

## Decision aid

### Antipsychotic medicines for treating agitation, aggression and distress in people living with dementia

Information to help people living with dementia, their family members and carers and their healthcare professionals discuss the options

#### What are the options?

People living with dementia can sometimes become aggressive or very agitated. They might also hear voices or see things that are not really there (called hallucinations) or believe that something is real or true when it is not (called delusions). This can be very distressing for them and their carers, and the person may become violent. **Several things should be tried first to help calm the person** (for example music, exercise or aromatherapy). Antipsychotic medicines (often just called 'antipsychotics') can help control hallucinations and delusions and will also sedate the person (make them feel drowsy).

#### What does NICE recommend?

NICE recommends that a person should only try an antipsychotic if they are at risk of harming themselves or others, or if they are severely distressed. The antipsychotic should be tried **alongside** other activities to try to help their distress. It should be used at the lowest dose that helps the person, and for the shortest possible time. **The person should be assessed at least every 6 weeks and the antipsychotic should be stopped if it is not helping or is no longer needed.**

**The person does not have to have an antipsychotic. There are pros and cons**, which this decision aid will help your healthcare professional to explain.

#### How likely is the person to benefit?

Most people who take an antipsychotic will be less agitated (this will depend on the dose used). They will be much less likely to harm themselves or others. Many people with hallucinations or delusions will find these go or are much less troubling, but if they have difficulties communicating it might be hard to tell if the antipsychotic is helping with this. **It is not possible to know in advance what will happen to any individual person.**

## What are the side effects of antipsychotics?

The most common side effects of antipsychotics are:

- feeling sleepy or less alert (although some people have difficulty falling or staying asleep)
- headache
- changes in appetite, and weight gain
- symptoms like those of Parkinson's disease. These may include slowness or difficulty in moving, a sensation of stiffness or tightness of the muscles (making the person's movements jerky), and sometimes even a sensation of movement 'freezing up' and then restarting. The person may develop a slow shuffling walk, a tremor, increased saliva or drooling, and a loss of expression on the face.

Not everyone will get these but many people will. The higher the dose of antipsychotic and the longer the person takes it, the more likely they are to get these side effects. There are also other less common side effects, and your healthcare professional can explain further.

The most serious side effects include an increased risk of stroke and an increased risk of death. The diagrams on pages 3 and 4 show how likely this is to happen. **It is not possible to know in advance what will happen to any individual person.**

## Other things to think about

### *How are antipsychotics taken?*

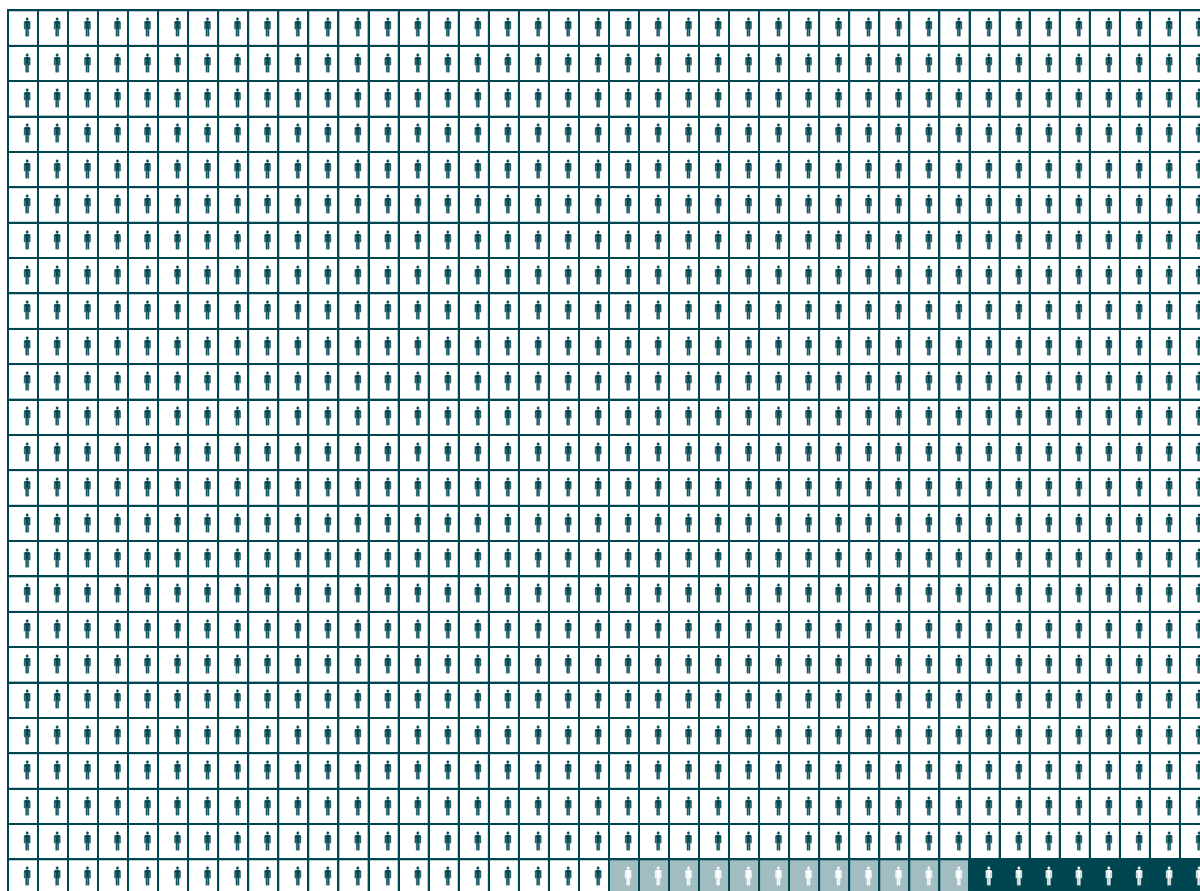
Antipsychotics are usually taken as a tablet or a liquid medicine, once or twice a day.

### *Off-label use of antipsychotics*




Only risperidone (for up to 6 weeks use) and haloperidol have a licence to treat these sorts of problems in people living with dementia. Other antipsychotics may still help, and your healthcare professional is allowed to prescribe them, but using them or using risperidone for longer than 6 weeks would be an 'off-label' use. There is more information about medicines licensing on [NHS Choices](#). Your healthcare professional can explain further about this and what it means for your decision.

Information about how this decision aid was produced and the evidence on which it is based is available on the [NICE website](#).

## Effect of antipsychotics on the risk of stroke over 6 to 12 weeks

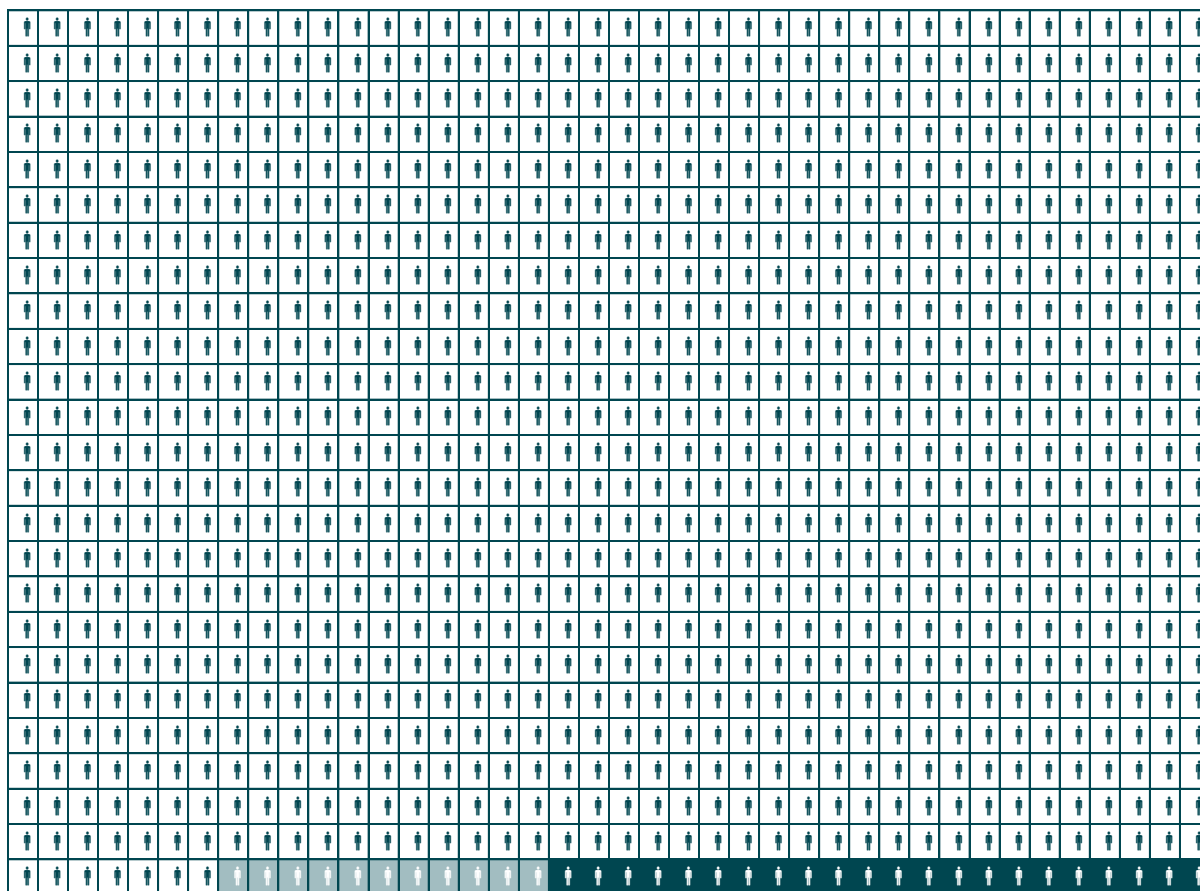


For every 1,000 people living with dementia who have hallucinations, delusions or agitation and who take an antipsychotic for 6 to 12 weeks, while they are taking it **on average**:




-  980 people do not have a stroke, whether they take an antipsychotic or not.
-  8 people have a stroke, whether they take an antipsychotic or not.
-  12 people have a stroke **because** they take an antipsychotic.

This is the **average**: some people will be at greater or lower risk of stroke. **It is not possible to know in advance what will happen to any individual person.**

## Effect of antipsychotics on the risk of death over 6 to 12 weeks



For every 1,000 people living with dementia who have hallucinations, delusions or agitation and who take an antipsychotic for 6 to 12 weeks, while they are taking it **on average**:

-  967 people do not die, whether they take an antipsychotic or not.
-  22 people die, whether they take an antipsychotic or not.
-  11 people die **because** they take an antipsychotic.

This is the **average**: some people will be at greater or lower risk of dying. **It is not possible to know in advance what will happen to any individual person.**