

Drugs to help with the impact of dementia - *Factsheet*

Dementia web 
Information resource for carers, professionals and you

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Drugs to help with the impact of dementia

Introduction

Dementia is not an illness in itself. It is an umbrella term for a collection of conditions and diseases which cause disorders of the brain. These diseases cause a person to have difficulties with “cognitive functioning” that is, thinking, remembering and reasoning.

Another fact sheet, A Guide to Dementia Drug Treatments, explains about drugs which are sometimes used to improve cognitive functioning in people with dementia.

This fact sheet is about the drugs which are available to treat other conditions or symptoms which can affect people living with dementia. They are discussed by their generic name with their proprietary name in brackets.

Other symptoms in dementia, and some considerations:

People living with dementia may experience depression, and they may be agitated, angry, restless or anxious. They may also display psychotic symptoms, such as firmly believing someone is trying to harm them or seeing things which are not there. They may lose their inhibitions, be very disturbed or unable to sleep, and they may shout or cry out repetitively.

It should be stressed that drugs should not be the first port of call. The first step should be to eliminate possible physical causes unrelated to the person’s dementia. For example, a person may be constantly crying out, not because they are disturbed, but because they are experiencing severe toothache but cannot explain this to anyone. They may be delirious, hallucinating and disorientated simply because they have a urine infection which has caused an acute confused state. Problems with hearing or sight can make it much harder for a person to cope with the challenges of dementia.

It may also be that the person’s lifestyle is contributing to their depression or their distress. They may be living in an environment which disables them, for example, somewhere where they cannot find their way about, where noise levels are distracting, where lighting is inadequate or where there are frightening physical hazards or confusing décor. They may be bored, frightened or frustrated. Their attempts to communicate their distress through their behaviour may be seen as unacceptable or impossible to cope with by those who support them – and drugs may mistakenly be seen as the only answer.

Before turning to medication as a solution, it is important to consider all these possibilities, and to make sure that someone living with dementia is healthy, pain free, and well looked after; that, within their limitations, they are able to be occupied with appropriate activities, stimulated and kept busy and helped to maintain relationships. Provision of such a lifestyle is likely to eliminate or reduce the need for drugs.

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Important factors to bear in mind:

If drugs are to be used, a problem can arise with consent. Ideally the person should be consulted, and should agree to take the drug. This is not always possible, because the person may be unable to do this. Perhaps they may not recognise that there is a problem with their behaviour, or their mental state may mean that informed consent is not achievable.

If this is the case, the doctor should consult with all concerned before prescribing the drug, and anyone assuming responsibility for administering the drug should clearly understand the importance of sticking to the correct dose, given at the right time. There should also be an understanding of possible side effects, so that these will be recognised and can be monitored.

These drugs are not a “quick fix” and it can be weeks or months before any benefits become apparent.

Drugs used to treat depression:

It is relatively common for people living with dementia to experience depression. In the early stages, and where the dementia is progressing slowly, or only part of the brain is affected, depression may be a reaction to the diagnosis. If the depression is mild it may be relieved by an exercise programme, by an increase in activity or by various talking therapies. The use of herbal preparations or over-the-counter remedies should only be undertaken with the say so of your GP or hospital specialist who is prescribing medications.

If an anti-depressant drug is prescribed it must be understood that any improvement in how the person feels may not become evident for several weeks. The drug will normally be prescribed for at least six months, and it is important that it is taken very regularly as prescribed, not intermittently.

There are many anti-depressants, which work on various chemical systems in the brain. They will all cause some drowsiness and shakiness. Some of them, such as dothiepin (Prothiaden) or lofepramine (Gamanil) can have side effects of constipation, confusion, unsteadiness, low blood pressure or can affect the heart. They can also increase confusion. More recently developed anti-depressants, known as selective serotonin reuptake inhibitors (SSRIs), are less likely to have the above side effects. However they may initially cause stomach upsets and could cause low sodium in the blood. Commonly used SSRIs include fluoxetine (Prozac) and citalopram (Cipramil).

Antidepressants are sometimes used to treat symptoms such as repetitive behaviour or emotional ups and downs, for example, where the person has laughing or crying fits for no apparent reason.

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Drugs used to treat anxiety:

People with dementia often exhibit anxiety, and reassuring them will usually help, while at the same time looking at how their daily experience can be improved to provide more company, stimulation, activities and interest. Sometimes people's anxiety will be accompanied by severe panic attacks and fearfulness, and it may interfere with their ability to carry out normal day-to-day tasks. Severe anxiety such as this may be part of depression, and could be helped with anti-depressant drugs (see above).

Anti-anxiety drugs, known as anxiolytics, include diazepam (Valium), lorazepam (Ativan) and oxazepam (Oxazepam). All anti-anxiety drugs have side effects, and may cause over-sedation, unsteadiness - and therefore a tendency to fall. They may also increase confusion and memory loss. People can also become dependent on these drugs, and they may experience withdrawal symptoms when they stop taking them.

Drugs used to treat sleep disturbance:

Sleep disturbance in a person with dementia can cause severe problems for carers. If the person is being cared for by their partner, for example, they will find it impossible to be on the alert by day and by night as well. However, many people with dementia are elderly, and elderly people in general often do not sleep for more than five or six hours. People with dementia may also spread their sleeping over the twenty-four hours. Sometimes, mixed messages about sleeping patterns are processed by a damaged brain, and the person gets into the habit of sleeping at the "wrong" time, or even reverses the normal sleep patterns, being awake all night and asleep during the day.

Before considering hypnotic drugs, other steps which can be taken include making sure that the person avoids caffeine-based drinks around bedtime and that the bed itself, and the bedclothes, provide maximum comfort. The bedroom may be too hot or too cold, too stuffy, or maybe uncomfortably draughty. There may be a light source, such as a glass panel over the door which is causing wakefulness. If the person has difficulties with communication it could also be that pain or some bodily discomfort which they are unable to explain is causing the sleeplessness.

The person's daily routine will also have a big impact on their sleeping patterns. If they are bored and unstimulated during the day, and enjoy no exercise or activity, or if prescribed drugs cause excessive sedation, the person may spend much of the day asleep, leading to an inability to go to sleep at a time decreed by others as bedtime.

Sleeping tablets can be good in the short term at inducing sleep, and so are useful in situations where the carer or the person with dementia is clearly urgently in need of a good night's sleep. Regular use is not to be recommended; it may worsen or even cause incontinence since the person may not wake to go to the toilet. It may also cause other problems such as increased confusion and unsteadiness, which may lead to falls.

The time a person is expected to go to bed also has a bearing on the situation, because sleeping

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tablets may get someone off to sleep, but not keep them asleep for a very long period.

Sleeping tablets are not the answer as a long term treatment because they quite quickly lose their effect and the person can become dependent on them.

In addition, withdrawal, even after a short period, can be difficult, and in some cases can even cause the insomnia to worsen.

If sleeping tablets are prescribed, they may be one of the more recently developed drugs, such as zopiclone (Zimovane), which has fewer side effects, is rather less addictive and gives less of a hangover effect the next day.

Drugs used to treat psychosis:

Major tranquillisers, also known as neuroleptics and antipsychotics, are sometimes prescribed for people living with dementia who exhibit aggression, restlessness, loss of inhibition, emotional instability or psychiatric symptoms.

These drugs were developed for use in the treatment of people (not specifically elderly people) with schizophrenia, and are effective for such patients. However, virtually none of these drugs is specifically licensed for the treatment of people with dementia, and the use of some of them has been shown to be highly inadvisable, especially for those with Lewy body dementia.

Due to the brain damage caused by dementia, a person can become confused and unable to make sense of the world around them. This can lead, not surprisingly, to fear, agitation and anger. The person may be unable to explain their feelings of insecurity or frustration, or may experience pain without being able to alert anyone to the problem. The severe distress caused by the person's situation may result in behaviour which others find too distressing or difficult to cope with. Doctors are therefore often asked to prescribe antipsychotics in order to sedate the person with dementia and make them easier to "manage". These drugs are thus often being used as a form of restraint, and it is estimated that their use is inappropriate in many cases.

Only if there is severe and constant risk of harm to the person, or to others, should the use of these drugs be considered, and then only as a last resort. Basic responses such as providing the person with company, maintaining their relationships, offering activity or psychological therapies, or using music, art or reminiscence can have excellent effects and may avoid the need for drugs which, while they may reduce symptoms such as restlessness and aggression, may also reduce mobility and coherence and increase the risk of unsteadiness and falls.

There is, however, a stronger reason for avoiding the use of antipsychotics for people living with dementia. The Committee on Safety of Medicines (The CSM) has made an announcement about two of these drugs, risperidone (Risperdal) and olanzapine (Zyprexa).

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The CSM announces that these two drugs should no longer be prescribed for the treatment of behavioural symptoms in people with dementia, and also cautions against the use of similar antipsychotic drugs.

Evidence from a number of studies has shown that the risk of stroke is increased threefold in people with dementia who are prescribed risperidone (Risperdal), and the data on olanzapine (Zyprexa) appears to be similar. In addition, the side effects of anti-psychotics may include sedation, dizziness and shakiness, abnormal movements, particularly around the mouth and tongue, muscle spasms and restlessness. These drugs may accelerate the rate of decline in people with dementia and increase the risk of premature death if combined with other sedative drugs.

Antipsychotics, and risperidone (Risperdal) and olanzapine (Zyprexa) in particular, appear to be potentially highly dangerous for people with Lewy body disease. They may cause fluctuations in temperature and blood pressure, breakdown of muscle tissue and even sudden death.

For this reason, if a person with Lewy body disease is prescribed an antipsychotic drug they should be under constant close supervision and under very regular review by their GP or consultant.

The CSM advises that those currently on low doses of antipsychotics should be taken off the drug immediately. A GP should be consulted about withdrawal, but the CSM recommends that those on high doses should have their dose reduced gradually over a period of three weeks. Trials have shown that behavioural symptoms do not deteriorate significantly when someone comes off these drugs.

If you are concerned about these drugs in relation to someone you care for, or someone in a care home, you can speak to the person's GP and/or those who support them in their daily life.

You may want to know whether the person is currently being prescribed an antipsychotic drug, which one, and in what quantity.

If the answer is yes, you could ask when it is proposed to review this treatment, and how it is proposed that the drug will be discontinued. You could point out the very severe risks, particularly to someone with Lewy body disease, and refer to the announcement of the CSM.

If the person is, or was, on risperidone (Risperdal) or olanzapine (Zyprexa), you could ask if this drug has been, or is to be, replaced with an alternative anti-psychotic? If so, why? You could suggest other action is tried, such as removing obvious triggers for aggression, checking if the person might be in pain, reducing noise levels or a stressful ambiance, giving the person more opportunities for occupation, activity or exercise or trying therapies such as aromatherapy, music or reminiscence.

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Summary:

As well as problems with thinking, remembering and reasoning, people with dementia may show other symptoms such as depression, aggression, anxiety, restlessness, or sleep disturbance. They may also be quite convinced of things which are untrue, or see or hear things which are not there, and they may have lost their inhibitions.

There are a number of drug treatments which are sometimes used to alleviate these problems, and they may be helpful in some cases. They all have side effects, including excessive sedation, constipation, low blood pressure, dizziness, proneness to falls and involuntary chewing and grimacing. The efficacy of some drugs will reduce over time, and some drugs will be addictive.

Anti-psychotic drugs, also known as neuroleptics or major tranquillisers, should be used for people with dementia only with extreme caution and where every other intervention has failed.

They increase the risk of stroke threefold and are particularly dangerous for people with Lewy body disease in whom they may cause severe side effects or sudden death.

You can ask questions about the use of antipsychotic drugs for people you care for or who are supported in residential or nursing home care.

Behavioural difficulties or psychological problems can often be resolved in ways other than with drugs. Reassurance, improvements in the environment or simply spending more time with the person may help. Investigations should be made into the person's physical health, including their eyesight and hearing. The person may react very positively to plenty of social interaction and therapies such as music, reminiscence, aromatherapy or reflexology. Psychological therapies based on an in-depth understanding of the person's needs and emotions may have a profound effect on the person's well-being.

Wherever possible the person with dementia should be fully involved in making the decision to take these forms of medication. Where an assessment has been made that a person lacks the mental capacity to consent to the prescription of a medication, all those involved - doctors, family members and care workers should ensure that the action is in accordance with person's best interests as described in the Mental Capacity Act 2005.(for more information see <http://www.publicguardian.gov.uk/docs/mca-code-practice-0509.pdf>)

Further information and support

Guideposts Trust provides specialist information and care services for people with dementia and their carers: www.dementiaweb.org.uk

Contact the Helpline number: **0845 4379901**, available Monday to Friday, office hours. There is an answer service at other times. Or you can email:

info@dementiaweb.org.uk

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The Alzheimer's Society is a care and research charity for people with Alzheimer's disease (and other forms of dementia) and their families. As well as a national helpline, there are over 250 local branches.

Helpline: **0207 423 3500**

Email: enquiries@alzheimers.org.uk

Website: <http://alzheimers.org.uk>

Alzheimer's Research Trust is the leading UK research charity for dementia.

Website: www.alzheimers-research.org.uk

Alzheimer's Research Trust

The Stables
Station Road
Great Shelford
Cambridge
CB22 5LR

Telephone: **01223 843899**

Email: enquiries@alzheimers-research.org.uk

Dementia Information Service for Carers

Helpline Number **0845 1204048**

Call in normal office hours. Answer phone at other times.

Email: info@dementiaweb.org.uk

Web: www.dementiaweb.org.uk

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