Who Should Be the Center of Our Attention?

The Person Living with Dementia!

What Does Having Dementia Do To The Whole System of Care?
- Changes in memory and thinking
- Changes in understanding and speaking
- Changes in impulsivity and initiation
- Changes in abilities and processing

What is Happening for the Person Living with Dementia?

Memory Damage:
- Can’t learn new things
- Forgets immediate past
- Does time and space travel
- Uses old memories like new
- May not identify self or others correctly
- Confabulates
- Follows visual cues
- Seeks out the familiar
- Can get stuck on an old emotional memory track

Language Damage:
- Has very concrete understanding of words
- Misses 1 our of 4 words: may miss “Don’t...”
- Word finding problems
- Word salad problems
- Covers
- Follows your cues
- Gets very vague and repeats
- Uses automatic responses
- Mis-speaks
What is Happening for the Person Living with Dementia?

Impulse Control Problems
- Say whatever they are thinking
- Swear easily
- Use sex words or racial slurs when stressed
- Act impulsively
- Not think thru consequences
- Can’t hold back on thoughts or actions
- Responds quickly and strongly to perceived threats: Flight, fight, fright

Performance Problems
- Thinks they can do better than they can
- Can sometimes do better under pressure, sometimes worse
- Uses old habits
- Attempts can be dangerous or fatal
- They will tell you one thing and then do another
- Families may over or under ‘limit’ activities

But … Who Else is Affected?

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 and Regulators

Family
- Spouse
- Kids
- Grandkids/Great-Grandkids
- Long distance relatives/extended family
- Siblings

Friends
- Faith community friends
- Neighborhood friends
- ‘Old Life’ Friends
- ‘New Life’ Friends

Residents without Dementia
Other Residents with Dementia

Surveyors and Regulators

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# Let’s Talk about Staff Perspectives

## For Direct Caregivers:

<table>
<thead>
<tr>
<th>For All Residents:</th>
<th>For Those With Dementia:</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Need to help the person with personal care</td>
<td>- Challenges with delivering care</td>
</tr>
<tr>
<td>- Need to help with basic room neatness and care</td>
<td>- Challenges with identifying needs in a timely manner</td>
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<tr>
<td>- Need to get care done for the whole assignment list</td>
<td>- Unusual or unexpected behaviors</td>
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<tr>
<td>- Need to respect personal choices</td>
<td>- Increased refusals</td>
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<td></td>
<td>- More room care needs</td>
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<tr>
<td></td>
<td>- More time needed to complete care</td>
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<td>- Less appreciation for help or ability to respond</td>
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## For Med Techs:

<table>
<thead>
<tr>
<th>For All Residents:</th>
<th>For Those With Dementia:</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Give prescribed meds at prescribed times</td>
<td>- More problems with getting meds in</td>
</tr>
<tr>
<td>- Document delivery and refusals</td>
<td>- More time to deliver meds</td>
</tr>
<tr>
<td>- Check for acute changes in status</td>
<td>- More alteration of meds required to get in</td>
</tr>
<tr>
<td>- Monitor for specific side-effects as ordered</td>
<td>- Difficulty with determining changes, side-effects, PRN need, impact</td>
</tr>
<tr>
<td>- Give PRNs as requested</td>
<td>- Typically, more meds to deliver</td>
</tr>
</tbody>
</table>
For Engagement Staff:

For Those Without Dementia:
- Need for programming to meet social, physical, cognitive, spiritual, emotional needs
- Need for some group and some individual interactions
- Trying to match preferences to what is available and possible
- Resident-resident relationships
- Need for staff and community support for programs

For Those With Dementia:
- Can't do or disrupt more traditional activities
- Won't stay till end or won't leave
- Less able to engage and do
- More intrusive or isolated
- Keep changing, less predictable
- Need 24/7 programming that is more individualized

For Nurses and RCDs:

For Those Without Dementia:
- Must be assessed
- Care needs determined
- Care plan developed
- Staff care matched to abilities and needs
- Family expectation met
- Care done in a timely and effective manner
- Keep staff and 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 and staff reports don't match
- More family/staff/resident conflicts

For Food Service:

For Those Without Dementia:
- Meet nutritional needs of people
- Meet food preferences of people
- Meet health/safety food/fluid needs of people
- Serve attractive meals with 'dining' appeal in a nice setting
- Provide snacks and drinks between meals

For Those With Dementia:
- More refusals and changes
- Changing abilities to: eat, swallow, know they have eaten, report accurately, make choices, ask for something, use utensils, find the room, stick to restrictions, care about others, wait, serve themselves, get around, give feedback, leave décor alone
For Business Office:

For Those Without Dementia:
- Contracts and Agreements
- Billing and Payments
- Monthly statements
- Charges for services
- Handling of complaints

For Those With Dementia:
- More arguments and accusations of lying or errors
- More denials that things have been talked about or agreed to
- More ‘deals’ with family members or covering
- More time spent talking about issues

For Laundry:

For Those Without Dementia:
- Follow signs about doing someone’s wash or not
- Wash personal items safely
- Need to wash linens
- Get items from rooms and return personal clothing and linens to correct locations
- Deal with occasional body fluids in laundry
- Keep enough linens on unit

For Those With Dementia:
- More changes in who does what
- More laundry needs doing
- More complaints from families about lost or damaged items
- More problems with taking things out and returning them
- More feces, urine, and blood

For Housekeeping:

For Those Without Dementia:
- Keep personal spaces looking and smelling nice
- Keep common areas looking and smelling nice
- Clean up common areas on a regular basis
- Clean up personal areas on a regular basis
- Monitor for and clean up ‘accidents’

For Those With Dementia:
- More problems with keeping rooms clean and neat and smelling nice
- More problems with common area looks and smells
- More interference with cleaning process – refusals
- More accusations of theft and stealing
- More ‘hiding’ and taking things
For Maintenance:

For Those Without Dementia:
- Keep room temperatures comfortable for residents
- Keep bathroom equipment working well
- Keep electrical systems safe and functional
- Keep furniture and equipment operational
- Deal with emergencies
- Fire safety plan and 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

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, etc.
- Reminding residents about events, appointments, rules

For Those With Dementia:
- Elopement risks
- Restrictions on phone use
- More questioning over and over
- More requests to see administrator or other leaders
- More resident-resident issues
- More arguments about info
- More interrupting and complaining

For Transportation:

For Those Without Dementia:
- Get to appointments
- Take on outings
- Keep safe while transporting
- Keep on schedule and follow plans
- Load up and unload

For Those With Dementia:
- More problems with appointments
- More ‘last minute’ changes
- More problems with loading and unloading
- More problems with safety during outings
- Less ability to communicate preferences, needs, and appreciation
For Marketing:

For Those Without Dementia:
- Bring in appropriate residents
- Sell the community and program
- Do tours and 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 straightforward
- Quick fill can be a disaster more often

For Administrators:

For Those Without Dementia:
- Different personality traits, life experiences and 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 and 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 and he said/she said conflicts

For Outside Service Providers:

For Those Without Dementia:
- Providing services covered by 3rd party insurance or family funding
- Providing services for ‘part’ of the day or per visit
- Need to get referral and agreement to treat
- Need to show value
- Need to communicate info and plans/recommendations

For Those With Dementia:
- More ‘other’ involvement
- More refusals
- More ‘non-compliance’
- More questions about value and purpose
- More communication challenges and problems with follow-through
- Less consistency in performance
Now…
Let’s Talk About Families

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

For Siblings:

For Those Without Dementia:
- Are aware of their long histories and relationships
- Are keeping up their life-long patterns
- Have a chance to work things out
- Can talk and interact
- Can connect emotionally
- Can make choices and appreciate what that means

For Those With Dementia:
- Frequently lose or mistake generational relationships
- May represent their own future
- May embarrass and frustrate the other person with their behaviors and mistakes
- May react strongly and emotionally with pleas to leave, help, get mom, or get out
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 and forth
- Are feeling all kinds of feelings and can’t talk or work them out
- Feel overwhelmed and unsure

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

For Nieces/Nephews or Other Family Members:

For Those Without Dementia:
- Can visit, but not feel overly responsible for the person
- Can share family history and enjoy the person
- Can go out if physical health allows
- Can tell them everything that is going on
- Can plan to do things and get to do them

For Those With Dementia:
- Feel like they need to ‘keep an eye on things’ and report back when they visit
- Feel like they have to be careful about what they say and don’t say
- Never know how its going to go when they came
- Can get caught in the middle
For Grandkids:

For Those Without Dementia:
- They can have fun, if they are well behaved
- They will be the center of attention
- Can have fun with Grandma or Grandpa and may have lots of others also to play and visit with
- Can count on fairly short visits and then parent attention later

For Those With Dementia:
- Not sure what to expect
- May be scared of how people behave, look, talk, touch
- May not know what to do or how to respond
- May not have a problem at all
- May be upset, because parents are upset

For Great-Grandkids:

For Those Without Dementia:
- Can be the highlight of the day, week, month
- Can be a topic of conversation among residents from pictures, letters, phone conversations, and visits
- Can brighten the whole community

For Those With Dementia:
- Can be a highlight for a few minutes
- Can get many people all excited
- Can remind some folks of their own children and increase distress and need to leave later in the day
- Can cause jealousy and possessiveness

What About Friends and Neighbors?
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’ and 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

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 okay

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 downhill’
- Seem to be in a safer place, but….
- Are a ‘duty visit’ and unsure what to say or do

For ‘Old Life’ Friends:

For Those Without Dementia:
- May be frail, but still seem pretty much they have always been – in spirit
- 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 things 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
For ‘New Life’ Friends:

For Those Without Dementia:
- Are fun to be around and can behave
- Can share new memories and experiences
- Can learn new things along with you
- Can remember who you are to them
- Can come out and participate in activities with common interests

For Those With Dementia:
- Get worse and worse over time
- Can’t be depended on, may demand your time and attention, even when you aren’t up for it
- May not remember you at all or may mis-remember you
- May misbehave and be unpredictable
- May be limited in what they can do and say

What About Other Residents?

For Residents/Participants 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 and resources
For Other Residents/Participants 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

So...
Who Is Affected By Dementia?
- Everyone!

What Should We Do?
- Learn more about the condition and what it means for each group affected – think and 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
Some Basic Skills:
- Positive Physical Approach™
- Hand-under-Hand® for connection and assistance
- Consistent and skill-sensitive cues
  - Visual, verbal, physical
- Supportive Communication

Knowledge and Skills Will Allow You 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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