



Video: <https://www.hrw.org/report/2018/02/05/they-want-docile/how-nursing-homes-united-states-overmedicate-people-dementia>

I am Bethany Brown, a researcher on older people's human rights at Human Rights Watch. We investigate human rights violations, expose them to the world, and seek to use this leverage to create accountability for change.

Everyone in this room probably already knows that the world is rapidly aging – older people are the fastest growing population group around the world, and it is changing the shape of societies in ways that have never before been seen in human history.

Older people now account for one in seven Americans, almost 50 million people. The number of older Americans is expected to double by 2060. Put another way, one third of all babies born in the UK last year will live to celebrate their 100<sup>th</sup> birthday. The number of Americans with Alzheimer's disease, the most common form of dementia, is expected to increase from 5 million today to 15 million in 2050. The system of long-term care services and supports will have to meet the needs—and respect the rights—of this growing population in coming years.

Too often, older people are belittled, dehumanized, demeaned. Violations of their human rights go unrecognized and unpunished. Human Rights Watch is seeking to change that.

We have a long history of working for the rights of people living in institutions: Human Rights Watch has a rich body of work on the rights of children in orphanages, people with disabilities in psychiatric institutions, and has researched older people in prisons in the United States. Part of why we focus on people living in these situations is because of the inherent tension between an individual life and an institution's efficiency.

In an average week, nursing facilities in the United States administer antipsychotic drugs to over 179,000 people who do not have diagnoses for which the drugs are approved. The drugs are often given without free and informed consent, which requires a decision based on a discussion of the purpose, risks, benefits, and alternatives to the medical intervention as well as the absence of pressure or coercion in making the decision. Most of these individuals—like most people in nursing homes— are older, and have Alzheimer's disease or another form of dementia. According to US Government Accountability Office (GAO) analysis, facilities often use the drugs to control common symptoms of the disease.

While these symptoms can be distressing for the people who experience them, their families, and nursing facility staff, evidence from clinical trials of the benefits of treating these symptoms with antipsychotic drugs is weak. The US Food and Drug Administration (FDA) never approved them for this use and has warned against its use for these symptoms. Studies find that on

average, antipsychotic drugs almost double the risk of death in older people with dementia. When the drugs are administered without informed consent, people are not making the choice to take such a risk.

18.2 percent of residents in Kansas nursing facilities were on these drugs in 2016, down from 23.8 percent in 2011. Our analysis found that in 2017, the proportion of nursing home residents given antipsychotics, after excluding residents with diagnoses of Schizophrenia, Tourette's Syndrome or Huntington's Disease, and facilities where fewer than 50 percent of residents are over age 65 ranked 42nd. This is a ranking below Ohio, Missouri, and Tennessee. 32 facilities, or about ten percent of the facilities in Kansas, have 30 percent or more older residents without an exclusionary diagnosis on antipsychotics.

The drugs' sedative effect, rather than any anticipated medical benefit, too often drives the high prevalence of use in people with dementia. Antipsychotic drugs alter consciousness and can adversely affect an individual's ability to interact with others. They can also make it easier for understaffed facilities, with direct care workers inadequately trained in dementia care, to manage the people who live there. In many facilities, inadequate staff numbers and training make it nearly impossible to take an individualized, comprehensive approach to care. Many nursing facilities have staffing levels well below what experts consider the minimum needed to provide appropriate care.

In this context, inappropriate use means taking antipsychotic drugs without an exclusionary diagnosis of schizophrenia, Huntington's disease, or Tourette syndrome. Kansas has some of the highest proportions of residents on antipsychotic drugs in the country. 2550 people, about 18 percent of Kansans in nursing facilities, are on these drugs.

Federal regulations require individuals to be fully informed about their treatment and provide the right to refuse treatment. Some state laws require informed consent prior to the administration of antipsychotic drugs to nursing home residents. Yet nursing facilities often fail to obtain consent or even to make any effort to do so. While all medical interventions should follow from informed consent, it is particularly egregious to administer a drug posing such severe risks and little chance of benefit without it.

Such nonconsensual use and use without an appropriate medical indication are inconsistent with human rights norms. The drugs' use as a chemical restraint—for staff convenience or to discipline or punish a resident—could constitute abuse under domestic law and cruel, inhuman, and degrading treatment under international law.

The US has domestic and international legal obligations to protect people who live in nursing facilities from the inappropriate use of antipsychotic drugs, among other violations of their rights. These obligations are particularly important as people in nursing facilities are often at heightened risk of neglect and abuse, violations of their rights. Many individuals in nursing facilities are physically frail, have cognitive disabilities, and are isolated from their communities. Often, they are unable or not permitted to leave the facility alone. Many depend entirely on the institution's good faith and have no realistic avenues to help or safety when that good faith is violated.

US authorities, in particular the Centers for Medicare & Medicaid Services (CMS) within the US Department of Health and Human Services, are failing in their duty to protect some of the nation's most at-risk older people. On paper, nursing home residents have strong legal protections of their rights, but in practice, enforcement is often lacking. Although the federal government has initiated programs to reduce nursing homes' use of antipsychotic medications, and the prevalence of antipsychotic drug use has decreased in recent years, the ongoing forced and medically inappropriate use of antipsychotic drugs continues to violate the rights of vast numbers of residents of nursing facilities. The US government should use its full authority to enforce longstanding laws, including by penalizing noncompliance to a degree sufficient to act as an effective deterrent, to end this practice.

For example, inappropriate use of these drugs is required by CMS to be cited as a condition causing actual harm. But in Kansas, 97 percent of citations of deficiencies in nursing facilities for inappropriate use of antipsychotic drugs were classified as "no harm" deficiencies. That is 226 out of 233.

This report documents nursing facilities' inappropriate use of antipsychotic drugs in older people as well as the administration of the drugs without informed consent, both of which arise primarily from inadequate enforcement of existing laws and regulations. The report is based on visits by Human Rights Watch researchers to 109 nursing facilities, 20 of which were in Kansas, and over 300 interviews with people living in nursing facilities, their families, nursing facility staff, long-term care and disability experts, officials, and others.

*The American Psychiatric Association (APA) Practice Guideline on the Use of Antipsychotics to Treat Agitation or Psychosis in Patients with Dementia* states that, after eliminating or addressing underlying medical, physical, social, or environmental factors giving rise to manifestations of distress associated with dementia, antipsychotic drugs "can be appropriate" as a means to "minimize the risk of violence, reduce patient distress, improve the patient's quality of life, and reduce caregiver burden." However, given the "at best small" potential benefits and the "consistent evidence that antipsychotics are associated with clinically significant adverse effects, including mortality," it is essential that the drugs are used when appropriate.

Nursing facility staff, individuals living in facilities, their families, long-term care advocates, and others told Human Rights Watch that the drugs are not used only as a last resort, after all factors potentially giving rise to a person's distress have been ruled out, and after nonpharmacologic interventions have been attempted unsuccessfully. Instead, antipsychotic drugs are used sometimes almost by default for the convenience of the facility, including to control people who are difficult to manage.

One facility social worker said that one of the most common "behaviors" leading to antipsychotic drug prescriptions was someone constantly crying out "help me, help me, help me." An 87-year-old woman reflected that at her prior facility, which gave her antipsychotic drugs against her will, "they just wanted you to do things just the way they wanted." A social worker who used to work in a nursing facility said the underlying issue is that "the nursing homes don't want behaviors. They want docile." A state surveyor said: "I see way too many people overmedicated.... [Facilities] see it as a cost-effective way to control behaviors."

Human Rights Watch interviewed people who live in nursing homes and their family members who described the harmful cognitive, social, and emotional consequences of the medications that all too often should never have been administered in the first place: sedation, cognitive decline, fear, and frustration at not being able to communicate. Most or all antipsychotic drugs are associated with sedation and fatigue in people with dementia.

A 62-year-old woman in a nursing facility in Texas who said she was given Seroquel, a common antipsychotic drug, without her knowledge or consent said: “[It] knocks you out. It’s a powerful, powerful drug. I sleep all the time. I have to ask people what the day is.” The daughter of a 75-year-old woman in Kansas said that when the nursing facility began giving her mother an antipsychotic drug, her mother “would just sit there like this. No personality. Just a zombie.... The fight is gone.”

Nursing staff, social workers, long-term care ombudsmen, and state surveyors echoed this perception. One director of nursing said: “You actually see them decline when they’re on an antipsychotic. I think it’s sadder than watching someone with dementia decline.”

The use of antipsychotic drugs to control people without their knowledge or against their will in nonemergency situations violates international human rights. The practicalities of obtaining consent from an older person with dementia can be fraught. However, in many of the cases Human Rights Watch documented, nursing facilities made no effort to obtain meaningful, informed consent from the individual or a health proxy before administering the medications in cases where it clearly would have been possible to do so.

Our research suggests that in many other cases, facilities that purport to seek consent fail to provide sufficient information for consent to be informed; pressure individuals to give consent; or fail to have a free and informed consent procedure and documentation system in place. Under international human rights law, in the absence of free and informed consent, a nonemergency medical intervention that is not necessary to address a life-threatening condition is forced treatment.

One former nursing facility administrator explained:

The facility usually gets informed consent like this: they call you up. They say, “X, Y, and Z is happening with your mom. This is going to help her.” Black box warning (the government’s strongest warning to draw attention to serious or life-threatening risks of a prescription drug)? “It’s best just not to read that.” The risks? They gloss over them. They say, “That only happens once in a while, and we’ll look for problems.” We sell it. And, by the way, we already started them on it.

A current director of nursing admitted, “We are supposed to be doing informed consent. It’s on the agenda. But really antipsychotics are a go-to thing. ‘Give ‘em some Risperdal and Seroquel.’ We tell the family as we’re processing the order. The family is notified.” The daughter of a woman in a nursing facility described having consented to antipsychotic drugs for her mother

without understanding the risks: “I had no idea, not at all, that the drugs were dangerous. I had *no* idea.... I’m guessing most people have no idea.”

### Government Obligations

In 2012, CMS created the National Partnership to Improve Dementia Care in Nursing Homes, in recognition of the unacceptably high prevalence of antipsychotic drug use. While the initiative—which set targets for the industry to reduce antipsychotic drug rates—may have contributed to the reduction of the use of antipsychotic medications over the last six years, it cannot substitute for the effective regulation of nursing homes, including by ensuring that facilities face meaningful sanctions for noncompliance with mandatory standards. Our research found that CMS is not using its full authority to address this issue. Recently, CMS is in fact moving in the opposite direction, limiting the severity of financial penalties and the regulatory standards with which facilities must comply.

CMS and the state agencies with which it contracts to enforce federal regulations are not meeting their obligation to protect people from the nonconsensual, inappropriate use of antipsychotic drugs. Human Rights Watch identified several key areas of concern:

- Failure to adequately enforce the right to be fully informed and to refuse treatment or to require free and informed consent requirement. The Nursing Home Reform Act of 1987 grants residents the right “to be fully informed in advance about care and treatment,” to participate in care planning, and to refuse treatment without penalty. If it were enforced fully, these protections would not differ substantially from the right to free and informed consent. However, without adequate enforcement, current practice falls far short of this protection.
- Lack of minimum staffing regulations. Adequate numbers of sufficiently competent staff are at the crux of nursing facility care. Yet government regulations do not set a minimum staffing requirement for nursing facilities, instead requiring that facilities determine for themselves what amounts to “sufficient” and “competent” staff for their residents. While experts put minimum adequate nursing staffing time at 4.1 to 4.8 hours per resident per day, most facilities self-reported to the government providing less than that; almost one thousand facilities self-reported providing less than three hours of staff time per day.
- Weak enforcement of federal regulations specifically banning chemical restraints and unnecessary drugs. Federal regulations prohibit chemical restraints—drugs used for the convenience of staff or to discipline residents without a medical purpose—and unnecessary drugs: a technical term meaning drugs used without adequate clinical indication, monitoring, or tapering. The regulations also provide for the right to refuse treatment. However, federal and state enforcement of these regulations is so weak that the drugs are routinely misused without significant penalty. Almost all antipsychotic drug-related deficiency citations in recent years have been determined to be at the level of causing “no actual harm,” curtailing the applicability and severity of financial sanctions.

With such vast numbers of nursing facility residents still getting antipsychotic drugs that many do not need, do not want, and that put their lives and quality of life at risk, federal and state governments need to do more to ensure that the rights of residents are adequately protected. An industry entrusted to provide care—and paid billions of public and private dollars to do so—cannot justify compounding the vulnerabilities, challenges, and loss that people often experience with dementia and institutionalization.

#### Recommendations To State Legislatures:

##### *For Free and Informed Consent:*

- Pass legislation to require written, free, and informed consent prior to the administration of antipsychotic medications to individuals in state-licensed nursing facilities, ensuring that the violation of this right is actionable under state law by providing a private right of action and that individuals in need of support for decision-making are afforded it.
- Expand supported decision-making measures and amend relevant statutes to require that supported decision-making processes and supports be available and used as appropriate for people who need support to exercise their right to free and informed consent.
- Take steps to minimize and ultimately reduce to zero the number of individuals in nursing facilities who are deprived of their legal capacity, formally or informally, requiring outreach where appropriate to those who know the individual and can assist, formally or informally, with decision-making.
- Pass legislation to ensure that an individual's treating physician is not the same person authorized to make a capacity determination and determine subsequent treatment.

##### *For Adequate Minimum Staffing:*

- Pass legislation establishing stronger minimum nurse staffing levels and qualifications. Alternatively, pursue other measures to ensure staffing is adequate to provide all residents with necessary care to achieve their *highest* practicable wellbeing.

##### *For Enforcement Specific to Antipsychotic Medications:*

- Eliminate statutory provisions that curtail enforcement for lower level citations.
- Pass legislation to require nursing facilities to adopt, implement, and enforce a policy requiring any employee providing direct care to an individual with Alzheimer's disease or other forms of dementia to complete a training on providing care to meet their needs.

##### *For General Enforcement to Protect Residents' Rights and Wellbeing:*

- Pass legislation to require more significant state civil money penalties and fines instead of adhering to the federal minimum ranges, with a focus on abuse and neglect.