

Drugs for behavioural and psychological symptoms in dementia

Factsheet 408LP
January 2017



People with dementia often develop changes as their condition progresses. These include changes in their behaviour and feelings, the things they think and how they perceive the world. Collectively, these changes are referred to as 'behavioural and psychological symptoms'. They are often more troublesome and distressing for the person with dementia and those supporting them than problems with mental abilities, such as memory loss.

In most cases, behavioural and psychological symptoms can be successfully managed without medication. However, if non-drug approaches have not worked or if symptoms are severe, there are drugs that can be used to treat them. This factsheet looks at these drugs. It explains when and how they should be prescribed, and what the benefits and side-effects might be.

For more about non-drug approaches available see factsheets 525, **Changes in behaviour**, and 509, **Dementia and aggressive behaviour**.

The behavioural and psychological symptoms that people with dementia may develop include apathy, depression and anxiety. For information about these see factsheet 444, **Apathy, depression and anxiety**.

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Drugs for behavioural and psychological symptoms in dementia

Behavioural and psychological symptoms

Behavioural and psychological symptoms are very common in dementia. They usually develop as the person's condition progresses. They may come and go over time, or they may persist. These changes can be very distressing, both for the person with dementia and those caring for or supporting them. Distressing symptoms may include:

- Delusions – persistently believing things that are not true, such as that the carer or a family member is an impostor. This may cause the person to feel angry and behave in a hostile way.
- Hallucinations – seeing or hearing things that aren't there, such as hearing strange voices. This might make the person with dementia feel afraid and they might act defensively as a result.
- Agitation and aggressive behaviour – these are sometimes known as 'behaviours that challenge' because they are challenging for both the person and those around them.

If a person with dementia develops any of these changes, it is important to remember that they are not to blame or 'behaving badly'. Their symptoms may be a direct result of changes in their brain, or because of a general health problem such as discomfort caused by pain or infection.

These symptoms can also be related to the care a person is receiving, their environment or how they are spending their time. For example, the person may be agitated because they are anxious or because they are somewhere that is very noisy. Symptoms can become worse because the person's dementia makes it harder for them to make sense of the world.

There are a number of different ways to relieve behavioural and psychological symptoms in a person with dementia. This factsheet explains the different types of drugs that can be used. However, they shouldn't be the first thing that is tried. Most behavioural and psychological

symptoms improve within four weeks of making simple changes – such as treating pain and spending more time with the person – without the need for medication. These non-drug approaches should generally be tried first.

Non-drug approaches

Although everyone should be treated individually, it can be helpful to take a consistent approach that follows the same broad steps. The underlying principle is that behavioural and psychological symptoms should be seen as a sign of distress or an attempt to communicate an unmet need, such as being in pain or feeling threatened.

The challenge is to work out the unmet need that lies behind the person's distress, and then find a way to address this. This will mean looking at the person as an individual and thinking about their personality, history, likes and dislikes.

If you are caring for someone and they go into hospital or a care home, staff may ask you to complete a form on their behalf such as Alzheimer's Society's This is me. This form lists a person's history, preferences and routines. It can help staff know the person better and help work out what might be causing the person's distress. For more go to alzheimers.org.uk/thisisme

The first step is to find out whether any underlying physical or medical factors may have triggered, or may be aggravating the person's symptoms (making them worse). For this reason, if a person with dementia develops behavioural and psychological symptoms, they should have an assessment by their GP at the earliest opportunity.

The doctor should look for conditions such as pain, infection, constipation or the side effects of medication. If any of these are found, the doctor should try to manage them appropriately. If a mental health problem, such as depression or anxiety, is identified, treatment can be offered. For more on this see factsheet 444, **Apathy, depression and anxiety**.

It is important to make sure that the person with dementia is comfortable (for example, not thirsty or hungry) and well cared for. If the person has a hearing aid or glasses, these should also be checked. If they are not being

worn or are not working properly, this can contribute to confusion and misperceptions, and can cause the person distress.

The next step is to consider the person's environment to make sure it is not too noisy, too bright or cluttered. These can all cause the person to become over-stimulated and agitated.

Some behaviours will be a response to a specific event, perhaps an offer of personal care (such as help to undress) that was misunderstood. Keeping a diary of when behaviours happen, and what was going on at the time, may show a pattern and in doing so suggest a solution.

A person's behavioural and psychological symptoms often lessen if they are helped to stay active and stimulated. Finding interesting and engaging daily activities that are matched to the person's abilities can help. These could include arts and crafts, reminiscence or anything else that is meaningful for the person. By doing this, it is often possible to avoid the use of drugs altogether.

If a person with dementia develops any of these changes, it is important to remember that they are not to blame or 'behaving badly'. Their symptoms may be a direct result of changes in their brain, or because of a general health problem such as discomfort caused by pain or infection. These symptoms can also be related to the care a person is receiving, their environment or how they are spending their time.

Simple things such as social interaction can also prevent the need for drugs. For example, research suggests that some symptoms can be reduced by just 10 minutes of one-to-one time each day. 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 on communicating with a person with dementia see factsheet 500, **Communicating**.

Other examples of non-drug approaches that may help include life story work, physical exercise, music, dance and hand massage. For more information see factsheets 509, **Dementia and aggressive behaviour**, and 521, **Exercise and physical activity**.

If these general approaches do not work, more specialist advice may be needed. For more specialised non-drug approaches this could mean referral to a clinical psychologist, or perhaps to a music therapist or speech and language therapist. These professionals should develop a care plan created specifically for the person.

Drug treatments – general information

The non-drug approaches described above should be tried before drugs are used, unless a person's symptoms are very bad and are causing them severe distress or risk of physical harm. If they are, it may be a good idea to prescribe medication immediately, once any medical cause for the behaviour (such as pain or infection) has been ruled out. Even then, drugs must be used as well as, and not instead of, non-drug approaches.

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

The doctor should discuss with the person and/or their carer what symptom or symptoms they are prescribing a drug for, and they should then monitor how it is working. Don't expect immediate results in people taking drugs for behavioural and psychological symptoms. Any benefits may take several weeks to appear. Drugs may also stop working. This is because dementia is a degenerative condition, meaning that the chemistry and structure of the brain will change during the course of the illness.

All drugs have side-effects which are usually related to dose, so the doctor will often begin by prescribing a small dose and then gradually increase this until the best balance of benefits and side effects is achieved. This approach is sometimes known as 'start low and go slow'.

Once treatment has begun it is important that it is regularly reviewed by a doctor, often the person's GP. For antipsychotic drugs (see below), this review should be after six or 12 weeks, or both.

Drugs should always be taken as prescribed by the doctor and be kept safe and secure. They can be dangerous if accidentally taken in large quantities. 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 example, they might recommend a 'dosette' box which has compartments for different days and times. This helps to prevent someone forgetting and accidentally taking more than the recommended dose.

Antipsychotic drugs

Antipsychotic drugs (also known as 'neuroleptics' or 'major tranquillisers') are a group of medications that are usually used to treat people with mental health conditions such as schizophrenia. They are also the drugs most commonly prescribed for behavioural and psychological symptoms, such as aggression or hallucinations, in people with dementia. In some people antipsychotics can eliminate or reduce the intensity of certain symptoms. However, they also have serious side effects.

There are many antipsychotic drugs that are used to treat behavioural and psychological symptoms in dementia. Not all antipsychotics have the same benefits, and risperidone is the only one that is approved for this use. Risperidone is licensed for the short-term treatment of aggression in Alzheimer's disease, if aggression poses a risk or the person has not responded to non-drug approaches.

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 rules set out by the General Medical Council. The latest recommendations are that an antipsychotic other than risperidone should only be prescribed for a person with dementia if they have psychosis (delusions or hallucinations) that developed before – and so is not caused by – their dementia.

The risks and benefits of taking an antipsychotic should always be discussed with the person with dementia, where possible, and any carer. The first prescription of an antipsychotic should only be done by a specialist doctor. This may be an old-age psychiatrist, geriatrician or GP with a special interest in dementia. The doctor should explain the alternatives, the symptoms that are being targeted, and plans to review, reduce and stop the antipsychotic.

When the prescription 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). In either case, the effect on the person's symptoms should be closely monitored.

Who can antipsychotic drugs help?

Drug trials have shown that risperidone has a small but significant beneficial effect on aggression and, to a lesser extent, psychosis for people with Alzheimer's disease. These effects are seen when the drug is taken for a period of 6–12 weeks.

Antipsychotic drugs may be prescribed for people with Alzheimer's disease, vascular dementia or mixed dementia (when it is usually a combination of these two). If a person with Lewy body dementia (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 Lewy body dementia, who often have visual hallucinations, are at particular risk of severe adverse (negative) reactions to antipsychotics.

Antipsychotic drugs do not help with other behavioural and psychological symptoms such as distress and anxiety during personal care, restlessness or agitation. These symptoms need other, more individualised, approaches.

For people with mild-to-moderate behavioural and psychological symptoms of any kind, the National Institute for Health and Care Excellence (NICE) recommends that antipsychotic drugs should not be prescribed in the first instance. The non-drug approaches outlined above should be used for these symptoms.

People with severe psychotic or aggressive symptoms may be offered an antipsychotic drug in the first instance, before trying non-drug approaches. Symptoms are considered severe if they are happening frequently or are causing a great deal of distress – for example, very upsetting hallucinations. Severe symptoms would also include behaviour (such as physical aggression) that poses an immediate risk of harm to the person or others around them.

For example, a woman with dementia who sometimes gets irritable and shouts at care home staff would be best managed by understanding why she is distressed and how the staff are communicating with her. But someone who has hit other residents and staff, causing injury, may need short-term treatment with risperidone together with these non-drug approaches.

When an antipsychotic is given for severe symptoms like this before non-drug approaches have been tried, the prescription should still be reviewed after 6–12 weeks.

Issues with the use of antipsychotic drugs in people with dementia

Antipsychotic drugs can cause serious side effects, especially when used for longer than 12 weeks. This is why all prescriptions should be monitored and if possible stopped after 12 weeks. People can stop taking the drugs after this period with no worsening of symptoms. If distressing symptoms return, they can start taking them again. People should always consult their doctor first before they stop taking any medication.

Possible side-effects of antipsychotics include:

- sedation (drowsiness)
- parkinsonism (shaking and unsteadiness)
- increased risk of infections
- increased risk of falls
- increased risk of blood clots
- increased risk of ankle swelling
- increased risk of stroke
- worsening of other symptoms of dementia
- increased risk of death.

The risks and benefits of taking an antipsychotic should always be discussed with the person with dementia, where possible, and any carer. The first prescription of an antipsychotic should only be done by a specialist doctor. This may be an old-age psychiatrist, geriatrician or GP with a special interest in dementia. The doctor should explain the alternatives, the symptoms that are being targeted, and plans to review, reduce and stop the antipsychotic.

Because of these side effects, any benefit in reducing behavioural and psychological symptoms may be at the expense of the person's quality of life. When considering the risk of prescribing an antipsychotic, the doctor will look particularly closely at cardiovascular factors (for example, high blood pressure, irregular heartbeat, diabetes and history of stroke).

The side effects of antipsychotics were widely publicised in 2009 but there is evidence that some people with dementia who don't need antipsychotics are still being prescribed them. For example, antipsychotics are being prescribed for people with mild symptoms before non-drug approaches have been tried. Other people may be kept on an antipsychotic for too long without a review at 12 weeks or a plan for them to come off the drug.

There is an ongoing national drive to reduce the inappropriate prescribing of antipsychotic drugs. Alzheimer's Society would like to see these drugs used only when they are really needed.

Tips for carers: questions to ask the doctor about antipsychotics

Where possible, both the person with dementia and their carer should be closely involved in decisions about the person's treatment and should be shown their care plan. The following questions may help with discussions:

- Why is the person being prescribed an antipsychotic? Which symptoms is the drug meant to be helping with?
- Have possible medical causes of their symptoms (such as infection, pain or constipation) been ruled out?
- Can non-drug approaches be tried first?

- What can I do as a carer to help? Do you need to know more about the person as an individual to work out what may be causing their symptoms?
- How will we know if the drug is working?
- What side-effects might the drug cause?
- What is the plan for the person to come off the antipsychotic?
- When will the use of this drug be reviewed?

Alternative drugs to antipsychotics

Antipsychotics are the drugs most often prescribed for people with dementia who have symptoms such as aggression and psychosis, but other drugs are available. Certain anti-dementia drugs, antidepressants and anticonvulsants may also be helpful in treating these symptoms. There is less evidence about whether some of these drugs work than there is for antipsychotics, but they also generally have less severe side effects.

Anti-dementia drugs

There are two types of anti-dementia drugs that are routinely offered to people with Alzheimer's disease, mixed dementia (Alzheimer's-vascular) and sometimes dementia with Lewy bodies. The use of these drugs has been well studied in people with Alzheimer's disease and they generally cause only minor side effects. They should not be offered to people with 'pure' vascular dementia or frontotemporal dementia as they haven't been shown to bring any benefits. For more information see factsheet 407,

Drug treatments for Alzheimer's disease.

One of these drugs, memantine, slows the progression of some symptoms (eg disorientation) in people with moderate to severe Alzheimer's disease. There is some evidence that memantine also helps with aggression, agitation and delusions for people in this group.

The other anti-dementia drugs – donepezil, rivastigmine and galantamine – are known as ‘cholinesterase inhibitors’. They improve mental abilities (such as memory and concentration) in people with Alzheimer’s disease, mixed dementia (Alzheimer’s and vascular) and dementia with Lewy bodies. However, the effect of cholinesterase inhibitors on behavioural symptoms (such as aggression or agitation) is not clear.

Donepezil or rivastigmine may be tried for severe behavioural symptoms in people with dementia with Lewy bodies. This is because there is such a high risk of severe reactions to antipsychotic drugs for people with this type of dementia.

People with dementia with Lewy bodies often have hallucinations and delusions. Donepezil and rivastigmine successfully reduce these in many people with this type of dementia. NICE guidance recommends the use of a cholinesterase inhibitor for a person with dementia with Lewy bodies if psychotic symptoms are causing distress, or if challenging behaviour is posing a risk of physical harm.

Antidepressants

Antidepressants such as sertraline, citalopram, mirtazapine and trazodone are widely prescribed for people with dementia who develop depression. Some recent trials have shown that common antidepressants do not work well in this group, but they may still be tried. For more information on depression see factsheet 444, **Apathy, depression and anxiety**.

Studies have shown that the antidepressant drugs sertraline and particularly citalopram may help to reduce agitation in people with dementia. Citalopram worked about as well in people with Alzheimer’s disease as an antipsychotic. However, the dose of citalopram that was needed to do this worsened people’s memory and caused side effects to the heart. Citalopram is not licensed for treating agitation and NICE do not recommend it for this purpose – even off-label – because of the side effects.

Anticonvulsants

Anticonvulsant drugs are used to prevent fits in people with epilepsy. They are occasionally used for symptoms of aggression and agitation in people with dementia. The drug carbamazepine can be effective for the treatment of aggression, where other drugs have failed. However, carbamazepine has many side effects including sedation, falls, skin rashes, low sodium levels and blood disorders. It is often not a safe drug to use in someone with dementia.

There is now good evidence that another anticonvulsant called valproate should not be given to control agitation or aggression in people with dementia. Research is being done into the benefits of other anticonvulsants (for example, gabapentin) for people with dementia, but there is not yet enough evidence to say whether they work or not.

Factsheet 408LP

Last reviewed: January 2017

Next review due: January 2020

Reviewed by: Dr Daniel Harwood, Consultant Psychiatrist and Clinical Director and Dr Alice Mills, Clinical Psychologist, Mental Health of Older Adults and Dementia, South London and Maudsley NHS Foundation Trust

This factsheet has also been reviewed by people affected by dementia.

A list of sources is available on request.

Alzheimer's Society National Dementia Helpline England, Wales and Northern Ireland:

0300 222 1122

9am–8pm Monday–Wednesday

9am–5pm Thursday–Friday

10am–4pm Saturday–Sunday

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