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THE DOPING OF OREGON'S SENIORS

BY TIM SILLS

You're old. Why else would you be wearing an orange polyester cardigan? Come to think of it, you don't know where it came from...you don't even like the damn thing. Clothes, food, furniture — nothing's right here! Especially that person who feeds you pills, medicine to make you forget how much you hate this place. Lord! Here she comes again. Smiling.

A Stephen King script? Unfortunately, no. This scene will be played out today in hundreds of Oregon homes, as it has been for the past decade and a half. That's how long the state Department of Senior & Disabled Services has licensed homeowners to take older, often senile Oregonians into their residences and "stabilize" them with chemicals now recognized as dangerous, debilitating and rarely warranted.

Like Oregon's foster program for children, private care for disabled adults is a profit-generated cottage industry. But unlike the parent business, clients of adult home care are usually not wards of the state; major decisions affecting their lives are determined among family, physician and provider. That arrangement leaves seniors vulnerable to the long standing practice of medically masking unwanted senility symptoms — a solution rejected by today's geriatric researchers. What's holding up enlightened care, however, isn't an issue of education. It's bureaucracy.

"Chemical restraint" in larger, commercial outlets, also known as nursing homes, is prohibited by federal law. Enforcing local compliance in that sector is the same office sanctioning chemical overuse in the foster care setting — Oregon Senior & Disabled Services.

In 1990, the U.S. Omnibus Budget Reconciliation Act (OBRA '90) dramatically restricted the use of psychoactive drugs in America's nursing homes. This came after years of investigation into the bleak benefits of "pharmaceutical intervention" with victims of Alzheimer's, stroke and other age erosions of mental clarity, generally referred to as dementia. Experts concluded that many such patients didn't need the dope and were, in fact, doubly disabled by chemical management. Federal regulation was also prompted by evidence that while such medications are necessary in extreme cases, they are particularly hazardous to the health of seniors.

"State Senior & Disabled Services does a very intense survey of facilities we serve," observes Eric Lintner, pharmacist with Northwest Pharmacy Services in Portland which has contracts with dozens of nursing homes in Oregon and Washington. "They go over all medical documentation. They make on-location inspections, right down to taking residents' temperatures. If they find chemical restraint above federal limits, they can force the facility to hire a fulltime monitor, or close it altogether."

Dave Olson, coordinator for the state's adult foster home program, says the federal criteria doesn't apply to the thousands of foster care recipients in Oregon. "If it's a standard order," Olson says of long-term prescriptions for psychoactive drugs, "it's not considered restraint." Senior Services, he adds, currently has no plans to redefine restraint along federal lines.

According to Georgina Carrow, executive assistant for SDS's administrator, sedating the senile is ultimately a matter of jurisdiction. Oregon is compelled to recognize federal requirements only in those domains indicated by Congress. In spite of parallel patient diagnoses, Oregon's foster care citizens fall through the cracks of a separate mandate, legally zombied into submission by prescription. "Foster home residents are not the wards of the state," Carrow offers in defense of department policy. "And we don't see them as suffering."

But the truth is, jurisdiction is not holding up humane care in adult foster homes; it's more a question of dollars. Updating foster care along OBRA '90 guidelines is a cost-deficient dilemma. OBRA-correct ventures are pricey, while in-home providers willing to use sedation are spared the expense of constant personal intervention, which is the recommended alternative. At current rates of reimbursement, a husband and wife crew with five chronically confused seniors in their home could simply not afford the around the clock demands of drug-free care.

"When we were required to pursue chemical restraint reduction by the Omnibus Act," says Lee Ferris, "we had to

implement a number of changes." Ferris is director of Nehalem Valley Care Center on the Oregon coast. Five miles south of Manzanita and overlooking its namesake estuary, this 40-patient facility is planted in the heart of the state's most popular retiree zone. "Staff here had to be trained to respond to people's behavior rather than treat them with medication that would conform behavior," Ferris recalls. "A fulltime social worker was also hired. Even the structural environment was redesigned to be supportive of the residents' unique needs. The cost of it all means just breaking even is now considered good."

Like others in his league, Ferris' operation cannot escape charging private-pay patients something close to cost in order to pick up the slack of facility residents dependent on Medicaid. "We're paying \$2,990 a month, but it's worth it," says Kathleen Confer of nearby Tillamook, whose mother-in-law has Alzheimer's and lives at NVCC. "The center has a sophisticated staff. There are activities instead of sedatives. It's all very home-like, which is important: I've known my mother-in-law since I was eight years old. I don't want to see her personality robbed by drugs." Yet, as she and her husband, Steve, watch savings evaporate, the more economical but chancier choice of foster care begs consideration. One home provider close by says finding a foster situation without the old-style chemical agenda is a tough task.

"Behavior medication is the easy out," claims Merry Johnson, a Tillamook provider. "It's the shortcut to all the work involved in quality care. Unfortunately, too many providers take that shortcut." For 12 years the 33 year old Johnson has been licensed to read the faces of mentally-afflicted seniors who share her small home — people whose internal storms deny normal communication. Her disclaimer of psychoactive medicine is personal. "My grandmother was in a nursing home in the early '80s, before the OBRA changes," Johnson says. "She had senile dementia. She was also on strong doses of Haldol, an anti-psychotic, and it was altering her from the woman I knew. Sometimes she was controlled so completely by the drug, she was immobilized — sitting and staring blankly out of a wheelchair. So I brought her home and stopped the medication. From that time until she passed away, she was able to enjoy many moments of life."

Parlaying the experience into her current occupation, Johnson remains convinced that mind-numbing medications are used far more than necessary. But she concedes that the drug-

free difference in her duties means a minimum 20% more work per resident. "I watch for the onset of agitation-confusion patterns in my residents," she says. "Then I work to change the outcome by intervening with whatever it takes — a hug, soft music, a walk, a treat. It's trial and error, but the alternatives to control drugs are nearly unlimited. It's about quality of life."

Johnson gave up trying to convert her licenser. "As long as there are doctors' orders," she says disgustedly, "that's all the state cares about. None of it is illegal, but that doesn't make it right."

When it comes to medicating, and over-medicating, Oregon's foster providers are nearly unimpeded. Prescription refills find no resistance, and state caseworkers rarely get involved. Citations for chemical restraint are virtually nonexistent. Though Senior & Disabled Services refused to submit any documentation for this report — including name-deleted medical records — interviews with licensed providers around the state indicate persuasions such as Merry Johnson's are in a distinct minority.

Health professionals also are not exactly stemming the tide of overdosed oldsters. In Oregon, any physician can prescribe for dementia. Worse, a staggering number of doctors continue to embrace the old-school conviction that a mild and temporary "chemical lobotomy" is not only a humane answer to the chronic frenzies of dementia, but also the most pragmatic one.

"You can't roll back the clock," protested one family practice physician who, describing himself as "out of fashion but not out of touch," requested anonymity. "This isn't the 19th century with its predictable society and nuclear families — grandmother and grandfather, perhaps a bit rocky upstairs (tapping his head) but still tucked neatly into supportive niches of interaction with the kids and grandkids. Today we have grandmother taking care of grandfather alone on Social Security. She can't give her spouse all those appropriate interventions every time he acts out some manic dysfunction. She doesn't have the strength. But she does have as much right to quality of life, so she gives him medication. Very few seniors can afford the luxury of OBRA '90 care."

There is a new breed of specialist, however, who flatout rejects the social-limitations argument. Cliff Singer, a geriatric psychiatrist at Oregon Health Sciences University, has nine years research in the field, and says most colleagues share his perception that a medicate-away-symptoms approach is not only dated but dangerous. "There's a fairly strong recognition in geriatric study that the clinical practice of medicating dementia has failed," says Singer. "We've over-medicated behavioral problems which rarely responded well to that form of treatment in the first place. And there has been the failure to monitor the side effects of all this medicating."

But Singer is less certain about how to translate the new information to wholesale change — particularly in respect to the glaring need for reduced drug dependency in foster care provision. Without an organization to lobby for administrative overhaul, tuned-in but professionally captive experts such as Singer will need more than goodwill to crusade against the inertia of institutional apathy. "There is definitely an economic disincentive for physicians to spend a lot of time educating and training families and caregivers," Singer claims. "Doctors are stuck in their offices with the demands of practice. If you want them to educate the public about options to medication, then they must be paid."

In fairness, bottom-line sensitivities like Singer's can be traced along a nerve that says more about the picture than the players. Entrepreneurs, experts, advocates — even the bureaucrats — all are elements of a culture that began warehousing its castoffs over a half century ago. Cheap compassion-for-hire tenements are nothing new. But the once convenient cost of that decision has soared with the current efforts of good conscience.

What that means is that we can no longer dodge the original question: Is society ready to pay what it takes to tend to the victims of its own folly?

Tim Sills is a freelance investigative reporter living in Rockaway Beach. This article is reprinted from *The Oregon Spectator*.

GOLDEN DAZE?

Confused and enfeebled seniors are unlikely candidates for initiating change in their care — no voice, no choice. This is especially true if their treatment includes prolonged sedation with classic dementia prescriptions. Such drugs usually fall into one of three slots:

- ~*anti-psychotics* (sometimes called neuroleptics; all come with unpredictable side effects; example, Haldol);
- ~*hypnotics* (highly addictive stuff; examples, Valium and Halcion);
- ~*anti-depressants* (acute loss of appetite is a frequent side effect here; example, Prozac).

New on the dementia drug block are chemicals aimed at jump-starting failed memory wiring (such as Cognex). This is in stark contrast to the predecessors listed above, which pull a number of functioning neural plugs in order to still the static of a few bad connections.

Haldol is among the most common behavior conformers used in Oregon's adult foster care homes. It is a proven calmer-downer; cognition, experience, response — the full volume of existence is on this, and all anti-psychotics, turned w-a-a-a-a-a-y down. For patients who already have troubles with awareness and communication, this is simply bad medicine.

Most of the common dementia prescriptions also hide symptoms which are the direct consequence of the sedation in question. *Tardive dyskinesia*, a condition of involuntary movements of the face, tongue and extremities, is a well known anti-psychotic reaction, often irreversible. Other such backfires include: neuroleptic malignant syndrome (NMS); bronchopneumonia; breast cancer; acute depression; liver disease; and sudden unexplained death. Moreover, no few anti-psychotics, including Haldol, are still without explanation for their mechanism of biological action.

Oregon Senior & Disabled Services would do well to read the following label precaution found on all 50-odd species of dementia prescriptions still approved by the state as routine foster care medication: "Use ONLY after alternative treatments and interventions have been exhausted."

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