

They Still Have Rights: The Art of Promoting Resident Rights In An Era of Non-Pharmacologic Dementia Care



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Objectives Of Today's Presentation

- **Gain an understand of the barriers to quality care.** Why we need to Rely less on pharmacologic management of BPSD, how the new Paradigm Shift better supports, encourages and promotes Resident Rights and Patient Centered Care.
- **You will be provided with hands on tools useful in the new environment.** The tools will help us identify our residents as so much more than a person with Dementia, and how to meet their individualized needs in their new reality.
- **You will learn the New Standards of Practice for Medication Management.** Prevent Regulatory Difficulties.
- **You will learn effective Conflict Resolution Strategies.** How to defuse the saboteurs, talk with families and get the entire IDT coming to the table with the Goal of promoting self- actualization for all of our residents.

When you change the way you look at
things, the things you look at change.



Unknown

Its All About Perspective

Barriers To Quality Care

- A fragmented system regulated by different sets of rules creates a confusing, segregated, and disconnected array of services and providers involved in health care of older people. At times there is little communication between providers in order to maximize continuity of care.
- At times there is little communication between providers (nursing home, hospital, Rehab, Emergency Rooms, Hospice Mental Health Clinics) in order to maximize continuity of care.
- Older adults are less likely to self-identify mental health problems or seek mental health services, Embarrassed families withhold vital life history
- All older people possess culture. One critical aspect of culture is age itself. Older adults are not a homogeneous group with similar needs and capacities.

Barriers (cont.)

- Long Term Care residents are presenting with increasingly complicated Behavioral and Psychological Symptoms of Dementia (BPSD) .
- Studies have found that more than 90 percent of people with dementia develop at least one BPSD with a significant percentage of these individuals having serious clinical implications.
- Residents of long-term care facilities were increasingly being placed on antipsychotic medications to "manage" these BPSDs despite having no proper diagnosis to warrant their use.
- Antipsychotics are especially dangerous when prescribed to elderly individuals and have been linked to numerous resident deaths. Many of these medications carry BLACK-BOX warnings for increased incidence of mortality from cardiac issues, stroke and pneumonia.
- Furthermore, the misuse and overprescribing of antipsychotics in long-term care facilities is extremely costly for the Medicare program and for consumers, as these medications tend to be high-priced.

Why Medicare Cares!

- Fourteen percent of elderly nursing home residents had Medicare claims for atypical antipsychotic drugs.
- Eighty-three percent (83%) of Medicare claims for atypical antipsychotic medications for elderly nursing home residents were associated with off-label indications; 88 percent were associated with the condition specified in the Food and Drug Administration (FDA) boxed warnings.
- Forty-one percent (41%) of Medicare atypical antipsychotic medication claims for elderly nursing home residents were erroneous, amounting to \$116 million.
- Twenty-two percent (22%) of the atypical antipsychotic medications claimed were not administered in accordance with CMS standards regarding unnecessary medication use in nursing homes.
- 17% of nursing home patients had daily doses exceeding recommended levels in 2010.

OIG/CMS

The Shifts

- On March 29, 2012, CMS launched the National Partnership To Improve Dementia Care and Reduce Unnecessary Antipsychotic Drugs Use in Nursing Homes. (This is now referred to as the Partnership to Improve Dementia Care in Nursing Homes).
- On May 18, 2012, Helen EF redefined who was an appropriate candidate for detention under a Chapter 51 mental health hold. Also forces counties to utilize the Protections under Chapter 55, which up until now were greatly underutilized.

Chapter 51

- Provides for treatment of individuals with mental illness
 - To be committed under Ch. 51 You must:
 - Be an individual with mental illness
 - Must be capable of being treated
 - And, be an imminent danger to themselves or others
- Treatment should be sought in an appropriate Chapter 51, Mental Health Facility

Chapter 55

- Chapter 55 provides for Protective Placement and Protective Services
- Eligibility For Protective Placement:
 - Having an impairment that is likely to remain permanently
 - Must be totally incapable of providing for their own cares
 - Which leaves them at risk for harm to self or others
 - Incompetency
- Eligibility for Protective Services:
 - There must be a substantial risk of physical harm to self or others, if the protective services are not provided
 - Incompetency

Guidance For Law Enforcement and County Agencies Re: Ch. 51

On January 28th 2013, Dan Knodl, Chair Special Committee on Legal Interventions for Persons With Alzheimer's Disease and Related Dementias, Requested that:

- DHS publish Guidance for Law Enforcement and County Human Service Agencies as to the process to be followed for involuntary treatment of individuals with dementia
- DHS educate The Public about the appropriate usage of Chapter 51 (mental health act) or Chapter 55 (protective service system) when dealing with Residents that are a danger to self or Others.

DHS Further Supports That:

The overall goal is maintain individuals in their current placement with adequate treatment and supports, until such time as their behaviors require the least restrictive alternate placement

- CH 51 detention is still a viable option for a resident with dementia and a concurrent TREATABLE mental illness
- For residents without a treatable mental illness CH 55 allows:
 - If threatening behaviors exist because of a change in environment, or a medical condition, they should be addressed first
 - In the absence of the above, transportation to the designated CH 55 facility should occur

A Case In Point

A PERFECT EXAMPLE
OF WHAT NOT TO DO

Case Factors To Consider

- Never solved the problem, just moved it.
- Never drilled down far enough to identify the root cause.
- Lack of appropriate staff training.
- Lack of appreciation for how the environment can affect behaviors.
- A fragmented healthcare delivery system with poor communication between them.
- Inappropriate usage of chapter 51 Mental Health hold.
- Lack of engagement with appropriate community resources.

Questions To Ask Now

- Does your County have a functioning acute crisis team and Chapter 55 facility?
- If not, how can you work with your county to establish one? Join your I-Team.
- Is your staff adequately trained and are there written policies and procedures in place?
- Are your resident medical records current with all applicable diagnosis and medications?
- Are contact number readily available?
- Have you trained your staff as to how to proceed, and what records need to be available when law enforcement or Crisis Services are asked to intervene.

WE ALL HAVE RIGHTS

Unfortunately....

Sometimes They Can Seem To Be Conflicting Rights



Resident's Rights

Federal and state nursing home/CBRF/RCAC/AHF laws prohibit the use of chemical restraints and unnecessary drugs. Facilities need to provide:

- Quality care so individuals attain and maintain their highest functional capacity,
- Enhance an individual's quality of life by supporting their dignity, respect, self-direction, and choice,
- Honor freedom of choice in care and treatment decisions, including being able to provide informed consent for, or refusal of, any proposed treatment,
- Provide individualized care based on a thorough evaluation and dynamic care plan
- Prompt response to complaints

Facility Rights

- The right to accurate pre-assessment information, from all appropriate parties, in order to commit to a new resident
- The right to honest and up to date information from all involved parties
- Develop an appropriate network of healthcare providers in order to facilitate open discussion and care planning surrounding residents with BPSD
- Access to necessary and appropriate medical providers and services to determine care plans and manage behaviors
- To decide that the prospective resident is not a "good fit" for their current community

Family/POA Rights

Generally, They have the rights that the Residents give them

However....

- They have the right to actively participate in care planning
- They have a right to ask questions and be heard,
- The right to be fully informed
 - About a change in condition
 - About a recommendation from a Health Care Provider
 - About a change in services to be provided
 - About any condition that may jeopardizes a residents ability to remain as part of their community

According to the American Geriatrics Society, "Non-pharmacologic interventions have been shown to be more effective than pharmacologic treatment for BPSD and therefore should be attempted first

Non-Pharmacologic Care Principals

- **Person Centered/Directed Care**
 - Individualized Approaches to Care
 - Tools For Assessing Challenging Behaviors (BPSD)
- **Quality and Quantity Of Staff**
 - Have received dementia specific training
 - Thorough Evaluation Of New Or Worsening Behaviors
- **Quality Assurance Considerations Related To The Usage Of Anti-Psychotic Medications**
 - Appropriate Usage
 - Standards Of Practice

Non-Pharmacologic Interventions

- Person Centered Care/Life Stories are important
- Music during meals and/or bathing
- Walking or light exercise
- Aroma Therapy/Massage
- Reducing environmental stimuli including light and sound not only to prevent challenging behaviors but to help promote overall well-being
- Engaging in meaningful activities, e.g., the TimeSlips Music and Memory, Reminiscence, program,
- Pet therapy

Person-Directed/Centered Perspectives

- Resident viewed as the whole person.
- Dementia is only a disability of certain parts of the person's brain.
- Dementia doesn't define them.
- We need to shift from seeing dementia as a terminal diagnosis, to seeing it as purposeful journey to a life's conclusion.
- We need to develop approaches that build on strengths and use them to overcome challenges.
- We need to involve them in daily decision making.
- We need to respect decisions and personhood.
- We need to ensure that rights related to self-determination are honored and upheld.
- That Resident feels validated, empowered, respected, supported.

ELDERSPEAK

- Language, translated into action & attitude, that encourages treating persons as labels, symptomatic behavior "problems" or diagnoses.
- Can be misperceived or mistakenly translated as patronizing, not respectful, not dignified.

Examples of Elderspeak

- They act just like a child
- They are not in their right mind
- They don't know any better
- They will just forget anyway
- They can't tell the difference

Consequences of Elderspeak

- Excessive disability (functional decline)
- Dehumanization
- Feelings of isolation, alienation
- Depression
- Withdrawal
- Anger
- Anxiety
-

7 Values of Person-Centered Care in Practice

1. Building on the **Unique qualities** of every person as the starting point for relationships*
2. **Promoting Social Confidence** - ensuring that each person can expect to interact positively with others
3. **Recognizing Self-Worth** - providing roles and activities that complement a person's self worth
4. **Inspiring Hope** that there are things to look forward to every day
5. Treating every person with **Respect** and always **choosing truthfulness**
6. Recognizing that **Engagement is a sign of well-being** and offering opportunities for every person to interact with the environment and others in **meaningful ways**
7. **Supporting Independence**

From Beth Meyer Arnold/Lynn Geboy

Tools For Assessing Challenging Behaviors

- Universal Checklists to Assessment Physical and Psycho-social Needs
- Root Cause Analysis
- The Five Whys
- ABC's
- Convene the IDT
-

Understanding Behavior

All Behavior should be viewed, primarily as attempts at communication, related to unmet needs. The caregiver needs to seek the meaning of the communication and to address the need.



Physical Checklist

- Need to toilet
- Unmet pain management
- Temperature
- Hungry
- Tired
- Bored/need exercise
- Effects of medications/change in medications
- Sensory impairment/ hearing and vision loss
- Acute illness
- Dehydration or constipation
- Substance withdraw
- Medical diagnosis/missed diagnosis
- Mental health diagnosis/missed diagnosis

Psycho-Social Checklist

A Resident needs have the ability to:

- still care for self and others
- feel useful
- Participate in Meaningful Activities
- have self esteem boosted
- give and receive love
- still feel joy and laughter

ROOT CAUSE ANALYSIS

Root cause analysis helps us find and correct the primary cause of an issue. We do that by asking the following three questions:

1. What happened? Get facts, not opinions. This is where you collect data.
2. Why did it happen? Ask the "why" question repeatedly to get to the true answer. This is often called "drilling down" or The 5 Whys, to get to the true cause. The repeated questioning uncovers the bottom-line issue, and a process to correct the problem (symptom)
3. How can we reduce the likelihood that it will happen again? Develop a plan that addresses the true causative factors.

Harold Fell Today

- Why did Harold fall today?
 - He was pacing and tripped; Why?
 - He often gets restless between 2-6pm; Why?
 - He shows signs of sundowning; Why?
 - He worked second shift and thinks he needs to be going to work
- So what is the real issue to fix and how can we deal with it?



Let's Start At The Very Beginning : ABC's

A: Antecedent: What happened just before the behavior occurred that the resident may be responding to? Where?

B: Behavior: What did the Resident actually do? Be as descriptive as possible.

C: Consequence: What happened after the behavior occurred? Staff, intervention, medications, effect



ABC's (cont.)

Using an ABC form to log those events that occur before, during and after a problematic behavior can help provide the ground work for eliminating or managing a behavior. It helps determine how often a particular behavior is actually occurring, why a behavior may be occurring, and the success of interventions.

Harold Fell Today

- **Antecedent:** Resident was agitated and pacing throughout facility. He used to work second shift and wants to leave for work about 2pm.
 - History of falling and unsteady gait, and frequent urinary tract infections
 - He has occasionally started to show signs of sundowning
 - Recently had his blood pressure medications changed
 - He got up and started walking without his walker
- **Behavior:** Harold fell today, he was walking down the hall without his walker, and slid down the wall.
- **Consequences:** Staff cleared him from injury.
 - His blood pressure was normal
 - They unsuccessfully tried to get him to lay down and take a nap
 - They successfully re-directed Harold with a fishing catalogue, reassured him that he didn't work today, and monitored him for any significant changes in behaviors.
 - A quick dip came back positive/ the Dr. was notified

Building A Strong Team

Who is part of the IDT?

- **Resident**
- Legal decision makers
- **Family/Friends**
- Physician/Psychologist/Psychiatrist
- Nurses
- **C N A/ Resident Care Workers**
- Social Workers
- Therapists
- Dietary
- Medicare/Medicaid/Insurance Company



The Ultimate Questions For The IDT

- Is it a new behavioral symptoms or a change or worsening of a previous behavior? Is it harmful? To Whom?
- If new, was a medical work up performed to rule out underlying medical or physical causes of the behaviors, if yes what treatment is needed?
-
- Were current medications considered as potential causes of the behaviors (i.e., those with significant anticholinergic or other side effects)?
-

IDT (cont.)

- If medical causes were ruled out, did the staff attempt to establish the root causes of the behaviors, using a careful and systematic process and individualized knowledge about the resident when possible?
- Before medications are prescribed, what non pharmacologic treatments should be tried.
- Ultimately do we have a care plan that identifies individualized measurable goals, with reasonable appropriate outcomes
- Its Dynamic, monitor, reevaluate, re-assess.
-



Quality Assurance Considerations Related To The Usage Of Anti-Psychotic Medications

Residents Have The Right To Be Free of Chemical Restraints, and Unnecessary Medications

- Medication must never be administered for disciplinary reasons
- Must not be administered for staff convenience
- Must be used to treat a specific medical symptom/diagnosis and documented in the residents medical record
- Medications must always be used at there lowest doses and for the least amount of time.

What Antipsychotic Medicines Do Not Help:

- Not being social – when a person doesn't want to be friendly to others
- Not taking care of oneself
- Memory problems
- Not paying attention or caring about what's going on
- Yelling or repeating questions over and over
- Being restless – when it's hard for a person to sit still
- Wandering and elopement
- Agitation and aggression during personal cares

Quality and Quantity of Staff

- Regulation requires a facility to provide a supportive environment that promotes comfort and recognizes individual needs and preferences
- The facility must provide staff , both in terms of quantity (direct care as well as supervisory staff) and quality to meet the needs of the residents as determined by resident assessment and individual plans of care.
- Sometimes you will need a 1:1 emergency preparedness planning
- Policy and Procedure in place

Staffing Considerations (cont.)

- Consistency of staff, consistent assignment
- Retention of staff
- Appropriate dementia specific training
- Indicators of Adequate Staffing
 - Resident/Family attendance at Quarterly Care Plan Meetings, Needs are being met.
 - Resident Council Minutes
 - Annual Satisfaction Survey
 - Management visibility and involvement
 - Review of complaint and Grievance logs
 - Review Quality Assurance and Assessment Committee minutes.

New Standards Of Practice For Behavioral Treatment

CMS/DHS now requires:

- Facilities be knowledgeable about the new requirements and are expected to be in compliance at all times
- Surveyors are now expected to determine if there is appropriate usage of antipsychotic medications for the treatment of behavioral symptoms related to Alzheimer's disease, dementia, and other organic brain syndromes as part of their annual surveys

Applying The Standards: Staying in Compliance

If medications are used?

- Was the behavior new and/or persistent? Harmful?
- Were environmental, medical and psychosocial causes ruled out first?
- If yes to the above, and a medication is used, does it improve the behavior, and is it used for the shortest amount of time?
- Are they monitoring for risks and benefits?
- Are staff trained to identify, document and communicate as follow up is needed in the facility?
- Have the risks and benefits been discussed with the resident and legal decision maker?

The Standards (cont.)

- Does the care plan reflect an individualized team approach with measurable goals, timetables and specific interventions for the management of behavioral and psychological symptoms?
- Does the care plan include:
 - Involvement of the resident/representative to the extent possible?
 - A description of and how to prevent targeted behaviors?
 - Why behaviors should be prevented or otherwise addressed (e.g., severely distressing to resident)?
 - Monitoring of the effectiveness of any/all interventions?

Additional Focus Areas

- Medical Director is involved in setting policy and procedure
- Appropriate Practitioners informed and involved in addressing changing care needs
- Pharmacy consultants are appropriately utilized to identify and manage med related issues
- Input from the above are utilized in care plan development and implementation
- A complete assessment is needed prior to the use of medications to manage behaviors, or a facility may be culpable of using unnecessary medications
- Above all..... facilities must be continually, thoroughly and accurately documenting every step of the ongoing process'

When Conflict Arises



Anybody can be a saboteur of integrated care. Any member of the health care team can potentially present barriers to effective collaborative health care.



Effective Conflict Resolution Concepts

- Adversarial Conflict ruins relationships.
- To turn to the courts, is a long drawn out, costly experience for all.
- Look at interests not positions. allow all parties to express their issues and collaborate towards positive outcomes.
- Maintain relationships: separate the people from the problems.
- Find a common ground to focus on: quality care
- Let everyone be heard....
- Then work together to solve the issue, to the satisfaction of all parties involved

Preventing Conflict

- **SET THE STAGE- Prevent The Conflict:**
 - Preadmission assessment
 - Commit to your resident/ policy and procedures in place to meet needs
 - Realistic expectations all the way around
- **DELIVER THE GOODS – Prevent the Conflict**
 - Document the Life Story
 - Assess and Care Plan accurately
 - Staff to meet the needs
- **ASSESS THE OUTCOME – Prevent the Conflict**
 - Behavioral Tracking
 - Constant observation and discussion
 - Talk to all TEAM members
- **REVISE THE PLAN – Prevent the Conflict**
 - Daily, weekly, monthly, Quarterly
 - Root Cause Analysis

Talking with Families

- Talk often, regular evaluations, build rapport, don't wait until there is an issue
- Talk honestly, have concrete information and feedback from measurable goals
- Throw out the goals (all of them), discuss pros and cons
- Then work together to prioritize issues
- Be Firm, don't compromise on things that compromise residents rights, quality of care and life.
- Don't promise what you can't or won't deliver.

Working With Families Who Think Drugs Are The Answer, Or No Answer At All

It's the same solution.

- Get the experts involved.
- Offer a second opinion,
- Stand your ground, can't compromise
- Counsel them on consequences and alternative approaches to address behavioral symptoms provided?
- What has been tried and not worked
- Ultimately, There may need to be a discussion about the need for alternate placement

Can you spot the
the mistake?

1 2 3 4 5 6 7 8 9

A Families Story

Other Partners

Contact your Regional Ombudsman
1-800-815-0015

Contact Doug Englebert DHS pharmacist
1-608-266-5388

Contact your Regional Alzheimer's Organization

Contact your County I-Team for potential case
discussion

Contact your County ADRC

Resources

- The National Consumer Voice for Quality Long-Term Care www.theconsumervoice.org
- The National Long-Term Care Ombudsman Resource Center (NORC) www.lfombudsman.org
Pioneer Network www.pioneernetwork.net
- Advancing Excellence in America's Nursing Homes www.nhqualitycampaign.org
- CMS (Centers for Medicare & Medicaid Services) www.cms.gov
- CMS: Four Part Series- Institutionalized to Individualized Care (archived webcasts) <http://surveyortraining.cms.hhs.gov>

Resources

- CMS: Hand In Hand <http://www.cms-handinhandtoolkit.info/Index.aspx>
- Alzheimer's Association www.alz.org
- American Health Care Association (AHCA): The Quality Initiative (AHCA/NCAL) http://www.ahcancal.org/QUALITY_IMPROVEMENT/QUALITYINITIATIVE/Pages/default.aspx
- American Medical Directors Association (AMDA) <http://www.amda.com/advocacy/brucbs.cfm>
- LeadingAge <http://www.leadingagewi.org/>
- Wisconsin Board On Aging and Long Term Care <http://longtermcare.wi.gov/>

Questions
