Dementia

Memory Evaluation Center
Neurology
Topics

- Overview of dementia
- Stages
- Medications
- Advanced planning
What is Dementia?

Dementia = significant global decline in cognitive function not due to medicine side effects or depression.
Dementia causes

- Alzheimer’s
- Other common causes
  - Strokes
  - Parkinson’s and Parkinson’s variants
  - Lewy Body Dementia
  - Fronto-temporal dementia
Delirium vs. Dementia

Dementia
- Gradually progressive
- (Usually) not reversible

Delirium
- Sudden change
- Usually reversible
- Caused by other medical factors
  - Bladder infection
  - New medications
  - Dehydration
  - Etc.
Dementia is a progressive illness

- Most everyone gets worse
- Rate can be variable
- Different stages bring different challenges
Dementia: stage 1 (Mild) Needs reminding

- Impaired memory – but often can “cover”
- Family often sees problems
- Lists, notes, calendars help
- Loss of interest in more complicated hobbies and chores.
- May need reminding, prompting

**ACTIONS:**
- Encourage lists, calendars
- Check in and watch for safety, supervise as needed
- Driving safety?
- Advance directive, end of life preferences, legal and financial paperwork needs to be done NOW
Dementia – stage 2 (Moderate)

Needs supervision

- Memory loss is severe enough that can no longer “cover”
- Short term memory is very impaired
- Lots of repetitive questions
- May become anxious and confused in new situations
- Impaired ability to manage day-to-day
- A formerly neat person may become messy
- May start to socially withdraw
- Usually this is the stage where behavior problems are first seen

**ACTIONS:**

- Stop driving (if not already done)
- May be too late for advance directive, end of life preferences, legal and financial paperwork: but do it now if missed before and still able
- Regularly visit family member or hire someone to check in
- Make sure eating well, taking medications, that the environment is safe and that there are opportunities to connect with others socially.
- Someone other than patient needs to take over paying bills, shopping, cooking
Dementia – Stage 3 (Severe)

Needs assistance

- Highly impaired by dementia
- Severe memory loss with only fragments remaining
- Often with impaired communication
- Unable to make judgments or solve problems
- Needs assistance with the activities of daily living such as bathing and dressing
- Cannot live independently.
- Too disabled to take to functions outside the home
- Prominent behavior problems

ACTIONS:
- Consider assisted living / skilled nursing care / or full time live at home help
- Be aware that due to communication impairment changes in behavior may be the only signs of discomfort or illness
General approach to caring for dementia patients

- Calm, supportive
- Redirect rather than confront
- Watch for safety issues (example driving)

- If you are the one with dementia accept the help offered
Medication treatment of dementia

- Currently approved treatments help symptoms, not the disease itself.
- They do not slow the disease progression (even though ads say they “slow progression of symptoms”).
- Later stages usually don’t respond to currently available dementia medications.
Dementia Medications

- Donepezil = Aricept
- Galantamine = Razadyne
- Rivastigmine = Exelon
- Memantine = Namenda
Temporary symptom benefit at best

Figure 1. Time-course of the Change from Baseline in ADAS-cog Score for Patients Completing 24 Weeks of Treatment.
Treatment: about 25% better, 40% no change, 35% worse
Placebo: about 15% better, 35% no change, 50% worse
How to use dementia medications

- If never any improvement: Stop (let us know)
- If improved, Continue (let us know)

What is “improvement”? 
- Depends – but usually functioning better in some meaningful way
Where to go for help?

- Contact us for dementia related questions (email or (925) 295-6953)
- Contact your regular doctor for other questions
- Alzheimer’s Association (800-272-3900) and webpage
- Family Caregiver Alliance webpage
Have a game plan

- In case of a turn for the worse, you’ll be asked to make lot’s of decisions in a hurry
- It can be overwhelming – at an emotionally vulnerable time
- Have a game plan in advance and stick to it
- Share the plan with all the members of your “team”
Wishes vs. Reality

- 79% of people want to talk about life care planning if they’re seriously ill
  - 7% report ever being asked
- 82% of people say it’s important to put their wishes in writing
  - 23% do
- 70% of people want to die at home
  - 32% do
Dying at Home: Wishes vs. Reality

- **Wish To Die At Home**: 67%
- **Die At Home**: 24%

Massachusetts Residents
POLST vs. Advance Directive

**POLST** = doctors orders  
**Advance Directive** = patient (with capacity) appoints an agent

- If no capacity and no advance directive, family member can still do POLST

We recommend: do both
Dementia Specific Issues

- Tube feeding
  - Does NOT extend life in late stage dementia patients
  - Does NOT make patients more comfortable
  - Does NOT reduce the risk of aspiration pneumonia (may in fact increase it)
Dementia Specific Issues

- CPR
  - Only treatment we have that you need to die to get
  - Only works really well on TV
    - Acute CPR survival rate = 44%
    - But chances of leaving the hospital alive after CPR = 17%
    - Survival rate for advanced dementia patients after CPR is lower still: < 3%
Physician Orders for Life-Sustaining Treatment (POLST)

A. CARDIOPULMONARY RESUSCITATION (CPR):
- If patient has no pulse and is not breathing.
- If patient is NOT in cardiopulmonary arrest, follow orders in Sections B and C.

B. MEDICAL INTERVENTIONS:
- Full Treatment – primary goal of prolonging life by all medically effective means.
  - Trial Period of Full Treatment.
  - Selective Treatment – goal of treating medical conditions while avoiding burdensome measures.
  - Comfort-Focused Treatment – primary goal of maximizing comfort.

C. ARTIFICIALLY ADMINISTERED NUTRITION:
- Long-term artificial nutrition, including feeding tubes.
- Oral diet, if patient can tolerate.

D. INFORMATION AND SIGNATURES:
- Advance Directive dated and reviewed
- Advance Directive not available
- No Advance Directive

Signature of Physician:
- My signature below indicates to the best of my knowledge that these orders are consistent with the patient’s medical condition and preferences.

Print Name:
- Phone Number:
- Relationship (note self if patient).

Signature:
- Date:
- Phone Number:
- Office Use Only:

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED

Note: This form is intended for use by healthcare providers to document patient preferences regarding life-sustaining treatment. It is not a legally enforceable document, but it may be useful in guiding medical decisions in situations where patients are unable to communicate their wishes.
Questions to consider

- What is the role of the health care agent?
  - (Make decisions that the patient would have made when they can’t)

- What do you understand about your medical condition?
  - (Dementia – generally slowly progressive loss of brain function)

- What sort of bad things (“complications”) happen in late dementia?
  - (Loss of ability to eat, walk, communicate, take care of self, control bladder, etc.)

- How have experiences with someone who was seriously ill and had to make decisions about life sustaining interventions influenced you?
  - (For example, decision about ventilator, decision for hospice, CPR)

- How would you define quality of life?
  - (For example able to communicate, walk on own, enjoy interactions with family)
www.kp.org/watch

Planning video
www.clinicaltrials.gov
Questions?