Dementia: Preparing for the Future

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Alzheimer’s Disease

- Chronic, Progressive Memory Loss
- Associated with Behavioral/Personality Problems
- Trouble w/Language, Reasoning, Doing Things
- Usual Course around 10 Years, but Varies
- Large & Growing Public Health Issue ($100B/yr)
- Very Difficult for Families
- May Coexist with Other Types of Dementia
- Diagnosis can usually be made Clinically
  - Should Have Some Labs & Brain Imaging Done to Rule Out Other (Treatable) Conditions
- Can Often Be Managed by a Primary Doctor
- No Cure, but Medication Can Help
About Me

- Harvard, Ohio State, UCSD (Family Medicine)
- In North County full-time since 1992
- Mission Park → Sharp Mission Park → Scripps
- Mobile Physicians, Kindred Village Square, Life Care Center of Vista, Hospice by the Sea
- Long-Term Care Geriatrics
- Hospice & Palliative Care
- Medical Ethics
- Expert Consultation
- Lots of Boards, Committees, etc.
- Volunteer Faculty at UCSD and Camp Pendleton
- Love My Work!
About Me

- Take Dog(s) to Work Every Day
Memory/Alzheimer’s Facts

- Everybody Has Some Memory Problems
- Age-Associated Memory Impairment, Not a Pre-Dementia Condition
- Mild Cognitive Impairment—May Predict Future Alzheimer’s Dementia
- Mental Exercise Can Help Prevent Progression
- Incidence of Alzheimer’s Increases with Age
- Usually Affects Short Term Memory First, then Long-Term Memory
Stages of Alzheimer’s

- Pre-Clinical, then Mild Cognitive Impairment, then:
  - EARLY: Still May Go Several Years before Diagnosis
    - Examples of Forgetfulness:
      - Leaving Tasks Half Finished
      - Having Trouble Following Plot of a TV Show
      - Asking the Same Question Several Times
      - Withdrawing from Some Activities (Depression??)
      - Getting Lost While Driving
      - Forgetting to Take Medication
      - Missing Appointments
      - Irritability, Reduced Conversation (Depression??)
    - Usually Aware that There’s a Problem
    - Usually No Severe Behavioral Issues
Stages of Alzheimer’s

**EARLY: CAREGIVER STRATEGIES**

- Make Lists or Encourage Loved One to Make Lists
- Encourage Appropriate Level of (Active) Mental Exercise
- They Need to Stop Driving (Very Hard)
- Get Regular Physician Follow-Up—Address Other Medical Issues (Blood Pressure, Depression, Pain from Arthritis, Sleep Apnea, Diabetes, etc.)
- **Don’t** Constantly Quiz Them: Give Time to Respond to ???’s
- Talk to Others—Including Others in the Same Boat
- Share the Duties ▶ Optimize Vision/Hearing
- Look Into Community Options
- Accentuate the Positive !!
- **Get Affairs In Order !!! ***
Advance Care Planning

- Various Tools Available—make use of them!
  - Five Wishes, My Way Cards, GoWish Cards, etc.
- California Advance Health Care Directive
  - Durable Power of Attorney for Health Care
  - Usually just 2 basic choices: “Choice to Prolong Life” and “Choice Not to Prolong Life”—but there are many nuances.
  - Form is vague and open to a lot of interpretation—doesn’t tell us everything—but people assume that it does
  - You can specify other particular wishes or desires explicitly, like no tube feeding, no transfusions, no dialysis, etc.
  - You designate an agent and alternates to make decisions for you
  - BE SURE YOU PICK AN APPROPRIATE PERSON!
  - These forms are not doctor’s orders—hence, Paramedics cannot follow them
Everything Ages~!

Some Things (and People) Age Better Than Others
Advance Care Planning

- **POLST** — Physician Orders for Life Sustaining Treatment
- Became law in California in 2008
- Bright pink form
- Doctor’s Order, Actionable by Paramedics, Other Health Care Professionals Must Follow Orders
- More Specific than AHCD or traditional DNR forms
- CPR vs. No CPR (Do Not Resuscitate/Do Not Attempt Resuscitation)
- Full, Limited, or Comfort Care
- Tube Feeding: Long-Term, Short-Term, or None
POLST

- **Section A for complete cardiopulmonary Arrest**

<table>
<thead>
<tr>
<th>A</th>
<th>CARDIOPULMONARY RESUSCITATION (CPR): Person has no pulse and is not breathing.</th>
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<tbody>
<tr>
<td></td>
<td>☐ Attempt Resuscitation/CPR ☐ Do Not Attempt Resuscitation/DNR (Allow Natural Death)</td>
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<tr>
<td>Check One</td>
<td>(Section B: Full Treatment required)</td>
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When not in cardiopulmonary arrest, follow orders in B and C.

- **CPR is an act of violence**
  - Rib fractures, sternal fractures, liver lacerations...

- It’s not like on TV: Very low chance of survival for frail elderly who suffer cardiac arrest outside the hospital

- If you survive, you will be in ICU on a vent
Section B

**MEDICAL INTERVENTIONS:**

- **Comfort Measures Only**
  Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Antibiotics only to promote comfort. *Transfer if comfort needs cannot be met in current location.*

- **Limited Additional Interventions**
  Includes care described above. Use medical treatment, antibiotics, and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Generally avoid intensive care.

- **Do Not Transfer to hospital for medical interventions. Transfer** if comfort needs cannot be met in current location.

- **Full Treatment**
  Includes care described above. Use intubation, advanced airway interventions, mechanical ventilation, and defibrillation/cardioversion as indicated. *Transfer to hospital if indicated.*

**Additional Orders:** __________________________________________

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- **Everyone gets Comfort Care!**
- **“Limited” means roughly “no heroics”**
- **Full treatment includes intubation/shock**
Stages of Alzheimer’s

**MIDDLE STAGE:**

- More Behavioral/Psychiatric Problems Occur in Some Patients
  - Paranoia
  - Depression
  - Anxiety
  - Agitation
  - Aggression (Verbal/Physical)
  - Pacing

- Generally Need ‘Round-the-Clock Supervision

- More Trouble With Day-to-Day Activities (ADLs)
  - Continence
  - Getting Up & Down
  - Talking
  - Meals/Eating Tasks
  - Dressing
  - Socializing
  - Get Around the House
  - Bathing/Hygiene
Reminiscence is a Good Thing
Stages of Alzheimer’s

**MIDDLE STAGE: CAREGIVER STRATEGIES**

- Don’t Argue—Try to Redirect or Change the Subject
- Consider Respite Care
  - Adult Day Care
  - Paid Part-Time Caregiver Assistance In-Home
  - Family or Friend Caregiver Assistance
- More Trouble With Day-to-Day Activities (ADLs)
  - Continence
  - Getting Up & Down
  - Talking
  - Meals/Eating Tasks
  - Dressing
  - Socializing
  - Get Around the House
  - Bathing/Hygiene
- Take Time for Yourself Every Day!
- Get Help for Difficult Times (Bathing, Meals, Evening)
Stages of Alzheimer’s

**MIDDLE STAGE: CAREGIVER STRATEGIES**

- Make a Backup Plan for Emergencies
- Consider Transition to Assisted Living Setting or Specialized Dementia Unit
- Have Strategies to Distract Loved One when Agitated
  - Stuffed Animals
  - Pets
  - Dolls
  - Favorite Foods/ Snacks
- Take Care of Yourself! Keep a Sense of Humor!
- Child-Proof the House & Simplify Their Environment
  - Block Off Stairs and Exit Doors
  - Consider Alarms, Extra Latches
  - Lock Medicine Cabinets
  - Use Plastic Cups/ Plates
  - Avoid Throw Rugs
  - Baby Monitor Can Help
Stages of Alzheimer’s

MIDDLE STAGE: CAREGIVER STRATEGIES

- Simplify Tasks for Them: One Step at a Time
- Hands-On Touch, Hugging, Massage Can Really Help
- Use Simple Language and a Calm Tone of Voice
- Make Statements Instead of Asking Questions
- Don’t Try to Reason or Get Them to See Your Point of View
- Don’t Correct Them or Say, “You Just Asked Me That!”
- Stick to a Routine! Change Can Be Very Confusing
- Physical Exercise is Great, Like a Daily Walk or Stretching
- Simplify the Clothing and Be Sure It’s Comfortable
- Try Regular Bathroom Visits. Pull-Ups Better than Diapers.
- Get a Shower Bench, Be Sure Water is Warm Enough
Stages of Alzheimer’s

**MIDDLE STAGE: CAREGIVER STRATEGIES**

- Regular Physician Visits if Plausible (if not, phone calls)
  - If Non-Medication Strategies Fail, There are Drugs that Can Help!
- May Need Strategies for Getting Medications Down
  - Applesauce or Ice Cream
  - Get Rid of All Unnecessary Medications
  - In Some Cases, Other Formulations (Patches, Dissolving Tabs, Sprinkles)
- Move to More Finger Foods, Less Need for Silverware
- Don’t Try to Force Feed
- Keep the Dining Table Simple, but Offer Choices of Foods
- Nutritional Supplements, Frequent Snacks if Appetite Poor
- Give Tasks that They Like to Feel Useful—“Reading,” House Cleaning, Washing Dishes, Previous Job Tasks
Stages of Alzheimer’s

**MIDDLE STAGE: CAREGIVER STRATEGIES**

- Play Familiar, Beloved Music—Encourage Singing
- Try Not to Get Angry when Behaviors are Difficult
- Don’t Take It Personally
- If You are Depressed, Get Help for That!
  - Therapy and Medication are Both Effective
- Caregiver Burnout Very Common in Middle Stages
- Respite for You: Include Actual Vacations if Possible
- You Will Not Be of Help to Your Loved One if You Are Overwhelmed Yourself!
- Tune In to Their Body Language
- You May Need to Initiate Conversations
Pets Are Great Therapy!
Stages of Alzheimer’s

- **Late/Advanced/Severe Stage:**
  - No Longer Recognize Family or Know Their Own Name
  - Lose Ability to Walk, then to Sit Up
  - Incontinent of Bowel and Bladder
  - Lose Ability to Feed Self, then Ability to Swallow
    - Weight Loss Common, May Develop Aspiration Pneumonia
  - Lose Interest in Food and Fluids
  - Spend Most of Time In Bed
  - Skin Gets More Fragile—May Develop Bedsores
    - Be Sure to Turn/Reposition if They Can’t. Consider Special Mattress

- **The Good News:** Behaviors Less of a Problem
  - Usually More Passive and Uncommunicative
  - But Still Can Feel Sad/Lonely/Anxious or Happy/Comfortable
Stages of Alzheimer’s

**LATE STAGE: CAREGIVER STRATEGIES**

- May Need to Transition to Skilled Nursing Facility
- Should Consider Hospice When Totally Dependent
  - Inability to Feed Self, Weight Loss, Skin Breakdown, Swallowing Probs.
  - Hospice Can Help in All Care Settings
- CCRCs Are Ideal When There is a Spouse (Live On Campus)
- Care Needs May Be Too Great for Smaller Board & Care Setting
- If Keeping Them at Home, Learn Advanced Caregiving Skills
  - Turning/Repositioning
  - Incontinent Care
  - Range of Motion
  - Floating Heels
  - Fall Prevention
  - Bathing/Hygiene/Oral Care
  - Close Monitoring of Skin
  - Avoiding Shear on Skin
- Consider Other Equipment: Hospital Bed, Geri-Chair, Hoyer Lift
Stages of Alzheimer's

**LATE STAGE: CAREGIVER STRATEGIES**

- Allow Yourself to Grieve
- Keep in Mind that Dehydration is Not Painful or Uncomfortable
- Force feeding is not a kindness
- (If still in a private home setting:) Consider Respite Care in a Facility—Take Time for Yourself
- Talk Softly & Reassuringly, Tell Them Everything is OK
- Try to keep a consistent routine
- Play Soft Music that they Like
- Massage, Touching, Hugging, Applying Lotion, Brushing Hair
- Hospice can be a great resource and no cost to the patient/family
  - Needs to be at a stage of basically nonverbal or fairly rapid weight loss
Stages of Alzheimer's

**LATE STAGE: CAREGIVER STRATEGIES**

- Be Sure Necessary Medications for Comfort are Given
  - Consider Stopping Other Medications: Consult With Your Doctor
- Be Vigilant for Non-Verbal Signs of Discomfort and Treat Them
- Talk to Others Who Have Had Similar Experiences
- Consider Whether Hospitalization is Desirable or Necessary
  - Usually Felt to be Prolonging the Inevitable
  - Quality of Life vs. Quantity
- Feeding Tubes Are Usually Discouraged
  - Never Shown to Prolong Life
  - They have their own set of Risks (Aspiration Pneumonia, tube site infections, accidental removal—partial or complete)
- Death from dehydration does not appear to be uncomfortable
Care Considerations: Quality of Life
Signs of Caregiver Burnout

- Irritability/Grouchiness (toward loved one/others)
- Crying Spells
- Poor Concentration/Forgetfulness
- Impaired Sleep
- Changes in Appetite
- Sense of Hopelessness
- Extreme Fatigue
- Inappropriate Guilt Feelings
- Loss of Enjoyment in Activities
- Resentment of Others (for not helping, etc.)
Summary: Strategies for Burnout

- Recognize and Acknowledge the Difficult Situation You Are In
- Accentuate the Positive—Keep a Sense of Humor
- Take It A Day (Hour, Minute) At A Time!
- Acceptance of Situation and of Your Limitations
  - Spiritual Guidance if Appropriate
- Ask for Help (Family, Friends, Organizations, Doc)
- Consider Medication for Depression
- Get Respite!
- Talk to Others in Similar Circumstances
- PLAN AHEAD!
Resources

- www.alz.org  Alzheimer’s Association
- www.alzheimersplaybook.com  (Coach Broyles’ Playbook for Caregivers)
- San Diego County Office of Aging & Independence  1-800-510-2020
- www.sanalz.org  San Diego Alzheimer’s Assoc.
- www.eldercare.uniontrib.com/classes/suppalz.cfm
- www.caringadvocates.org
- www.coalitionccc.org
- www.fivewishes.org
- www.theconversationproject.org
I Wish You Smooth Sailing