

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-PSYCHOTICS

BRAND NAME(S) (GENERIC NAME(S))

JMPAZINE (prochlorperazine)	HALDOL (haloperidol)	INAPSINE (droperidol)
OXITANE (loxapine)	MELLARIL (thioridazine)	MOBAN (molidone)
AVANE (thiothixene)	ORAP (pirrozdine)	PROLIXIN (fluphenazine)
JERENTIL (mesoridazine)	SPARINE (promazine)	STELAZINE (trifluoperazine)
TARACTAN (chlorprothixene)	THIORAZINE (chlorpromazine)	TRILAFON (perphenazine)
TINDAL (acotophenazine)	VESPRIN (trifluorpromazine)	RISPERDAL (risperidone)

It is recommended that you take the medication named Zyprexa
 For the treatment of Aggressive 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 evoke 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 medicine 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: Sedation, drowsiness, dry mouth, constipation, blurred vision, extrapyramidal reaction, weight gain, edema, postural hypotension, sweating, loss of appetite, urinary retention.

SPECIAL ATTENTION FOR: Tardive dyskinesia, seizure disorder, chronic constipation, glaucoma, skin pigmentation.

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 this 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 Zyprexa, because I believe my emotional problem represents a greater danger to my health & wellbeing than do possible side effects.

Signature: [Redacted] Date: 11/4/10 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: [Signature]

Addressograph: [Redacted]

WEE MEMORIAL HOSPITAL
 Inpatient Nursing Unit

V0000847687 HCLN0
 ADVANCE DIRECTIVE 1

Informed Consent?

FACILITY <u>C.V. WEST</u>		First Name	Attending Physician	Room No.	Admission No.
Family Name		[REDACTED]		[REDACTED]	
Date/Time of Order	Date of Admission	ORDERS			Diagnosis
7.8.09) RISPERIDAL 20MG IM Q 2 weeks			
		(↑ INCREASE OF DOSE)			
) D/C HALOPERIDOL 1mg IM Q 4 HRS PRN.			
) D/C RISPERIDAL 0.5mg PO BID			
Signature of M. M. M. (Nurse/Physician)			Signature of Physician		Date
<input checked="" type="checkbox"/> On Med Order Sheet	<input checked="" type="checkbox"/> Med Tech Sheet	<input checked="" type="checkbox"/> Resident Informed drug effects / side effects		<input checked="" type="checkbox"/> Res. Care Plan	
<input checked="" type="checkbox"/> Pharmacy	<input checked="" type="checkbox"/> Nurse Notes	<input checked="" type="checkbox"/> And Documented in Nap. Notes / Med Sheet		<input checked="" type="checkbox"/> Communicated	

PHARMACY 10/18/08 10:00 AM

No Unnecessary Drugs

Inadequate Indications for Use:

http://www.cms.gov/manuals/Downloads/som107ap_pp_guidelines_ltcf.pdf (F-Tag 329, 42 CFR 483.25(l))

wandering; poor self-care; restlessness; impaired memory; mild anxiety; insomnia; unsociability; inattention; fidgeting; uncooperativeness; behavior that is not dangerous to others

Gradual Dose Reduction

Residents who use antipsychotic drugs receive gradual dose reductions, and behavioral interventions, unless clinically contraindicated.
(42 CFR 483.25(I))

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 Everywhere!



The Campaign to End Chemical Restrictions

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



TOXIC MEDICINE



WHAT YOU **SHOULD KNOW** TO
FIGHT THE MISUSE OF PSYCHOACTIVE DRUGS
IN CALIFORNIA NURSING HOMES

CANHR
Long Term Care Justice and Advocacy
650 HARRISON STREET, 2ND FLOOR
SAN FRANCISCO, CA 94107



California Advocates for Nursing Home Reform

The Campaign to **STOP** Chemical Restraints
in Nursing Homes.

HOME ABOUT DRUGGING DOWNLOAD GUIDE BLOG JOIN THE CAMPAIGN LEGISLATION NEWS & RESOURCES



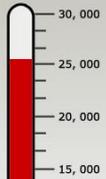
The Problem

About 25,000 California nursing home residents are currently given antipsychotic drugs that greatly increase their risk of death.

[Learn More](#)

Our Mission

Help end the drugging of California nursing home residents. The goal of the campaign is to stop nursing homes and doctors from misusing dangerous antipsychotic drugs and other types of psychoactive drugs to chemically restrain residents and to replace drugging with individualized care. Through education, advocacy and political action, we seek to bring Californians together to end this harmful practice.



Currently, **25,359** residents of California nursing homes are being given antipsychotic drugs.

Or, **25.6%** of all California nursing home residents.

Or, **1 in 4** of all California nursing home residents.

Get Involved

Drugging of California's Nursing Home residents is at an all-time high. Join our Campaign Against Drugging and sign our petition to the Governor urging him to crack down on misuse of psychoactive drugs in nursing homes. Together we can turn the tide of



THE CAMPAIGN TO **STOP** CHEMICAL RESTRAINTS

Search for:

The Stop Drugging Our Elders Blog

For Big Pharma, Off-label Is On-Target

Empty Batteries

"Outing" Nursing Home Drug Offenders

Blog Archive

Select Month

Contact Us

stopdrugging@canhr.org
or use

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!

