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Changing the Culture of Dementia Care One Mind at a Time

teepasnow.com

TeepaSNOW

Positive Approach to Brain Change™

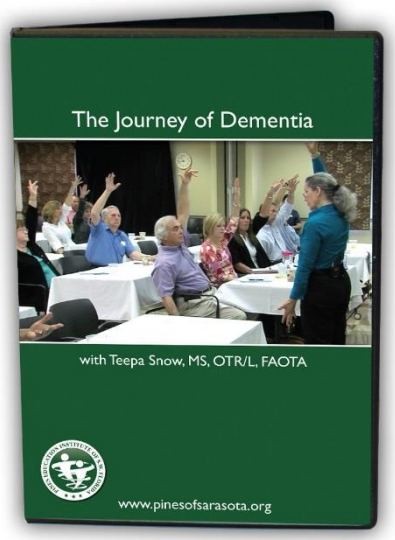
GEMS™

- Dementia Aware
- Dementia Knowledgeable
- Dementia Skilled
- Dementia Competent

www.TeepaSnow.com

Presentation slides for Teepa Snow program

“Journey of Dementia”



DVD available for purchase at **www.dementiacareacademy.com** or **www.amazon.com**

Planning for the Journey: Getting Started

Getting a Diagnosis
Understanding Dementia
Becoming an Advocate

Understanding the Different Dementias:

One Size Does Not Fit All!

Not normal … changes starting

- Inconsistent
- Worse when tired or sick OR in unfamiliar or uncomfortable setting

MCI

- The beginning of NOT NORMAL COGNITION
  - Memory
  - Language
  - Behavior
  - Motor skills
- Not life altering – BUT definitely different… for you

Ten Early Warning Signs

- memory loss for recent or new information – repeats self frequently
- difficulty doing familiar, but difficult tasks – managing money, medications, driving
- problems with word finding, mis-naming, or mis-understanding
- getting confused about time or place - getting lost while driving, missing several appointments
- worsening judgment – not thinking thing through like before
- difficulty problem solving or reasoning
- misplacing things – putting them in 'odd places'
- changes in mood or behavior
- changes in typical personality
- loss of initiation – withdraws form normal patterns of activities and interests

Is This ALWAYS Dementia?

- Some form of DEMENTIA
- Symptom of another health condition
- Medication side-effect
- Hearing loss or vision loss
- Depression
- Delirium
- Pain-related

TWO Mimics to KNOW

(copy cats & concurrent illnesses)

- 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***

  Typical and atypical

  sad

  mad - can look like agitation & confusion

  (this condition can improve with attention & treatment)

- These signal a vulnerable brain – heads up!

Mimics of Dementia

- 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

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 Lippencott, Wilkins & Williams , 2003

Medications – the Very Basics

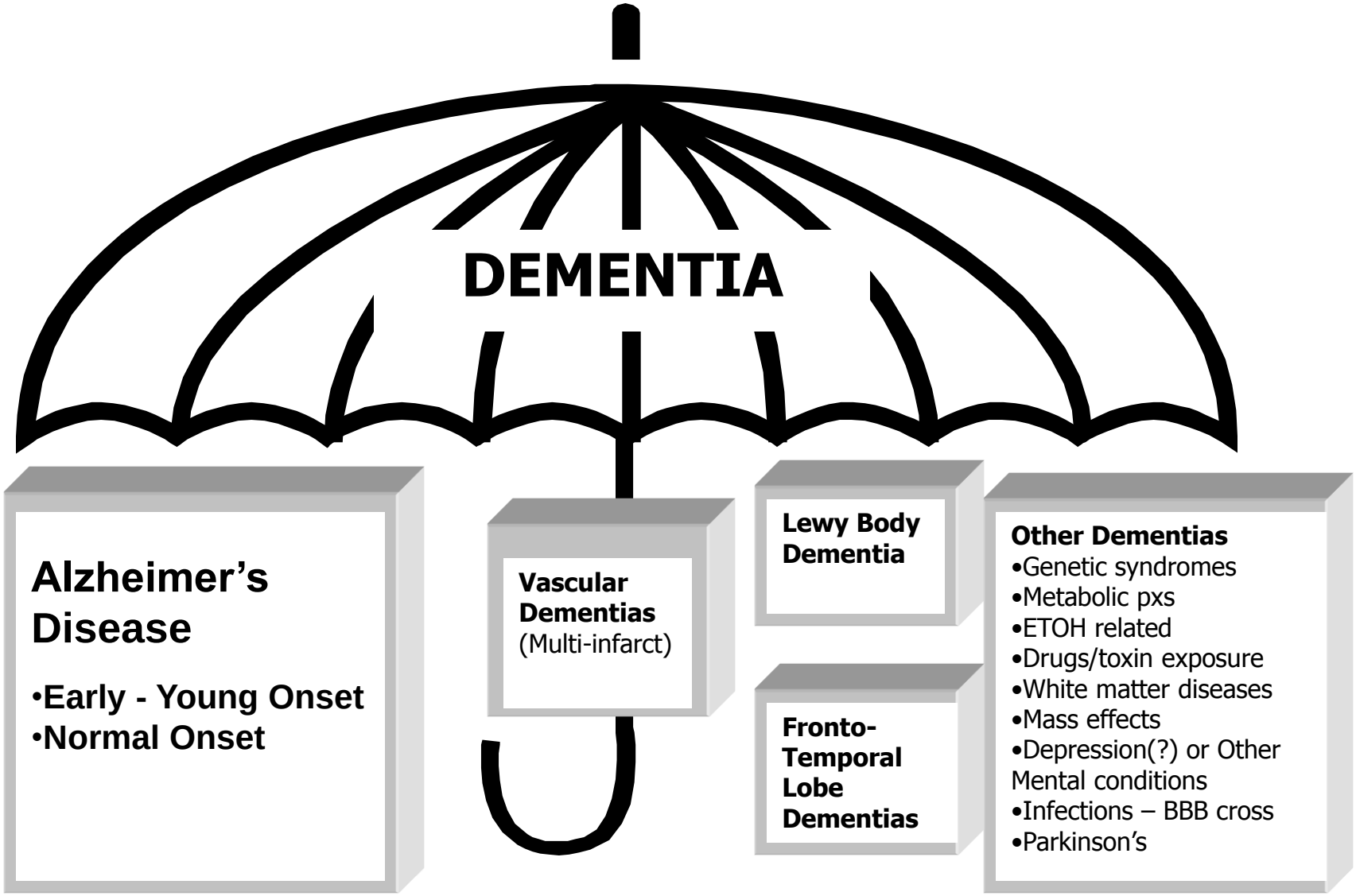
- All medications
  - Start low and go slow
  - Do one thing at time
  - Take away before adding on
  - Match the symptoms to the meds
  - Be aware of side effects
  - Keep track of what happens on the med – log books

Meds in Dementia Care

- Meds for the thinking changes
  - The earlier the better
  - Some will work for some folks some will not
  - Success may be a plateau not recovery
- Meds that manage with behavioral symptoms
  - These medications are sometimes necessary when other strategies don't work
  - Progressive disease…only use when needed

Dementia – What Changes?

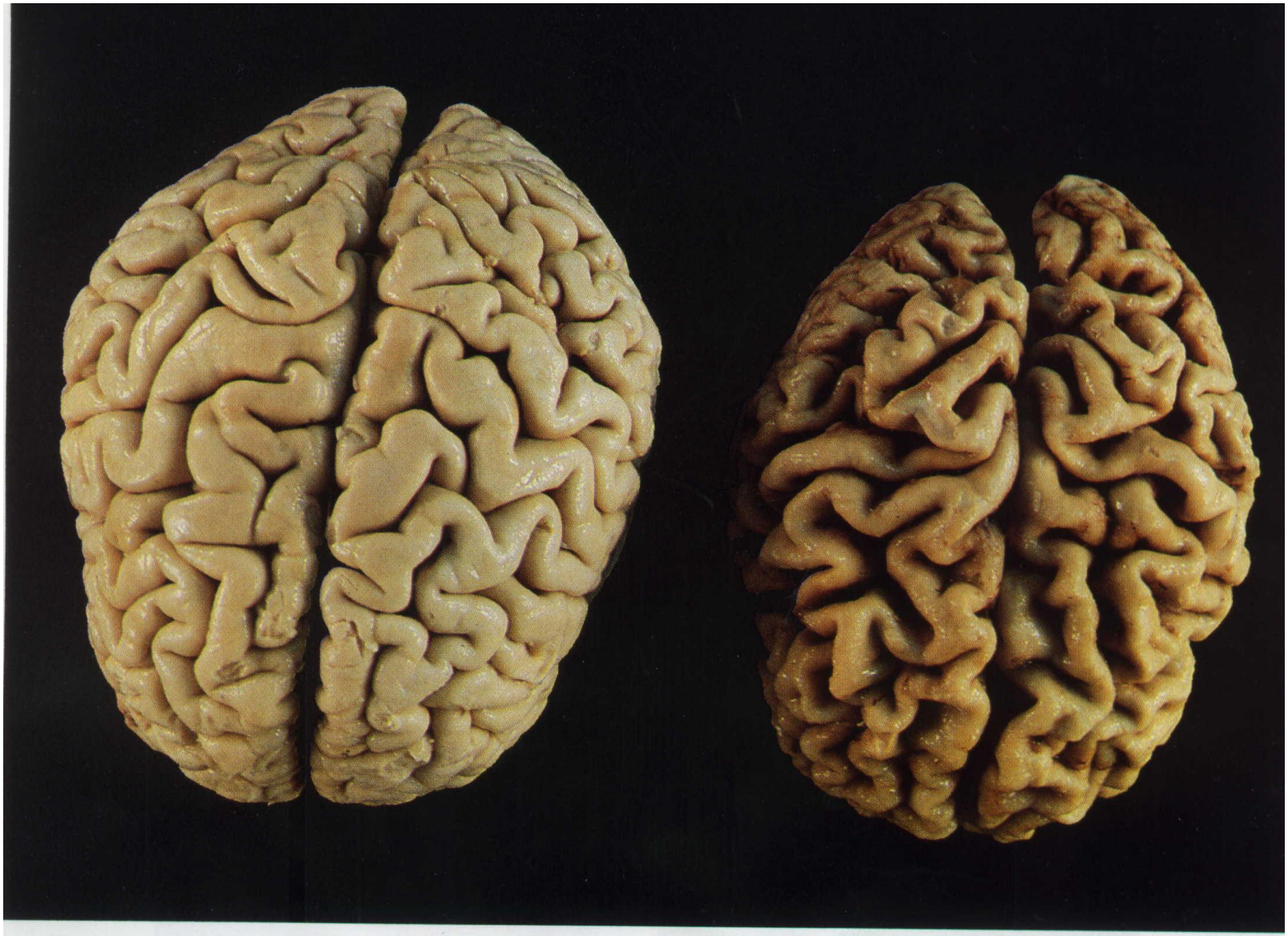
- Structural changes –permanent
  - Cells are shrinking and dying
- Chemical changes - variable
  - Cells are producing and sending less chemicals
  - Can ‘shine’ when least expected – chemical rush



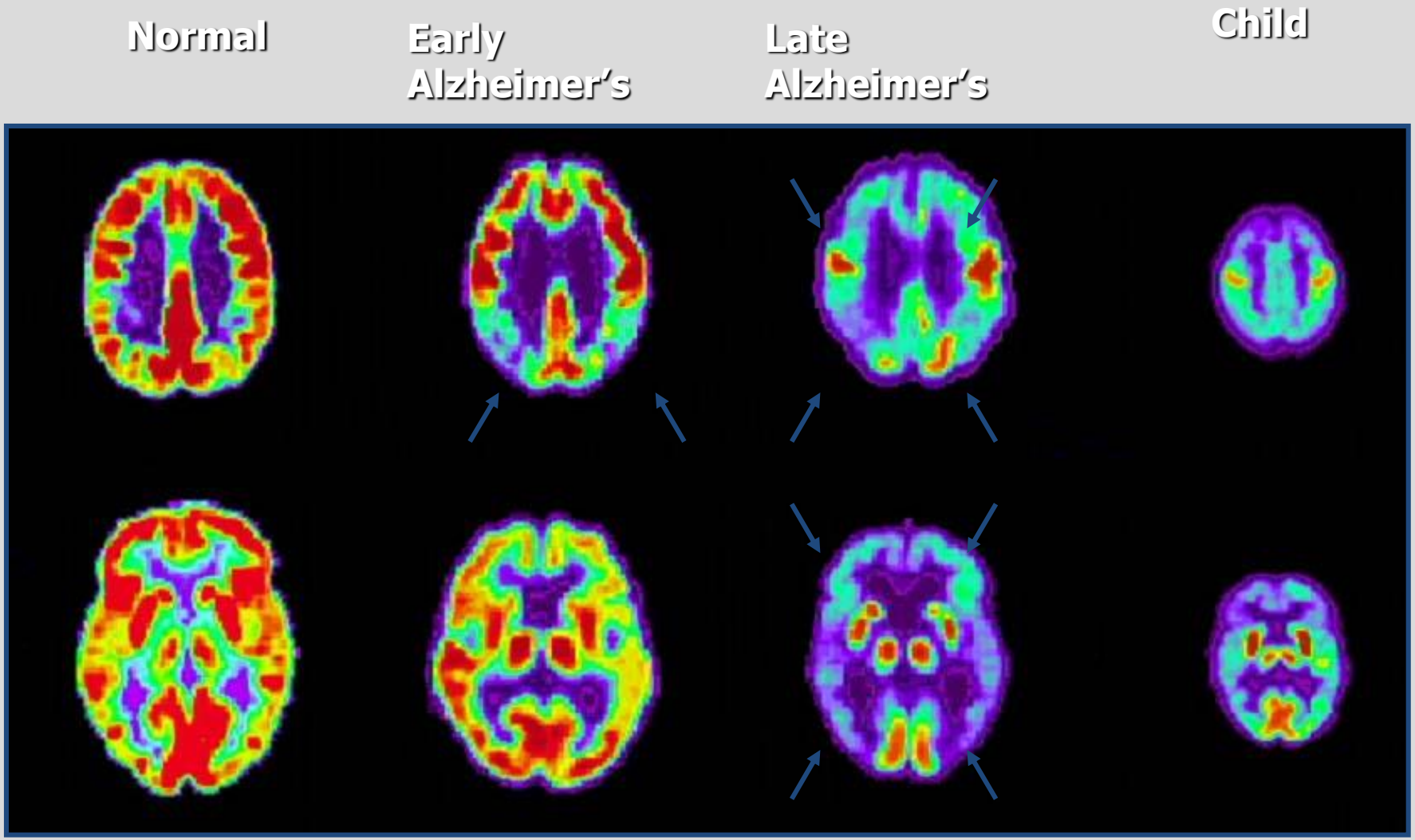
Alzheimer's –Two Forms

Young/Early Onset

Normal Onset



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



G. Small, UCLA School of Medicine.

Young Onset

- 3 groups – genetics, Down's, life style
- Young family – kids often involved
- Mis-diagnosis & non –diagnosis is common
- Work may be first place to notice
- Relationships are strained early - misunderstanding
- Services are a problem – usually
- Finances are problematic

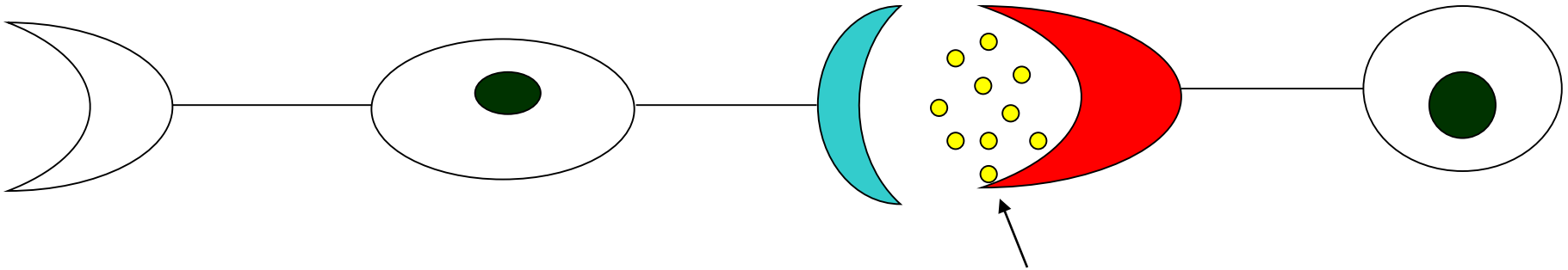
Alzheimer's

- New info lost
- Recent memory worse
- Problems finding words
- Mis-speaks
- More impulsive or indecisive
- Gets lost
- Notice changes over 6 m – 1 yr
- Lasts 8-12 years

Typical treatment for Alzheimers

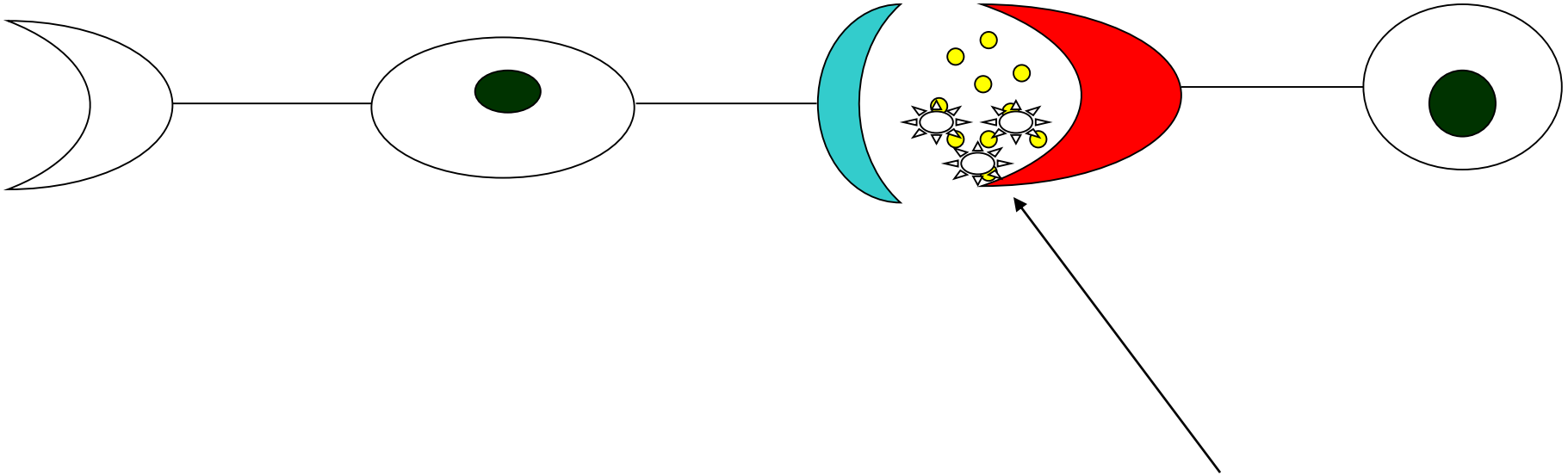
- Start with AChEI as soon as diagnosis is made
- If side-effects are too much – try another one
- Stay on the AChEI until --- 2 groups of thought
  - Placement in a ‘facility’
  - Considering other med stops – near end
- Add Namenda – mid-stage disease
- Stay on Namenda – as above

Normal Brain Cells



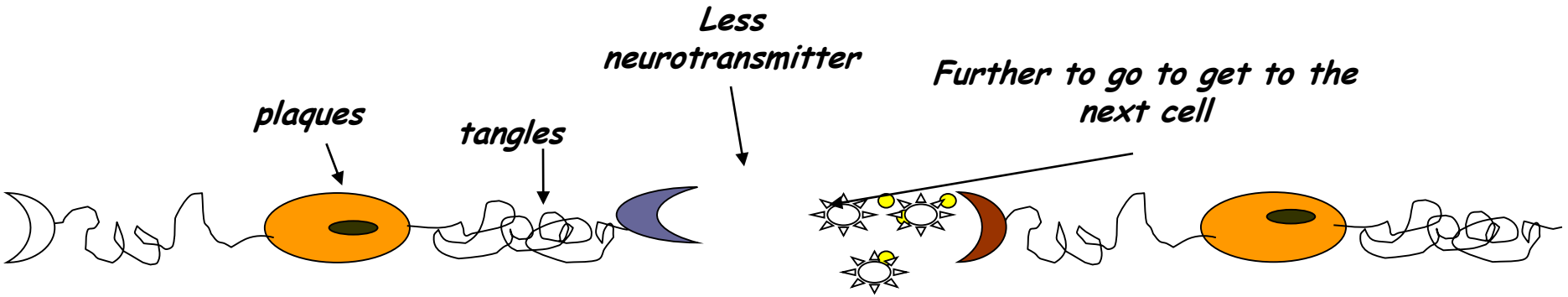
Neurotransmitters (AChE)– being sent – message being communicated to the next cell

Normal Brain Cells

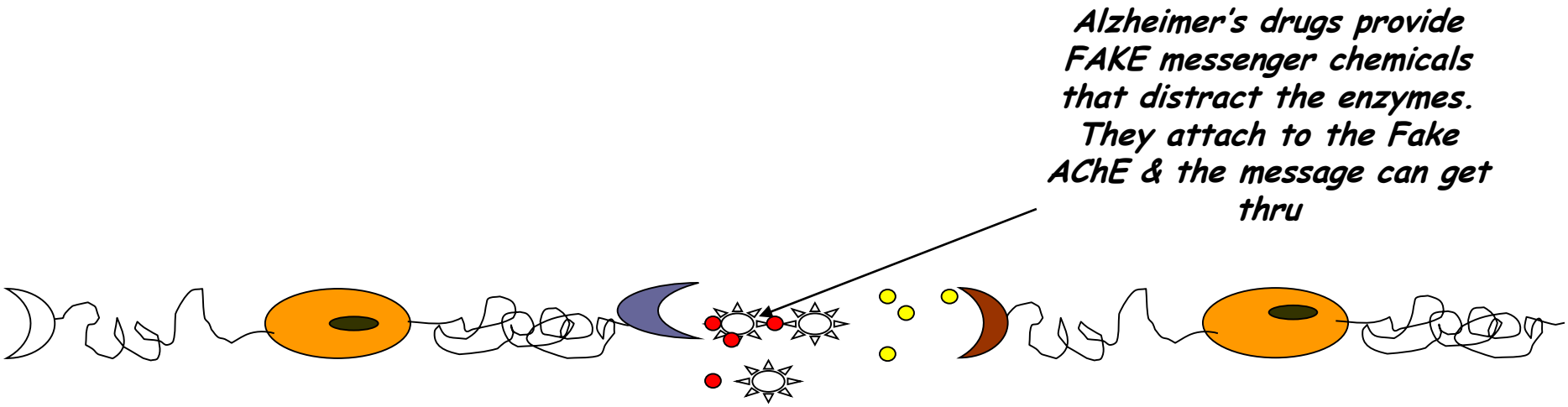


Once the message is sent, then enzymes lock onto the messenger chemicals and take them out of circulation so a new message can be sent

Brain Cells with Alzheimer's



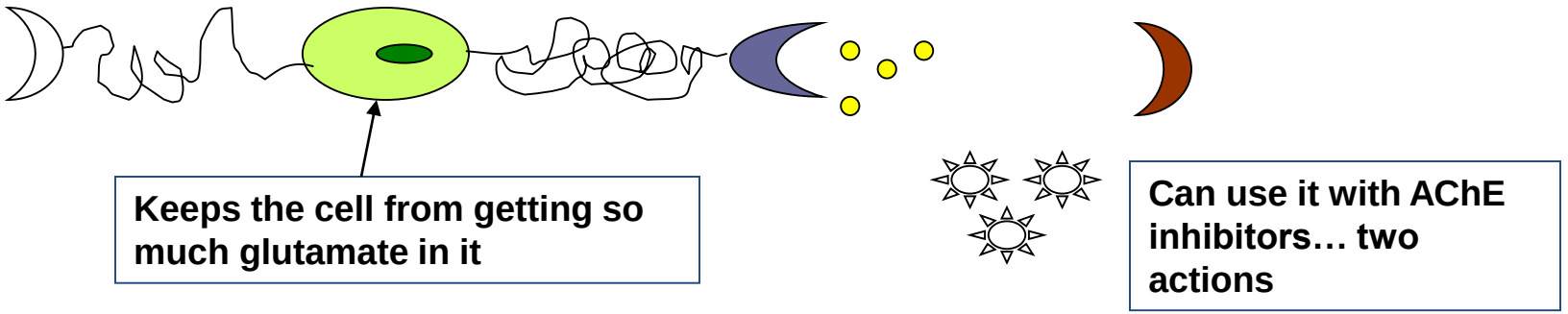
What do Alzheimer's drugs DO?



Aricept, Exelon, Reminyl (Razadyne)

One Other Dementia Drug

- Memantine - Namenda
  - from Europe - 10 years of research
  - came 4.5 years ago to the US
  - different effect
  - moderates glutamate absorption
  - Works best in combination with AChE inhibitors



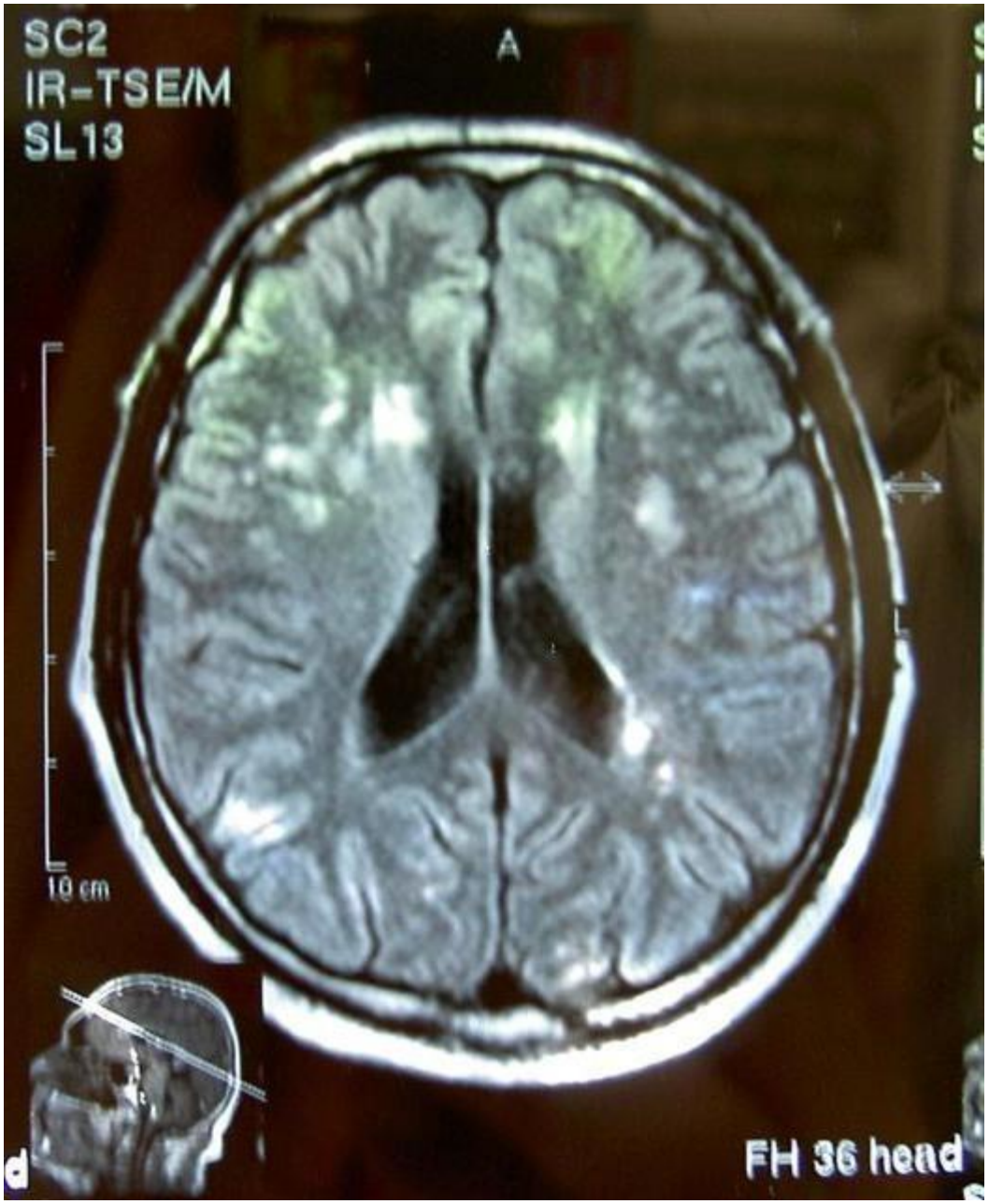
Vascular Dementia

- Sudden changes – stepwise progression
- Other conditions: DB, HTN, heart disease
- So, damage is related to blood supply/not primary brain disease: treatment can plateau
- Picture varies by person (blood/swelling/recovery)
- Can have bounce back & bad days
- Judgment and behavior ‘not the same’
- Spotty loss (memory, mobility)
- Emotional & energy shifts

Vascular dementia

CT Scan

The white spots indicate dead cell areas - mini-strokes



Latest Thinking About Vascular Treatment?

- Lots of similarity with Alzheimer's
- Manage blood flow issues CAREFULLY!
- Watch for and manage depression

Lewy Body Dementia

- Movement problems - Falls
- Visual Hallucinations – animals, children, people
- Fine motor problems – hands & swallowing
- Episodes of rigidity & syncopy
- Nightmares or Insomnia
- Delusional thinking
- Fluctuations in abilities
- Drug responses can be extreme & strange
  - Can become toxic, can die, can become unable to move
  - Can have an OPPOSITE reactions

Latest Thinking about Lewy Body Treatment

- Use AChIs
- Add Namenda early
- BE VERY careful about anti-psychotic meds
- Parkinson's meds – may help movement BUT may make hallucinations and delusions worse
- Anti-depressants & Anti-convulsants – may be used to help anxiety, sleep, & depression – can increase confusion, movement & drowsing

Fronto-Temporal Dementias

- Many types
- Frontal – impulse and behavior control loss (not memory issues)
  - 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

FTDs

- FvFTD – frontal varient of FTD
- FTD – frontal-temporal lobe dementia
- TLD – non-fluent aphasia
- TLD – fluent aphasia

Temporal Lobe
Non-Fluent Aphasia

- Can’t NAME items
- Hesitant speech
- Not speaking
- Worsening of speech production over time
- Echolalia
- Mis-speaking
- Word salad

- Receptive inability
- Other skills intact – early
- 25% never develop global dementia

FvFTD

- Mis-behavior
- Impulsivity
- Dis-inhibition
- Inertia
- Obsessive compulsive behaviors
- Inattention
- Lack of social awareness
- Lack of social sensitivity
- Lack of personal hygiene

- Becomes sexually over-active or aggressive
- Becomes rigid in thinking
- Stereotypical behaviors
- Manipulative
- Hyper-orality
- Language may be impulsive but unaffected OR may be reduced or repetitive

FTD (Pick's Disease)

Frontal Issues

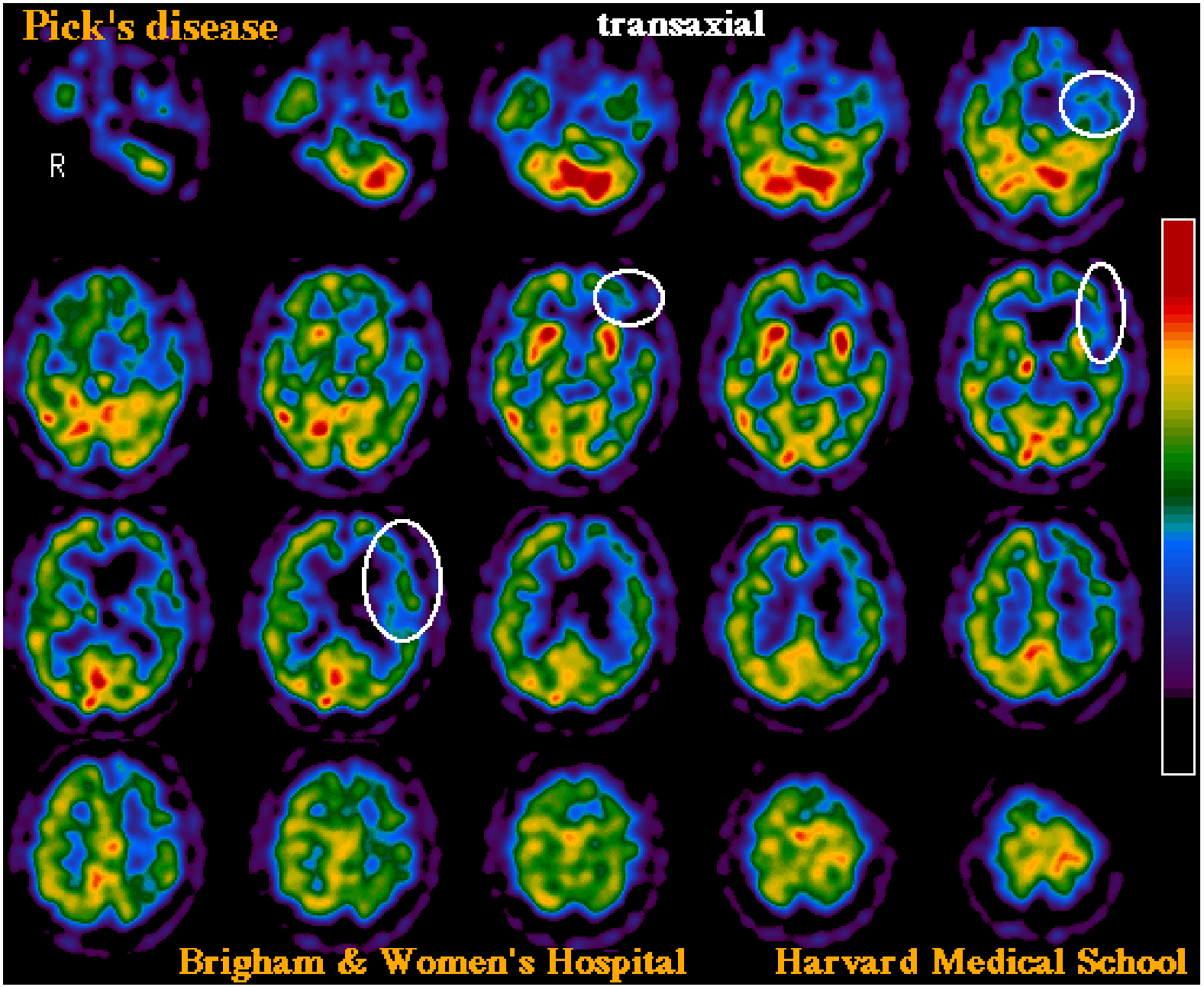
- Poor decision making
- Problems sequencing
- Reduced social skills
- Lack of self-awareness
- Hyper-orality
- Ego-centric
- Dis-inhibited – food, drink, words, actions
- OCD behaviors early
- Excessive emotions

Temporal Issues

- Reduced attempts to talk
- Reduced content in speech
- Poor volume control
- Public use of 'forbidden words'
- Sing-song speech
- Can't understand others' words

Pick's Disease

PET Scan


Pick's disease
transaxial
R
Brigham & Women's Hospital
Harvard Medical School

Latest Thinking About FTD Treatments

- Consider Namenda earlier
- Look at SSRI medications
- May use medications used to treat OCD
- May NOT use AChI Medications

What if it doesn't seem to be one of these?

- Atypical or other dementias
- Mixed picture

Other Dementias

- Genetic syndromes – Huntington's Chorea
- ETOH related –
- Drugs/toxin exposure – heavy metals, pesticides
- White matter diseases - MS
- Mass effects – tumors & NPH
- Depression and Other Mental Conditions
- Infections – BBB cross – C-J, HIV/Aids
- Parkinson's – 40%

Lots of other dementias

- 70 + forms, types, causes….
- Some progress very rapidly
- Some are genetic some are not
- Some are unique, some follow more traditional patterns

Mixed picture

- Can have multiples
- can start with one and add another
- Can have some symptoms – not all
- Also can have other life-long issues and then develop dementia (Down's, Mental illness, personality disturbances, substance abuse)

So, You are NOTICING CHANGES…

What Should You DO?

Get it assessed –

Go see the doctor!

Why Bother Getting a Good/Complete Diagnosis

- Future plans
  - Progression & prognosis
  - Finances
  - Health
- Being in control
- Medications can make a difference in quality of life

What Should Happen When You Go to See the Doctor?

If you are concerned but <65

- Screening of your thinking
- Simple ones
  - Animal fluency
  - Orientation &3 item recall
  - Clock drawing
- Short but helpful
  - MMSE
  - SLUMS
- Open discussion about who, what when, where, why?

If you are >65

- Screening of your thinking
- Simple ones
  - Animal fluency
  - Orientation &3 item recall
  - Clock drawing
- Short but helpful
  - MMSE
  - SLUMS
- Open discussion about who, what when, where, why?

If the Screen Indicates Concerns…

- R/O other 2 D's, Look at Meds
- Complete work-up & follow up

OR

- Send for a full Neuro-psychological eval
- THEN follow up with you

OR

- Refer to a specialist

Try to get a Work-Up – A Diagnosis

- Two possible situations…
  - Aware and cooperative
  - Not aware and NOT interested or willing

Getting a Diagnosis

What Should Happen?

What Should NOT?

What Should be DONE…

- A complete physical, medical, & psychological history
- A good history from the person and the family of the ‘problem’
- A thorough PE neurological & cardiac exams with blood work
- A complete medication review
- Imaging study (CT, MRI, PET)
- Neuropsychological testing – what works and what doesn’t
- FOLLOW-UP and counseling or at least a referral

What Should We Do If We Suspect Something Might Be Happening?

- Be supportive
- Be an ADVOCATE
- Work Out Health Care Support – HC-PoA
- Check with Your Doctor – Raise Your Concern
- Consider a Neuropsychological Assessment
- Consider Seeing a Specialist – geriatrician, neurologist, gero-psychiatrist

When Should You Consider getting a Second Opinion?

- When what we talked about didn't happen
- When you feel un-listened to about concerns
- When you are not offered options that seem reasonable
- When you think or feel that the MD is not skilled enough to do a good job of managing this
- When it is an atypical dementia

What Should You Do?

- Keep a Priority List for MD Visits
- Keep a Medication Log
- Keep a 'Behavior' Log
- Be willing to Listen
- Be willing to advocate
- Be willing to TRY
- Be willing to TRY AGAIN!
- Be open to hearing others

Learn more about Teepa at **www.teepasnow.com**.

Visit www.pinesofsarasota.org/amazon for Teepa Snow DVDs of the following titles:

- Activities: "Filling the Day with Meaning"
- Progression of Dementia: Seeing Gems - Not Just Loss
- It's All In Your Approach
- The Art of Caregiving
- The Journey of Dementia
- Lewy Body Dementia: It Isn't Alzheimer's or Parkinson's Disease-What Everyone Needs to Know
- End of Life Care & Letting Go
- Maintain Your Brain: Dementia Risk Reduction & Life After Diagnosis
- Dental Care for People with Dementia
- Improving Emergency Services for Dementia Patients
- El Arte de Cuidar – Spanish ONLY Version of “The Art of Caregiving”
- *Coming soon:* Frontotemporal Dementias
- *Coming soon:* Improving Hospital Stays for People with Dementia