

Six Steps to Managing Alzheimer’s Disease & Dementia




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- Royalties from Publishing for
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- Budson AE, O’Connor MK. *Seven Steps to Managing Your Memory: What’s Normal, What’s Not, and What to Do About It*, 2017 (Oxford University Press)
- Budson AE, O’Connor MK. *Six Steps to Managing Alzheimer’s Disease and Dementia: A Guide for Families*, 2021 (Oxford University Press)

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- “I always thought I had a lot of patience, but if he asks me what we are doing today one more time, I think I will scream.”
- “I love my wife but I have no time for myself— I haven’t been able to go to the gym or visit my friends or even see my doctor.”
- “He wants to drive but I don’t know if it’s safe.”
- “I’ve never fooled around in my life and now, at age 83, my wife is accusing me of having an affair.”
- “It’s happening every evening now— she keeps saying that she needs to go ‘home,’ but we already are home.”
- “He won’t use his walker and I’m afraid he’s going to fall.”
- “I don’t mind cleaning up when she doesn’t make it to the bathroom, but now she’s fighting me when I try to get her washed up.”
- “When I came home from the hairdresser he asked me who I was— he really didn’t recognize me.”
- “Yesterday I found a pan burning on the stove, so now I can’t leave her alone anymore.”

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Six Steps to Managing Alzheimer’s Disease and Dementia

- **Step 1: Understand dementia**
- **Step 2: Manage problems**
- **Step 3: Ask about medications**
- **Step 4: Build your care team**
- **Step 5: Sustain your relationship**
- **Step 6: Plan for the future**

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“What’s the difference between Dementia & Alzheimer’s disease?”



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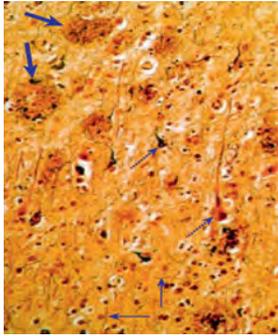
Dementia is...

- When there is a decline in thinking and memory enough to interfere with day-to-day function.

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Alzheimer's disease is...

- One type or cause of dementia, characterized by amyloid plaques and tau tangles.



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Mild Cognitive Impairment (MCI): When 3 things are present...

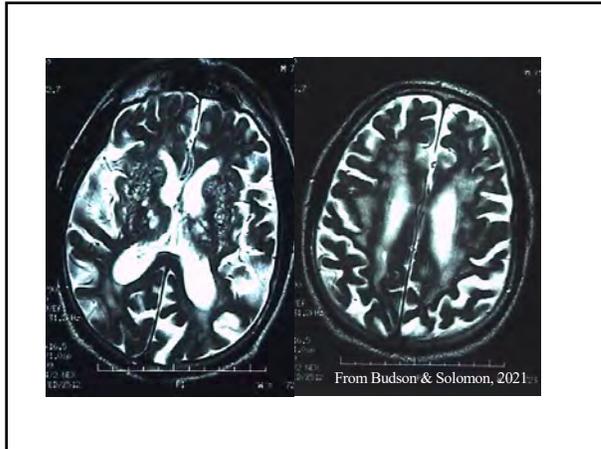
- Someone is concerned about their memory.
- Testing confirms the impairment
- Their day-to-day function is fine

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Mild Cognitive Impairment (MCI) over time

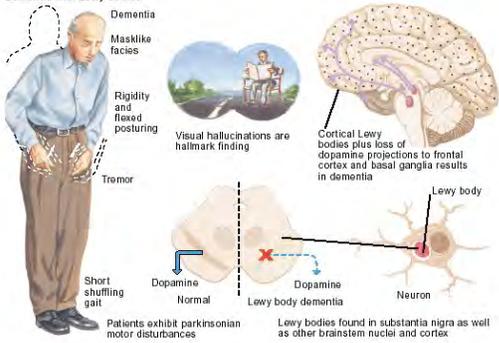
- 50% of people decline & develop dementia
- 50% of people do not; their memory may stay stable—or actually improve!

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Dementia with Lewy Bodies



Patients exhibit parkinsonian motor disturbances

Lewy bodies found in substantia nigra as well as other brainstem nuclei and cortex

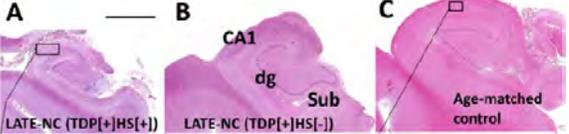
From Budson & Solomon, 2021

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doi:10.1093/brain/awz099 BRAIN 2019; 142: 1503–1527 | 1503

BRAIN
A JOURNAL OF NEUROLOGY

REVIEW
Limbic-predominant age-related TDP-43 encephalopathy (LATE): consensus working group report

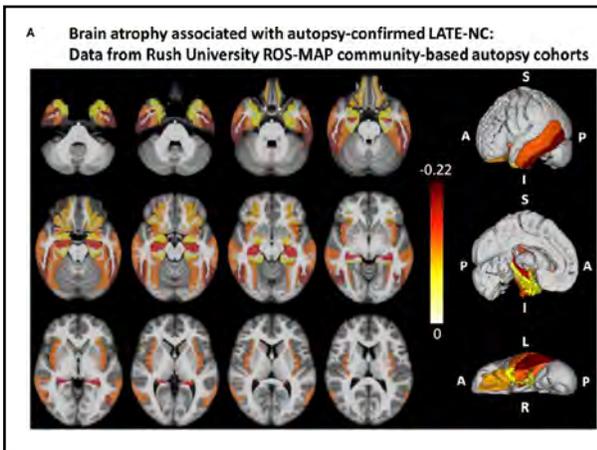


A LATE-NC (TDP+|HS+)

B CA1 dg Sub LATE-NC (TDP+|HS-)

C Age-matched control

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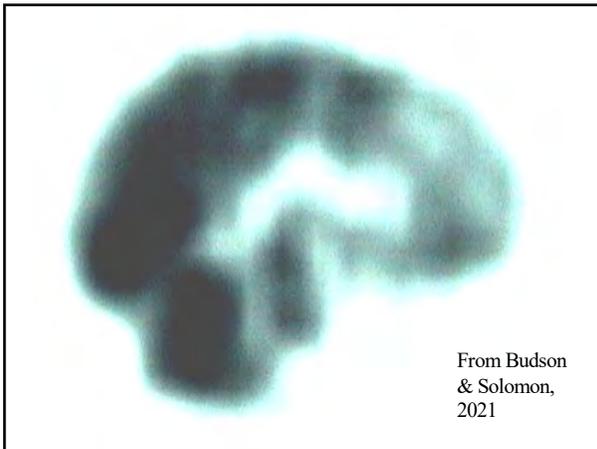


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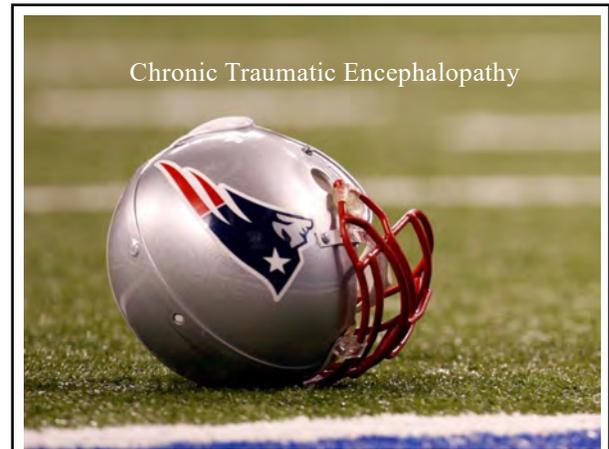
Table 2 A statistical analysis of attributable risk from research volunteers in two clinical-pathological studies of ageing from Rush University

Neuropathological indices	Fraction attributable % (95% CI) ^a
Alzheimer's disease (ADNC)	39.4 (31.5–47.4)
Vascular disease pathology ^b	24.8 (17.3–32.1)
LATE-NC	17.3 (13.1–22.0)
α -Synucleinopathy/Lewy body pathology	11.9 (8.4–15.6)

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- Six Steps to Managing Alzheimer's Disease and Dementia**
- Step 1: Understand dementia
 - Step 2: Manage problems
 - How to approach problems in dementia
 - How to manage memory problems
 - How to manage language problems
 - How to manage vision problems
 - How to manage emotional problems
 - How to manage behavioral problems
 - How to manage sleep problems
 - How to manage problems with bodily functions

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Six Steps to Managing Alzheimer’s Disease and Dementia

- **Step 1: Understand dementia**
- **Step 2: Manage problems**
 - How to approach problems in dementia
 - How to manage memory problems
 - How to manage language problems
 - How to manage vision problems
 - How to manage emotional problems
 - How to manage behavioral problems
 - How to manage sleep problems
 - How to manage problems with bodily functions

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4 Rs:

Reassure, Reconsider, Redirect, Relax

- Reassure them that everything is OK
- Reconsider things from their point of view
- Redirect them to another activity
- Relax—what we must do to avoid escalating the situation

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Three Time Principles & Start with small steps

- Take your time
- One thing at a time
- Offer timely praise
- Start with small steps

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The ABCs

Antecedents (Include the date, time of day, place, person[s] present, and events)	Behavior (specific, observable, measurable—frequency and/or duration)	Consequence (How did things change?)
<i>Sunday, 3 PM Me & my loved one Bath time</i>	<i>Yelling for 7 minutes</i>	<i>Decided to skip the bath that day</i>

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Manage memory problems

- We discuss memory strategies and aids for mildly impaired individuals.
- Unplug the stove or take off the knobs
- Stop the sink or tub from overflowing
- Try making people & places more like they looked before
- Look through photo albums to show how appearances changed
- Eliminate wandering
 - STOP sign, lock doors, alarm
 - Identification jewelry, tracking devices
 - Make a plan for wandering
- Don’t fight false memories—go with them!
- Don’t tell a person with dementia what not to do—tell them what they should do.
- Reminding people of their memory problems is rarely helpful

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Manage Language Problems

- Trouble finding words
- Trouble comprehending
- Check hearing
- Use pictures
- Non-verbal & emotional communication often preserved

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Manage Vision Problems

- Trouble recognizing family
- Thinks you are someone else or an imposter
- May not “see” things on one side. If so, adjust for neglect
- Check vision/glasses
- Increase lighting & contrast
- Reduce the impact of hallucinations



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Manage Emotional Problems

- Look for and treat anxiety and depression.
- Look for pseudobulbar affect (pathological laughing and crying)
 - How to tell them apart

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Manage Behavioral Problems

- Manage Driving
 - Patients with very mild AD have accident rates similar to 16-19 year old drivers.
 - Family member to ride as passenger monthly.
 - If family members are comfortable riding with patient driving, then patient may be OK to drive.
 - Adult children are best. (Am J OT 2015 69: 6903270030)
 - Driving evaluation at local registry of motor vehicles or rehabilitation hospital if controversy.
- Conquer apathy with routines
- Sidestep willfulness with the Three Time Principles and small steps
- For agitation, aggression, combativeness, and inappropriate/disinhibited behavior
 - Understand problem clearly (what is “agitation”?)
 - 4Rs, Three Time Principles, and ABCs.

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Manage Behavioral Problems (cont)

- Look for Medical Problems
- Stay safe
 - Guns, power tools, knives, childproof, car safety
 - Call family, friends, or the police
 - Get out of the house
- Control interactions out of the house
- Plan around sundowning
- Binge eating? Remove unhealthy food/lock cabinets
- Don’t argue with jealousy and paranoia (use 4Rs)
- Try soothing &/or familiar music
- Consider aromatherapy
- Comfort with real & robot pets/stuffed animals

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Manage Sleep Problems

- Start with a sleep log
 - Most older adults sleep 7-8.5 hours per night.
 - Up for 2 hours at night? Bed at 10 PM & up at 8 AM is 10 hours!
 - Naps count as part of total sleep time, should never be more than 1 hour or after 3 PM.
- Improve sleep habits
 - Eliminate wakeful activities in bed
 - Get into a good sleep cycle
 - Watch coffee, teas, colas
 - Exercise in day, peaceful activities at night
- Look for a medical disorder
 - Sleep apnea
 - Restless leg syndrome
 - Periodic limb movements of sleep
 - REM sleep behavior disorder
- Melatonin for sleep cycle disturbances
- Acetaminophen for aches and pains

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Manage Problems with Bodily Function

- Improve walking & reduce falls
 - Correct sleep to reduce drowsiness
 - Check medications (see Step 3)
 - Treat dizziness & vertigo
 - Treat Parkinson’s disease
 - Work with physical therapist for muscle weakness, cane, walker, brace, etc.
 - Consider yoga and tai chi
 - Consider medical problems, low blood pressure, diabetes/low blood sugar, arthritis, hip & knee problems
 - Avoid ice, mud, wet surfaces, and highly polished floors
 - Make sure they wear proper footwear
 - Remove clutter from floor
 - Move frequently used items from top shelves to lower shelves
 - Avoid carrying heavy or bulky items
 - Tape, tack down, or remove rugs & loose carpets
 - Install good handrails on stairs and grab bars in tubs & showers
 - Put nonskid mats or carpets on surfaces that may get wet
 - Provide frequent bathroom opportunities to avoid rushing

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Manage Problems with Bodily Function (cont)

- Reduce incontinence
 - Toileting schedule during the day
 - Eat less fruit and drink less liquid before bed
 - May need legs up on couch arms to drain excess fluid
 - Plan ahead to manage incontinence outside the home
- Increase flavors & spice of food
- Heavy silverware and mugs to dampen tremors
- Reduce choking with small bites and thick-it
- Help with skilled movements & activities
 - Reduce difficulty of task (lay out clothes)
 - Can try to relearn a lost skill, such as brushing hair
- Reduce scratching and picking with moisturizing soap

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Ask About Medications

- An example: dizzy for one day, meclizine for all the rest!
- Track medications including over-the-counter remedies, vitamins, herbs, & supplements
- These classes of medications can cause problems
 - Anticholinergic medications
 - Older antidepressants
 - Older antihistamines
 - Antipsychotics
 - Anxiety medications/benzodiazepines (Valium, Ativan)
 - Dizziness & vertigo medications
 - Many incontinence medications (anticholinergic)
 - Some migraine medications
 - Muscle relaxants
 - Narcotics: Opioids
 - Some nausea, stomach, & bowel medications
 - Some seizure medications
 - Sleeping medications (all except melatonin)
 - Some tremor medications
 - Herbal remedies

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Ask About Medications (cont)

- Cholesterol-lowering medications do not cause memory problems
- Alcohol impairs memory
 - One alcoholic beverage per day will not cause any permanent damage
 - Consider non-alcoholic beers and wines
- Properly administered anesthesia does not cause long-term memory problems or dementia.

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Medications which may help

- Track and quantify the effects of medications
 - Medications rarely eliminate unwanted behaviors, but they can often help.

Behavior	Intervention	Effect
Yells, stomps feet, and bangs the counter 5 out of 7 days, for an average of 17 minutes on each of those days.	New medication introduced	Yells, stomps feet, and bangs the counter 2 out of 7 days, for an average of 6 minutes on each of those days.

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Medications which may help

- Track and quantify the effects of medications
 - Medications rarely eliminate unwanted behaviors, but they can often help.
- Three strategies to improve function/reduce behaviors with medications
 1. **Enhance cognition:** Cholinesterase inhibitors (e.g., donepezil, Aricept) & memantine
 2. **Help them feel calmer:** SSRIs (e.g., sertraline, Zoloft; escitalopram, Lexapro), prazosin, dextromethorphan (Nuedexta)
 3. **Suppress behaviors:** Atypical neuroleptics (e.g., risperidone, Risperdal)
- Consider clinical trials

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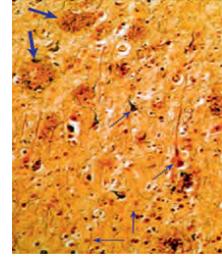
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How does Alzheimer's disease impair brain function?

- Accumulation of Amyloid
- Amyloid forms Plaques
- Plaques damage brain cells
- Tau becomes loose inside cells
- Tau forms Tangles
- Tangles kill brain cells
- Cells are making chemical Neurotransmitters
- Neurotransmitters allow cells to talk with each other
- Acetylcholine is an important Neurotransmitter; its levels drop



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Medications which may help

- Cholinesterase inhibitors (such as donepezil, brand name Aricept) can “turn back the clock” on memory loss & other problems by 6 to 12 months.
- **New Medications Being Developed**
 - May be able to “slow down the clock” on memory loss & dementia.



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Medications that don't work

- Prevagen
- Curcumin
- Gingko biloba
- Resveratrol
- Phosphatidylserine
- Acetyl-L-carnitine
- Creatine

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Build your care team

- Start with the most important member of your care team—YOU!
- Care for yourself—you can't pour from an empty cup!
 - Care for your physical and emotional health
 - Exercise
 - Sleep well
 - Eat a healthy diet
 - Maintain your social connections
 - Take time for yourself
 - Learn relaxation/mindfulness/meditation techniques

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Build your care team (cont)

- So many stories!
- Ask for help—engage family, friends, & neighbors
- Share information and organize your care team
 - Daily tasks
 - Doctor's appointments
 - Bills and financial matters
- Attend support groups
 - Informational
 - Skill building
 - Emotional
- Professional caregivers
- Respite care
- Day programs
- Alzheimer's Association
- The doctor

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Sustain your relationship

- Relationships change in dementia
- Changing abilities and interests
- Take the lead
- Plan ahead
- Start small
- Consider time of day
- Go with the flow
- Be in the moment
- Don't give up!

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Ways to sustain your relationship

- Visit a memory café
- Museums
- Performing arts
- Movies
- Music
- Arts and crafts
- Exercise
- Enjoying nature
- Touch and physical intimacy
- Participate together in meaningful activities
- Consider participating in research together

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Plan for the future

- Often difficult for families
- Plan early and involve your loved one
- If they are still working
- Take care of medical/legal issues
 - Living will
 - Healthcare proxy
 - Do Not Resuscitate
- Take care of financial/legal issues
 - Will
 - Estate planning
 - Power of attorney
 - Trusts
- Protect your loved one from scams, con artists, and poor judgment

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Plan for the future (continued)

- Housing
 - When is it time?
 - Assisted living
 - Nursing homes
 - Continuing care retirement communities
- Making the transition
 - An example
- When they refuse to plan

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Plan for the future (continued)

- The ceremony
- The death itself
 - Hospice & palliative care
- Dying from dementia
- To be there or not at the end
- The body
 - Consider brain donation in the context of ongoing research
- The grieving process and your emotional health
- Planning for your future

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Questions? Looking for more information?



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