Managing Advanced Dementia and Frailty:

Prognosis, Care Planning and Maintaining Quality of Life

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VICTORIA HOSPICE

Learning Objectives

- Recognize the Burden of Dementia
- Recognize the Natural History of Advanced Dementia and ID 3 predictors of Mortality
- Identify 5 Domains for "Goals of Care" for Frail people
- Recognize impact of Polypharmacy on QOL with Frailty
- Reconcile Medication Use with the Goals of Care
- Recognize some causes of Agitation in Dementia

Format

- 3 Case Presentations
- Brief Review of "Evidence" for Interventions

Conflicts of Interest

- None to Declare

Burden of Dementia

Alzheimer's Association, 2013 Alzheimer's Disease Facts and Figures, *Alzheimer's & Dementia,* Volume 9, Issue 2.

- Prevalence – **increases with age**
  - Age 70+ - 14%
  - Age 85+ - ***32%***
  - *1 case diagnosed every **68 sec** in the USA*

- ***$33b*** spent in 2015
  - (Alzheimer Society of Canada)
  - Direct and Indirect Care

Société Alzheimer Society CANADA

Burden of Dementia

- Survival from Diagnosis- **4-8 years** (up to 20)
  - **40%** of survival time is in **Stage of Moderate/Severe Dementia**
  - **75%** - are transferred to a nursing home (vs. 4% age/sex matched people without dementia)

- Significant Deterioration in **QOL** and cause of **Suffering**

- Significant Cause of **Caregiver Burden** (***even after placement in a nursing home***)

Case #1

- 87 year old widower living in a Nursing Home for 3 years
- Retired engineer from Scotland and has very supportive family
- Paid Caregiver for 6 hours per day in the facility
- Severe Vascular Dementia-"**ABC**"
  - **ADL**
    - "Parkinsonism" and Wheel chair Mobility
    - Dependent for all ADL,
    - Assist with feeding, pills crushed, blenderized diet.
    - Incontinent of urine
  - **Behaviour**
    - Agitation, paranoia and sun-downing - well controlled with low dose risperidone
  - **Cognition**
    - Language – mild deficits,
    - Significant cognitive slowing
    - Recognizes family most of the time, problems with names. "Where is my (deceased) wife"?
- 3 Episodes of Aspiration pneumonia in the past year
- Meds: Thyroxine, Pantoprazole, B12- 250, Ecasa 81, Risperidone 0.0625mg 16:00 and HS

Weekend Call to "On-Call" Physician

- Call from Nurse:
  - Coughing and Wheezing, Moaning at times
  - Weaker and more confused
  - Not Eating and Problems Swallowing Pills
  - O2 sat 90%, Temp 37.7 HR 76 BP 108/56 Crackles RLL, bilateral rhonchi
  - Should we send him to ER?

What Would You Do?

Original Article

The Clinical Course of Advanced Dementia
CASCADE Study

Susan L. Mitchell, M.D., M.P.H., Joan M. Teno, M.D., Dan K. Kiely, M.P.H., Michele L. Shaffer, Ph.D., Richard N. Jones, Sc.D., Holly G. Prigerson, Ph.D., Ladislav Volicer, M.D., Ph.D., Jane L. Givens, M.D., M.S.C.E., and Mary Beth Hamel, M.D., M.P.H.

N Engl J Med
Volume 361(16):1529-1538
October 15, 2009

The NEW ENGLAND JOURNAL of MEDICINE

Clinical Course of Advanced Dementia

- As Mortality rates from leading causes of death **decrease,** death from dementia **increases**.
- Cohort – **followed 18 months**, Assessed every 3 months
- **N= of 323** people with **Advanced Dementia** with health care proxies (68% children, 10% spouses; 17% other family))
  - Mean Age **85,**
  - MDS Cog Performance scale 5-6 (= **MMSE of 5**)
  - **GDS- Stage 7** (don't recognize family, minimal verbal communication, non-ambulatory, incontinent and 100% dependent in ADL)
  - **ALOS – 3 years** in the nursing home
- 22 nursing homes in greater Boston Area, (55% participation rate and 99% follow up)

Results

- **55% Died**
  - Median Survival **16 months**
  - 25% died within **6 months**
- **Predictors of 6 month Mortality**

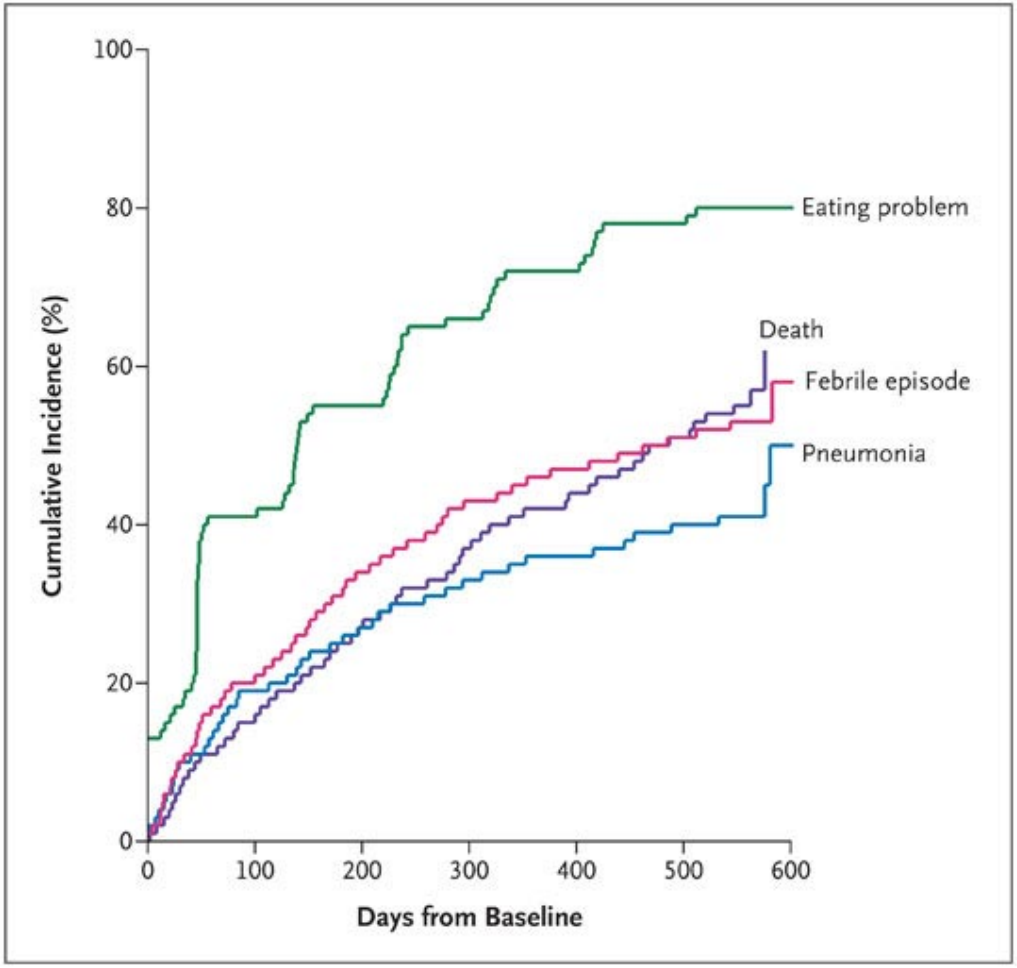
  (after adjusting for age, gender and duration in facility):
  - **Pneumonia**- 47%
  - **Febrile illness-** 45%
  - **Eating problem**-39% (dysphagia, reduced intake, chewing, needing to be fed)

Substantially higher mortality than people with advanced dementia without these problems

Other Sentinel Events (10% of residents) did *not* predict death within 3 months:

e.g. Seizures, Stroke, MI, GI Bleed, Hip #

Overall Mortality and the Cumulative Incidences of Pneumonia, Febrile Episodes, and Eating Problems among Nursing Home Residents with Advanced Dementia



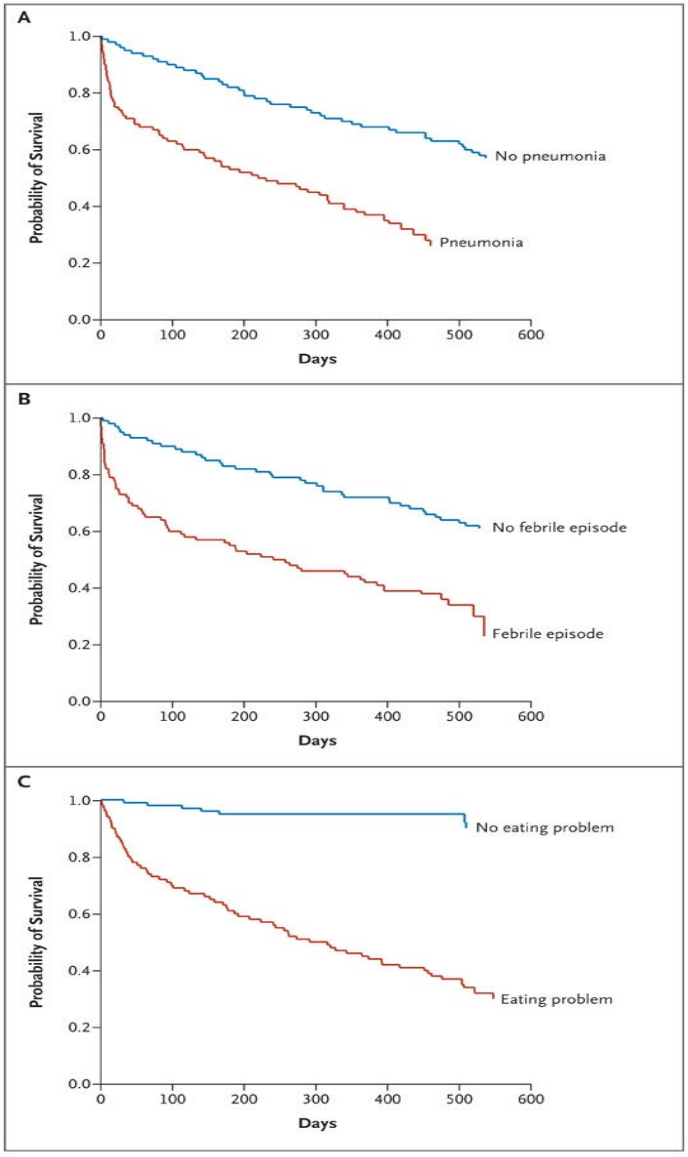
Incidence over 18m:

- Eating Problem-85%
- Febrile Illness- 53%
- Pneumonia-41%
- Death- 55%

Mitchell SL et al. N Engl J Med 2009;361:1529-1538

The NEW ENGLAND JOURNAL of MEDICINE

Survival after the First Episode of Pneumonia, the First Febrile Episode, and the Development of an Eating Problem



First Pneumonia

First Febrile Illness

New Eating Problem
Needing to be fed

Mitchell SL et al. N Engl J Med 2009;361:1529-1538

The NEW ENGLAND JOURNAL of MEDICINE

Cascade Study Results
Quality of Life

- **Distressing Symptoms** (> 5 days per month) **Common**
  - 46% - **SOB**
  - 39% - **Pain**
  - 53% - **Agitation**
  - 41%- **Aspiration/choking**
  - 39% - **Decubitus Ulcers**
- **Burdensome Interventions** in the **last 3 months of life** **Common**– **41%**
  - **Acute Care Transfer-** ER or Admission - (15%) most common cause was pneumonia (68%) and other infections (14%)
  - **IV/s.c/i.m** – fluids and meds (29%)
  - **Tube feeding**- 7%

Results
Caregivers

- **96% -believed Comfort was the Primary Goal of Care**
- **20% believed resident had <6m to live**
- **18% - received any counselling about prognosis from a doctor**
- **Those that received counseling about prognosis were much less likely to have burdensome interventions in last 3 months of life**
  - **Odds Ratio – 0.12** (95% CI -0.04-0.37)

Our Case

- Sent to ER by Dr. on Call:
  - Delirious
  - IV pulled out
  - DC back to NH on Moxifloxacin, a bit better
- 5 days later relapsed, increased distress, Persistent crackles, low grade fever and O2 sats 88% RA, difficulty swallowing pills, coughing with puree
  - Long Discussion with family about prognosis
  - Goals of Care –**Comfort and alleviate suffering**
  - Stopped oral meds
  - SC hydromorphone
    - 0.5-2mg Q4-6h **regularly**
    - ½ dose q 2 h for Breakthrough symptoms
  - Prn Lorazepam 1mg SC q 4h prn for restlessness or agitation
  - Atropine 0.6-1.2 SC q4h prn for end of life secretions
- Died peacefully in his room with family at his side 3 days later

Case #2- **Advanced Frailty** Establishing **Goals of Care** and Managing **Polypharmacy**

- 83 year old retired commercial pilot from Vancouver
- Married –devoted and loving wife and has supportive daughter in Victoria and son in Vancouver
- Transferred to Residential Care after prolonged hospitalization

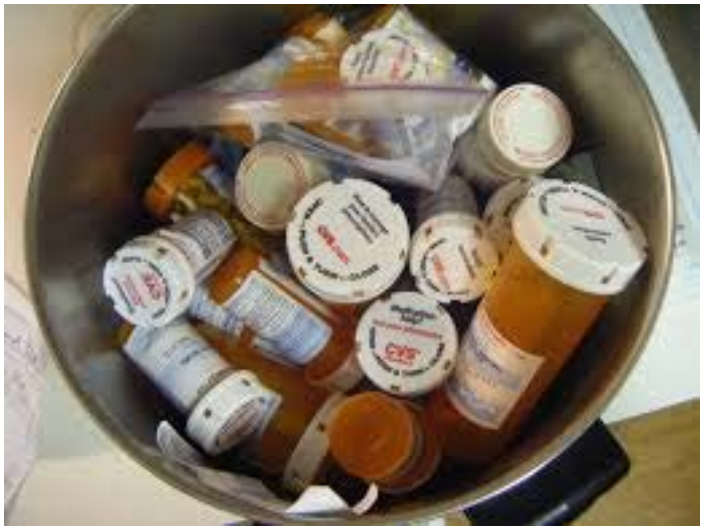
Case #2

- Well and completely independent , hiking the Grouse Grind – until 2 years prior to transfer
- Dx with Prostate Cancer with pelvic mets
  - Rx with chemo and radiation and goserelin (Zoladex)
- Year Prior to Admission
  - Developed progressive gait and balance problems with a tremor
  - Fell on visit to Victoria and admitted to hospital From April-July
- Other PMHX- HTN, high LDL,
- Non Drinker, Non Smoker

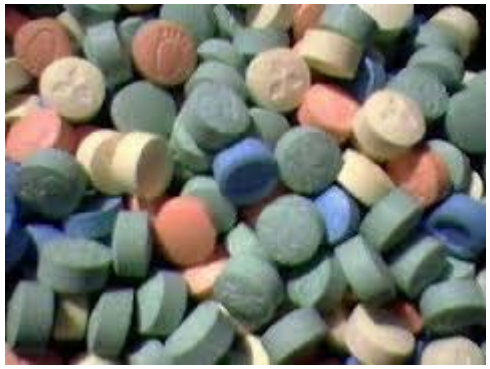
Initial Assessment

- **Mild Dementia-** MMSE 20
- **Mood- Denied Depression** – GDS 0/5
- **Back and leg pain – no findings, severe muscle wasting**
- **Neurodegenerative Dx NYD– Ataxia, Tremor, Rigidity - Paraneoplastic?**
- **Severe Frailty**
  - Not wt bearing- Mechanical Lift, Total Care for BADL
  - Poor trunk mobility and leaning with sitting
  - Poor stamina and can only tolerate being up in chair 1 hr Ltd. by:
    - Weakness
    - Vertigo and nausea
  - Severe dysphagia and dysarthria- refused pureed diet choking with eating
  - Severe Tremor and ataxia in hand – difficulty eating, A.M. Care
  - Vision Diplopia and difficulty reading or watching TV
  - Incontinent – in pads ; Severe Constipation
- **Other PX findings**:
  - BP 104/50 lying and 94 /48 sitting,
  - Severe edema and mild weeping of legs
- **Severe Caregiver Burden**

Medications



Hospital Chart Reviewed
Match Drugs to DX



- Atorvastatin -20mg OD- **high LDL**
- Amlodipine 10mg od - **HTN**
- Ramipril 5mg bid - **HTN**
- Metoprolol 12.5mg BID **–HTN (No angina or CHF)**
- Furosemide 40mg **– HTN and edema**
- Nitropatch 0.6- **Severe HTN in hospital (no angina)**
- ASA - **Prevention Stroke and MI?** (no hx, primary prevention?)
- Alendronate 70mg weekly – **Osteoporosis**, No #
- Calcium 500mg bid and Vitamin D 4000 units-**Osteoporosis**
- Zoladex q 3 months –**Prostate Cancer**
- Bicalutimide – **Prostate Cancer**
- Sertraline – **Depression and Anxiety**
- Dilantin 300 – "**seizures**"- faints followed by shaking for a minute
- Zoplicone 7.5 HS - **Sleep**
- K+ and B12 1000 MCG , Ferrous Fumarate ……

N=17

Lab Tests

- Hgb -102; Lymphocytes (↓)
- B12 963; Ferritin 190 (↑)
- TSH - <0.03; T4 and T3 (↑)
- Albumin 33 (↓)
- BUN (↑), GFR 33 (↓) and lytes normal
- PSA 16 (↑)
- LFT -normal

What would you do for this man?

Goals of Care

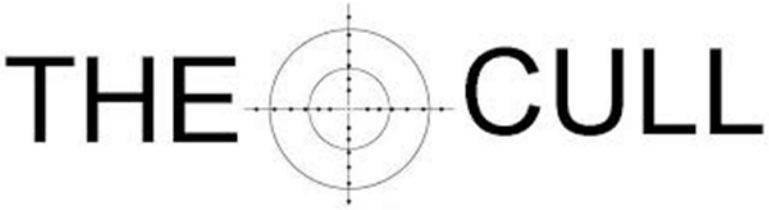
- **His Goals**
  - **Symptom Control**
    - Less dopey
    - Stronger/Fatigue - sit up longer and read paper, talk with family
    - -Less Dizzy
    - alleviate pain in legs and back
    - Improve Appetite
    - Relieve constipation
    - Reduce Nocturia (hourly)
    - -relieve uncomfortable edema.
  - **Function**
    - ADL-Alleviate Tremor – can feed self and brush teeth/AM Care; get out of diapers
    - Social: Stay up long enough to visit with Daughter without severe fatigue
  - **Medical Interventions**:
    - No CPR, Not go to hospital, No tubes, no IM Zoladex etc….
    - Doesn't want to go out for medical appointments
    - Blood tests OK if done at home.
    - Antibiotics OK if he will feel better
  - **Survival** – "I am ready to go", Doesn't want to prolong life.
  - **Caregiver Burden-** Reduce Strain on his wife
- **Wife's Goals**
  - Delay his death as long as possible including CPR
  - Hospital for any illness
  - Improve his comfort

Summary of Care-Plan and Convergence of GOC

GOC Outcomes- Symptoms, Function Health Care CG burden

Goals	Agents/Factors	Actions	Impact of Change/Goal
Fatigue/Dopey/weak	**Hypotension** **Sedation** **Thyrotoxic** **Renal Failure**	Taper off zoplicone Taper dose dilantin Taper off all BP pills/nitrodur Stop Zoladex/bicalut. **Rx Thyrotoxicosis-tapazole**	Sleep Better Can stay up 3 hours Ramipril 5mg od FU BP 142 No "Seizures"
Less Dizzy	**BP** **Psychoactive meds**	" "	**Gone**
Back and Leg Pain	**Statin** **Sertraline RLS?** **Chair and Bed**	**Stop Statin** **Taper Sertraline** **Add Reg. Acetamin.** **PT- ROHO Cushion**	**Leg Pain gone** **Back pain manageable** **No Depression** **Sleeps Well**
Anorexia Constipation Edema and Nocturia	Rx Medications OTC medications Hydration	Stop OTC, Ca++ Iron, ASA, Alendronate , etc Dietician Stop amlodipine + lasix	Enjoys food again Edema +1 Nocturia x2
Social : visit with family Read Paper ADL: Feed Self, A.m. Care Get out of pads Not be dependant on wife	**Tremor** **-treat thyroxicosis** **-taper Sertraline** **Fatigue**	" " Taper off Sertraline Rx Thyrotoxicosis tapazole	Can eat with left hand, brush teeth Visits with Daughter in PM, reads paper Still in pads GDS 0,
Health Care burden- Care giver burden	Multiple specialists	Call and cancel appts MOST 2	Wife and him more relaxed

After



- Medications
  - Acetaminophen 500mg TID- for Pain
  - Methimazole 10mg OD -for Thyrotoxicosis

9 months later

- Progressive dysphagia with recurrent aspiration pneumonia
  - Multiple meetings with wife – wanted Rx with Antibiotic
  - Not Transferred to hospital
  - EOL Meds (dilaudid, atropine and lorazepam)
  - Died Wife and daughter present

Case #3
Agitation with Advanced Dementia

- 85 year old Widow living with supportive daughter and son-in-law in downstairs suite in their home.
- Originally from East Africa- refugee to Canada in the 70's, speaks 3+ languages
- High School Educated – worked in family business
- Advanced Alzheimer's/Vasc Disease –MMSE 0
- Complete Dependence in Care- currently needs mechanical lift, needs to be fed
- Family committed to caring for her at home
- 24 hour live-in caregivers

Past History

- Dementia-mixed AD+VaD
- Lacunar Infarcts
- Depression
- Diabetes
- HTN
- MI
- GERD
- Osteoarthritis

Medications

- Zopiclone 7.5 mg HS
- Venlafaxine 75mg OD
- Risperidone 0.25mg bid (or crying all day and night, hallucinating and looking for mother)
- Memantine 10mg BID (or could not follow instructions)
- Amlodipine 10 – (or BP 190 and more confused)
- Lantus- 5 units HS (or blood sugars are 28-30 and weaker)

Problems

- **Relapse of "BPSD"**
  - Calling out –Caregiver up all night –exhausted
  - Anxiety when left alone
  - Cries and sobs looking for her mother
  - Yelling with care
    - They think it may be painful OA in her knees
    - Peaceful when daughter is present
    - Has plush doll that holds onto.
- Exam – Ear Wax and dental problems
- Labs - unremarkable

Situation not sustainable
Live –in Caregiver threatening to quit
Daughter in tears

Goals of Care

- Reduce the woman's distress
- Survival- don't want anything that may hasten death
- Die at Home
  - Daughter promised her that she would not put her in a facility
    - Need to be able to do ADL
    - Live- in - Caregivers need to Sleep at Night
- Don't want transfer to hospital

What would you do?

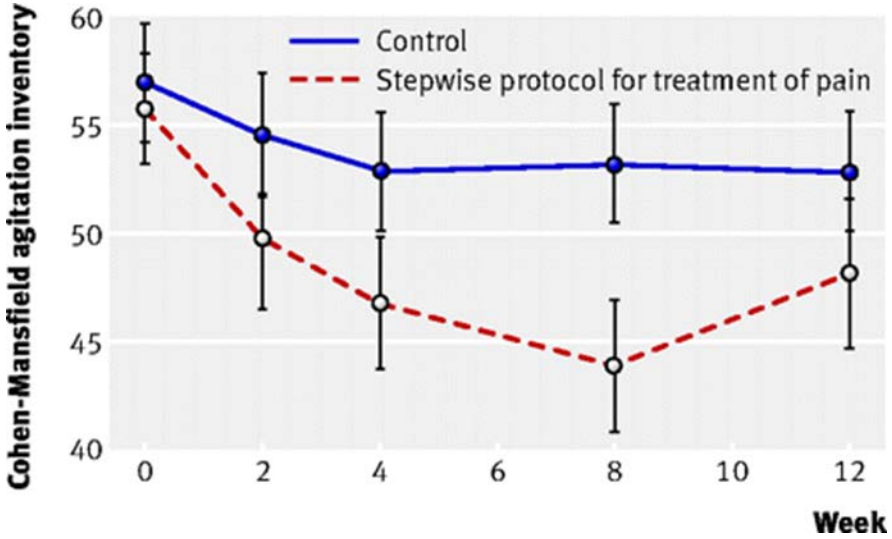
Analgesia for BPSD

BMJ 2011;343:d4065

- Clustered RCT- Norway n=60 clusters (352)
- Nursing homes – Residents' mean MMSE -8
- Facilities Randomized to:
  - Stepped Analgesia
    - Tylenol (69%) – up to 3gms
    - Morphine (2%)- up to 20mg
    - Buprenorphine (22%) -10
    - Pregabalin (7%)
  - Usual Care

Results- BMJ

- Reduction
  - Agitation (CMAI) – 17% Reduction
  - NPI –BPSD - - 9.0 points
  - No worsening of ADL or Cognition



Equivalent to the impact of risperidone in a RCT

Actions

- Syringed Ears
- Dental Extraction at Home
- Trial of tapering off each medication – worse
- Added Acetaminophen 1000mg tid – slight improvement
- Injected knees with Triamcinolone – improvement with transfers and care

Actions

- **Buprenorphine 5 mcg** OK. Other narcotics:
  - Hydromorphone 0.5- severe escalation of confusion and impacted
  - Sufenta- tiny dose before transfers and ADL – slept for 10 hours
  - Fentanyl patch 6mcg –better but sedated and sleeping most of the time.
- **Outcomes**
  - Calling out stopped
  - Sleeping thru the night
  - OK with ADL
  - Tapered off risperidone
  - Reduced Zoplicone to 3.75mg HS

6 months later…..

- Agitation is escalating
- Calling out and crying :
  - at night – worse when turned and changed
  - with all care and transfers

What would you do?

Medication changes

- Buprenorphine increased to 10 .
  - Could not tolerate 15
- Very slight improvement

Actions

- Physical exam- stiffens up and cries when shoulders and thighs touched.
- CRP 20
- PMR?
- Trial of Prednisone 15mg OD
  - Calling out stopped
  - Could do her ADL
  - No problems with transfers
- Changed to Depomedrol 80 mg i.m. q 3-4 weeks
- Buprenorphine Reduced to 5mcg weekly

Conclusions

Conclusions

- **Advanced Dementia is a Palliative DX**
  - 6 month mortality 25% and Median Survival 1.3 years.
  - Prognosis similar to Metastatic breast cancer or Class 4 CHF
- **Most deaths are predictable** and **not** PPT by other acute events (e.g. MI)
- **Sentinel Predictors of higher 6 month mortality (40-50%)**
  - **Feeding problems**,
  - **Pneumonia**
  - **Febrile Illness**
- **Distressing symptoms are:**
  - **Common (similar pattern to terminal cancer)**
  - **Under- reported**
  - **Under-treated**
- **Educating Caregivers** and Proxies and **Establishing Goals of Care** can **prevent burdensome interventions** and aggressive care and improve QOL

Conclusions

- **Think of Goals of Care in Domains**
  - (QOL, Function, Health care, CG Burden and Survival)

- **Review Medications to determine if consistent with GOC**
  - *Prevention of long term complications become less important – eg ACEI for DM CKD*
  - *Adverse Events may be <tolerable with advanced frailty -e.g.metformin and anorexia*
  - *Pill burden may be a problem*

- **Individualize GOC, Interventions and Synchronize:**
  - with Patients,
  - Family Caregivers other Health Care Workers

-

Conclusions

- **Cautiously Use "Palliative Medications"** even if people don't have "cancer"
  - People with Advanced Dementia may not be able to communicate their distress and present with "agitation"
  - Cautiously "Palliate as you go" regardless of diagnosis – e.g.
    - Pain- analgesic, steroids, narcotics
    - Dyspnea-
    - Itch
    - Constipation
    - Depression
  - Deploy End-of-life- back up orders esp in a facility environment.
    - SC: narcotic, lorazepam, haloperidol , atropine
    - Make sure regular sufficient dose.
- **Mobilize Resources and Supports**
  - Team- PT, OT, SW, Nutrition, SLP
  - Geriatric psychiatry