

Many Illinois nursing home residents get psychotropic medications they don't want or need. The result? A threat to the lives of our elderly.



DAVID PIERINI/TRIBUNE PHOTO

**“This wasn't right. This was horrible.”**

— Patl Jockisch, whose father was drugged hours after moving into a nursing home. He then suffered a fatal fall. PAGE 5

# Drugged without cause

**By Sam Roe** | TRIBUNE REPORTER

Frail and vulnerable residents of nursing homes throughout Illinois are being dosed with powerful psychotropic drugs, leading to tremors, dangerous lethargy and a higher risk of harmful falls or even death, a Tribune investigation has found.

Thousands of elderly and disabled people have been affected, many of them drugged without their consent or without a legitimate psychiatric diagnosis that would justify treatment, state and federal inspection reports show.

Lloyd Berkley, 74, was in a nursing home near Peoria for less than a day before staff members held him down and injected him with a large amount of an antipsychotic drug, according to a state citation. A few hours later he fell, suffering a fatal head injury.

One woman was given a psychotropic drug partly because she refused to wear a bra. Nursing home staff administered an antipsychotic medication to an 87-year-old man because he was “easily annoyed.”

In all, the Tribune identified 1,200 violations at Illi-

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**FIRST OF TWO PARTS**

**Coming Wednesday: Doctors' role in misuse of psychotropics**

# Drugging seniors without cause

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nois nursing homes involving psychotropic medications since 2001. Those infractions affected 2,900 patients.

The actual numbers are likely far higher because regulators inspect some facilities just once every 15 months, and even then they usually check only a small sample of residents for harm.

The Tribune's unprecedented review of more than 400 state and federal inspection reports found that nursing homes ranging from "five-star" establishments on the North Shore to run-down facilities in urban neighborhoods have been cited for improperly administering psychotropic drugs.

The paper's review took into account violations for "chemical restraint" and "unnecessary drugs" as well as cases involving dosages that exceeded safety standards or falls in which psychotropics possibly played a role.

While some nursing home residents suffer from major mental illnesses, such as schizophrenia, the inspection reports show that many patients harmed by antipsychotic drugs had not been diagnosed with psychosis. They were disabled by Alzheimer's disease, cancer or Parkinson's disease. Some were blind or so frail that they could not breathe without the aid of an oxygen tank.

The findings come at a difficult time for Illinois nursing homes, which are already under fire for housing violent felons alongside geriatric patients and for failing to accurately assess the risk posed by the most serious offenders.

The misuse of psychotropics, which some experts say is a nationwide problem in nursing homes, suggests a troubling future for many seniors. The Tribune found 12 patients, including Berkeley, whose deaths led to nursing home citations involving misuse of psychotropics.

In testimony before Congress two years ago, Food and Drug Administration scientist Dr. David Graham estimated that thousands of nursing home residents die each year because antipsychotic drugs are administered to patients who are not mentally ill. Graham is known for blowing the whistle on Vioxx, the painkiller tied to heart attacks, but his warning on the psychotropic issue has drawn little attention.

New York researcher Christie Teigland, who is analyzing medical data on 275,000 nursing home residents with dementia, said she is finding that those on psychotropic drugs were more likely to fall or experience general decline than others.

When taken off the medication, the patients improved, she said. "These residents come alive," said Teigland, of the nonprofit New York Association of Homes & Services for the Aging. "It's like they become functional individuals again."

## Easier to deal with

Inspection records show that hundreds of nursing home residents in Illinois displaying no psychotic symptoms have been placed on antipsychotic medications for such reasons as "restlessness," "anxiety" or "acting out."

Why? Often, it's to make them easier to care for, the records show.

Some health care workers defend the use of psychotropics in nursing homes, saying they help patients, particularly those with Alzheimer's disease and other forms of dementia, live happier and more independent lives.

But the medications can be extremely dangerous. The most commonly used antipsychotics carry so-called black-box warnings, the FDA's highest advisory. Side effects may include severe lethargy, permanent involuntary muscle movements, seizures and sudden death.

For decades there were few rules regulating the sedation of nursing home residents. But in 1987, Congress passed landmark laws that protected patients from unnecessary drugs.

New facilities cannot give psychotropic drugs — which include antipsychotics, antidepressants and anti-anxiety medications — without a doctor's orders, a patient's consent and justification that the treatment is needed.

But a Tribune analysis of inspection reports on 742 Illinois nursing homes that care for traditional geriatric patients found that two-thirds of them were cited at least once in the past eight years for incidents involving psychotropics. Dozens of homes had violations year after year.

The Illinois Department of Public Health, which conducts the vast majority of the inspections, said in a statement that its ability to regulate psychotropic drugs in nursing homes "is bound by the extent of the law." The agency noted that it is a member of the state's nursing home safety task force, formed in response to an ongoing Tribune investigation, and that it "wel-



One home tried to give the antipsychotic Seroquel for 16 days to a man with no psychotic symptoms. He kept saying no, but on the 17th day, a nurse gave it to him without saying what it was. The Tribune found 600-plus instances of residents given psychotropics without consent. **JOSÉ M. OSORIO/TRIBUNE PHOTO**

## Black box warnings, side effects for antipsychotic drugs

A black box warning is included with drug label information when medical studies indicate use of a drug presents the risk of serious adverse effects.

Drug (generic name) <i>Illnesses it is used to treat</i>	BLACK BOX WARNING		
	Increased risk of death in elderly patients with dementia-related psychosis	Increased risk of suicidal thinking and behavior*	Some additional side effects (not a complete list)
<b>Abilify</b> (aripiprazole) <i>Symptoms of schizophrenia and bipolar disorder</i>	✓	✓	Fever, sudden numbness or weakness, increased thirst or urination, seizure, dizziness
<b>Geodon</b> (ziprasidone) <i>Schizophrenia and manic symptoms of bipolar disorder in adults and children at least 10 years old</i>	✓	✓	Fever, dizziness, tremor, agitation, increased thirst or urination
<b>Haldol</b> (haloperidol) <i>Schizophrenia and Tourette's syndrome</i>	✓	✓	Drowsiness, tremors, seizure, pale skin, stiff muscles, chest pain, mood changes, dizziness
<b>Risperdal</b> (risperidone) <i>Schizophrenia, symptoms of bipolar disorder and symptoms of irritability in children with autism</i>	✓	✓	Fever, stiff muscles, restlessness, muscle spasms, tremors, trouble swallowing, fainting
<b>Seroquel</b> (quetiapine) <i>Symptoms of schizophrenia and bipolar disorder in adults and children at least 10 years old</i>	✓	✓	Fever, sudden numbness or weakness, sudden headache, increased thirst, urinating less than usual or not at all
<b>Zyprexa</b> (olanzapine) <i>Symptoms of schizophrenia and bipolar disorder in adults and children at least 10 years old</i>	✓	✓	Fever, headache, confusion, increased thirst, frequent urination, fainting, nausea

SOURCE: Food and Drug Administration, Drugs.com

\*For children, adolescents and young adults

KEITH CLAXTON / TRIBUNE

comes the opportunity to improve the health and safety of long-term care residents."

State and federal inspectors document violations in reports that do not name patients but often describe in vivid terms what happened to the elderly residents, including side effects.

Investigators visiting one facility in northwest Illinois reported finding an 85-year-old woman with Alzheimer's disease who was continually pacing, a common side effect of the antipsychotic drug she was given.

"I'm sorry," the woman frequently told nursing staff. "I'm so restless and can't help it. I can't sit still."

At a north-central Illinois home, inspectors described a 78-year-old woman walking around with a blank look on her face. Her eyes were wide open, and she rarely blinked.

When health inspectors checked her medical records, they discovered that the nursing home had been giving her large doses of antipsychotic drugs, even though she was not psychotic.

The woman could barely speak to inspectors. But with the same blank expression on her face, she did manage to tell them this: "I want to go home."

## Drugged for 'yelling out'

An 84-year-old blind woman at a nursing facility in west-central Illinois was given the antipsychotic Abilify because, the home said, she was "yelling out" and "easily annoyed."

A woman with Alzheimer's at a home near East St. Louis was given the antipsychotic Seroquel because of "her inability to perform her personal hygiene."

An 86-year-old woman with congestive heart failure at a facility outside Peoria was started on the antipsychotic Zyprexa because she was teasing another resident and generally being "nasty."

These incidents all resulted in nursing homes being cited for giving drugs without a proper reason. In all, the Tribune found more than 700 instances since 2001 of facilities administering psychotropics without just cause.

To be sure, some nursing home residents can be extremely difficult to control, especially those with dementia who might repeatedly lash out at staff or try to leave. "Everybody likes to think of the nursing home resident as this nice little old gray-haired granny who's

## 5 things to know about psychotropics

**Your rights:** Nursing homes cannot give a psychotropic drug without a doctor's order, informed consent and an adequate diagnosis, according to federal and state regulations. Drugs cannot be administered simply because a resident is disruptive or restless. Rules and guidelines dictate that staff must first try to calm patients; root causes of agitation, such as an infection, must be ruled out. When drugs are given, facilities must check for side effects and reduce dosages when possible.

**The consent:** Consent forms must be signed by patients or someone with power of attorney. In general, consents must say what drug will be given, how much and how often. If a doctor wants to add a drug, the consent must be re-signed. The patient must be fully informed of risks.

**The drugs:** Psychotropics include antipsychotics, antidepressants and anti-anxiety drugs, with antipsychotics generally posing the greatest risks. Antipsychotics are intended primarily to treat serious mental illnesses, such as schizophrenia, but doctors may prescribe them "off label" for other conditions. Psychotropics may be used in nursing homes with adequate and documented justification.

**Your risks:** Some psychotropics can cause drowsiness, dizziness and confusion, which can lead to falls and extreme lethargy. Some antipsychotics can cause tardive dyskinesia, or repetitive movements such as rocking, tics, tremors and chewing. These movements can become permanent.

**To complain:** Contact the nursing home's administrator or nursing director if problems persist, call the Illinois Department of Public Health at 800-252-4343.

SOURCE: Centers for Medicare & Medicaid Services, Illinois Citizens for Better Care

a sweet little old darling," said Robert Hodges, a former nursing home regulator with the Illinois Department of Public Health who now co-owns five facilities. "There's a lot of them out there who are mean and nasty and will spit on employees and other residents and hit them and carry on."

Even then, however, standard nursing practices dictate that workers try to redirect patients' attention, such as by involving them in a new activity, showing them pictures of family or offering them a snack.

"You try a number of things before you jump to drugs," said Ellen Greif, who oversees regulatory enforcement of Midwest nursing homes for the Centers for Medicare & Medicaid Services. "You always look for the least restrictive and least invasive approach to care."

But the state inspection reports show that nursing home staffs often bypass the step of trying to calm residents and instead call a patient's doctor seeking a psychotropic drug. The doctors frequently OK the request over the phone without seeing the patient.

In some cases, an unwarranted diagnosis of mental illness is added to the patient's medical record to justify use of the drug. Residents also have been treated with psychotropics while the underlying cause of their anxiety, such as pain or an infection, was ignored.

At VIP Manor near St. Louis in 2006, a woman with Alzheimer's cried and became extremely anxious when she had to urinate. She also repeatedly asked to go to the bathroom.

Nurses responded by giving her injections of two antipsychotics, inspection reports state. When that didn't work, the woman was sent to a hospital for a psychiatric evaluation.

The psychiatrist reported back that the woman had a urinary tract infection.

VIP Manor's nursing director, whom the report did not identify, told state inspectors that her staff was still learning to look for medical issues before administering psychotropics. "We aren't there yet, but close," she said.

Sometimes, when questions are raised about treating a patient with psychotropics, doctors simply change the person's diagnosis. At Metropolis Nursing and Rehab Center in Metropolis, near the Kentucky border, a woman arrived

with diagnoses of heart disease and kidney problems. Four months later, the woman's dialysis doctor put her on the antipsychotic Risperdal. Her medical records said she was anxious because of being on dialysis, but she had no history of psychosis, according to the state's 2004 citation.

When the home's nursing director asked the doctor what diagnosis led to the use of the antipsychotic drug, the physician told her "insomnia and depression."

The nursing director told the dialysis doctor that those issues did not justify prescribing a powerful antipsychotic, so the doctor switched the diagnosis. The new one: "organic psychosis."

Officials at the home did not respond to the Tribune's requests for comment.

## Lack of consent

For 16 straight days, nurses at Heritage Nursing Home in Chicago tried to give an antipsychotic drug to a man who had a history of heart troubles but no psychotic symptoms. He steadfastly refused the medication.

But on the 17th day according to state inspection records, a nurse gave him the drug without telling him what it was until after he had swallowed it.

State inspection reports reveal more than 600 instances since 2001 of nursing homes violating regulations by giving residents psychotropic drugs without permission. Many patients received the medicine after explicitly saying they did not want it, and some with dementia have been allowed to give consent with little understanding of the consequences.

The man at Heritage was given Seroquel against his will last year. His doctor told inspectors that the 65-year-old was not psychotic, and nursing notes documented no behaviors that would justify the use of the drug.

The doctor had ordered the antipsychotic "because he thought it would help (the man's) mood," according to an inspection report. The physician said he did not know the man refused the drug — or that permission was even needed. "Once I was made aware I discontinued the medication," he said.

The state cited the nursing home, which promised to better train staff on the use of psychotropics. When contacted by the Tribune, Heritage declined to comment.

Some nursing homes cited for giving drugs without permission blame paperwork errors, saying that when regulators find problems, facilities immediately ask patients to sign consent forms. But records show that some residents and family members who sign releases may not understand the true risks of psychotropic drugs because nursing homes downplay the dangers.

In 2003, an 83-year-old woman without a diagnosis of mental illness was placed on Haldol — among the most dangerous antipsychotic drugs — two days after being admitted to the Heartland Health Care Center in Moline. A registered nurse who administered the drug told inspectors she had asked the woman whether she wanted medication for her "nervousness," and she agreed.

The state cited the home for giving an antipsychotic without reason, and the woman was taken off the medication. In a statement to the Tribune, the home said it "was cleared upon review and is currently in compliance with state and federal regulations."

## Tics, tremors, lethargy

Abnormal muscle tics, twitches and tremors, involuntary movements of the tongue, a "zoned-out"

Compromised care **TRIBUNE WATCHDOG**

look — these sights are familiar in nursing home patients, but they are not always caused by old age. They are another sign of antipsychotic drug use.

Hundreds of Illinois residents have suffered these ailments because nursing facilities have given them too many of the drugs or failed to monitor the side effects, the Tribune's analysis of inspection reports shows.

Although nursing homes are required to test for involuntary repetitive movements — a potentially permanent and life-threatening condition called tardive dyskinesia — many facilities fail to do so. When they do detect harm, they frequently do not contact doctors to reduce the doses of antipsychotic drugs. That is critical, medical experts say, because the longer patients are on the medication, the greater the chance that the abnormal movements will become permanent.

At one Downstate nursing home cited for administering unnecessary drugs, an elderly woman was on the same dose of an antipsychotic for five years even though she experienced tremors and lethargy. An inspector observed her at 9:30 a.m. in bed asleep, her breakfast tray untouched. At 11 a.m. she was in her wheelchair, "slumped over with drool coming out of her mouth." At noon she tried to drink milk, but she "spilled the milk out of the glass while trying to drink due to hand tremors."

Some residents on antipsychotic drugs become so lethargic they must be hospitalized. They cannot feed themselves, attend physical therapy or talk with loved ones. Residents once capable of caring for themselves become immobile and incontinent. It is common for nursing staff to struggle to wake up residents at mealtimes.

In addition, the Tribune found, more than 200 nursing home residents were administered psychotropic drugs and subsequently fell, at times within hours of taking the medication. Several died, and dozens broke major bones such as hips.

Because it is difficult to pinpoint why someone falls, regulators usually do not conclude that psychotropics caused the accidents. But many psychotropics cause drowsiness and confusion, and the reports often cite nursing homes for failing to consider the drugs as possible causes of the falls.

One man on multiple antipsychotics — without adequate justification — fell 48 times in a four-month span. A blind woman who did not consent to taking Risperdal fell five times after being given the medication.

At the Evergreen Nursing & Rehabilitation Center in Elmhurst, ham, southeast of Springfield, a woman who suffered from Alzheimer's and who was on numerous psychotropics fell eight times in 2008, an inspector reported. After most of the falls, the facility did not take new steps to prevent further accidents. Her last fall fractured her spine, and she died 11 days later.

The state cited the home for not considering the possibility that psychotropics were causing her to fall. In an interview with the Tribune, Hedges, the former regulator and the nursing home's co-owner, called the case "a very isolated incident" and said there was no evidence that psychotropic drugs contributed to the woman's death. He said she had complex medical and behavioral problems as well as a history of falling.

"We tried to get her family to agree to physical restraints, and they declined," he said. "You cannot have a staff member sitting there and holding a resident in a wheelchair all the time. That's not practical."

Nursing homes are required to carefully document instances when patients display side effects, but the Tribune found that some facilities misrepresented the true condition of their residents.

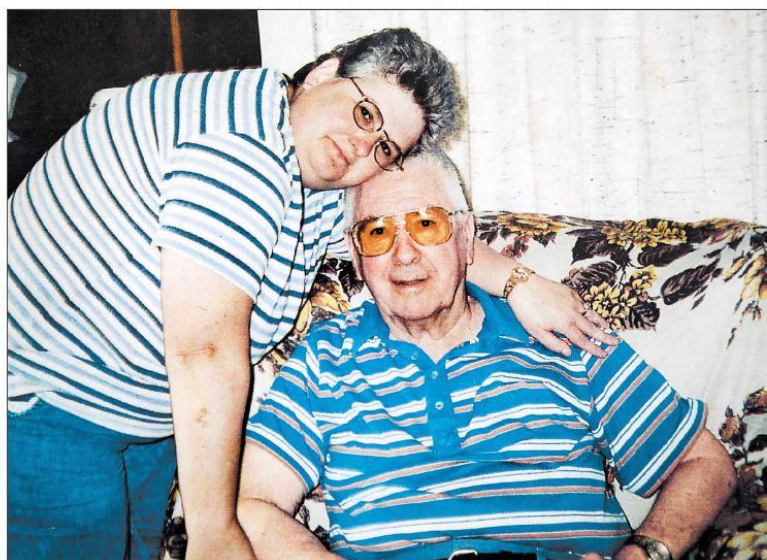
At the Tower Hill Healthcare Center in suburban South Elgin, an inspector in 2002 noticed a 78-year-old woman on two antipsychotic medications and cited the facility for unnecessary drugs. Officials at the Tower Hill facility recently declined to comment, saying it is under new ownership.

The inspector noted that the woman continually rocked back and forth over four days. Yet the facility's testing results contended that she showed no abnormal movements.

When the inspector pointed out the woman's rocking, the facility updated records to state that she "will rock in chair in attempt to get up."

But the inspector didn't buy it. "Rocking is completely involuntary and was observed even as she tried to butter her bread and eat her meal," the inspector wrote. "The behavior was not the result of an attempt to rise from the chair."

Tribune reporter Nicole Leonhardt contributed to this report.  
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"Don't let anything happen to my dad," Pati Jockisch recalled telling nursing home staff when Lloyd Berkley arrived. 2004 PHOTO COURTESY OF PATI JOCKISCH

## Sedated by force on 1st day, newcomer suffers a fatal fall

By Sam Roe and Nicole Leonhardt  
TRIBUNE REPORTERS

Just eight hours after he moved into the nursing home, state inspection records show, Lloyd Berkley was approached by four employees, one of whom had a needle behind her back.

While three of them held down the 74-year-old man, the fourth injected him with a high amount of the antipsychotic drug Haldol, which quickly sedated him, according to state records. Several hours later, Berkley fell in his room, hurt his head and died at a hospital.

The worker with the needle, investigators discovered, was not licensed as a nurse and did not have a doctor's order to give the man the medication.

Berkley's death offers a dramatic example of a common problem in nursing homes: heavily drugged residents falling and suffering injuries — or worse. Though inspectors have documented hundreds of instances of residents falling while on psychotropic drugs since 2001, authorities have done little to address the issue.

Berkley was admitted to the Pekin Living and Rehab Center in Downstate Pekin in July 2005. He had diabetes and breathed with the aid of an oxygen tank, but state and coroner records do not indicate that he was psychotic.

"This is the first time he'd been in a nursing home, which is hard for us because we had to put him there," his youngest daughter, Pati



Lloyd Berkley's wedding ring sits on his death certificate. A coroner's inquest ruled the death a homicide. DAVID PERIN/Tribune Photo

Jockisch, told investigators. "We didn't have a choice and we'd promised him we never would."

Before she walked out of the facility that day she said she told staff: "Please don't let anything happen to my dad."

A few hours later, unlicensed nurse Karissa Bent recorded in her notes that Berkley had become "very angry and combative," saying he was "going to blow up the facility with his oxygen tank," according to a state investigative report. A nurse's aide later told investigators that Berkley did not want to be in the home and tried to hit staff members.

The oxygen tank was removed from his room, and Bent, then 23, instructed three nursing aides to hold Berkley down, records show. She then injected him with the

that Bent intentionally hurt Berkley.

The Illinois Department of Public Health fined the facility \$55,000, and the home fired Bent. But the Illinois Department of Financial and Professional Regulation granted her a nursing license three months later. The department also said that if Bent agreed to a written reprimand — the lowest penalty — the agency would not pursue harsher sanctions.

"This will be on her record the rest of her career," said agency spokeswoman Susan Hofer, defending the agreement. "She will have to explain it every time she applies for a job."

Bent, now a nurse at a hospital west of Peoria, said she regrets her actions and was treated fairly by the state. She said she administered the drug without an order after unsuccessfully trying to reach the patient's doctor by phone.

Now, she said, "I won't even give a Tylenol without the doctor order."

The family settled a lawsuit against the nursing home out of court for \$380,000. The facility has since been acquired by Petersen Health Care and has changed its name to Timbercreek Rehab and Health Care. Petersen Health Care declined to comment.

Jockisch said she misses her father every day. "I'm one of those people who believe that when it's your time, it's your time," she said.

"But this wasn't right. This was horrible."

Explore the Tribune's updated nursing homes database at [chicagotribune.com/nursinghomes](http://chicagotribune.com/nursinghomes)

## Uncovering psychotropic misuse

Examples of Illinois nursing homes improperly giving psychotropic drugs to patients are often buried in state and federal inspection reports. To identify these cases, the Tribune used computer software to search for key words in more than **40,000 reports**, covering inspections at **742 Illinois facilities\*** from 2001 to 2009. Records that could not be electronically searched were obtained

through Freedom of Information Act requests. The newspaper then reviewed by hand **several thousand reports** to confirm and analyze citations involving medications that are often improperly used to sedate patients, including antipsychotics, antidepressants and anti-anxiety drugs. Incidents ranged from residents being drugged without consent to patients falling while on psychotropics.

The Tribune's database on Illinois nursing homes has been updated to include hundreds of citations for violations involving psychotropics.

**69%**  
of facilities searched had at least one violation

**1 in 12**  
had four or more violations

<p><b>666:</b> Nursing home residents suffered tremors, falls or extreme lethargy while on the drugs</p>	<p><b>483:</b> Residents suffered tremors, falls or extreme lethargy while on the drugs</p>	<p><b>68:</b> Number of times one resident fell while on psychotropics</p>
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Violations involving psychotropics

Heritage Manor-Mt. Zion

Heritage Manor-Mt. Zion has been cited at least **two times** between Jan. 1, 2001, and June 1, 2009, for violations involving psychotropic drugs. Begin reading the explanations of the violations, or read the Chicago Tribune's coverage of the misuse of psychotropic drugs in nursing homes.

- 72 residents lived at this facility
- 2 were diagnosed with a mental illness
- 4 were under 65 years of age
- 0 were felons
- 0 were registered sex offenders

Licensed nurses spent 57 minutes

\*The Tribune reviewed reports for nursing homes that have generic patients and accept Medicare or Medicaid money. It excluded facilities where all patients had a primary diagnosis of mental illness. SOURCE: Tribune reporting. NOTE: Some cases involve multiple violations. TRIBUNE