

# Dementia: 360°

Seeing It from Many Perspectives

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*Why Do We Need a TEAM Approach in Dementia Care?*

**It Takes a Village!!!!**

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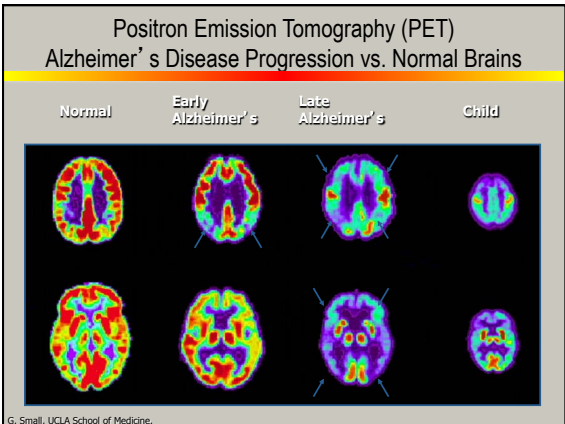
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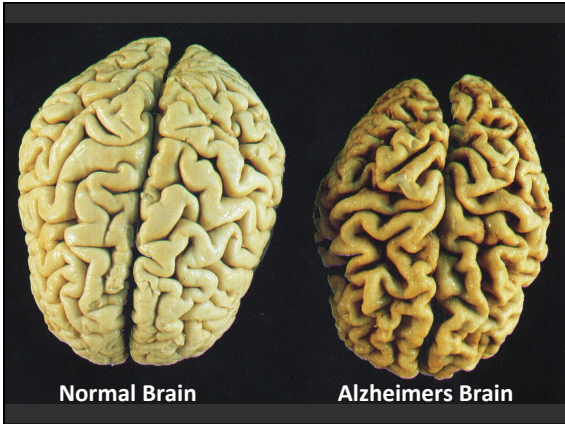
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Because...  
When **ONE** person develops dementia – **EVERYONE** around them is living with dementia

***Dementia Changes Everything for EVERYBODY involved***

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What Does Having Dementia Do To Our Whole System of Care?

- Changes in memory & thinking
- Changes in understanding & speaking
- Changes in impulsivity & initiation
- Changes in abilities & processing
- Changes in personality & preferences
- Loss of independence & changes in roles

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## Why Is Dementia Complicated?

- People with dementia have an average of 3 other medical conditions
- There are 3 D's that imitate one another & can be combined
- Health care needs will change over time
- Ability to engage and communicate will change over time
- It is a syndrome NOT a diagnosis

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## Cognitive Changes with Aging

- Normal changes = **more forgetful & slower to learn**
- MCI – Mild Cognitive Impairment =
  - Immediate recall, word finding, or complex problem solving problems (½ of these folks will develop dementia in 5 yrs)
- Dementia = **Chronic thinking problems in > 2 areas**
- Delirium = **Rapid changes in thinking & alertness**  
*(seek medical help immediately)*
- Depression = **chronic unless treated, poor quality, I "don't know", "I just can't" responses, no pleasure**  
*can look like agitation & confusion*

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***Dementia***  
does not equal  
***Alzheimers***  
does not equal  
***memory problems***

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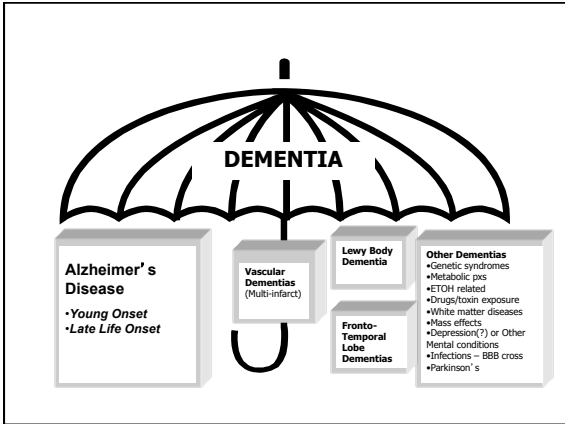
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### Four Truths About Dementia

- At least 2 parts of the brain are dying
  - One related to memory & the one other
- It is chronic – can't be fixed
- It is progressive – it gets worse
- It is terminal – it will kill, eventually

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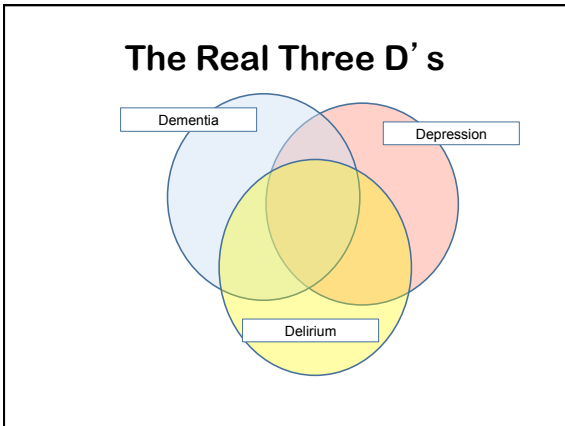
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## There are Mimics of Dementia BOTH deserve ID & Rx

- Depression
  - can't think
  - can't remember
  - not worth it
  - loss of function
  - mood swings
  - personality change
  - change in sleep
- Delirium
  - swift change
  - hallucinations
  - delusions
  - on & off responses
  - infection
  - toxicity
  - dangerous

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## What are the Different Care Approaches to Consider?

- Health Promotion
- Curative
- Restorative - Rehabilitative
- Maintenance
- Compensatory
- Palliative

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## Why is Dementia So Complicated

- Of all the major chronic illnesses it is the least well reimbursed for health care provision & yet will require massive amounts of care provision (3<sup>rd</sup> most expensive)
- There is still social stigma attached to the condition
- There are currently NO medications that actually change the disease – only help with some symptoms

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## Drugs that can affect cognition

- Anti-arrhythmic agents
- Antibiotics
- Antihistamines - decongestants
- Tricyclic antidepressants
- Anti-hypertensives
- Anti-cholinergic agents
- Anti-convulsants
- Anti-emetics
- Histamine receptor blockers
- Immunosuppressant agents
- Muscle relaxants
- Narcotic analgesics
- Sedative hypnotics
- Anti-Parkinsonian agents

Washington Manual Geriatrics Subspecialty Consults edited by Kyle C. Moylan (pg 15) – published by Lippincott, Wilkins & Williams, 2003

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## Why is dementia so complicated?

- Because ‘normal’ is a range – without a baseline we will not know if YOU have changed
- The #1 risk for Alzheimers is getting older
- Health care professionals spend less than 1% of their coursework on dementia (on average) and yet they will typically spend almost 30-50% of their career working with people who have dementia

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## Why is Dementia So Complicated?

- At this time, 1/5 families are dealing with it – within 10-15 years it will be ½
- The number of people with dementia is expected to increase by 150-250% in the next 15 years
- There are more young onset cases than ever before
- Care capacity is running 15-20 years behind need

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## Why is Dementia So Complicated?

- Diagnosis typically occurs in mid-disease – early symptoms are missed & mis-understood – missed opportunities & bad habits
- Symptoms occur inconsistently & episodically
- Dementia progresses over time – progression patterns are based on type(s) of dementia the person has
- There are 75-90 known causes and types of dementia

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## Dementia – What Changes?

- **Structural changes –permanent**
  - Cells are shrinking and dying
- **Chemical changes - variable**
  - Cells are producing and sending less chemicals
  - Can ‘shine’ when least expected – chemical rush

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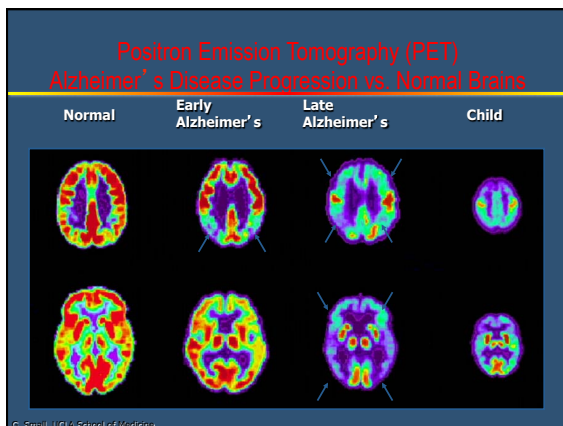
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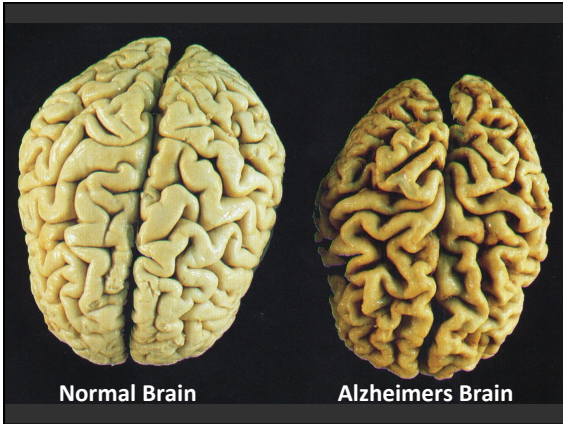
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**Screening Options**

- OLD – MMSE
- New
  - AD-8 Interview
  - Animal fluency – 1 minute # of animals
  - Clock Drawing – 2 step
  - SLUMS – 7 minute screen
  - SAGE – self-test (with scoring)
  - Full Neuropsychological testing

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**AD8 Dementia Screening Interview**

- Does your family member have problems with judgment?
- Does your family member show less interest in hobbies/activities?
- Does your family member repeat the same things over and over?
- Does your family member have trouble learning how to use a tool, appliance, or gadget ?
- Does your family member forget the correct month or year?
- Does your family member have trouble handling complicated financial affairs ?
- Does your family member have trouble remembering appointments?
- Does your family member have daily problems with thinking or memory?
- Scores:  
*Changed, Not Changed, Don't Know*

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## Animal Fluency

- Name as many animals as you can
- Give one minute – (don't highlight time limit)
- Count each animal named (not repeats)
- OLD - Normal/Not Normal - >12 or >18
- NEW - Establish Baseline for YOU
  - Compare you to you OVER time – notice

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## Clock Drawing

- Give a BIG circle on a blank sheet of paper
- Ask to draw the face of a clock - put in the numbers
- Watch for construction skills & outcome
- Ask to put hands on the clock to indicate 2:45
- Watch for placement and processing
- Scoring: 4 possible points
  - 1-12 used                      correct quadrants
  - minute hand correct        hour hand correct

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## SLUMS

- Orientation – day of week, month, state (3)
- Remember 5 items – ask later (5)
- \$100 – buy apples \$3 and Trike \$20
  - What did you spend? What is left? (2)
- Animal fluency (0-3) (<5, 5-9, 10-14, >14)
- Clock drawing (4) – numbers in place, time right
- Number reversals (2) – 48 – say 84...
- Shapes (2) – ID correct, which is largest
- Story recall (8) – recall of info from a story – 4?s

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## SLUMS - rating

### High School Education

- 27-30 – Normal
- 21-26 – MNCD (MCI)
- 1-20 - Dementia

### Less than High School

- 25-30 – Normal
- 20-24 – MNCD (MCI)
- 1-19 - Dementia

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## Why is dementia so complicated?

- You can have more than one type – mixed picture
- You can have other medical conditions that are impacted by dementia and impact your dementia
- How and where you live will be affected by your dementia
- How you get care and get around will be affected by your dementia

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## Why is dementia so complicated?

- Your ability to manage your finances and access to care will be affected by dementia – only 50% will know/be able to recognize this
- Your ability to communicate your preferences and live according to your values will be affected by dementia
- Each person you come in contact will have beliefs and opinions about dementia ... and about you and your behavior

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Why is dementia so complicated?

- Because of your symptoms, you are frequently targeted by criminals and predators – fast growing area of white collar crime
- Is it abuse or neglect OR providing necessary care or letting you do what you want?
- Involuntary commitment is possible and even probable without ‘due process’

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Why is dementia so complicated?

- Care provider preparation and training is varied and in most cases non-existent
- Their behavior will affect your behavior – you will probably be ‘blamed’ & ‘treated’
- It is a terminal illness that takes on average 8-12 years to happen
- At end of life the very thing that typically sustains us may work to kill us – eating and drinking and moving around

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**So ...  
Who is Affected When  
Someone Has Dementia?**

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## Who is Affected by the Person with Dementia?

### Staff

- Direct Caregivers
- Med Techs
- Activities staff
- RCD
- Food Service
- Business office
- Housekeeping & Laundry
- Maintenance
- Reception
- Transportation
- Marketing
- Administrator
- Outside Service Providers – Hospice, HH

### Surveyors & Regulators

### Family

- Spouse --- Siblings
- Kids --- Extended family
- Grandkids --- Great-Grand kids
- Long distance relatives

### Friends

- Faith community friends
- Neighborhood friends
- 'Old Life' Friends
- 'New Life' Friends

### Residents without Dementia

### Other Residents with Dementia

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## Let's Talk about Staff Perspectives

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## For Direct Caregivers

### For All Elders

- Need to help the person with personal care
- Need to help with basic room neatness & care
- Need to get care done – for the whole assignment list
- Need to respect personal choices

### For Those With Dementia

- Challenges with delivering care
- Challenges with identifying needs in a timely manner
- Unusual or unexpected behaviors
- Increased refusals
- More room care needs
- More time needed to complete care
- Less appreciation for help or ability to respond

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## For Supervising Nurses

### For Those Without Dementia

- Must be assessed
- Care needs determined
- Care plan developed
- Staff care matched to abilities & needs
- Family expectation met
- Care done in a timely & effective manner
- Keep staff & residents 'well'

### For Those With Dementia

- Everything varies... Plans?
- Responses can be staff, time, task, location, visitor dependent
- Resident desires and willingness doesn't match health/care needs
- Resident & staff reports don't match
- More family/staff/resident conflicts

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## For Maintenance

### For Those Without Dementia

- Keep room temperatures comfortable for residents
- Keep bathroom equipment working well
- Keep electrical systems safe & functional
- Keep furniture and equipment operational
- Deal with emergencies
- Fire safety plan & practice

### For Those With Dementia

- More problems with temperature controls, bathroom equipment failures, damage to furniture, equipment failure, safety concerns
- More emergency calls
- More difficulty with drills
- More elopement concerns
- More 'exit' safety issues

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## For Reception

### For Those Without Dementia

- Check in/out
- Taking calls
- Making calls
- Posting information
- Helping with transportation
- Answering questions about activities, meals, schedules, visitors...
- Reminding residents about events, appointments, rules

### For Those With Dementia

- Elopement risks
- Restrictions on phone use
- More questioning over & over
- More requests to see administrator or other leaders
- More resident-resident issues
- More arguments about info
- More interrupting & complaining

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## For Marketing

### For Those Without Dementia

- Bring in appropriate residents
- Sell the community & program
- Do tours & make promises
- Seek out referral sources
- Bring in financially viable residents
- Fill empty slots ASAP

### For Those With Dementia

- Harder to tell about 'appropriate'
- Harder to describe what you are 'selling' – meeting customer preferences/needs
- Tours are less predictable
- Finances can be less straight forward
- Quick fill can be a disaster more often

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## For Administrator

### For Those Without Dementia

- Different personality traits, life experiences & values
- Potential conflicts between residents, family-resident, family-family, family-staff, resident-staff, staff-staff
- Questions about ability to continue to provide care as a progressive illness progresses
- Mismatch between what we planned to do & what happened

### For Those With Dementia

- Inconsistency of behaviors, preferences, expectations
- More conflicts in ALL possible areas
- More questions about ability to provide what is 'best' or 'needed' as dementia advances
- More 'emergency' problems
- More mismatches & he said/she said conflicts

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## For Outside Service Providers

### For Those Without Dementia

- Providing services covered by 3<sup>rd</sup> party insurance OR family funding
- Providing services for 'part' of the day or per visit
- Need to get referral & agreement to treat
- Need to show value
- Need to communicate info & plans/recommendations

### For Those With Dementia

- More 'other' involvement
- More refusals
- More 'non-compliance'
- More questions about value and purpose
- More communication challenges & problems with follow-thru
- Less consistency in performance

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## For Spouses

### For Those Without Dementia

- Continue their long-term relationships
- Maintain previous life roles or adapt to changes as a couple
- Still have the past and a shared present
- Can still communicate – if they could before

### For Those With Dementia

- Are losing their life partner
- Are losing their job – if caregiving before admission
- Are emotional and can't see things clearly
- Are afraid of giving up
- Are not sure how to let go, or if they should
- Are looking for someone or something to blame for all this

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## For Grown Up Kids

### For Those Without Dementia

- Are trying to figure out the new roles they are taking on and how to work with one another
- Are still connected by old ties along with the new ones
- Can still work things out – or not
- Can communicate – sometimes

### For Those With Dementia

- Are struggling with new relationships
- Are losing old relationships
- Are experiencing the person in old and new ways at the same time or back & forth
- Are feeling all kinds of feelings and can't talk or work them out
- Feel overwhelmed & unsure

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## For Long Distance Family

### For Those Without Dementia

- Can get feedback from the resident about their experiences and follow-up appropriately
- Can visit, be recognized, get credit for coming, and be remembered for what they did and did not do
- Can use the phone, internet, info from staff

### For Those With Dementia

- ALWAYS feel uncomfortable if the resident isn't satisfied
- Don't feel like they can rely on the resident's report or staff's report
- Feel like what they hear is not what happens when they are there... who is lying?
- Most communication is about crises or emergencies

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## For Faith Community Friends

### For Those Without Dementia

- Desire to offer support to the person
- Desire to offer support to family members
- Come with a sense of 'duty' or mission
- Have concern for the person's spiritual well-being

### For Those With Dementia

- Misbehave – seem like 'badly behaved people' – not like the person we always thought s/he was
- Should be grateful for the visit and want the interaction
- Shouldn't take part in regular services or worship
- Don't seem to benefit from the visit

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## For Neighbors

### For Those Without Dementia

- Looks and physical abilities are changing, but they still know the person
- They feel connected to the person by their recent past living situations
- They feel like the person is living in another place, but that they are still OK

### For Those With Dementia

- Get very confused and upset easily
- Seem lost and make mistakes in what they say, think, and want to do
- Seem to be 'going down hill'
- Seem to be in a safer place, BUT....
- Are a duty visit... not sure what to say or do

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## For Old Life Friends

### For Those Without Dementia

- May be frail, but still seem pretty much they have always been – inspirit
- Can share old memories and build new ones
- Can share emotional connections from the past and the present

### For Those With Dementia

- Seem confused about stuff most of the time
- May be upset and seek your help to get out or go back to the past
- Can't be reasoned with and can't seem to get it
- Make things up and tell you the same thing over and over again

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## For Residents Without Dementia

### For Those Without Dementia

- Have relationships that are more equal
- Pick those they will hang out with and those they will not
- Can either like or not like and adjust their behaviors to reflect those preferences
- Can communicate with each other without staff help

### For Those With Dementia

- Can represent their greatest fear
- Can remind them of BAD times and past losses
- Can cause them to stop coming to activities or social gatherings
- Behave in ways they would typically not do
- Can seem to take more than their fair share of care and staff time & resources

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## For Other Residents WITH Dementia

### For Those Without Dementia

- May seem annoyed or upset with the other person
- May seem to avoid the other person
- May be helpful and friendly
- May treat the person like they are a good/bad child
- May treat the person like they are stupid
- May watch out for them

### For Those With Dementia

- May appear to be old friends or family members
- May frighten or scare me with their behaviors
- May come too close or stay too far away
- May point out all my errors and not notice their own
- May make me angry and make me want to say or do 'bad' things

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## What About OTHERS?

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## For Surveyors & Regulators

### For Those Without Dementia

- Make sure the rules are being followed
- Make sure the community is doing what it says it is
- Make sure personal autonomy, dignity, safety, and justice is being ensured
- Interpret guidelines and what is observed & documented

### For Those With Dementia

- More mis-match between reports, observations, and documentation is probable
- More interpretation versus hard guidelines are used
- Variable knowledge and skill working with people who have different stages of dementia
- Harder to know what is BEST

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## For Public Service Providers Fire Fighters, Police, EMS

### For Those Without Dementia

- Need to respond to calls for help
- Need to follow up on reports and complaints
- Need to treat all calls as logical, reasonable, and accurate UNLESS they are 'pranks', false reports, or pre-meditated lies
- Need to uphold the law, rules, guidelines

### For Those With Dementia

- Elopement & wandering issues
- Reports keep changing
- Can't tell WHO is telling the 'truth'
- More 'false' calls
- More refusals and anger toward help
- Harder to know what is 'right'
- More risk of abuse, neglect, verbal & physical attack

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So...  
Who Is Affected By Dementia?

Everyone!

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## Why a Team? Because...

- Life happens 24/7
- Care needs are complicated & multi-factorial
- Dementia affects everyone
- Each person will decide to participate or not...
- To optimize positive outcomes, it works best if we
  - Have a common goal
  - Start off in the same place
  - Have a game plan
  - Move in a planned, consistent direction
  - Check in regularly
  - Make adjustments as needed
- CELEBRATE the AH HA moments & share the AH OHs

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## What Should We Do?

- Learn more about the condition & What it means for each group affected – think & talk about it
- Educate everyone about the condition – what it is and what to expect
- Train ALL employees in how to interact with people who have dementia
- Gather personal preference and history for each person
- Recognize and understand the progression of the condition

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## The Knowledge & Skills Needed

Insert the Other PPT Slides Here!

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**If you do this, you will be able to...**

- Develop services that WORK
- Recognize and help staff cope with the challenges they face every day
- Reduce RISK
- Use resources more wisely
- Make changes that will help
- Build Programming that MATCHES the person
- Satisfy everyone more consistently

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**Who Needs to Know This?**

Better Question... Who Doesn' t?

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**Some Key Issues**

- Screening for the Condition – w/Follow Up
- Early Diagnosis
- Medications & Treatment
- Legal Issues - HC PoA, F PoA, Guardianship
- Financial Issues – fraud, abuse, resources
- Care Options & Funding
- Family Support & Education
- Staff Support and Education

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## Why Do Early Diagnosis?

- Failure to ID
  - safety issues
  - family disasters
  - \$\$\$ disasters
  - mis-diagnosis
  - untreated problems
  - fear & stress
  - panic
- Early Detection
  - drugs may work better
  - personal planning
  - decision making
  - \$\$\$ planning
  - treat the treatable
  - counseling & support

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## Middle Disease Symptoms

- Difficult to 'help' & fill the day
  - need some help with personal care
  - can't see the 'need for help'
  - easily frustrated and angered
  - easily distracted & yet perseverates
  - makes significant errors, un-noticed
  - language is very impaired
  - frequently lost in time & place

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## Public Health Concerns Mid-Disease

- Elopement & wandering (> 60% will)
- Refusal of assistance & help
- Social isolation
- Problems with hygiene & health management
- False reports to police and 911
- Public behavior problems
- Caregiver burn out
- Higher risk of abuse & neglect
  - harder to figure out

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### End of Disease Issues

- Constant walking, rocking, or rolling
- Weight loss
- Hand skill loss
- Decreased alertness & arousal
- Difficulty swallowing & eating
- Constant humming, vocalizing, or yelling
- Contractures and immobility

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### Health Concerns End of Disease

- High cost for care
- Fewer locations available
- Most folks run out of money by now
- High risk of neglect or mis-handling
- High risk of doing too much – try to fix
- Lack of caregiver understanding of the end of the disease
- Lack of sustainable resources for care

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### Why Do We Need a TEAM Approach in Dementia Care?

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## What Makes 'Good Care' Happen?

- SIX pieces to consider...
  - The type & level of cognitive impairment ... NOW
  - The person & who they have been
    - Personality, preferences & history
  - Other medical conditions & sensory status
  - The environment – setting, sound, sights
  - The whole day... how things fit together
  - People - How the helper helps -
    - Approach, behaviors, words, actions, & reactions

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Let's get started

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