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

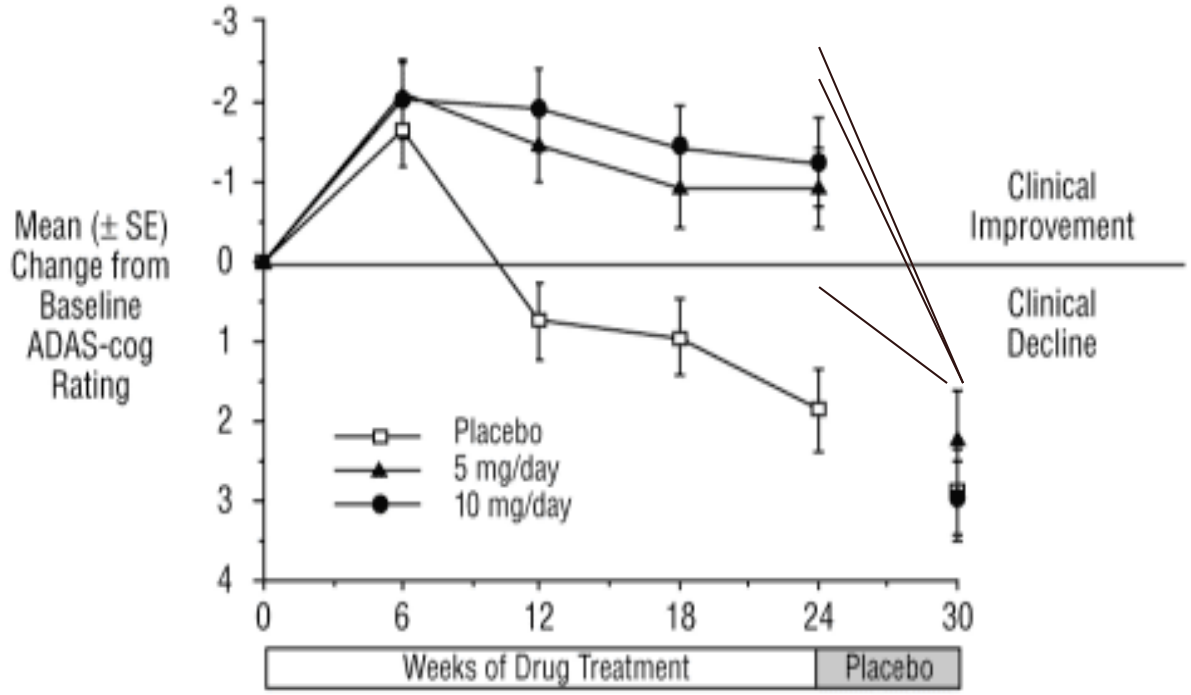


Figure 1. Time-course of the Change from Baseline in ADAS-cog Score for Patients Completing 24 Weeks of Treatment.

Treatment: about 25% better, 40% no change, 35% worse

Placebo: about 15% better 35% no change, 50% worse

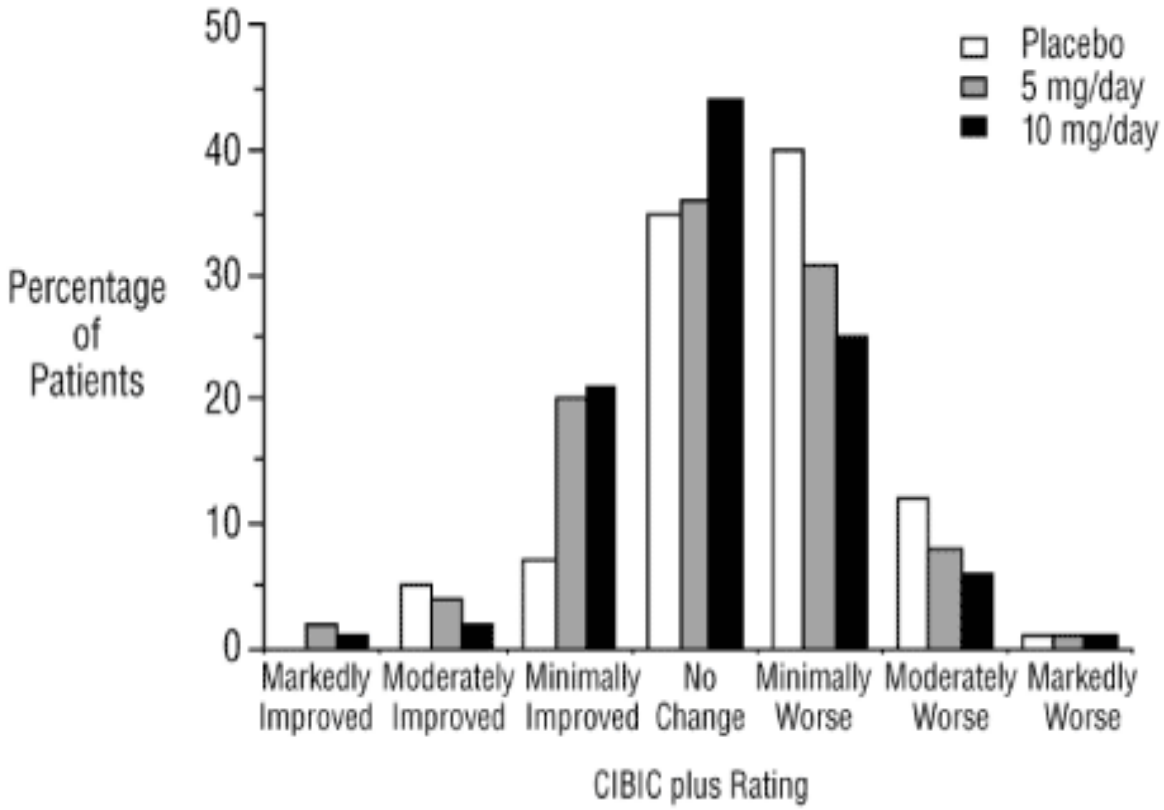


Figure 3. Frequency Distribution of CIBIC plus Scores at Week 24

How to use dementia medications

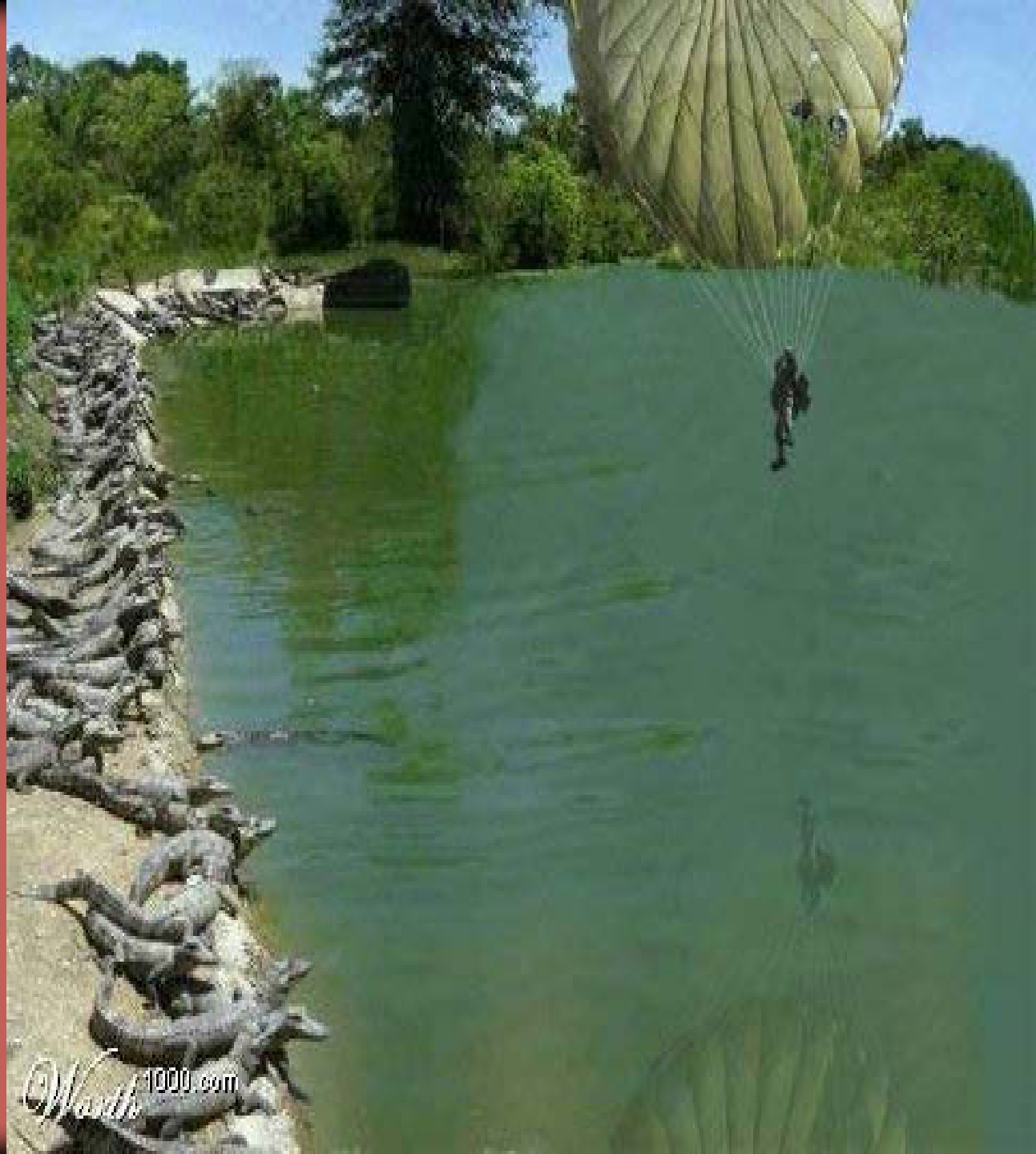
- If never any improvement: Stop (let us know)
- If improved, Continue (let us know)

- 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

Big picture thinking

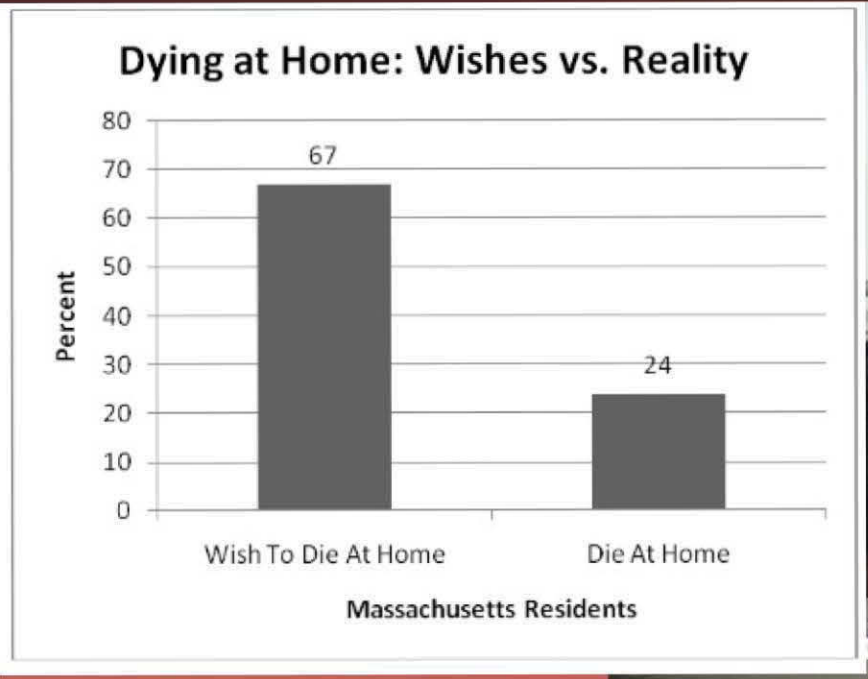


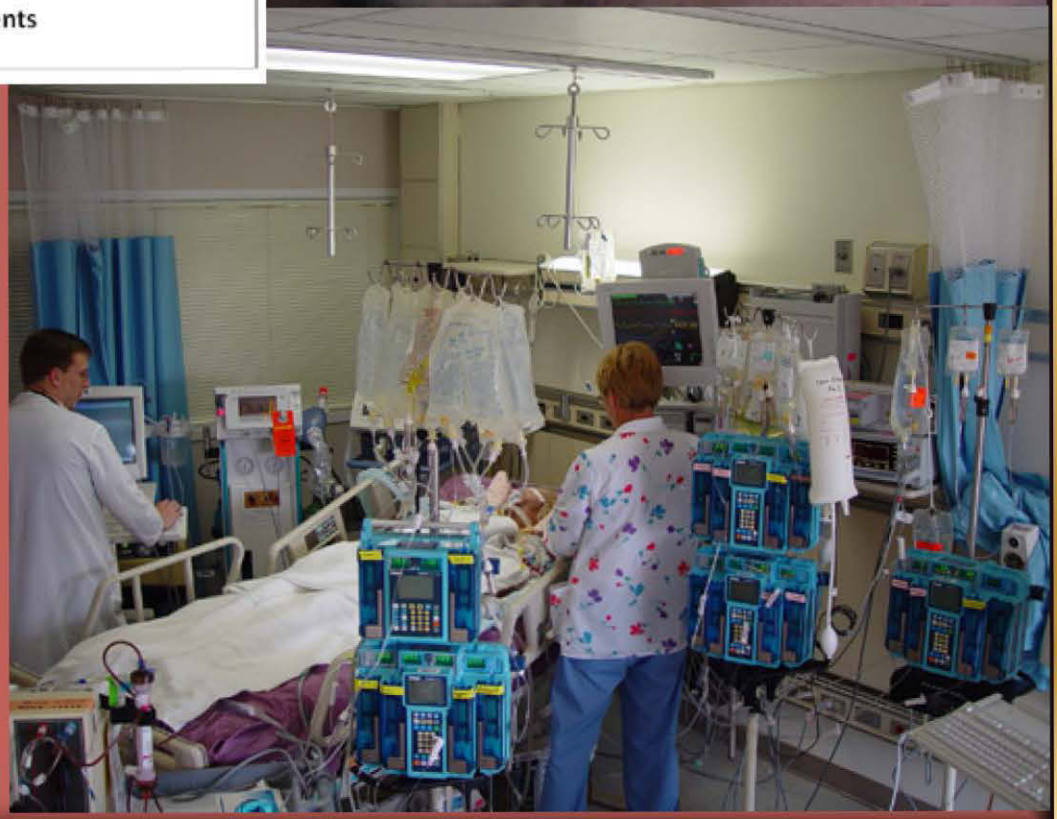
Have a game plan

- 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
Percent
80
70
60
50
40
30
20
10
0
67
24
Wish To Die At Home
Die At Home
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

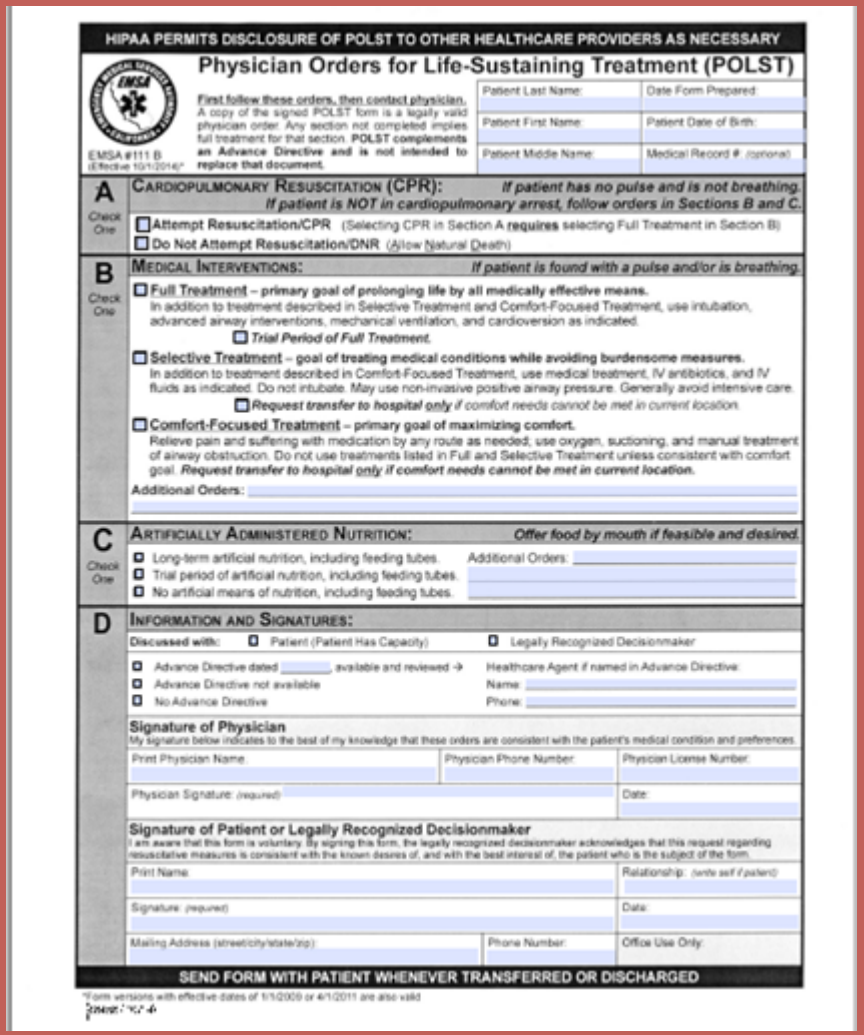
- Tube feeding
  - Does NOT extend life in late stage dementia patients
  - Does NOT make patients more comfortable
  - Does NOT reduce the risk of aspiration pneumonia (may in fact increase it)

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%

POLST

Physician Orders for Life-Sustaining Treatment (POLST)



HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTHCARE PROVIDERS AS NECESSARY

Physician Orders for Life-Sustaining Treatment (POLST)

EMSA #111 B (Effective 10/1/2014)*

First follow these orders, then contact physician. A copy of the signed POLST form is a legally valid physician order. Any section not completed implies full treatment for that section. **POLST complements an Advance Directive and is not intended to replace that document.**

Patient Last Name:	Date Form Prepared:
Patient First Name:	Patient Date of Birth:
Patient Middle Name:	Medical Record # (optional):

A — Check One

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.

- ☐ **Attempt Resuscitation/CPR** (Selecting CPR in Section A **requires** selecting Full Treatment in Section B)
- ☐ **Do Not Attempt Resuscitation/DNR** (Allow Natural Death)

B — Check One

MEDICAL INTERVENTIONS: *If patient is found with a pulse and/or is breathing.*

- ☐ **Full Treatment – primary goal of prolonging life by all medically effective means.**
  In addition to treatment described in Selective Treatment and Comfort-Focused Treatment, use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated.
  - ☐ ***Trial Period of Full Treatment.***
- ☐ **Selective Treatment – goal of treating medical conditions while avoiding burdensome measures.**
  In addition to treatment described in Comfort-Focused Treatment, use medical treatment, IV antibiotics, and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Generally avoid intensive care.
  - ☐ ***Request transfer to hospital only if comfort needs cannot be met in current location.***
- ☐ **Comfort-Focused Treatment – primary goal of maximizing comfort.**
  Relieve pain and suffering with medication by any route as needed, use oxygen, suctioning, and manual treatment of airway obstruction. Do not use treatments listed in Full and Selective Treatment unless consistent with comfort goal. ***Request transfer to hospital only if comfort needs cannot be met in current location.***

Additional Orders:

C — Check One

ARTIFICIALLY ADMINISTERED NUTRITION: *Offer food by mouth if feasible and desired.*

- ☐ Long-term artificial nutrition, including feeding tubes.
- ☐ Trial period of artificial nutrition, including feeding tubes.
- ☐ No artificial means of nutrition, including feeding tubes.

Additional Orders:

D

INFORMATION AND SIGNATURES:

Discussed with: ☐ Patient (Patient Has Capacity) ☐ Legally Recognized Decisionmaker

- ☐ Advance Directive dated _____, available and reviewed →
- ☐ Advance Directive not available
- ☐ No Advance Directive

Healthcare Agent if named in Advance Directive:
Name:
Phone:

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 Physician Name:	Physician Phone Number:	Physician License Number:
Physician Signature: (required)		Date:

Signature of Patient or Legally Recognized Decisionmaker
I am aware that this form is voluntary. By signing this form, the legally recognized decisionmaker acknowledges that this request regarding resuscitative measures is consistent with the known desires of, and with the best interest of, the patient who is the subject of the form.

Print Name:		Relationship: (write self if patient)
Signature: (required)		Date:
Mailing Address (street/city/state/zip):	Phone Number:	Office Use Only:

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED

*Form versions with effective dates of 1/1/2009 or 4/1/2011 are also valid

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?