recommends the following to make things safer for you:

- Sign out at the nurse's station and let staff know your destination and approximate time of return.
- Travel with a companion.
- Carry a cell phone preprogrammed with emergency numbers.
- Assist phone/wheelchair are charged, bring charge.
- Have an emergency plan.
- Go to populated areas, avoid isolated locations.
- Carry hot and water.
- Time a walk, avoid crowds, social distance, and wash hands.
- Wear sun/hand with facility phone number.
- Travel in daylight hours when there are likely to be people around.
- Wear clothing appropriate for the season.
- Wear sunscreen, hat.
- Avoid smoking, drugs or alcohol when out on your own.
- Use good judgment of risk or need, if weather is bad, do not go out by yourself.

Community Signature of Resident Representative: _____ Date: _____

Signature of FACILITY Staff Member: _____ Date: _____

Resources

- Sample statement of understanding for leaving the facility unattended
- OT/PT develop standardized assessment.
- Sample Physician order:

the resident has been assessed and determined to have the decision making capacity to exercise their right to leave the facility unattended and been informed of recommendations to make this safer.

•

•

Driving?

- Fernando lets you know he is driving now and wants to park his new van in the parking lot. He shows you his drivers license. He said his van has hand controls (he is a quadriplegic with some use of hands). He is a daily drinker despite being in the nursing home and can be aggressive when drunk. He is taking medications for chronic pain.

•

•

Driving

- Individual perspective:
- Regulations:
- Relationships:
- Staff roles:
- Finding win-win:

•

•

Poster on driving?



Let's get physical

The supervisor was called to the nursing unit by the charge nurse one evening. One of the staff nurses had been passing by a resident room that had the door open. The curtain was drawn around the bed but the nurse could see that the ceiling lift was being pulled along the track with jerking movements. She knocked on the open door and called out the resident's name who resides in the room. When no one answered, she became alarmed and pulled the curtain aside to make sure the resident was okay. The resident is a woman with quadriplegia and moderate cognitive deficits. Her boyfriend, also a resident, with hemiparesis from a CVA was using the lift to support himself while they were engaged in sexual activity.

Or for the advanced...

- 31 year old man who is a quadriplegic but has intact sensation. He cannot masturbate and has purchased a sleeve device that goes over the penis. He needs staff help to apply it. He asks, can you help me?
- 28 year old found using her personal computer to take videos of herself topless and post on line for money. Also, finding "dates" who give her things.

Sexuality

- **Individual perspective:**
- **Regulations:**
- **Relationships:**
- **Staff roles:**
- **Finding win-win:**

Sexuality

- **Individual perspective:** sexuality is normal, nursing homes have no privacy—all gossip
- **Regulations:** activities of interest, privacy, reasonable accommodation, assessment, safety
- **Relationships:** Know them and what is going on. Help counsel on unsafe situations (not preach).
- **Staff roles:** What is part of my job? What is optional? What is not allowed? Capacity assessment, identifying and preventing liaisons that are not mutual.
- **Finding win-win:** achieving privacy, intimacy without harm to staff or peers

Sample care plan interventions

- Staff can provide privacy but not assistance
- What assistance are staff comfortable with—all staff required, or volunteers?
- Have indicator of needing privacy.
- Checking parameters—how often, and how
- Beds are designed for one person; lifts can only be operated by staff.

Mental Illness

Mina is 42 and has schizophrenia with multiple psychiatric hospitalizations and suicide attempts since age 18. Her family stays away because she is so angry at them as a result of their being her conservator on and off for years and her lack of insight into her need for assistance. When homeless, she was victimized. She used drugs, smoked and drank, and was likely a prostitute for drugs. She speaks in wild delusional statements, gets irritable, and mostly keeps to herself. She refuses to be touched in any way.

if staff argue with her delusions, she may get frustrated and slap them, and she occasionally gets angry at a peer who gets incorporated into a delusion. She is on two antipsychotics, a mood stabilizer, and an antidepressant. She ambulates, but needs prompting to do ADLs. She needs a modified diet. Her cognition seems poor. She looks like she is in her 60s.

Mental Illness

- Individual perspective:
- Regulations:
- Relationships:
- Staff roles:
- Finding win-win:

Mental Illness

- **Individual perspective:** fear, low motivation, desire for connection
- **Regulations:** Mandated medication reductions, keeping others safe justifying her to stay at your facility. Discord between mental and physical health systems.
- **Relationships:** build trust, don't push, do not argue delusions
- **Staff roles:** Understand dementia, prevent harm to self and others, learn about co-management of mental illness and dementia. MDS coding, documentation critical.
- **Getting to win-win:** Can become facility expert! Families can reconnect when loved one in stable environment, and function improves. Dementia diagnosis reduces pressure for rehab.

Sample care plan for serious mental illness.

- **Goal:**
 - To assure that psychosis does not result in any distress to the resident or harm to self or others.
 - Avoid acute psychiatric hospitalizations for 90 days.
 - Avoid metabolic complications of antipsychotics.
- **Interventions:**
 - PASRR on admission and with change in diagnosis—review recommendations and document those which can and cannot be accommodated, accepted or refused by the patient.
 - Obtain informed consent for psychotropic medications.
 - Monitor for risks such as: Elongment, psychiatric exacerbation, aggression, non-compliance, medication side effects.
 - Document triggers, non-pharmacological interventions and outcomes of use of psychotropic medications.
 - Do not challenge delusions or argue with them (like with dementia, validate the feeling behind it: e.g. "That sounds scary")
 - Monitor signs of psychosis that the individual exhibits (delusions, responding to internal stimuli, irritability, aggression, misperceptions, auditory hallucinations. Report any withdrawal or refusal of care, poor impulse control, low frustration tolerance, unable to think clearly, difficulty communicating needs.
 - Assure that medications are swallowed/ingested and not pocketed.
 - Provide music or television viewing to drown out auditory hallucinations.
 - Provide a structured environment with consistent staff.
 - Activities of interest - encourage participation.
 - Interdisciplinary psychotropic reviews quarterly and as needed.
 - Weight, lipid and glucose values to be measured periodically to evaluate for side effects of antipsychotics. (exception: comfort care status; monitor for SX only)
 - Routine measurements of levels of lithium and anticonvulsants used for diagnoses. (exception: comfort care status; monitor for SX only)
 - Drug reduction as indicated if patient is stable over a period of time and benefits outweigh risks, but not mandated for those with schizophrenia, Tourette's, HD and schizoaffective disorder.
 - Monitor behaviors (CNA). Lx to assess and document new behavior with triggers
 - Assess daily routine of resident and, develop/create a structured environment/routine with consistent staffing that the resident can easily adapt to himself/ herself without forcing him/ her.

Demanding excessive use of resources

Constance wants her care done a certain way. She has quadriplegia so she needs your help. She wants her vulva and legs shaved every other day, daily showers which take more than an hour and extensive help straightening her clothing, applying tight garments and applying make up and fixing her hair. "Just one more thing before you go."

I want it now

- **Individual perspective:**
- **Regulations:**
- **Relationships:**
- **Staff roles:**
- **Finding win-win:**

I want it now!

- **Individual perspective:** *I need help to do everything. I want things that I can no longer get. I am suffering from being sick and see you as a servant.*
- **Regulations:** Our mandate is "all your needs and some of your wants," your wants cannot take away others' needs.
- **Relationships:** Keeping your caregiver is key to your health and quality of life. "I am on your side, but I need to make sure that this happens or I may be reassigned."
- **Staff roles:** staff burnout and feelings matter, support staff in setting limits and providing "standard" care
- **Finding win-win:** celebrate compliance, offer choice of what to take away for new requests, celebrate staff and residents who can work it out together

How to do behavioral care plan

This guideline provides some assistance in dealing with residents who continue more than their share of facility requests, often for immediate, convenience, and/or convenience.

The main principle used to address these issues is that FACILITY first must meet all the needs and some of their wants and then we need to ensure that all needs are met before using resources to meet preferences that may take away from other's needs.

This guideline provides some suggestions to assist in care planning and is not meant to be a directive.

We use to address residents through the assessment support process and DIT meetings. The accumulation of these items may point to a need for more services or support to completing.

Principles:

- These interventions are effective in situations where the resident is not willing to change voluntarily, and where their demands are interfering with the care of others directly through time and indirectly through staff resources.

- Bring a team together with the individual and an Individual Director, Director of Therapy, Psychologist or social worker, and other staff who will support the resident. Residents who identify on the chart and/or in the room with staff who are not willing to change their behavior, who are not willing to change their needs, wants and resources are not that intervention may be successful or practical. Group will take into consideration resident diversity and identity. Do not try to solve the problem and you have thoroughly evaluated it.

- The team reviews the characteristics of the individual team members, documentation, resident's needs based on their medical condition, assessment for their behavior, preferences, observations and the needs of other residents who are impacted. Clearly define new preferences. Attempt to identify which preferences are the most important to the resident.

- Use trauma informed language and analysis to understand underlying emotional needs.
- Meet with all three staff and ensure you are meeting with staff who care for the individual to get appropriate input on what they are observing and what has worked or not worked, but do not put them in a position to solve the problem.

- It may be necessary for DIT to identify other aspects of care to develop complete or assess it is being followed.

- Detail behavior and complete list of rules of these statements ensuring behavior requests are being made of both staff and resident. Document it all three adults to review.

- Assess resident's ability to comply with all staff and other residents' choices ("If you tell, I will say yes," "If you tell, then that is what we will do,").

- Finalize it, then give a copy to the resident. Notify the resident at least 24 hours prior to implementation. They do not have to agree, just be notified.

- The goal of these guidelines care plan is to protect your choices in preference, but to ensure that you discuss in detail other than want and that the needs of all the residents are protected. Consider the time spent on the plan and the time spent on the plan. Your plan must address the care plan that you have, by whom and in what time frame(s), as well as any practices that will not be done for team members. Include consistently assigned staff to be the person and there is a written commitment to evaluate success and correct staff of the plan to reduce staff and miscommunication.

- Initially, when the care plan is implemented, it is expected there will be challenges, it is important to plan for these, and provide support for staff during this period. Changes as proposed should be reviewed by multidisciplinary and communicated to the team as a whole.

- Subsequent type care plan may be made available in page for all team members. They are stored on the 5 drive in a restricted folder (5-2025/Consent/2_Care/2025 Care Plan).

- Evidence of violation of the care plan should be reported to the supervising nurse for investigation and correction. In cases of these residents, any violations are expected to occur. The response of reporting violation is not to punish staff, but to provide support and education and management to improve.

- Individuals in behavioral care plan are seen by the psychologist designed more frequently.
- Social psychological services staff will participate in the development and resident adaptation to the care plan as well as support and education into the team and assist in facilitating communication, and management.

- As much as possible, there should be consistency between what it considered a good and a bad team between residents with similar health concerns.

GOALS: Consistent staff and good staff-resident relationships without burnout or injury, provide all medical needs and some preferences for her and others and assure that her preferences do not impact needs of others for care.

THREATS

- **Principles for getting up or going to bed are:** approximately 9:30a.m., 7:30p-9:00p.m. **6:15-8:30 if not on pain** and 5-4-4 a.m. **6:30-9 a.m. on some days** (not always **not working for the hospital**). Can get up or go down one per shift only. Standard care is half dressing on night shift and complete on day shift. Night shift can't do full dressing on night and leave any time between 5 a.m. and 4 a.m. staff time however, you must have a full shift as they **will time for selection or changes**.
- If sick or abnormal shift signs, exceptions are made, but the would need to be in bed until resumption. If resident requests to be assisted back to bed at 5:00p.m. (day in night), **16-30 minutes (often)** (upper body or shoulder, pants in bed). **Lower body is provided later**.
- If goes to bed on night shift AND wants to get up 9:30p, then night shift can do either top or bottom dressing when bed with routine care.
- **Standard health related care is estimated to take 10 minutes**. After standard care, there is 15 minutes for preferences which may include open male-patients, hair, nails, adjust the chair, phone issues. If resident is not selected, then choosing outfit counts against the time taken. If resident is not ready to participate in standard care at accepted time, staff may only provide care and then available for any. **Make-up get up occurs at 10 a.m. If can occur usually 30 minutes and care needed when going on or not shift, making set up can do time permitting.**
- **PR staff can assist resident daily to pick up or choose outfits for the next day.**
- **Special considerations:** Use of the resident's own clothing is encouraged, but as much as possible, can talk in place and cater to bathing, placing, skin and change as they are able. As possible, allow to move up and down in her care as she begins to slide through opening.
- Do not put on clothes that are not clean.
- If meal is room, all requests for meal must be made prior to try to bring something.
- Hair care – brush, can condition or detangle, but not remove or cut.
- Shower is 30 minutes in the water, two showers only. If not ready by 7:30p.m., skip to next scheduled day. No bathos.
- Special exception requests are submitted by RESIDENT via email to the DOH/Nursing Supervisor, and/or directly signed to ONI (C of the hospital), all hours in advance including what compensates she is willing to make. All requested shift requests must be against the exception.
- If staff caring for her has extra time and the inclination and if not off take away from others in their assignment, from time to time, they may honor special requests that are not on their plan; however, this is not to be perceived as an expectation.

resources

- Sample behavioral care plan
- Sample policy on behavioral care plan

Further Reading

- Oliver, S., Gosden-Kaye, E. Z., Jarman, H., Winkler, D., & Douglas, J. M. (2020). A scoping review to explore the experiences and outcomes of younger people with disabilities in residential aged care facilities. *Brain Injury*, 34(11), 1446–1460.
<https://doi.org/10.1080/02699052.2020.1805124>
- Chapman, H., Bethell, J., Dewan, N. *et al.* Social connection in long-term care homes: a qualitative study of barriers and facilitators. *BMC Geriatr* **24**, 857 (2024).
<https://doi.org/10.1186/s12877-024-05454-8>