How Dedicated Advocates Are Changing Dementia Care From Drugs to Hugs

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Meet Cal and Reggie
I’m going to do this one upside-down
Hallmarks of Dementia

- Memory Loss
- Other Cognitive Impairment (speech, fine motor skills, executive functioning)
- Gradual and Continuous Decline

*So what does this mean?*
This often means:

- Loss with attendant sadness
- Decreased activity
- Confusion
- Fear
- Less ability to meet immediate needs
- Less ability to engage help

Immeasurably exacerbated in a nursing home
The 6 dirtiest words in long-term care

Behavioral and Psychological Symptoms of Dementia
Think about it

- “Behaviors” are not symptoms of dementia - they are the natural response to distress and unmet needs.

- What we are observing are behavioral and psychological symptoms of being a person with lots of confusion and no way to verbally communicate.
From Positive Discipline:

- It’s not misbehavior if they don’t know what they’re doing
- Calm atmosphere
- Model good behavior
- Care recipient will absorb your energy
- Anticipate triggers and re-direct before they strike
- Sense of belonging is critical
- *People do better when they feel better*
A crying baby

What do you do?

Drug them or comfort them?
Why I Am Here.

When you medicalize the behaviors, you will medicalize the response.

But the only medical response is to medicate.

And there is no medication to treat dementia.
This is Chemical Restraint

• Federal: imposed for purposes of discipline or convenience, and not required to treat the resident's medical symptoms (42 C.F.R. Sec. 483.13(a))

• State: used to control behavior and used in a manner not required to treat the patient's medical symptoms (22 Cal. Code Regs 72018)

Convenience: any action by the facility to control or manage a resident’s behavior with a lesser amount of effort.

Neurologic Suppression is ALWAYS the goal.
Drugging Dementia

- It is ineffective
- It is deadly
- It is elder abuse
- It is time to end it
It is no longer the standard of practice

- **AHCA**: These drugs don’t get to the heart of the reason for the person’s actions.
- **Leading Age**: Antipsychotics rarely help and present significant dangers.
- **AMDA**: I do not prescribe antipsychotic drugs for treatment of agitation or other behaviors in patients with dementia.
- **APA**: Antipsychotics ought to be the last resort for dementia.
The Law Demands Good Dementia Care

- Informed Consent
- No Unnecessary Drugs
- Chemical Restraints Prohibited
- Gradual Dose Reduction
Informed Consent?

INFORMED CONSENT - ANTI-PYCHOTICS

BRAND NAMES: AMNESE, NEURON, D-B.

- NIMAZINE (nortriptyline)
- OXITANE (oxaprozin)
- AVANE (amitriptyline)
- SERENTIL (sertraline)
- TARACTAN (chlorpromazine)
- TINDA (acetaminophen)
- HALDOL (haloperidol)
- MELANAL (meprobamate)
- VERSPRIN (tamsulosin)
- INAPSINE (droperidol)
- MOBAR (mirtazapine)
- TRLAFON (perphenazine)
- FRONOSIL (fluphenazine)
- STELAZINE (fluphenazine)
- VICTATI (haloperidol)
- RISTEDAL (desipramine)

It is recommended that you take the medication named **Supplied**

For the treatment of aggression/verbal/behavior.

ADVANTAGES: The medication is designed to relieve you of your symptoms. Research & clinical experiences have shown that it is safe & effective. The benefits from taking the medications usually outweigh the risks. Resident &/or responsible party always retain the right to revoke this decision.

SIDE EFFECTS: Any medication may produce unwanted side effects along with the desired results. Some effects may appear even before benefit from the medication is experienced. If side effects do appear, consult your physician. Side effects usually disappear with continued treatment, although some side effects will persist, even after stopping the medication.

COMMON SIDE EFFECTS: Grand mal, depression, dry mouth, constipation, blurred vision, extrapyramidal reaction, weight gain, edema, postural hypotension, sweating, loss of appetite, urinary retention.

SPECIAL ATTENTION FOR: Nausea, dry mouth, constipation, blurred vision, extrapyramidal reaction, weight gain, edema, postural hypotension, sweating, loss of appetite, urinary retention.

When you consent to treatment with this medication, you will have been informed as to the amount of medication, how often it will be given to you, whether or not it is available on request (PRN), how it will be given and how long you may expect to take it. Often different medications within the group may be given or adjustment made to dosage. You have been informed of the common side effects of all listed medications, however some side effects are more likely to occur with one or more medications than others. Also, some residents are more prone to side effects. For this reason, you should notify your doctor if you think you are having side effects.

I hereby give consent to start treatment with **Supplied**, because I believe my emotional problem represents a greater danger to my health & wellbeing than do possible side effects.

Signature: [Redacted]
Date: 11/1/10 Relationship: Self

The information above has been discussed with the resident or responsible party who reports having read & understood it except for comments listed.

Physician Signature: [Redacted]
Address: [Redacted]

MEMORIAL HOSPITAL
Illegible Nursing Unit

[Handwritten] ADVANCE DIRECTIVE
Informed Consent?

<table>
<thead>
<tr>
<th>Date</th>
<th>Order</th>
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| 7-8-09 | 1) EPOETIN CONCENT 2.5mg IM Q 2 weeks  
       |       | 2) ENDOXAN 150 mg IM QAM FOL.  
       |       | 3) E/ES RISPERDAL 0.5mg PO BID |
No Unnecessary Drugs

Inadequate Indications for Use:


- wandering;
- poor self-care;
- restlessness;
- impaired memory;
- mild anxiety;
- insomnia;
- unsociability;
- inattention;
- fidgeting;
- uncooperativeness;
- behavior that is not dangerous to others
Residents who use antipsychotic drugs receive gradual dose reductions, and behavioral interventions, unless clinically contraindicated. (42 CFR 483.25(l))
Law is Good, Enforcement WEAK

Approximately 95% of federal deficiencies are “no harm”
The Campaign to End Chemical Restraints

• CMS’s National Initiative
• Good Dementia Care Training is Everwhere!
The Campaign to End Chemical Restraints

But this will only go as far as the Advocates take it.
This Ain’t New

1970: Nat’l Council of Sr. Citizens asks Congress to investigate chemical restraints

1975: First Senate Hearing on the subject – “misuse, high costs, & kickbacks”

1987: OBRA ’87 / NHRA

2011: OIG Report (88% of atypical antipsychotics prescribed off-label)
We Know We Can Succeed

Campaign to reduce use of physical restraints dropped use from 21% in 1991 to 2.6% in 2010
The Current Campaign

www.canhr.org/stop-drugging
Advocacy Options

EDUCATION: End the wrongdoing and promote the rightdoing

- Get to consumers and their families
- Get on the news
- Put together a listserv
- Host a symposium
Advocacy Options

ENFORCEMENT – Don’t take business as usual

• File complaints
• Sue the wrongdoers
• Engage your state S&C agency
• Statewide partnerships
Advocacy Options

LEAD: Get in the buildings

• Take cases, read med records
• Provide or facilitate in-services
• Ask questions about drug rates
• Form dementia care committees
Advocacy Options

Get Creative

• Mismarketing settlement money
• Dementia Beyond Drugging for everyone!
• Certificates for Provider/Leaders
• Lobby for Improved Protective Laws
This is a once in a decade opportunity. The momentum is here to make a lasting real improvement in the quality of the lives we serve.
Think About it - One More Time

• Forgetful, confused
• Sent into a strange, invasive environment
• React accordingly
• Drugged into submission
• Needs go unmet, distress unalleviated
• People die
Thank you!