

A Guide to Dementia Drug Treatments - *Factsheet*

Dementia web 
Information resource for carers, professionals and you

www.dementiaweb.org.uk



A Guide to Dementia Drug Treatments

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.

There is, at present, no drug available which offers a cure for dementia. However, there are drugs which have been licensed to treat one form of dementia, namely Alzheimer’s disease (see fact sheet on Alzheimer’s disease).

The specific drugs described here are used primarily for the purpose of temporarily improving cognitive functioning, and may delay the progression of the underlying disease for a time. They are not intended for the treatment of symptoms such as agitation, hallucinations, depression, aggression etc. (Another fact sheet “Drugs to help with the impact of dementia” deals with the different drugs which might be prescribed for these other symptoms that people might experience).

Although the drugs described here are only licensed for the treatment of Alzheimer’s disease, they may sometimes be prescribed for other forms of dementia. Doctors are able to prescribe drugs for conditions other than those for which they are licensed, as long as they have taken appropriate steps to consider the evidence available, and make arrangements for overseeing the patient’s care, monitoring and follow-up treatment. (http://www.gmc-uk.org/guidance/ethical_guidance/prescriptions_faqs.asp)

This fact sheet discusses the types of drugs which have been developed to improve the way the person functions. It tells you what they are and how they work, and describes some possible side effects. The current guidelines from NICE (The National Institute for Health and Clinical Excellence) are briefly explained, and some information about obtaining the drugs is included.

What drugs are available?

The first drug which was discovered to be effective in the improvement of cognitive functioning in Alzheimer’s disease was licensed in 1997. This was donepezil, usually known by its brand name, Aricept.

Other drugs followed over the next six years. Galantamine and rivastigmine, whose brand names are Reminyl and Exelon, like Aricept, have been licensed only for the treatment of mild to moderate Alzheimer’s disease. This is because they have not been thought to be effective for people in the later stages of this disease. Exelon, as well as being licensed for the treatment of Alzheimer’s disease, is also licensed for mild to moderate dementia in people with Parkinson’s disease.

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A fourth drug, memantine, the brand name is Ebixa, was licensed in 2002. This drug works in a different way to the others, and is licensed for the treatment of moderate to severe Alzheimer's disease.

How these drugs work:

Aricept, Reminyl and Exelon all work in the same way. They are known as acetylcholinesterase (or AChE) inhibitors.

Nerve cells in the healthy brain are helped to communicate with each other by a chemical, known as a neurotransmitter, called acetylcholine. In the brain of a person with Alzheimer's disease this chemical is attacked and broken down by an enzyme called acetylcholinesterase. Communication between brain cells is vital, and the damage caused leads to the isolation and eventual death of the brain cells. The person's symptoms will therefore worsen as levels of the neurotransmitter decrease.

These three drugs work to prevent (or inhibit) acetylcholinesterase from breaking down the important neurotransmitter, acetylcholine. In this way they enable communication between nerve cells to continue or perhaps improve. This action may temporarily slow the rate of decline, and the person's difficulties with thinking, remembering and reasoning may be seen to stabilise or even lessen.

Although these three drugs work in a very similar way, one of them might be found to be more suited to a particular person than another. It might also be that one of these drugs causes specific side effects in an individual, whereas one of the other two might not.

Ebixa is the newest drug which has been developed and it works in a different way to the other three.

Abnormally high levels of the brain chemical glutamate are released when brain cells are affected by Alzheimer's disease. An excess of glutamate is thought to be responsible for decreased nerve cell function, and, eventually, nerve cell death. Ebixa reduces the action of glutamate, thus protecting the brain cells.

How to obtain these drugs:

Aricept, Exelon and Reminyl can only be prescribed initially by a consultant, so it will be necessary for the person's GP to refer them for assessment by a specialist. Normally the specialist will conduct tests to determine how far the person's dementia has progressed, in order to determine whether the drug is likely to be effective. It is important that the views of the person with dementia and also of their carers, are taken into account when considering drug treatment. Benefits, risks and possible side effects should be discussed. It is vital that these drugs are taken exactly as prescribed, and that regular follow-up appointments are made and kept.

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Ebixa is currently not available as part of NHS care, but prescription of this drug may be sanctioned as part of a research programme.

Once a person has been approved to take these drugs by a specialist, a GP can continue to prescribe them.

It is possible to obtain all these drugs privately, through a GP, a consultant, or a private hospital. In this case there would be variable fees for each aspect to be met, for example, the consultant's fee, the charge for a private prescription and the cost of the drugs themselves.

However these drugs are obtained, the person taking them should be able to consent, and should understand that there may be risks or side effects as well as benefits. They, or their carers, should also understand the importance of making sure that the drugs are taken regularly and at the prescribed times.

How effective are these drugs?

At the outset, it must be said that these drugs are not effective for everyone. In addition, if they do prove to be of benefit, they are not a cure, and improvement in function is likely to be only temporary.

The percentage of people who benefit from treatment with Aricept, Exelon or Reminyl is thought to be between 40% to 60%. Improvements can be seen in both symptoms and functioning – people may be less anxious and more confident as well as experiencing fewer problems with memory and reasoning.

Possible side effects:

Generally all the drugs described in this fact sheet are well tolerated. The most common side effects of Aricept, Exelon and Reminyl include feeling or being sick, diarrhoea, loss of appetite, dizziness and headache. The most common side effects of Ebixa are sleepiness, dizziness, high blood pressure, constipation, headache and breathing problems.

However, not everyone will experience any side effects at all, and the degree to which they are experienced will also differ. Some side effects may only last a short time, and then disappear, whereas others may persist.

There are many cautions associated with these drugs; a few examples are their use in pregnancy or for those with certain heart problems, asthma, liver disease and stomach ulcers. This is why a careful and detailed assessment by a specialist is required before embarking on a course of treatment.

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Will these drugs work for other types of dementia?

Aricept, Exelon and Reminyl were developed for the treatment of Alzheimer's disease. In addition, Exelon is licensed as a treatment for the dementia sometimes associated with Parkinson's disease. It may be that AChE inhibitors are effective in the treatment of dementia with Lewy bodies and with vascular dementia but they are not licensed for such use by NICE. Individual medical practitioners may decide to use them "off-licence". Research is ongoing.

Guidance from NICE

The purpose of the National Institute for Health and Clinical Excellence is to review drug treatments and make a judgement as to whether they should be made available on the NHS, based on their efficacy and value for money. Until recently, Aricept, Exelon and Reminyl were approved for use for people experiencing the early to moderate stages of Alzheimer's disease.

This guidance has been updated, and it is now recommended that only people with dementia in the moderate stages of either Alzheimer's disease, or the dementia experienced by people with learning disability should have access to these drugs as part of NHS treatment.

However, it is also recognised that there should be some flexibility around what constitutes a definition of "moderate stages".

The current NICE view on Ebixa is that it should not be prescribed as part of NHS treatment – but it is recognised that research into Ebixa must continue, and it can be prescribed as part of a research programme.

NICE requires that when Aricept, Exelon or Reminyl are prescribed for someone in the moderate stage of Alzheimer's disease, certain guidelines should be followed.

These include a requirement that, as long as it suits the person, the cheapest option should be tried first, that treatment should only be sanctioned by a specialist and that it should be reviewed six-monthly. In addition, there should be an initial assessment of the person's behaviour and abilities, so that regular checks can ascertain whether or not the drug is having a positive effect.

The usual way of assessing the severity of dementia is the Mini Mental State Examination which consists of a test using a set of questions directed at the person. The maximum score is 30. A score of 21 – 26 indicates mild dementia, 10 – 20 suggests moderate dementia and under 10 indicates severe dementia.

An important recommendation is that those involved in the person's care should be consulted and their views taken into account, both at the onset of treatment and every time the treatment is reviewed.

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NICE recommends that the drug is withdrawn if it is obviously not having any beneficial effect, or if the person has a score on the Mini Mental State Examination which indicates that the dementia has progressed from “moderate” to “severe”.

NICE guidelines do not cover the use of these drugs for other forms of dementia such as dementia with Lewy bodies or vascular dementia.

Summary

Although there is no known cure for dementia, a number of drug treatments have been developed which may reduce the symptoms of dementia or delay the inevitable progression of the underlying disease. They may improve the person’s confidence to function day-to-day and may significantly assist carers in carrying out their care tasks.

These drugs will not work for everyone, and may have beneficial effects for 40% to 60% of those who are prescribed them. The effects will not be permanent, and the risks and side effects associated with any drug must be understood and taken into account.

These drugs are primarily for the treatment of Alzheimer’s disease, although there is some indication that they might have some positive effect on dementia with Lewy bodies and vascular dementia. One of them is also specifically licensed for treating the dementia associated with Parkinson’s disease.

The drugs can be obtained via a referral from the GP to a specialist or via a private prescription. If they are obtained through the National Health Service there is guidance on restricting who can have them. These are set out in guidelines from the National Institute for Health and Clinical Excellence.

If one of these drugs is prescribed, but after a regular programme of review and testing is found not to be having any beneficial effect, or if the person deteriorates and is found to be experiencing severe dementia, the drug may be withdrawn.

As with any medical treatment, you should be sure that you are aware of

- The range of options available to you.
- Their respective benefits.
- Their respective side-effects.
- Any costs involved.

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- What sort of monitoring/ follow up you will need.
- How quickly you will notice a difference, and so on and so on.

Make sure that you prepare for your meetings with your doctor by preparing a list of questions that you would like to have answered.

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 1204048** available Monday to Friday office hours, answer service at other times or by email at info@dementiaweb.org.uk

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: **020 7423 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

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Telephone: **01223 843899**

Email: enquiries@alzheimers-research.org.uk

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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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