

Disease Modifying Therapy in Patient with Progressive Disabilities

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- **Social History:**
- 57 yr old male
- Married to German-born spouse while serving in the Army. Two young adult sons.
- Home: Wheelchair non-accessible split entry house in northwestern Wisconsin, near Duluth MN.
- Education: 1.5 yrs college and 4 yrs vocational training, worked as a Union Carpenter, quit for disability.

- **PMH:**
- Multiple sclerosis --- EDSS 8.0
- Cognitive impairment with behavior problems
- Vision impairment: rotary nystagmus, optic neuritis, right extropia
- Mild to moderate dysarthria
- Mild upper extremity weakness
- Paraplegia, wheelchair bound, impaired sensation to lower limbs
- Neurogenic bladder managed with suprapubic catheter
- Neurogenic bowel managed with QOD suppository
- Lower extremity spasticity: Clonazepam, Baclofen, ROM
- Depression with suicide attempts and threats treated with Bupropion and Depakote.
- ETOH abuse
- Tobacco use

- **Multiple Sclerosis disease course:**
- 1978 Symptoms: blurred vision and fatigue
- 1981 Exacerbation with lower extremity weakness
- 1983 Exacerbation with generalized numbness and tingling
- 1998 Brain MRI: “MS findings of the corpus collosum, pons”
- 1999 Brain MRI: no change
- 2000 Exacerbation with tingling. Ambulates with wheeled walker. Brain MRI: no change

- **2000** Suicide attempt: overdose of Prozac, Neurontin and Clonazepam.
- Suicide gesture by laceration of wrists and legs (superficial lacerations).
- Betaseron discontinued for ineffectiveness and possible contribution to depression (unknown start date for Betaseron). Start Copaxone.

- **2001** Legally blind, severe executive function disability, increased physical impairments, falls, unable to self cath. Start indwelling catheter. Brain MRI: no change
- **2002** Suicide attempt by drinking combination of Drano, liquid cleaning products and coffee. Brain MRI: no change, T-spine: abnormal signal at T11. Depakote started “for behavior”.
- **2005** Wheelchair bound, lower extremity spasticity: Baclofen/Clonazepam started. Brain MRI: no change.

- 2008 Admitted for caregiver respite.
- Found to have multiple cigarette burn marks on bilateral thighs. Spouse is advised to cover his lap with a welder's apron to protect him from dropped cigarettes.
- Spouse is unwilling to stop providing alcohol and cigarettes to the patient. Drinking "beer and shots" about 5/day.
- Social Services involved. Long term care placement strongly advised. Spouse vacillates, eventually declines placement.

- 2009, 2010 Respite admissions notable for episodes of behavior problems.
- Spouse continues to vacillate about long term placement and caregiver burnout.
- Followed closely by Social Worker.

- 2011 Spouse states she is no longer able to care for her husband, presents at VA Emergency Department. Patient is admitted to Medicine Service for “detox”, “failure to thrive”.
- ETOH: 7 drinks/day. Inappropriate behavior toward nursing staff, suicide threats while hospitalized. No evidence of alcohol withdrawal.
- Clonazepam is discontinued.
- Neuropsychological testing: indicative of confusion/disorientation and gross cognitive impairment.
- Behavior problems persist but are now manageable with distraction, redirection.

- Neurology unwilling to advise on whether to stop Copaxone without MRI.
- MRI: sub optimal study due to patient unable to lie still despite being medicated, but does show increased lateral and 3rd ventriculomegaly.
- Spouse struggling to decision whether to stop Copaxone, asking the Neurologist to make this determination.
- “It is reasonable to stop Copaxone since patient has not had a relapse in many years.”
- Copaxone is discontinued. Patient is placed in VA long term care facility and is doing fairly well.

- **Comments:**
- 1) Despite MRIs showing “stable”, “unchanged” MS lesions, patient displayed progressive physical and mental disability over time.
- 2) Betaseron was discontinued due to breakthrough exacerbation and concern for depression.
- 3) Copaxone was well tolerated but finally discontinued due to “having no exacerbations”.

- **Questions for Thought:**
- 1) Is MRI the gold standard for determining disease modifying medications? What about progressive disability?
- 2) Is it reasonable to stop DMT when relapses stop, in the setting of progressive disability?
- 3) When cognitive impairment prevents an informed personal choice about treatment, the burden of that decision lies upon the caregiver. How is this similar to a caregiver making a decision for long term care placement?
- 4) In what ways does the emotional investment, isolation, and fatigue of years-long caregiver role interfere with the ability to make these important decisions?