Using medicine in a wrong way for people with dementia in the United States

They Want Docile: How Nursing Homes in the United States Overmedicate People with Dementia
We are called Human Rights Watch.

We work to make sure that everyone in the world is treated fairly and gets their rights.

About this report

This report is about people with dementia who live in the United States.
Dementia is a problem that happens in the brain. It can make it hard for people to remember things, think and communicate.

Dementia happens more to older people.

Many people with dementia in the United States live in big homes mostly with other older people. The homes are called nursing homes.

But there can be big problems with the way people with dementia are treated. Many people with dementia are given medicine that they do not need or want.
We looked at what was happening to older people with dementia in nursing homes in the United States.

In 2016 and 2017, we visited many nursing homes in the United States.

We spoke to many people.

This includes:

- People who live in nursing homes
- The families of people who live in nursing homes
- Doctors and nurses
- Staff in nursing homes
- People who support the rights of older people with dementia

We also read lots of reports and information.
Many people with dementia in nursing homes are given medicine that they do not need.

The medicine can be used for certain health conditions.

Many people with dementia do not have these health conditions.

But staff may give people with dementia the medicine for other reasons.
People with dementia may sometimes get very upset.

Staff may give people with dementia the medicine to control the way they behave and make them quiet.

This can make work easier for staff because:

- There may not be enough staff in the nursing homes to support everyone
- Staff may not have the right training to support people with dementia.

For example, they may not know how to calm people with dementia if they are upset.

**Problems that the medicine may cause**

The medicine may be dangerous when it is used to control the way people behave and make them quiet.
People with dementia may be more likely to die if they take the medicine.

The medicine can cause other problems for people with dementia and make their lives worse.

For example, the medicine can make people very tired so they want to sleep a lot and do nothing.

The medicine can make it hard for people with dementia to talk to other people.

This can upset and scare people.

Staff often do not ask people with dementia if they want the medicine.

For example, staff may not talk to people with dementia and their families about:

- What the medicine is for
- How it might help
- What problems it might cause
- What other choices there are
This means that people with dementia:

- May not know that the medicine could be dangerous
- Cannot decide if the medicine is right for them

**What should be happening**

People with dementia should be able to choose if they want to take the medicine.

There are laws and rules in the United States about giving people medicine.
For example, there are laws and rules that say:

- People should only be given medicine if they need it for medical reasons. Not to control their behavior.

- People should get all the information they need about medicine. This will help them decide if they want to take it.

- People should be able to say no to medicine without any problems from their families, doctors or staff.

- People should help make plans about their own care.
People in nursing homes should be safe and get their rights.

But this is often not happening.

The government of the United States has done some work to stop nursing homes using medicine in this way.

But too many people with dementia still get this medicine when they do not want or need it.

This is wrong.

It goes against laws in the United States and human rights laws in the world.
The United States government should do the following things:

Stop staff giving people with dementia medicine to control the way they behave or keep them quiet.

Make sure that people with dementia in nursing homes are told:

- What the medicine is
- The good and bad things that could happen if they take it
- What other choices there are

Make sure that people with dementia can say yes or no to the medicine.

Make sure that staff:

- Do not force people to take the medicine.
- Write down what people decide
Check that nursing homes are following all the laws and rules about:

- Giving people medicine.
- People’s rights

Take action straight away if nursing homes are breaking the laws and rules.

Make sure there are enough staff in all nursing homes in the United States.

Make sure staff in nursing homes have the right training to support people with dementia in the best way.

Make sure there is better information for the public about nursing homes.

For example, information to show:

- How many hours staff spend supporting people in nursing homes every day
- How many staff stay working in nursing homes and how many leave