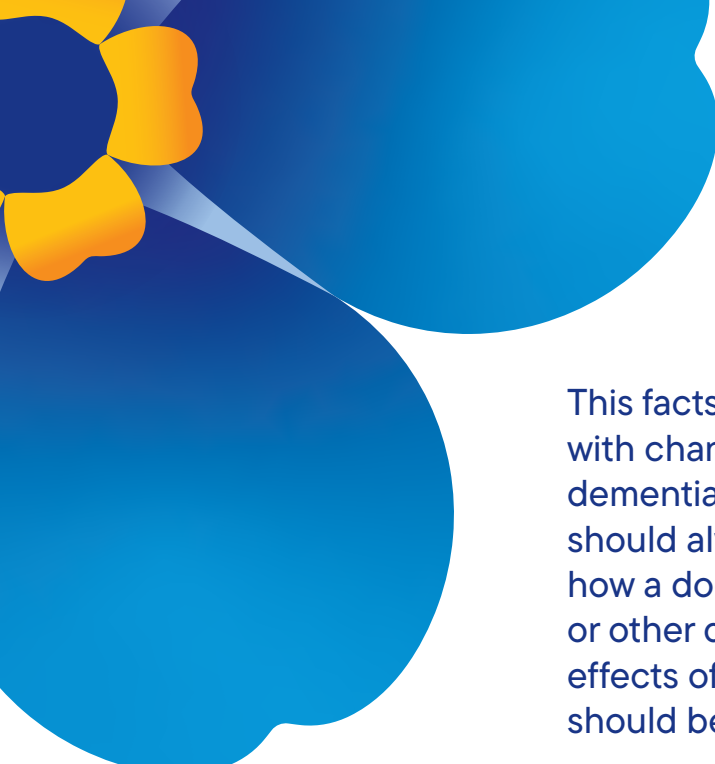


Antipsychotic drugs and other approaches in dementia care



**Alzheimer's
Society**

Together we are help & hope
for everyone living with dementia



This factsheet looks at ways of managing and coping with changes in mood and behaviour associated with dementia. It outlines the non-drug approaches that should always be tried first. It also describes when and how a doctor may decide to prescribe antipsychotics or other drugs. It looks at what the benefits and side effects of these drugs might be, and how their use should be carefully monitored.

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1 Changes in mood and behaviour

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A person with dementia will experience changes in the way they think and feel as their condition progresses. Certain tasks and activities will become more difficult.

Damage to the brain may make it harder for them to understand what is real and what isn't. This can cause them to react to situations differently from how they used to. It can also become more difficult for the person to see things from someone else's point of view. They may no longer be able to understand how their actions make someone feel.

The person may experience changes in their mood, perception and behaviour.

Changes in mood

- Depression – feeling sad, worthless, guilty or hopeless most of the time.
- Anxiety – feeling afraid, tense, worried or threatened.
- Apathy – having less energy, motivation or interest in things they used to do.

For more information on changes in mood see factsheet 444, **Supporting a person with dementia who has depression, anxiety or apathy.**

Changes in perception

- Misperceptions – when a person sees one thing as something else. For example, mistaking blue floor tiles for water.
- Misidentifications – when a person has problems identifying specific objects and people. For example, mistaking their son for their husband.
- Delusions – when a person believes things that are not true, such as a family member being a stranger.
- Hallucinations – when a person senses things (such as seeing people or hearing voices) that aren't really there.

Delusions and hallucinations are forms of 'psychosis', which is where a person loses contact with reality. For more information on changes in perception see factsheet 527, **Changes in perception.**

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Changes in behaviour

- Aggression – intimidating outbursts or trying to harm or threaten another person, either verbally (shouting, swearing or screaming) or physically (such as resisting care, slamming doors or breaking things). For more information see factsheet 509, **Aggressive behaviour**.
- Sleep problems and night-time disturbance – for example, insomnia (not being able to go to sleep or waking frequently during the night). For more information see factsheet 534, **Understanding sleep problems, night-time disturbance and dementia**.
- Losing inhibitions – behaving in ways that others may find embarrassing, such as making inappropriate comments or undressing in public.
- Agitation – becoming excited and restless without any obvious purpose – for example, pacing, fidgeting or making repetitive gestures.
- Social withdrawal – interacting and communicating less with other people and doing fewer activities.

For more information on changes in behaviour see factsheet 525, **Changes in behaviour**.

These changes can be very upsetting for the person with dementia and for those close to them. It can feel difficult to understand why they are happening. It's important to try to see things from the person's point of view, and not to blame them for their behaviour.

Changes in mood or behaviour are often signs of stress or distress. They may be an attempt by the person to communicate that something is making them feel bad. For example, they may have pain or discomfort, or feel overwhelmed and afraid. Or they may need more stimulation and interaction with other people.

Most problems improve within a few weeks of identifying the problem and making simple changes without the need for medication. Spending more time with the person or changing their daily routine are examples of small changes that can make a big difference.

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2 Non-drug approaches

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Supporting a person to get better means looking closely at their situation and working out what might be causing the problem. This means thinking about the person as an individual. Their personality, life history, likes, dislikes and relationships with other people will all affect the person's physical and mental health. As will their surroundings, their medical conditions and the types of care they are receiving.

Person-centred care

Helping the person to live well involves providing practical and emotional support, based on what you know about them. The following suggestions may be helpful:

- If the person has a hearing aid or glasses, it's important to make sure they are clean, correctly prescribed and used. If they are not being worn or are not working properly, the person may become confused or disoriented. This can lead to them becoming anxious or distressed.
- Helping the person to have a daily routine can provide them with a sense of comfort and familiarity. Sudden changes to this routine can be confusing or distressing for the person.
- The person's environment should not be too noisy, too hot or cold, uncomfortably bright or cluttered. These can cause the person to become over-stimulated and agitated.
- If the person does not have enough interaction with other people, this can sometimes contribute to changes in behaviour. Having regular one-to-one time can help significantly. When communicating, it is important to listen carefully to the person, look for non-verbal cues (such as facial expressions and body language) and try to understand the reality they are experiencing. For more advice see factsheet 500, **Communicating**.
- Staying active and involved can help to reduce feelings of stress, frustration and boredom. The person may enjoy activities that are matched to their interests and abilities. These could include arts and crafts, music, exercise, reminiscence or anything else that is meaningful for the person including things they have previously enjoyed. For more information see factsheet 529, **Physical activity and exercise** and booklet 77AC, **The activities handbook**.

It can be helpful to keep a diary of the person's behaviour and the circumstances around it. This can often help to identify and resolve reasons for their distress before they get worse.

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Visit the GP

The next step is to find out whether underlying physical or medical problems have triggered the person's changes, or made them worse. If the changes in the person's mood or behaviour are not easily resolved, they should see their GP as soon as possible to check whether the person has:

- pain or discomfort
- an infection
- problems with hearing or vision
- dehydration
- constipation
- alcohol or drug withdrawal
- problems with their metabolism
- problems with sleeping.

If any of these are found, the GP will try to manage them appropriately. They will also be able to review the person's medications. Sometimes the interaction of different medications affects the person's mood or behaviour.

Occasionally the GP will refer the person to a specialist, such as a geriatrician, psychiatrist, occupational therapist, physiotherapist or dietitian. Together they can develop a care plan specifically for the person. However, if the problem is severe or urgent the person may need to go to hospital.

If you are caring for someone and they go into hospital or a care home, staff may ask you to complete a patient information form on their behalf such as Alzheimer's Society's This is me. This form helps staff know the person better and work out what might be causing the person's distress. Try to involve the person as much as possible when filling this out. For more information go to alzheimers.org.uk/thisisme

If the GP thinks that the person could have depression or anxiety, they may recommend trying a combination of drug and non-drug approaches. For more information see factsheet 444, **Supporting a person with dementia who has depression, anxiety or apathy.**

For more information on getting help from the GP see factsheet 425, **How the GP can support a person with dementia.**

3 Drug treatments – general information

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Non-drug approaches, such as those described on pages 4–5, can be very effective in reducing changes in mood and behaviour. However in some cases they don't help the person. If their problems continue to cause them severe distress or put them or others at risk of physical harm, a doctor may need to prescribe medication. Even then, drugs should always be used alongside individualised support and non-drug approaches, based on the person's needs.

If a doctor decides that a certain drug might be helpful, they should discuss this with the person where possible, and ideally also with their carer. They should explain which specific problems the drug is being used to treat and any risks associated with taking it.

If the person has the ability (known as 'mental capacity') to do so, they must consent before they can be given the drug. The only exception to this is if they are being treated under a relevant section of the Mental Health Act 1983, or the Mental Health (Northern Ireland) Order 1986. These allow treatment without consent in exceptional situations.

If the person does not have capacity to consent, the doctor will decide whether it is in their best interests to have the drug. The doctor should still involve the person as much as possible and talk to those close to them. For more information see factsheets 460, **Mental Capacity Act 2005** and 459, **The Mental Health Act 1983**.

If the drug is prescribed, the doctor will then monitor how effective the treatment is over a limited period of weeks or months.

The person's changes in mood and behaviour should be regularly assessed alongside any side effects. The doctor will often begin by prescribing a small dose and gradually increasing this until the best balance of benefits and side effects is reached. However, if it doesn't seem to have helped, the doctor may stop the drug and try prescribing a different one instead.

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Drugs should always be taken as prescribed by the doctor and be kept safe and secure to avoid accidental overdose. A pharmacist should be able to advise on storing and taking drugs, including ways to help someone remember to take them at the right times. For some types of drugs, they might recommend a 'dosette box', which has compartments for different days and times. If the person is struggling to swallow pills or capsules, it may be possible for them to take their drugs another way, such as in liquid form or a skin patch.

A person should never suddenly stop taking a drug they have been taking regularly without first checking with their doctor or pharmacist that it is safe to do so.

All medicines have at least two names: a generic name, which identifies the active substance, and a trade name, which may vary depending on the company that makes it. For example, Risperdal is a trade name for the antipsychotic drug risperidone. This factsheet only uses generic names.

For more information about these drugs see factsheet 407, **Medicines to help memory and thinking.**

4 Antidepressant, anti-dementia and anticonvulsant drugs

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Antipsychotic drugs may be prescribed for people with dementia who develop changes such as aggression and psychosis, but usually only after other drugs have been tried. Certain antidepressants, anti-dementia drugs and anticonvulsants may be helpful in treating these changes. There is less evidence about whether some of these drugs work than there is for antipsychotics, but they generally have less severe side effects.

Antidepressants

Antidepressants such as sertraline, citalopram, mirtazapine and trazodone are widely prescribed for people with dementia who develop changes in mood and behaviour.

There is some evidence that they may help to reduce agitation – particularly citalopram. However, the dose of citalopram needed to reduce agitation may cause severe side effects, including a higher risk of falls and a dangerously irregular heartbeat. For this reason, citalopram is not licensed for treating agitation. However, some doctors may prescribe it in lower doses if they think that the person's agitation may partly be caused by anxiety or depression.

Anti-dementia drugs

The main type of drugs used to treat problems with memory and thinking are acetylcholinesterase (AChE) inhibitors. These include donepezil, rivastigmine and galantamine. They are routinely offered to people with Alzheimer's disease, dementia with Lewy bodies, Parkinson's disease dementia, or any mixed dementia that includes one of these types (for example, Alzheimer's disease with vascular dementia). They are normally prescribed soon after diagnosis and continued throughout the course of the person's dementia.

There is some evidence that these drugs may also slightly reduce agitation in people with moderate-to-severe Alzheimer's disease. They may also help to reduce hallucinations and delusions in people with Lewy body dementia. However, they are rarely prescribed specifically for these purposes because most people with these types of dementia will already be taking them anyway.

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Another drug used to treat problems with memory and thinking is memantine. This tends to be used in addition to an AChE inhibitor as dementia progresses. Memantine is sometimes prescribed to reduce levels of aggression or psychosis and has fewer risks and side effects than antipsychotic drugs. It should not be prescribed if the person has vascular dementia.

Anticonvulsants

Anticonvulsants are used to prevent fits in people with epilepsy. They are occasionally used for aggression and agitation in people with dementia. However, there is little evidence that they are effective, and they have a wide range of side effects, so they are not recommended for this purpose.

5 Antipsychotic drugs

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Antipsychotic drugs are used to treat people experiencing severe agitation, aggression or distress from psychotic symptoms, such as hallucinations and delusions. They tend to be used as a last resort, such as when the person, or those around them, are at immediate risk of harm. For some, antipsychotics can help to reduce the frequency or intensity of these changes. However, they also have serious risks and side effects, which the doctor must consider when prescribing them.

The first prescription of an antipsychotic should only be done by a specialist doctor. This is usually an old-age psychiatrist, geriatrician or GP with a special interest in dementia.

There are several antipsychotic drugs that may be used. Each has slightly different potential risks and side effects.

The drug with the most evidence to support its use in dementia is risperidone. It is licensed for short-term (up to six weeks) treatment of persistent aggression in people with moderate-to-severe Alzheimer's disease when there is risk of harm to the person or others. However, this is only if non-drug approaches have already been tried without success.

An antipsychotic called haloperidol is licensed for use in people with Alzheimer's disease or vascular dementia. However, most doctors consider its risks and side effects to be too severe. It tends to be used only as a last resort.

Other antipsychotic drugs prescribed for people with dementia are done so 'off-label'. This means that the doctor can prescribe them if they have good reason to do so, and provided they follow guidance set out by the General Medical Council.

A doctor may choose to prescribe an off-label antipsychotic drug when it offers a better balance of benefits and risks for an individual patient. For example, risperidone may be effective in people with dementia, but it also increases the risk of having a stroke. So if a person has already had a stroke it might be safer to prescribe an off-label drug that doesn't carry this risk.

The off-label antipsychotics most often used for patients with dementia are:

- quetiapine and clozapine – These drugs are mostly used if a person has dementia with Lewy bodies or Parkinson's disease dementia. This is because they interfere less with drugs that treat other symptoms of these conditions. However, there is very little evidence that they are effective. They may also cause the person to become drowsy or dizzy, which can increase the risk of falling

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- olanzapine – This is not as effective as risperidone, but may be prescribed if the doctor needs to sedate the person to stop them becoming agitated. However, it can make confusion worse, affect the person's metabolism and increase the risk of them having a stroke
- aripiprazole – This is one of the newest antipsychotic drugs. Although it works well for people with schizophrenia, there is much less evidence that it reduces hallucinations and delusions in people with dementia, so it is not often used.

Antipsychotic drug treatments should be reviewed after six or 12 weeks, or both. When the prescription of an antipsychotic is reviewed, the doctor may suggest stopping the drug in one go (for people taking a low dose of antipsychotic) or a more gradual reduction (for people on a higher dose) known as 'tapering'. In either case, the effects on the person's behavioural and psychological changes should be closely monitored. If they seem to be getting worse, it may be necessary to restart or increase the dose again.

If the person had a pre-existing mental health condition before they developed dementia and this was managed with antipsychotic drugs, they should continue to take them as prescribed by their psychiatrist.

If a person with dementia with Lewy bodies or Parkinson's disease dementia is prescribed an antipsychotic drug, it should be done with the utmost care, under constant supervision and with regular review. This is because people with these types of dementia, who often have visual hallucinations, are at particular risk of severe negative reactions to most antipsychotics. The doctor is likely to choose a drug with the least side effects, but they will only be able to use very small doses. This is unlikely to have much effect on agitation and psychosis.

Who can antipsychotic drugs help?

Some antipsychotics can have a small but significant beneficial effect on agitation, aggression and, to a lesser extent, psychosis in people with Alzheimer's disease. Improvements are normally only seen once these drugs have been taken for several weeks.

Antipsychotic drugs may be prescribed for people with Alzheimer's disease, vascular dementia or mixed dementia (which is usually a combination of these two).

Antipsychotic drugs do not help with other behaviours such as:

- distress and anxiety during personal care
- repetitive vocalisations
- walking about
- social withdrawal
- changes in levels of inhibitions (for example, doing or saying things that may be inappropriate).

These changes are likely to need personalised non-drug approaches. For more information see factsheets 501, **Walking about**, 504, **Supporting a person with washing and dressing**.

Issues with the use of antipsychotic drugs

Antipsychotic drugs can cause serious side effects, and the risk increases with continued use over weeks and months.

Possible negative effects of antipsychotics include:

- drowsiness or confusion
- shaking, unsteadiness and reduced mobility
- worse than usual dementia symptoms, such as problems with thinking and memory
- higher risk of swelling around the lower limbs
- higher risk of infections (particularly chest and urinary tract)
- higher risk of falls and fractures
- higher risk of blood clots
- higher risk of having a stroke
- higher risk of dying earlier than if they hadn't taken the drugs.

The decision to use antipsychotics should be taken very seriously. Benefits may sometimes come at the expense of the person's health and quality of life. When considering prescribing an antipsychotic, the doctor will check if the person has high blood pressure, an irregular heartbeat, diabetes or a history of strokes. This is because these conditions carry additional risks for a person taking antipsychotic drugs.

There is evidence that some people with dementia who may not need antipsychotics are still being prescribed them. For example, they are being prescribed to treat distress or aggression before non-drug approaches have been tried thoroughly. Also, some people are kept on an antipsychotic for too long without a review at 12 weeks or a clear plan for when they should come off the drug.

There is an ongoing national drive to reduce inappropriate prescribing of antipsychotic drugs in dementia, especially for people in the later stages of dementia living in residential care. Alzheimer's Society would like to see these drugs used only when they are really needed.

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Questions to ask the doctor about antipsychotic drugs


If the person with dementia can consent to taking an antipsychotic drug, they need to be properly informed about the drug. If a doctor is making the decision, the person with dementia and their carer should still be involved as much as possible and should be shown their care plan. The following questions may help with discussions:

- Why is the person being prescribed an antipsychotic? Which specific behaviours or psychological changes is the drug meant to be helping with?
- Have possible medical causes of the changes (such as infection, pain or constipation) been investigated and ruled out?
- Are there any non-drug approaches that haven't been tried which might help?
- What can I do as a carer to support the person?
- Is there anything else you need to know about the person (such as their personality, life history or other health problems) to work out what may be causing the changes?
- How will we know if the drug is working?
- What are the risks associated with taking this drug?
- What side effects might the drug cause and how can they be managed effectively?
- What is the plan for the person to come off the antipsychotic?
- When will the continued use of this drug be reviewed?

Other useful organisations

Medicines and Healthcare products Regulatory Agency (MHRA)
020 3080 6000
info@mhra.gov.uk
products.mhra.gov.uk

The MHRA products website provides detailed information on specific drugs, and the 'Yellow Card' scheme for reporting side effects.



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At Alzheimer's Society we're working towards a world where dementia no longer devastates lives. We do this by giving help to everyone who needs it today, and hope for everyone in the future.

We have more information about **Adjusting to caring for someone with dementia.**

For advice and support on this, or any other aspect of dementia, call us on **0333 150 3456** or visit **alzheimers.org.uk**

Thanks to your donations, we're able to be a vital source of support and a powerful force for change for everyone living with dementia. Help us do even more, call **0330 333 0804** or visit **alzheimers.org.uk/donate**



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