Fighting for Dignity

Prevention of Distressing and Harmful Resident-to-Resident Interactions (DHRRI) in Dementia in Long-Term Care Homes

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Warning

This presentation does not mean to suggest that people with dementia are inherently aggressive, violent or dangerous.

Adopting this view would run the risk of reinforcing the stigma already experienced by this population.

Rather, distressing factors in the social and physical environment often contribute to their engagement in these incidents.

The majority of people with dementia do not engage in serious physically aggressive behavioral expressions toward others.

Those who do typically do so because their human needs and situational frustrations are not met in a timely manner by well-meaning but understaffed and undertrained direct care staff

The intersection between residents' unmet needs and cognitive disabilities contributes to the development of these incidents.

Warning

While the majority of people with dementia are not inherently dangerous, a small subgroup may have lifelong aggressive or violent tendencies that may continue or exacerbate after the onset of dementia.

The majority are doing their best to cope with distressing, frustrating, and frightening situations using their remaining abilities despite having cognitive disabilities caused by a serious brain disease.

If I had only one slide…

Residents with dementia are fighting with each other in an effort to preserve their dignity

Dignity: “The quality or state of being worthy, honored or esteemed”

(Webster Dictionary)

If I had only two slides…

“We are not trying to get rid of distressing behavior.

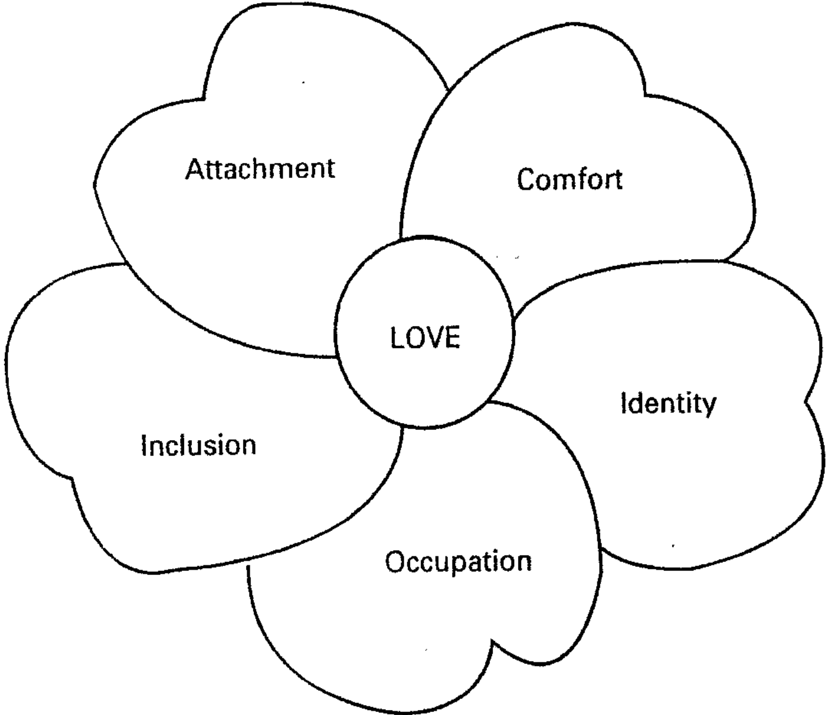
What we’re trying to do is to create well-being.”

– Dr. Al Power

The Experiential Model of Well-Being

The Eden Alternative Domains of Well-Being℠,
adapted by Power (2014)

The Main Psychological Needs of Persons with Dementia



Source: Kitwood, (1997, p. 82). Dementia Reconsidered: The Person Comes First.

Quote

“Be responsive to what their needs might be.

It’s all about our approach.

It isn’t us.

It isn’t them.

It’s about their needs.”

– Director of Recreation Therapies

Basic Premises

Behavioral Expressions labeled as “Aggressive” in people with dementia are mostly…

- **Expressions of unmet human needs**
- Have **meaning, purpose & function** *to the person…*
- Attempts at **communication** that need be explored with validation – Judy Berry, president, Dementia Specialist Consulting
- Attempts at **gaining control** over unwanted, frustrating, frightening or threatening situations
- Attempts at **preserving identity & dignity**

=> BAROMETERS for resident’s tolerance to stressful stimuli…

Experts' Opinion

"Labeling the behavior 'aggressive' assumes that this behavior is intentionally initiated by an individual with dementia.

In most cases, however, they **do not initiate** aggressive behavior **without provocation**."

– Professors Volicer & Hurley

Co-authors of the book:

Management of Challenging Behaviors in Dementia (2000)

A word about words…

Old culture "biomedical" / unhelpful terms

Behavior symptoms
Neuropsychiatric symptoms
Behavior problems
Disruptive behaviors
BPSD

Recommended "person-directed" terms

Behavioral Expressions; Expressive Behaviors; Reactive Behaviors; Responsive Behaviors

Caspi, E. (2013). Time for change: Persons with dementia and "behavioral expressions," not "behavior symptoms." JAMDA, 14(10), 768-769.

A word about words…

Old Culture Terms

Resident-to-Resident…

“Abuse” / “Abusive”

“Mistreatment”

“Violence” / “Violent”

“Aggression” / “Aggressive”

Suggestion: Describe what you see in the most neutral way possible without judging and labeling…

“Behavior”

When was the last time you heard the word “behavior” used in a positive connotation?

Can we *try* to avoid using the term altogether?

“I have moved to dropping the word ‘behavior’ completely”

– Dr. Allen Power

Background

Distressing and harmful
resident-to-resident interactions (DHRRI)
in the context of dementia

Over a Century-long Problem

"…when walking about **groped the faces** of other patients, and was often **struck** by them **in return."**

Auguste D. Year: 1901

Book: Lock (2013). The Alzheimer's Conundrum: Entanglements of Dementia and Aging.

Definition of Resident-to-Resident Incidents (RRI)

“Negative, aggressive and intrusive **verbal, physical, material, and sexual** interactions between LTC residents that in a community setting would likely be unwelcome and potentially **cause physical or psychological distress or harm** in the recipient.”

– Rosen, Pillemer, & Lachs, 2008; McDonald et al. (2014)

Decades-long dangerous normalization of these incidents in long-term care homes…

High Prevalence & Incidence of RRI

Lachs et al. (2016): *n*= 2011 residents; 10 NHs in NY;

Resident & staff interviews, chart reviews, direct observation

1-month prevalence of residents "involved" in R-REM = **20%**
(Verbal = 16%; Physical = 6%; Sexual = 1%; Other = 11%)

Castle, (2012): 249 NHs in 10 states;

Mail questionnaire: n = 4,451 nurse aides; past 3 months

The number of resident-to-resident "abuse" cases is **high**

McDonald et al. (2015): Review found **high incidence:**

One-third of all cases of "abuse" in LTC homes

Barriers for Change

- **Ageist perceptions**

Ageism: “The stereotypes to which people are subjected to when they grow old” – Dr. Robert Butler

“Discrimination based on age” – American Medical Association

- **“Dementism”** – Bioethicist Dr. Stephen Post

Barriers for Change

Underreporting

“**The majority** of RRIs are **not reported** in most nursing homes”
– Professor Jeanne Teresi

Low or poor quality documentation and reporting

Under investigated and delayed investigations – Internally and externally…

Barriers for learning and prevention…

Barriers for Change

Death Certificates

Un-"Natural Cause"

A persistent barrier for timely and thorough investigations of fatal RRI

Barriers for Change

Unwitnessed

- Nearly **40%** of ‘resident-to-resident physical aggressive’ incidents were **not witnessed** by staff

– Bharucha et al. (2008)

- **Majority of entries into** other residents’ **bedrooms** were **not witnessed** by direct care staff

– MacAndrew (2016)

But also witnessed and not reported…

The Biggest Barrier for Prevention

Low and poor staffing levels of well-trained staff

“Half of U.S. nursing homes have low staffing and at least one-quarter have dangerously low staffing levels”

– Review of research studies by Harrington et al. (2016)

Objectives

Identify…

1. Consequences

2. Contributing factors, causes, and situational triggers

3. Psychosocial strategies for prevention and de-escalation

Consequences

Quotes

- *"This is a matter of **serious concern**. It happens very often and will be fatal."* – Resident with Alzheimer's disease
- *"Some of them really get **afraid** of him, and when I say get afraid…I mean get afraid…When they see him coming, they don't want to sit in the dining room…"* – CNA
- *"I am **afraid** that he will hurt someone when we don't see it…especially someone frail whom he can take down with one blow."* – CNA

CDC Division for Violence Prevention (2016)

"The amount of attention given to phenomena such as resident-to-resident aggression has increased over the last decade…

Its occurrence produces **injuries and wounds identical to those resulting from abuse** and

may result **when** institutions **fail to take action to prevent or manage aggression** or take actions that are not sufficient to assure resident health and safety."

Consequences

Residents on the receiving end 🡐

Residents exhibiting the behavioral expressions

Residents witnessing

Care staff
Family members
LTC home
Society

Permission to use the picture was received from JDC-ESHEL (Photographer Moti Fishbain)

+ Substantial healthcare cost implications…

$1.9 Million Settlement in Oakland, CA

Deceased resident: 88 years old Olivia Deloney

NY Times: Dementia Patients Fuel Assisted Living's Growth. Safety May Be Lagging (Dec 13, 2018):

https://tinyurl.com/y6fzrj2q

Elder law attorney Felicia Curran re the Negligence:

"We can try to make such conduct too expensive for corporate owners to risk it in another instance with other elders."

Consequences

- **Psychological**

Frustration, anger, anxiety, fear, sadness, depression, social isolation, avoidance of activities

- **Physical Injuries**

Falls, dislocations, bruises, hematomas, reddened areas, lacerations, abrasions, hip fractures, brain injuries

- **Deaths**

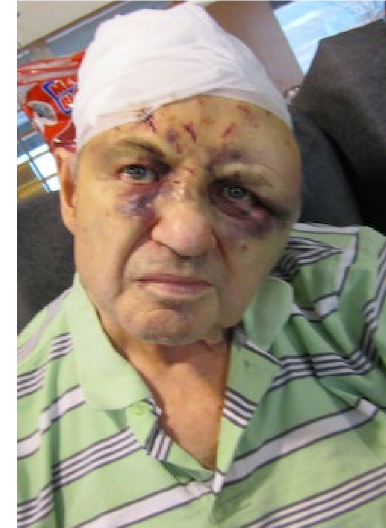
Frank Piccolo

On February 18 2012 around 8:30pm…

Hit repeatedly over face and head with an activity board by another resident with dementia who entered his bedroom…

Physical condition deteriorated and he died 3 months later.

"My husband couldn't defend himself or yell for help."



Frank Piccolo with dementia in a nursing home in Toronto

Permission to use the image was received from Frank Piccolo's wife Theresa

Devastated Family Members

“It’s horrible to think how he died…that he was put in that much pain and distress…”

Daughter of 87 years old Warren Leaf with dementia who died 3 days after entering the bedroom of another resident who kicked him in his stomach

A staff member heard his cries…

Newspaper article (May 24, 2019): https://tinyurl.com/y6k6zouy

1st Study on Injurious RRI in Nursing Homes in MA

Identified 294 physical injuries during a 1-year period!

Shinoda-Tagawa et al. (2004). Resident-to-resident violent incidents in nursing homes. *JAMA, 291(5),* 591-598.

1st Nationwide Study on Fatal RRI in Australia

Examined 28 deaths using Coroner records

Murphy et al. (2017). Deaths from resident-to-resident aggression in Australian nursing homes. *JAGS, 65(12)*, 2603-2609.

1st Exploratory Study on Fatal RRI in U.S. and Canada

Examined 105 deaths

Caspi, E. (2018). The circumstances surrounding the death of 105 elders as a result of resident-to-resident incidents in dementia in LTC homes. *Journal of Elder Abuse & Neglect, 30(4)*, 284-308.

2nd Study on Fatal RRI in U.S. Nursing Homes

Examined 101 deaths

DeBois, K.A., Evans, S.D., & Chatfiled, S.L. (2019). Analysis of structured and unstructured data from the National Violent Death Reporting System, 2003-2016. *Journal of Applied Gerontology.* Online Ahead of Print, July 18, 2019.

Two Deaths in One Incident

Casa Verde Inquest, Toronto (2005):

https://tinyurl.com/zh68jlu

Inquest with potentially life-saving recommendations…

Death of two roommates in Houston, Texas (2014):

https://tinyurl.com/yyd3o6tt

“Is there any way we can please move this person out of the room?”

– Father asked his daughter on the day of the fatal incident

Devastated Family Members Ask…

“*We want to see a solution. We don’t want the death of our father to be in vain….I want to see something done so this doesn’t happen again*.”

– Son of a resident with Alzheimer’s who died 4 days after being pushed by a resident with dementia

Inquest (2015): https://tinyurl.com/j2lc5fd (Winnipeg, Manitoba)

2. Contributing factors, causes, and triggers

Common Causes and Triggers

Resident's personal history and background factors

- Traumas
- Personality
- Behavioral expressions labeled as "aggressive" prior to admission
- Poor relationships
- Depression

Common Causes and Triggers

Physiological, medical, and functional causes

- Pain
- Constipation
- UTI
- Delirium
- Delusions
- Hallucinations
- Dementias: bvFTD; Vascular dementia; TBI; CTE, Korsakoff Syndrome
- Serious Mental Illness: Schizophrenia, Personality Disorder
- PTSD

Contributing Factors in the Physical Environment

- Segregation of a large number of residents with dementia
- Large care unit size limiting staff ability to supervise residents
- Inadequate landmarks/signage (wayfinding difficulties)
- Crowdedness
- Noisy, overstimulating, hectic environment
- Lack of privacy and private away spaces (beyond bedroom)
- Private vs. shared bedrooms and bathrooms
- Indoor confinement
- Hallways (too narrow; “dead ends”)
- TV
- Elevators
- Access to sharp / dangerous objects

Situational Causes and Triggers

- Frustration with being institutionalized / Lack of control and choice
- Boredom
- Situational frustrations / Interpersonal stressors
- Miscommunications and misunderstandings; misperceptions
- Invasion of personal space (e.g. unwanted touch)
- Problems with seating arrangement
- Intolerance of another’s behavioral expressions (repetitive questions)
- Taking another’s belongings / Competition for limited resources
- Unwanted entries into one’s bedroom or bathroom
- Conflicts between roommates (such as about “rules” for using the room)
- Racist and ethnic comments and slurs
- Harassment of people who are LGBT

Care Staff and Organizational Factors

- Low staffing levels
- Lack of training
- Insufficient support and guidance from managers
- New, inexperienced, and unsuitable care staff members
- Tensed and dysfunctional relationships between care employees
- Hierarchical organizational structure
- Staff burnout
- Inappropriate approaches, attitudes, and communication style
- Inattentiveness (such as to early warning signs of distress / anxiety)
- Language or cultural mismatch (staff-residents)

Prevention & De-escalation Strategies

We all want a magic bullet and quick fix…but the reality is…

These episodes typically occur as a cumulative effect of multiple factors in the social and physical environment (unmet human needs and situational frustrations) – operating at several levels of the care organization – intersecting with residents’ cognitive disabilities

A multi-factorial phenomenon requiring a multi-level assessment-based individualized approach

Procedures and Strategies at the Organizational Level

- Address DHRRI in your polices and procedures
- Set realistic admission and discharge criteria
- Conduct pre-admission behavioral assessment
- Follow regulations re Care Plans
- Employ the right people and then Train them well and support them!
- Implement consistent (“dedicated”) assignments
- Implement mechanisms for knowing residents’ life histories
- Develop roommate selection and reassignment policy
- Strengthen reporting policy (Shift from a Culture of Blame → Learning)
- Improve quality of documentation

Guiding Principle

“The most important principle…is the effort to understand **the meaning of the sequence** that let to the aggressive behavior.”

– Professor Jiska Cohen-Mansfield

Encouraging Research Findings

- Early warning signs and situational triggers can be observed prior to the majority of DHRRI (Caspi, 2013; Snellgrove, 2013)

"I told them that if I have to spend one more night with that man, then I would kill myself. And they still ignored me."

– 77 years old James Parker

Photo credit: David Joles, Copyright 2017, Star Tribune

Remote Trigger from the Past

- Horticulture group activity in VA Medical Center – A group of Veterans are transplanting blooming tulips…
- Mr. W became pale, tremulous, anxious, hyperventilated, and pushed another resident…
- He was physically restrained and returned to the locked care home
- Conversation revealed: Became distressed on seeing the tulips
- Life history

During WWII, several of his platoon mates were killed after being cornered in a tulip field…

Encouraging Research Findings

- DHRRI tend to occur in patterns (time of day, location, events, people, objects), which are one of the keys for anticipatory prevention

- A small number of residents are typically involved in a large portion of DHRRI (Malone et al., 1993; Negley & Manley, 1990; Allin et al. 2003; Almvik et al. 2007; Bharucha et al. 2008)

Proactive Measures

- "The best way to handle aggressive behaviors is to prevent them from occurring in the first place" – Judy Berry, Dementia Specialist Consulting

- "…but unfortunately we spend most of our time reacting to the behavior when we should be reacting to the cause" – Jan Garard, MN DHS

Fire Inspector vs. ~~Fire Extinguisher~~ (Dr. John Brose)

Walking Group Intervention
(Holmberg, 1997)

- Frequent and distressing RRI during early evening hours at a care home for people with dementia…

- Intervention: Immediately after dinner volunteers led a 30-minute walking group for 3 consecutive days

- Comparison: 4 days without walking groups

- Outcome: 30% reduction in “aggressive” incidents during 24 hours after walking… (RRI & Resident-Staff)

Proactive Measures

Train staff in caring for and communicating with people with dementia:

1. Habilitation Method (Dr. Paul Raia)
2. Validation Method (Naomi Feil / Vicki de Klerk-Rubin)
3. Hand in Hand Training (CMS)
4. Eilon Caspi, Dementia Behavior Consulting LLC

Protect direct care staff:

Train-the-trainer Non-Violent Self-Protection Training Certification Programs – Thomas J. Archambault (TJA) Protect Systems International (PSI)

Proactive Measures

- Strengthen information transfer / Be informed about previous episodes
- Ensure everyone knows residents involved in DHRRI (w/o labeling them)
- Be clear about risky circumstances in which the need to share information overrides resident's confidentiality
- Teamwork! It is not possible to do it alone…
- Provide structured/consistent routine (but be flexible…)
- Instill empathy and compassion between residents

Proactive Measures

- Be proactive! “Stop the vicious cycle of reactivity” (Zgola, 1999)
- Regularly move around care home (avoid congregating in 1 place)
- Modify the physical environment (dementia-friendly guidelines)
- Remove or secure objects used as weapons
- Ensure content on TV is enriching, calming, and enjoyable
- Ensure *active* presence of managers (evenings, weekends, & holidays)
- Recruit volunteers (e.g. “Buddy System” for new residents – Judy Berry)
- Install emergency call buttons in key locations & use hand-held radios
- Use assistive technology (e.g. Vigil Dementia System)

Proactive Measures

Personally Meaningful Engagement

Permission to use the picture was received from JDC-ESHEL and photographer Ofir Ben Natan

Experts' Opinion

"Activities are the main weapon against behavior difficulties and violent behavior" – Dr. Paul Raia

"If a person with dementia is engaged in a meaningful activity, the person can not simultaneously be exhibiting problematic behavior"
– Dr. Cameron Camp

Unless…

Unmet medical need; fatigue; remote trigger from past; something negative in physical environment; activities not planned or delivered professionally or incompatible to resident's preferences, abilities, disabilities

Personally Meaningful Engagement

But the reality is…

Majority of residents are **not engaged** in **activities most of the time**

(Cohen-Mansfield et al. 1992; Burgio et al. 1994;

Schreiner et al. 2005; Wood et al. 2005)

Boredom = The enemy of a *subgroup* of residents with dementia!

“A resident most at risk of an assault is bored!” - Administrator of a nursing home

Encourage Creative Approaches

When bored…a resident with dementia engaged in “aggressive” behaviors toward other residents…

He wanted to work and feel useful…

The care team bought him a manual lawn mower…

He is now using it all the time to mow the lawn outside and it reduced his ‘aggressive’ behaviors.

“This is the best $79 I’ve spent.” – Judy Berry

Evenings = Vulnerability Time Period

- Half of RRI occurred between 5pm – 8pm (Donat, 1986)

- Half of RRI requiring police involvement occurred between 4pm – 10pm (Lachs et al. 2007)

- Most nursing homes do not offer *meaningful* engagement during the evening hours. A major missed opportunity for prevention

- Higher number of direct care partners during evening hours was found to reduce distressing RRI (Donat, 1986)

Weekends = Vulnerability Time Period

A study found that 58% of fatal RRI occurred during evening hours (44%) and night (14%) in nursing homes and assisted living residences

– Caspi (2018)

We all know what should but doesn't always happen during the evenings and weekends (e.g. adequate staffing levels, meaningful engagement, active presence of managers).

A missed opportunity for prevention!

“A wise lawyer will first approach the activity director and ask:

‘How did you engage the resident in a way that would have prevented the violence/injury against my client?’”

– Dr. Paul Raia

Immediate Strategies During Episodes

“The behavior can not be changed directly, only indirectly by changing either our approach or the person’s physical environment.”

– Dr. Paul Raia

Immediate Strategies During Episodes

- "Engage in a swift, focused, decisive, firm, and coordinated intervention" (Soreff, 2012).
- Immediately defuse "chain reactions." Anxiety is contagious!
- Redirect resident(s) from the area
- Avoid overcrowding resident (will strike if feels "cornered")
- Offer to take a walk together
- Distract/divert to a different activity or change the activity
- Refocus/switch topic to his/her favorite conversation topic
- Position, reposition, or change seating arrangement

Immediate Strategies During Episodes

- Physically, calmly, and skillfully separate residents
- Avoid conversations in loud/crowded places
- Slow down!
- Avoid approaching from behind/side…usually from the front
- Establish eye contact (unless threatening/culturally inappropriate)
- If he starts to walk away, don't try to stop him right away (Judy Berry)
- Maintain a safe distance (slightly beyond striking range)
- Speak at the level of the eyes (never above the resident)
- Speak *with*…not *at* the resident

Immediate Strategies During Episodes

- Try to stay calm! They will “mirror” your emotional state!
- They’ll respond to the unspoken…even if you said the right thing! – Jan Garard
- Be sincere. Many people with dementia can detect insincerity!
- Be firm and direct (rather than angry or irritated)
- Use short, simple, familiar words/sentences & 1-step directions
- Never ignore their emotions…
- Encourage expression of feelings (frustration; anger; fear) but do it in a safe way and location...

Immediate Strategies During Episodes

- Encourage a compromise
- “Save face”
- Avoid arguing, reasoning, correcting, or criticizing a resident with dementia
- “Validate the subjective truth, internal reality, & feelings of the person, no matter how illogical, chaotic, or paranoid...” (Naomi Feil, Validation Method)
- Avoid using Reality Orientation (in mid-to-late stages of Alzheimer’s)
- Avoid questions that challenge short-term memory (“Didn’t I just tell you…?”)
- LISTEN TO FEELINGS, less to facts
- RESPOND TO EMOTIONS, not to the behavior
- Identify & proactively address underlying needs behind the words & behaviors
- Turn negatives into positives
- Avoid using words: “No!” ”Don’t…” & “Why?”

Immediate Strategies During Episodes

- “Never command/demand. Instead ask for their help” – Judy Berry
- Apologize sincerely when things go wrong…
- Ask the person for permission
- It is (usually) not intentional. Try not to take it personally!
- Be patient and supportive. They face an avalanche of losses!!!
- “If what you are doing is not working, STOP! Back off – Give the person some space and time. Decide on what to do differently. Try again!” – Teepa Snow

  But don’t leave resident(s) alone when unsafe!
- Seek assistance from co-workers (especially those the resident trusts)
- Be consistent in approach (across staff, shifts, days, weekends, holidays)
- Promptly notify interdisciplinary team and physician re episodes

Recommended DVD

Carly Hellen & Peter Sternberg (1999). Dealing with Physical Aggression in Caregiving: Physical and Non-Physical Interventions. *Terra Nova Films*

Techniques demonstrated:

- Release from a grab
- Deflecting a strike or a kick
- Dealing with your hair pulled
- Planned containment
- Unplanned containment

Post-Episode Strategies

- Provide (adult-to-adult) reassurance!
- Hold de-briefing procedures and meetings (a "360-degree" approach)
- Document sequence of events/triggers prior to DHRRI (Behavior Log)
- Seek emotional support from a trusted co-worker or supervisor
- Consult with nurse and physician (1st aid; nursing & medical treatment; evaluation of medical cause; change in meds)
- Inform & consult with family (timely; reliable; value their input/insights)
- Consider change in seating arrangement
- Consider change in bedroom/roommate assignment (follow Regulations)
- In true emergency (e.g. potential for immediate harm), consider transfer to psychiatric hospital / neurobehavioral unit for evaluation

Assessment Is Key

Characteristics of effective individualized assessment:

- Proactive
- Comprehensive
- Interdisciplinary
- Well-coordinated
- Whole person & Person-directed
- Stigma-and-labeling-free
- Life course perspective
- Needs-based
- Persistent / Systematic

Assessment-based "Anticipatory Care Approach" – Professor Christine Kovach

What's in your quiver?

- Recognizing Early Warning Signs of Distress (Caspi)
- Behavioral Expressions Log (Caspi)
- R-REM Instrument (Teresi et al. 2013)
- ABRAT-L for newly admitted residents (Kim et al. 2017)
- Brøset Violence Checklist (Almvik et al. 2007)
- Evaluation of Urgency of DHRRI Form (Caspi)

- Interdisciplinary Screening Form (RRI & dementia-specific) (Caspi)

- Behavior Intervention Plan Form (adapted from Dr. Paul Raia)

Final Recommendations

Provide adequate staffing levels (at all times) of well-trained care staff

Final Recommendations

- **Train all direct contact employees in DHRRI in dementia and serious mental illness:**

- Understanding
- Recognition
- Assessment
- Documentation
- Reporting
- Investigating
- Individualized Care Planning
- Prevention
- De-escalation

Expert's Recommendations to Policy Makers

"*We talk about violence-free schools. Why we don't talk about violence-free nursing homes? What about ending violence in nursing homes as* ***a policy goal****?"*

"Develop a comprehensive and data-driven **national action plan** to eliminate violence in nursing homes"

– Professor Karl Pillemer (2018)

Residents have a human and federal right to live in a safe long-term care environment

Disclaimer

The content and suggestions contained in the powerpoint presentation are only meant to provide long-term care homes with *general directions* for consideration.

Administrators and interdisciplinary care teams in each care setting should use their best clinical judgment when considering whether or not to use each of the suggestions.

The suggestions are *not* a substitute for an in-person specialized dementia-specific staff training program by an experienced, skilled, and qualified trainer.

The author of the powerpoint presentation is not responsible for use of any information and suggestions contained in it.