What’s New in Dementia Screening and Care?

Teepa Snow, MS, OTR/L, FAOTA

Where did we start?

- Alzheimer’s first diagnosed in 1907
- OBS – organic brain syndrome - common term – 60’s
- Psychiatric illness – mentally ill – 60’s-80’s
- SDAT became popular – 80’s
- De-institutionalization - nursing homes – 70’s-80’s
- Drugs and restraints – 60’s-80’s
- Diagnosis of Alzheimer’s at death – till 90’s
- Little could be done once diagnosed – until the 90’s
- Families - ‘do the best you can’ – 60’s – 90’s
- 1st family support program - Duke - early 80s
Over the past 20 years research and knowledge has increased dramatically.

Where are we NOW...
- 90-95% accuracy on syndrome id – if done
- Early diagnosis offers best treatment & planning
- Some drugs may help with some symptoms
- Strategies to improve care & quality of life
- 5.8 million diagnosed people in the US
- 90-110 known causes of ‘dementia’
- Pseudo-dementias are reversible – with early ID & tx
- We can reduce our risks
- Genes are getting Ided – for more study
- New info each week
- Differential diagnosis matters

What is on the horizon...
Research & Genetic work to –
- identify all genes
- slow the progression
- keep it from happening
- determine family inheritance
- identify who is at risk and what they should do to reduce risk
- better targeted treatments
What is available now...

- Risk reduction
- Improved diagnosis
- Better symptom management
- Better care strategies
- Increased public awareness
- Some support for those with dementia
- More understanding of different dementias

Topics to Talk About

- Understanding of the condition
- Diagnostic & screening tools
- Medications to help with symptoms
- Disease prevention – ‘vaccine’
- Disease ‘slow down’ or ‘stop’ progression
- Disease ‘reversal’ – the cure
- AND More...

Understanding the Condition

- Differential diagnosis is possible
- There is a latency period of 5-15 years
- We are closer to understanding what causes some dementias –
  - Alzheimer's, VaD, LBD, FTDs...
- As we get closer to the causes we may be able to develop treatments that address what is wrong – less ‘shot gun’
Tools & Diagnostics

- Autopsy
- X-Ray
- CAT scan or CT Scan
- MRI
- PET Scan or Functional MRI
- SPECT scan
- Protein evaluation of CSF
- Clinical interaction & report of observable behaviors
PET and Aging

PET Scan of 20-Year-Old Brain  PET of 80-Year-Old Brain

ADEAR, 2003

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

<table>
<thead>
<tr>
<th>Normal</th>
<th>Early Alzheimer’s</th>
<th>Late Alzheimer’s</th>
<th>Child</th>
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E. Green, JHU School of Medicine

Alzheimer’s: a window of opportunity

Loss of brain function in 20-40 year olds with a common AD risk gene
SO…. What is Dementia?

- It's a syndrome, not a single condition
- It can be 1st or 2nd & cortical or sub-cortical
- It can strike at any age – older = more
- It has many causes, forms, & patterns
- It has two major mimics – the 3 D’s
- It is progressive – duration varies
- It is a terminal illness – 5th leading cause

What is it NOT…

NORMAL Aging
Slower to think
Slower to do
Hesitates more
More likely to 'look before you leap'
Know the person but not the name
Pause to find words
Reminded of the past

NOT Normal Aging
• Can’t think the same
• Can’t do like before
• Can’t get started
• Can’t seem to move on
• Doesn’t think it out at all
• Can’t place the person
• Words won’t come – even later
• Confused about past versus now

But BE Careful!
It Could Be…

- Another medical condition
- Medication side-effect
- Hearing loss or vision loss
- Depression
- Delirium
- Severe but unrecognized pain
- Other things…
## Drugs that can affect cognition

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<tr>
<th>Anti-arrhythmic agents</th>
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<th>Anti-hypertensives</th>
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## 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

## Dementia does not equal Alzheimer's does not equal memory problems

- Dementia
- Alzheimer's
- memory problems
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

How common is Dementia?

- The risk goes up dramatically with increasing age
- America is aging
- Dementia’s may increase by 400% over the next 50 years… without medical advances
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 – for Alzheimers & some other dementias

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 from normal patterns of activities and interests
Is This ALWAYS Alzheimer’s? NO – so check it out!
- Not Alzheimers – another form of DEMENTIA
- Symptom of another health condition
- Medication side-effect or effect
- Hearing loss or vision loss
- Depression
- Delirium
- Pain-related – meds or chronic pain issue

Screening Options
- OLD – MMSE
- New
- AD-8 Interview
- Animal fluency – 1 minute # of animals
- Clock Drawing – 2 step
- SLUMS – 7 minute screen
- SAGE
- Full Neuropsychological testing panel

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
Animal Fluency

- Name as many animals as you can
- Give one minute – (don’t highlight time limit)
- Count each animal named (not repeats)
- Establish Baseline versus Normal/Not Normal
  - OLD: 12 normal for > 65 and 18 for < 65
  - NEW: Compare you to you OVER time

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

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 – 47s
### SLUMS - rating

<table>
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<tr>
<th>High School Education</th>
<th>Less than High School</th>
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<td>27-30 – Normal</td>
<td>25-30 – Normal</td>
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<tr>
<td>21-26 – MNCD (MCI)</td>
<td>20-24 – MNCD (MCI)</td>
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<tr>
<td>1-20 - Dementia</td>
<td>1-19 - Dementia</td>
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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

### Alzheimer’s – 3-5 onsets/forms noted

Young Onset – pre-senilin – dominant gene
Down syndrome – trisomy 21
Late Life Onset – APoE alleles
Others…
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 - misunderstood
- Services are a problem – usually
- Finances are problematic
- Executive decision making & sequencing DOWN
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 Alzheimer's

Try an AChEI as soon as diagnosis is made
If side-effects are too much – try another one
Stay on the AChEI until --- 3 groups of thought
  • Placement in a ‘facility’
  • Considering other med stops – near end
  • Not sure if helping or hurting – taper and see
Try 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

Less neurotransmitter – Further to go to get to the next cell

Enzymes (AChE inhibitors) – get to them BEFORE they deliver their message

What do Alzheimer’s drugs DO?

Alzheimer’s drugs provide fake messenger chemicals that distract the enzymes. They attach to the fake AChE & the message can get thru.

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 Dementias

Secondary
Old term – MID
Many variations
CADASIL - genetic

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

Try AChIs – Start Low & Go Slow
Then Try Namenda early – Start Low & Go Slow
BE VERY careful about anti-psychotic meds – (not Haldol)
  • Balancing movement losses & aid to function – not working?
Parkinson’s meds – may/may not help movement BUT may make hallucinations and delusions worse
Anti-depressants – may be used to help anxiety, sleep, & depression – can increase confusion, movement & drowsing
Sleep aids or Anti-anxiety meds – can cause paradoxical rxs

Fronto-Temporal Dementias

Many types – Typically Younger Onset
Frontal – impulse and behavior control loss (not memory issues)
  • Says unexpected, rude, mean, odd things to others
  • Dis-inhibited – food, drink, sex, emotions, actions
  • OCD type behaviors
  • Hyperorality
Temporal – language loss
  • Can’t speak or get words out
  • Can’t understand what is said, sound fluent – nonsense words
FTDs

FvFTD – frontal variant of FTD
FTD – frontal-temporal lobe dementia
TLD – non-fluent aphasia
TLD – fluent aphasia
CTE – chronic traumatic encephalopathy

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

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
Temporal Lobe 
Fluent Aphasia

- Has smooth delivery
- More nonsense words
- Word salad
- May think they make sense
- Expect rhythm back
- Fixates on a few phrases
- Chit-chats if enjoying company

Volume control varies – limited awareness of others' needs
- There are frequently 1-2 'value words' mixed in to speech
- Picks up on 'value words' they hear – they then connect & want to talk more

Chronic Traumatic Encephalopathy

- Caused by repeated head injuries or concussions – doesn’t happen to all
- Symptoms
  - Frontal lobe issues
  - Temporal lobe issues
  - Sometimes rapid progression into 'Alzheimer' patterns
  - Sometimes rapid progression into FTD patterns

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 – Wernickes or Korsakoffs
- 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, Lyme
- Parkinson’s – 40% about 5-8 yrs in
- Progressive Supranuclear Palsy

Alcohol-Drug Related Dementia
May be called - Wernicke’s & Korsakoffs syndrome
- Possibly caused by neurotoxicity &/or Vitamin B1 & thiamine deficiency
- Common Symptoms
- Decreased ability to learn ‘new’
- Decreased interest in valued activities, people, life
- Impaired judgment and decision making
- Emotional lability or apathy
- Problems with balance and coordination
- Problems with social control and behaviors
- Problems with initiation & termination
Dual Diagnosis – Young Dementia
- Underlying psychiatric illness
- Diagnosed and treated
- Undiagnosed but suspected
- Undiagnosed and unrecognized
- Newer onset of symptoms of dementia
- Diagnosed and treated
- Undiagnosed but suspected
- Undiagnosed and unrecognized

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!
Building Caregiver Skills & Knowledge
- Understand dementia & its progression
- Know how symptoms affect behavior
- Describe needs connected to behavior
- Optimize interaction skills

What Could/Should be DONE?
- Establish a baseline of function & be curious about changes
- A thorough physical & medical history for rapid shifts
- Blood work and cultures r/o infections, inflammations and possible new onset of treatable health issues
- A neurological and psychological assessment
- A good history from the person and the family of the changes or the ‘problem’
- A complete medication review – OTC plus all others
- Neuropsychological testing – screening for cognitive changes → full eval
- FOLLOW-UP and counseling or at least a referral
- A CAT scan, MRI, or a PET scan – “for cause”

Treatment with medications
- Meds to treat depression or mood swings
- Meds to help with pain from other conditions
- Meds for severe problems with –
  - Paranoia
  - Hallucinations that are scary
  - Violence that is unprovoked
Medications Research…

- Mice and animal studies do not lead to success with human studies
- Flurizan – at first looked promising then failed – keep proteins from sticking
- Prevent the formation of plaques – Alzemed – didn’t show effectiveness – still in Europe
- Get amyloid plaques out of the brain – Immuno-gobulin pheresis – failed in phase 3 trials

Newer Medication Research…

- a new BACE inhibitor - is being tried to keep proteins from grouping
- CHF5074 – is being used to turn down inflammation in the brain by modulating microglial cells – worked best for people with APoE4 allele – many people had problems with the med
- More trials happening – details at www.clinicaltrials.gov

More chemical research …

- Managing cholesterol levels – trying ideas out – could it help VaD or LBD?
- Control sugar processing – Type II diabetes medications to help keep brain from having problems in microcirculation – in process – it at least buys time with better health
- Use of curry – curcumin - causes an enzyme called hemoxygenase to be produced – it may prevent brain lipid peroxidation – ongoing research
**Intervention & Programming to:**

- physical activity
- mental activity
- social activity
- spiritual involvement
- well-being and self-worth
- minimize ‘risky’, challenging, or ‘dangerous’ behaviors
- reduce anxiety or distress

**Latest Thinking - RISK REDUCTION**

Help…
- De-stressing
- Get enough sleep
- Work to stay in good health
- Get changes in function looked in timely manner
- Aerobic activity
- Engage socially
- Have fun with your brain – learn new stuff
- Consider meditation/mindfulness & yoga

Help…
- Lower weight
- Reduce risk of head injuries
- Manage BP
- Keeping iron in limits
- Manage depression & anxiety
- Control diabetes better
- Right levels of vitamins
  - complexes D, C, B, E
- Mediterranean Diet
  - Fish, vegetables, whole grain

**Family and Caregivers…**

- Take care of yourself – Stress → dementia
- Understand the symptoms & progression
- Skills in support & caregiving
- Skills in communication & interactions
- Understand the condition - Letting go NOT giving up
- Identify & use resources - BEFORE
- Set limits for yourself – It’s a Marathon!
Support Groups or Services
HELP for -
- people with dementia
- care givers
- family members
- those recovering from the loss of the person they have cared for

Community Resource Development
- Programs
- Volunteers
- Funding
- Options

Dementia
is not a medical condition
It is a LIFE condition
It changes EVERYTHING!
People with Dementia are doing the best that they can…
- You must be willing to change how you behave to improve outcomes...
- The person with dementia cannot change… without your help