Six Steps to Managing Alzheimer’s Disease & Dementia

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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)

“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

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

Dementia is...
• When there is a decline in thinking and memory enough to interfere with day-to-day function.
Alzheimer’s disease is...

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

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

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!

From Budson & Solomon, 2021

Dementia with Lewy Bodies

From Budson & Solomon, 2021

BRAIN

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

From Budson & Solomon, 2021
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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

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

<table>
<thead>
<tr>
<th>Neuropathological indices</th>
<th>Fraction attributable % (95% CI)*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s disease (ADNC)</td>
<td>39.4 (21.5–47.4)</td>
</tr>
<tr>
<td>Vascular disease pathology</td>
<td>24.8 (17.3–32.1)</td>
</tr>
<tr>
<td>LATE-NC</td>
<td>17.3 (13.1–22.0)</td>
</tr>
<tr>
<td>α-Synucleinopathy/Lewy body pathology</td>
<td>11.9 (8.4–15.6)</td>
</tr>
</tbody>
</table>

From Budson & Solomon, 2021

Chronic Traumatic Encephalopathy

Brain atrophy associated with autopsy-confirmed LATE-NC. Data from Rush University RDS-MAP community-based autopsy cohorts.
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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

Three Time Principles & Start with small steps

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

The ABCs

<table>
<thead>
<tr>
<th>Antecedents</th>
<th>Behavior</th>
<th>Consequence</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Include the date, time of day, place, person[s] present, and event)</td>
<td>(specific, observable, measurable—frequency and/or duration)</td>
<td>(How did things change?)</td>
</tr>
<tr>
<td>Sunday, 3 pm</td>
<td>Yelling for 7 minutes</td>
<td>Decided to skip the bath that day</td>
</tr>
<tr>
<td>Me &amp; my loved one</td>
<td>Bath time</td>
<td></td>
</tr>
</tbody>
</table>

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

Manage Language Problems

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

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

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.

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

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

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
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, medicize 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

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.

Medications which may help

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

<table>
<thead>
<tr>
<th>Behavior</th>
<th>Intervention</th>
<th>Effect</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yells, stamps feet, and bangs the counter 5 out of 7 days, for an average of 17 minutes on each of those days.</td>
<td>New medication introduced</td>
<td>Yells, stamps feet, and bangs the counter 2 out of 7 days, for an average of 6 minutes on each of those days.</td>
</tr>
</tbody>
</table>

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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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

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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• Consider clinical trials
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

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

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!
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

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

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

Questions?

Looking for more information?

https://www.health.harvard.edu/blog/author/abudson
https://www.psychologytoday.com/us/blog/managing-your-memory
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