



Dementia 360

Seeing Dementia from
Everyone's Perspective

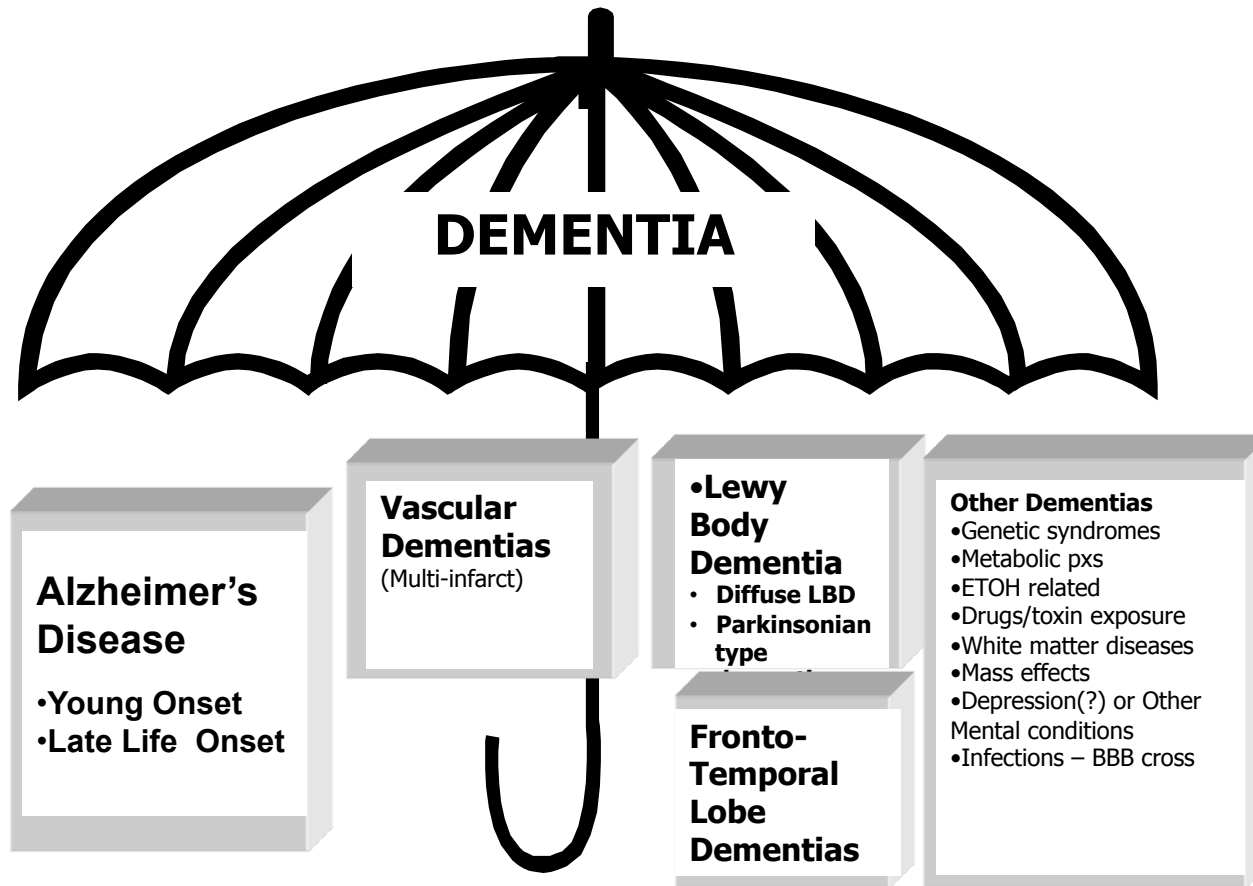


Who Should Be the Center of Our Attention?

- The Person Living with Dementia

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

- Changes in memory & thinking
- Changes in understanding & speaking
- Changes in impulsivity & initiation
- Changes in abilities & processing



Alzheimer's

- New info lost
- Recent memory worse
- Problems finding words
- Mis-speaks
- More impulsive or indecisive
- Gets lost
- Notice changes over 6 months – 1 year

Vascular Dementia

- Sudden changes
- Picture varies by person
- Can have bounce back & bad days
- Judgment and behavior 'not the same'
- Spotty losses
- Emotional & energy shifts

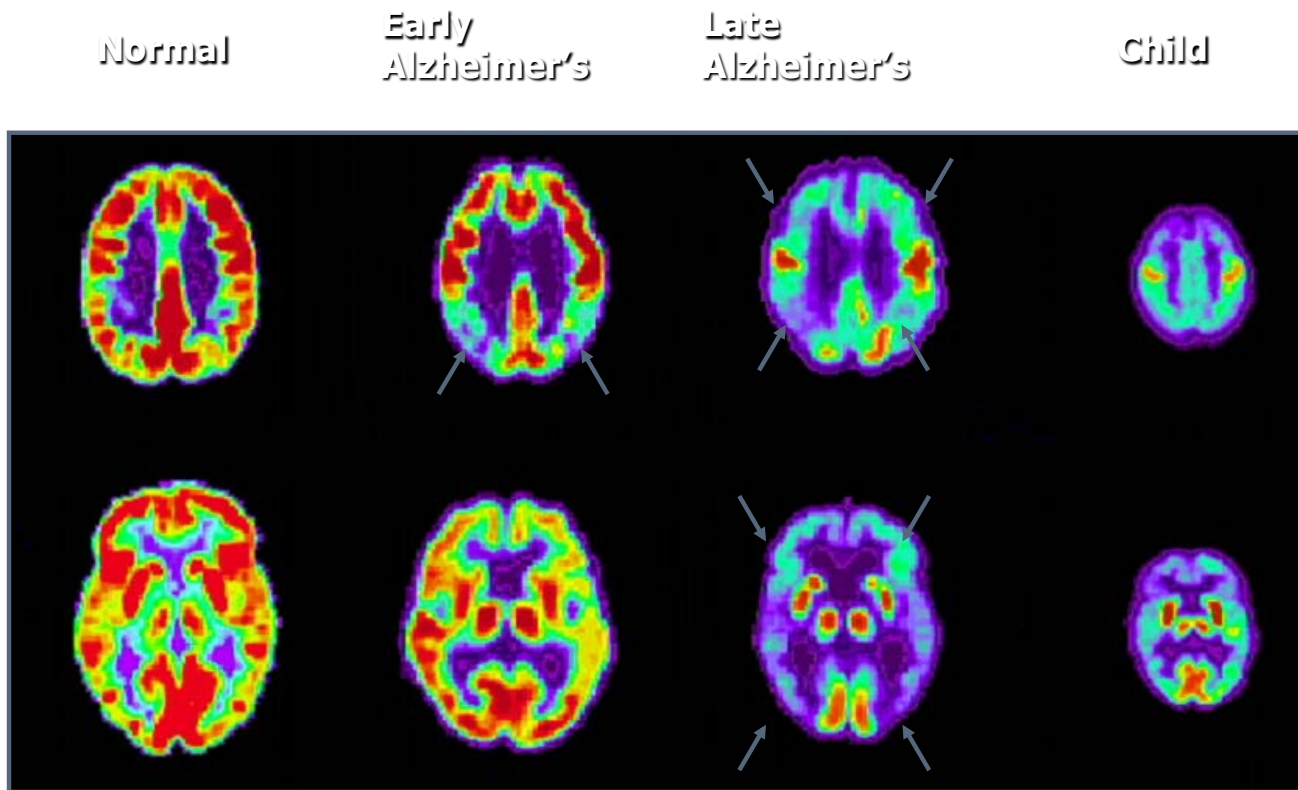
Lewy Body Dementia

- Movement problems - Falls
- Visual Hallucinations
- Fine motor problems – hands & swallowing
- Episodes of rigidity & syncopy
- Nightmares
- Fluctuations in abilities
- Drug responses can be extreme & strange

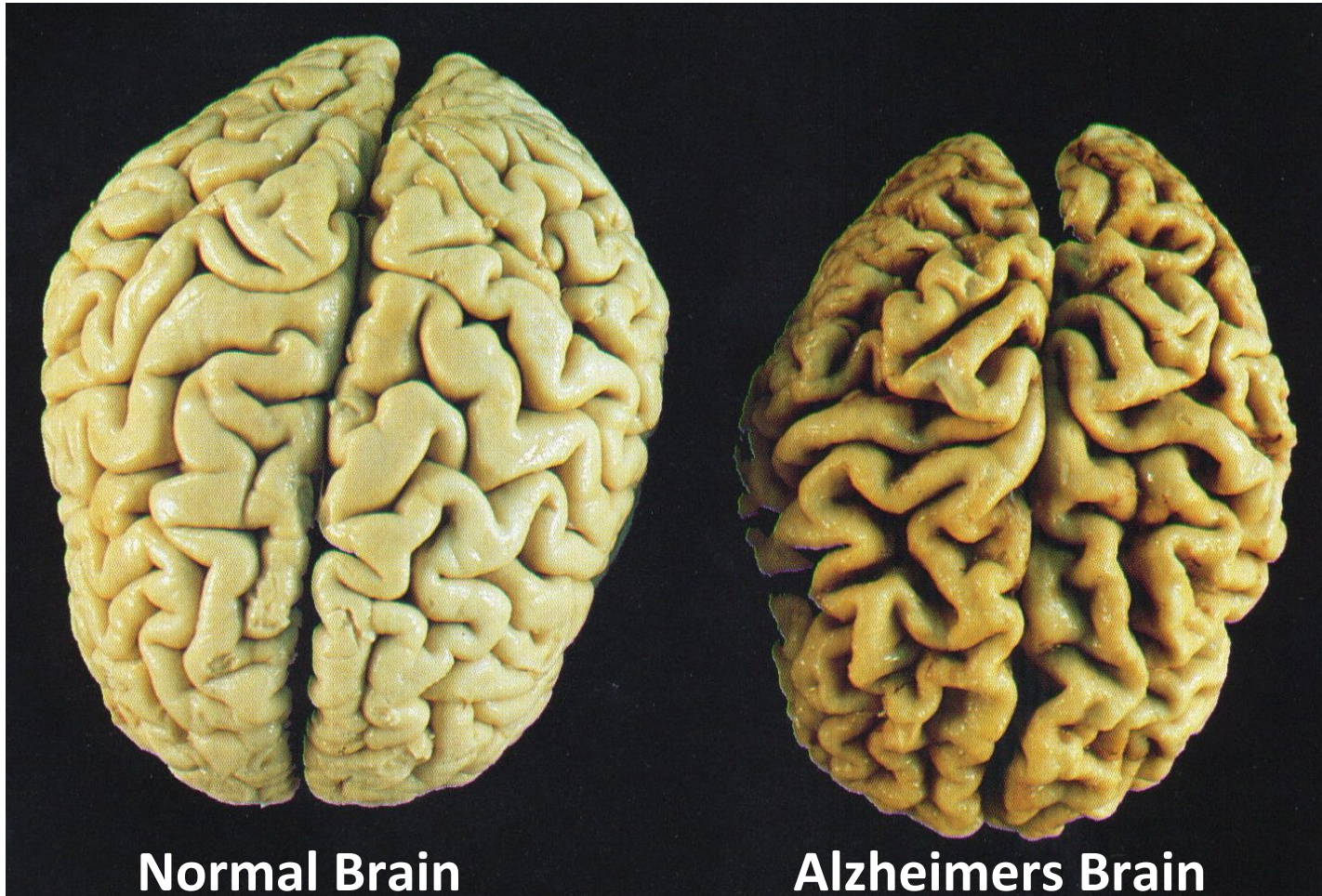
Fronto-Temporal Dementias

- Many types
- Frontal – impulse and behavior control loss
 - Says unexpected, rude, mean, odd things to others
 - Dis-inhibited – food, drink, sex, emotions, actions
- Temporal – language loss
 - Can't speak or get words out
 - Can't understand what is said, sound fluent – nonsense words

Positron Emission Tomography (PET) Alzheimer's Disease Progression vs. Normal Brains



G. Small, UCLA School of Medicine.



Normal Brain

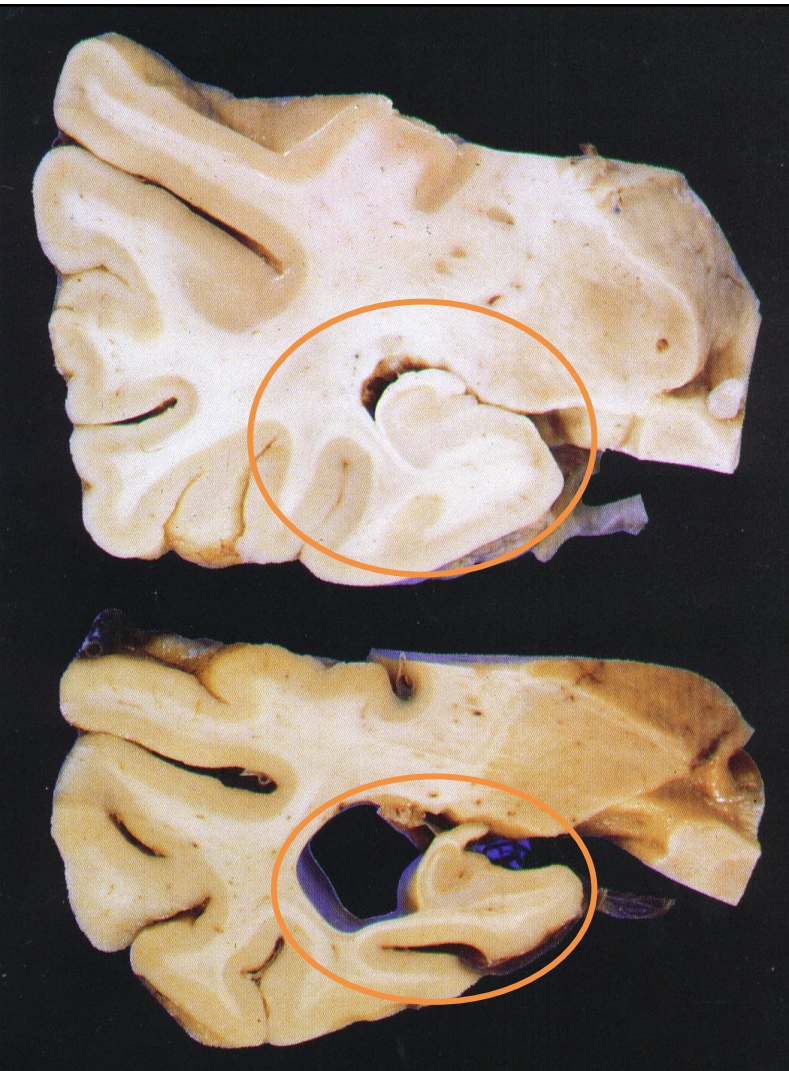
Alzheimers Brain

Brain atrophy

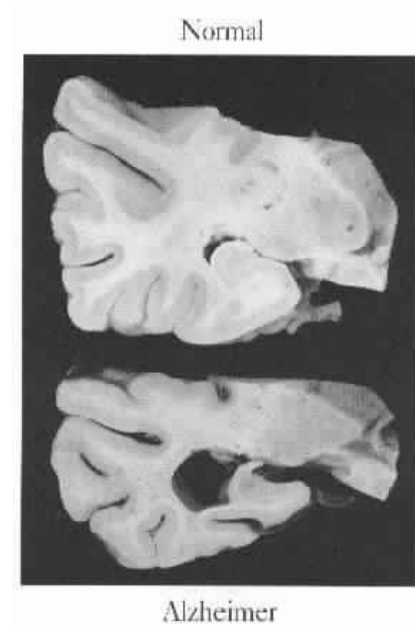
- the brain actually shrinks
- cells wither then die
- abilities are lost
- with Alzheimer's area of loss are fairly predictable
- ... as is the progression
- BUT the experience is individual...



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Memory Loss



Losses

- Immediate recall
- Attention to selected info
- Recent events
- Relationships

Preserved abilities

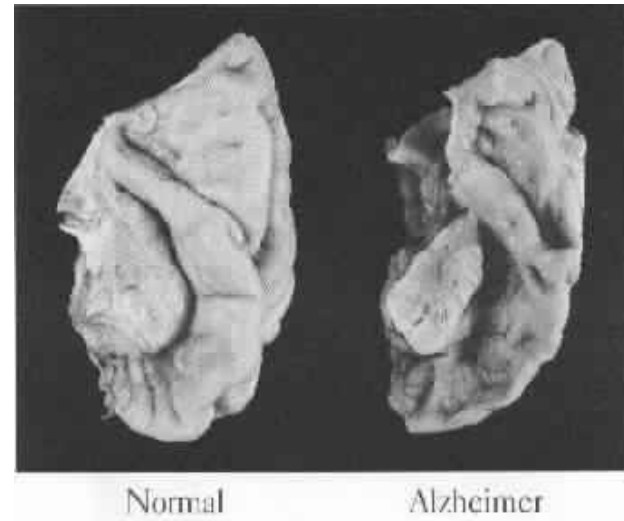
- Long ago memories
- Confabulation!
- Emotional memories
- Motor memories

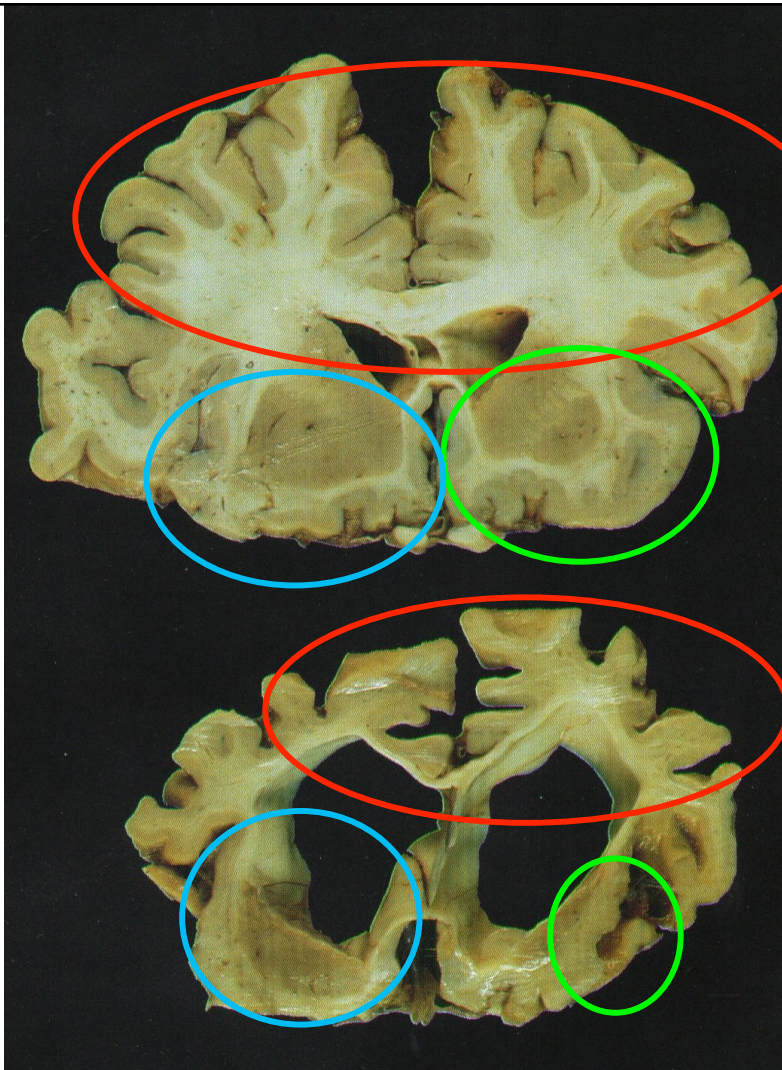




Understanding

- **Losses**
 - Can't interpret words
 - Misses some words
 - Gets off target
- **Preserved abilities**
 - Can get facial expression
 - Hears tone of voice
 - Can get some non-verbals
 - Learns how to cover





Sensory Strip
Motor Strip
White Matter Connections
BIG CHANGES

Automatic Speech
Rhythm – Music
Expletives
PRESERVED

Formal Speech & Language
Center
HUGE CHANGES

Sensory Changes

- Losses
 - Awareness of body and position
 - Ability to locate and express pain
 - Awareness of feeling in most of body
- Preserved Abilities
 - 4 areas can be sensitive
 - Any of these areas can be hypersensitive
 - Need for sensation can become extreme



Self-Care Changes

- Losses
 - initiation & termination
 - tool manipulation
 - sequencing
- Preserved Abilities
 - motions and actions
 - the doing part
 - cued activity



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Language

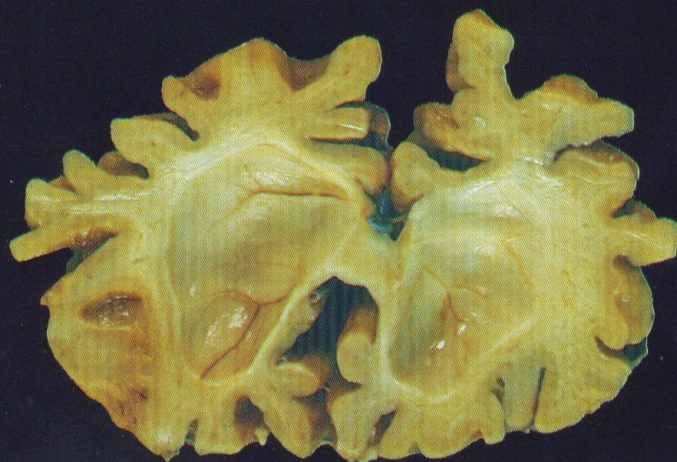
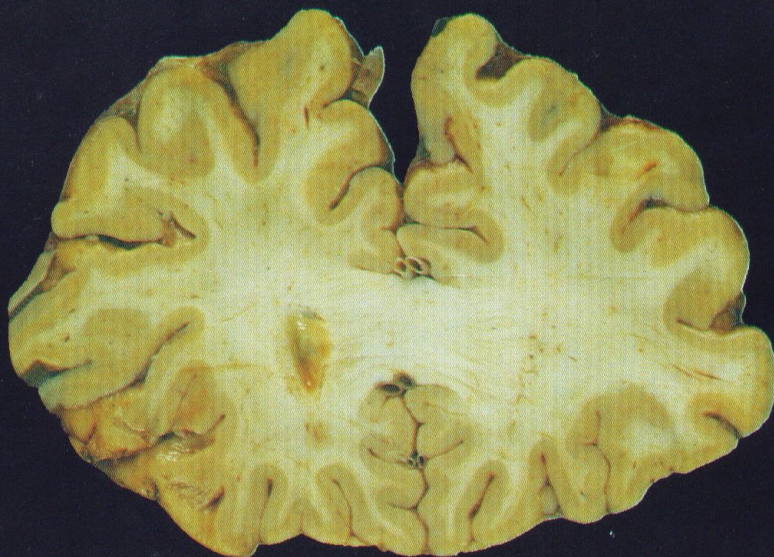


Losses

- Can't find the right words
- Word Salad
- Vague language
- Single phrases
- Sounds & vocalizing
- Can't make needs known

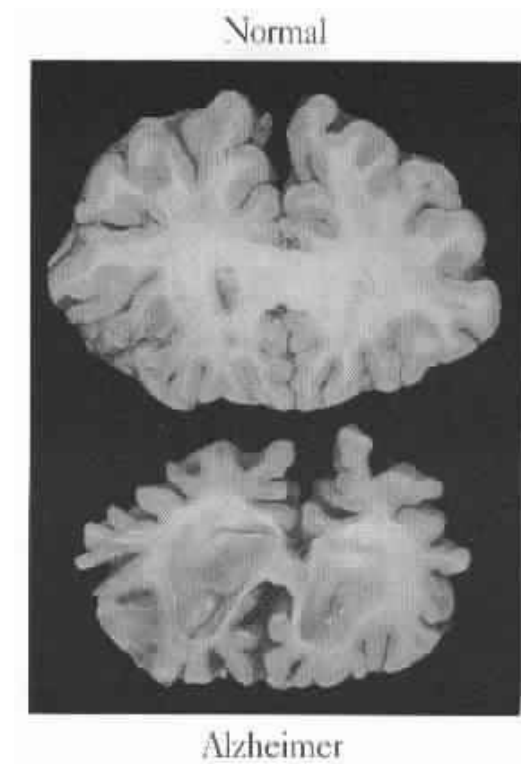
Preserved abilities

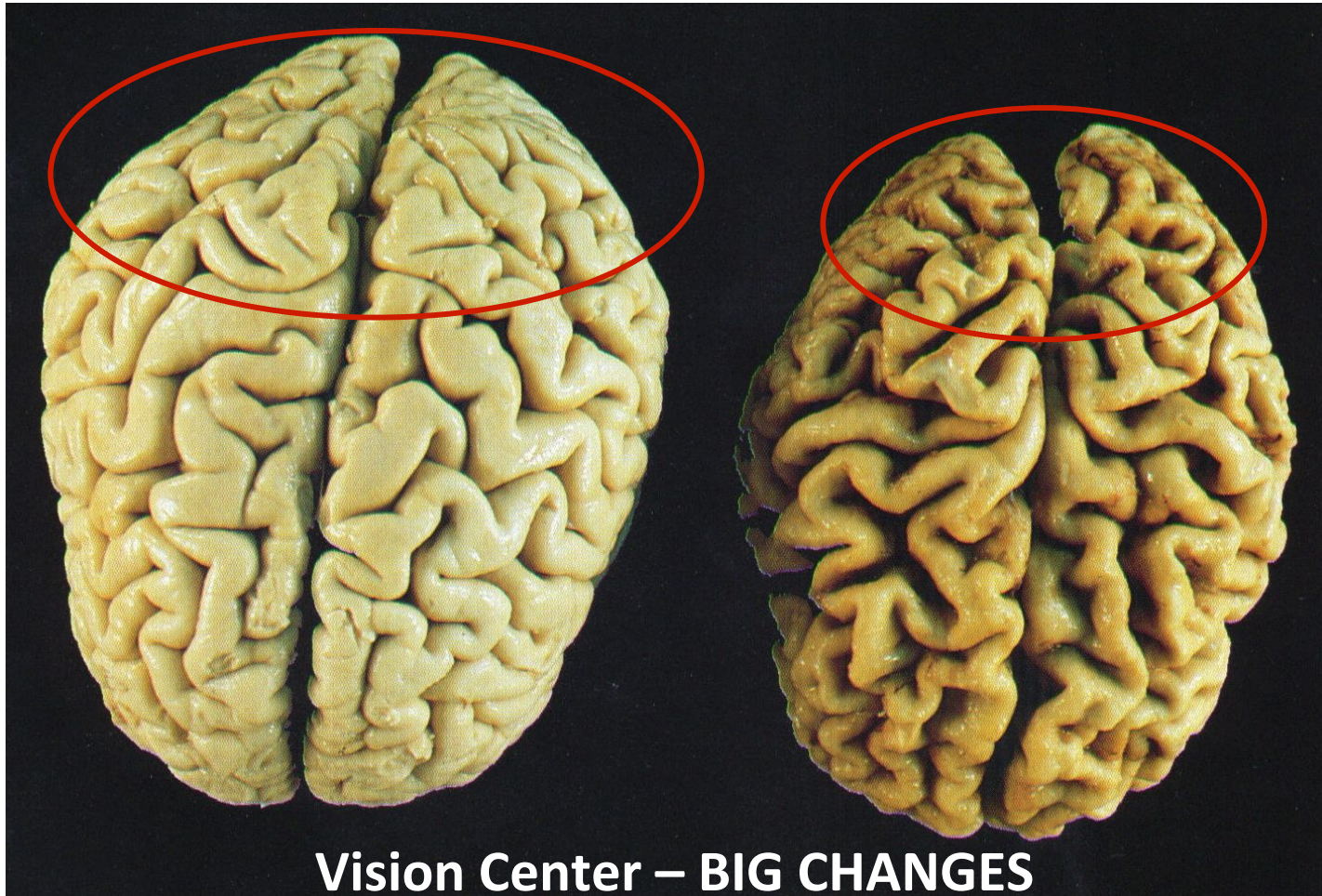
- singing
- automatic speech
- Swearing/sex words/forbidden words



Impulse & Emotional Control

- Losses
 - becomes labile & extreme
 - think it - say it
 - want it - do it
 - see it - use it
- Preserved
 - desire to be respected
 - desire to be in control
 - regret after action





Vision Center – BIG CHANGES

So... what is happening for the person?

Memory damage

- Can't learn new things
- Forgets immediate past
- Does time & space travel
- Uses old memories like new
- May not ID 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 out of 4 words – may miss “Don’t...”
- Word finding problems
- Word salad problems
- COVERS
- Follows your cues
- Gets very vague & repeats
- Uses automatic responses
- Mis-speaks

So... what is happening for the person?

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 & 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 & 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

Let's Talk about Staff Perspectives

For Direct Caregivers

For All Residents

- 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

For Med Techs

For All Residents

Give prescribed meds at prescribed times

Document delivery & refusals

Check for acute changes in status

Monitor for specific 'side-effects' as ordered

Give PRNs as requested

For Those With Dementia

More problems with getting meds in

More time to deliver meds

More alteration of meds required to get in

Difficulty with determining changes, side-effects, PRN need, impact

Typically, more meds to deliver

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 & 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 & do

More intrusive or isolated

Keep changing, less predictable

Need 24/7 programming – more individualized

For Nurses & RCDs

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

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 & 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 & Agreements

Billing & Payments

Monthly statements

Charges for services

Handling of complaints

For Those With Dementia

More arguments & 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 & return personal clothing & 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 & returning them

More feces, urine, & 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 & smells

More interference with cleaning process – refusals

More accusations of theft and stealing

More 'hiding' & taking stuff

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

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

For Transportation

For Those Without Dementia

- Get to appointments
- Take on outings
- Keep safe while transporting
- Keep on schedule & 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 & 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

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

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 & 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

- What's Different for Them?

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 & forth

Are feeling all kinds of feelings and can't talk or work them out

Feel overwhelmed & 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... Others

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' & report back when they visit

Feel like they have to be careful about what they say and don't say

Never know how it's going to go when they come

Can get caught in the middle

For Grand Kids

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 & 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-Grand Kids

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 & 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' – 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 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

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 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

For New Life Friends

For Those Without Dementia

Are fun to be around & 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 you time & attention, even when you aren't up for it

May not remember you at all – mis-remember you

May misbehave and be unpredictable

May be limited in what they can do & 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 & 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

What About OTHERS?

For Families of Other Residents/Participants

For Those Without Dementia

Meet these people casually, then decide whether to get friendlier...

Some folks will be good matches for friends to your person, some will not

Folks will respect your relationship with your relative & your preferences about privacy

For Those With Dementia

The person with dementia can interfere with your relationship with your family member

The person with dementia tends to direct interactions

You may be fearful of what they might do when you aren't there

They may annoy or scare you or invade space, belongings & person

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

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

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

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

The Knowledge & Skills Needed

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