



# Private prescription of dementia drugs

## Background

In late 2006, NHS Quality Improvement Scotland instructed health boards that drugs for Alzheimer's disease may only be prescribed on the NHS to people with moderate dementia. This means that people with mild dementia and those in the later stages may be denied treatment on the NHS. Although Alzheimer Scotland continues to campaign vigorously to overturn this decision, this information sheet has been compiled to help those who may be denied NHS drug treatment and who are considering obtaining treatment privately.

## Alzheimer's disease drugs

In the UK, there are currently four drugs licensed specifically for the treatment of Alzheimer's disease. They are sometimes used to treat the symptoms of some other forms of dementia. The drugs licensed for people in the mild to moderate stages of the illness are:

- donepezil (brand name Aricept)
- galantamine (brand name Reminyl)
- rivastigmine (brand name Exelon)

The fourth drug, called memantine (brand name Ebixa), is licensed for people in the moderately severe to severe stages of Alzheimer's disease.

These drugs do not cure Alzheimer's disease, and they do not help everyone who tries them. They are also not appropriate for every person

with dementia. They are normally prescribed only by specialists in hospitals, or GPs with specialist knowledge of dementia.

## Availability of the drugs

People have had difficulty obtaining these drugs on NHS prescription from as early as 1997 when donepezil became available in the UK, with people in some areas suffering from 'postcode prescribing'. In 2001, the National Institute for Health and Clinical Excellence (NICE) in England and Wales recommended that the NHS fund treatment for Alzheimer's disease drugs and the Health Technology Board for Scotland (HTBS) issued similar recommendations. In late 2002, memantine was launched in the UK but, following a decision in early 2004 by the Scottish Medicines Consortium, it was not recommended for use in Scotland, although it was available in England until the recent decision.

More recently, NICE conducted a cost-effectiveness appraisal of all four drugs. After much opposition it announced in late 2006 that donepezil, galantamine and rivastigmine should in future only be made available on the NHS to treat those with moderate Alzheimer's disease. NICE also recommended that memantine should not be used to treat people with moderately severe to severe Alzheimer's disease except as part of a clinical trial.

Although the NICE decision applies to England and Wales, the relevant body in Scotland, NHS Quality Improvement Scotland (NHS QIS), has

validated the NICE appraisal for the NHS in Scotland.

NICE and NHS QIS are not saying that these drugs are not clinically effective (that is, that they work well enough to help at least some of the people who try them), or that they are unsafe. Their decision is based on calculations about cost-effectiveness of the drugs (that is, how the overall cost of using the drugs for all patients compares with the value of the benefit they give for the people that the drugs help).

The Scottish Intercollegiate Guidelines Network (SIGN) reviewed the research and published guidelines in 2006 which recommend use of these treatments for all stages of Alzheimer's disease, as well as for some other forms of dementia. However, their evaluation was of clinical effectiveness, not cost effectiveness. The NICE/NHS QIS decision applies only to Alzheimer's disease. However, the drugs are not licensed for treating other forms of dementia, so it is up to individual doctors to decide whether they prescribe them. Prescribing 'off licence' in this way is at the doctor's own risk. However, if the doctor is willing to prescribe, the treatment will normally be covered by the NHS.

### **What this means for people with Alzheimer's disease in Scotland**

If you, or someone you care for, are already receiving any of these drugs you should carry on receiving them on the NHS, unless there is a good clinical reason to stop the treatment.

If you have mild Alzheimer's disease, the guidance says that you will not be eligible for treatment until your condition gets worse and you are assessed as being in the moderate stage. However, what happens in practice may be different in different parts of Scotland.

The doctor will use a test called the Mini-Mental State Examination (MMSE) to help decide what stage of Alzheimer's disease you have.

If you score between 10 and 20 points on this test, you are considered to have moderate Alzheimer's disease. You are eligible for treatment for your Alzheimer's disease on the NHS until your score falls below 10 points if your doctor believes the drugs are suitable for you.

If your doctor thinks drug treatment is right for you, he or she will normally start you off on the cheapest of the three drugs. If this isn't suitable then one of the other drugs can be prescribed instead.

You should be assessed every six months. The doctor should take your views, and those of your carer, into account in determining if the treatment is working. If the drug doesn't work for you or your MMSE score goes below 10 points, the drug will be stopped.

People with severe Alzheimer's disease will not be eligible to receive the drugs, except as part of a research study. If you score less than 10 points on the MMSE, you would be said to be in the severe stage.

### **Getting a private prescription**

Alzheimer Scotland (and many doctors) believe that if a doctor considers that you could benefit from being prescribed one of the Alzheimer's drugs, then you should be able to obtain it on the NHS. However, doctors are constrained by the guidance and people with mild dementia may feel they have to resort to private prescriptions.

Any doctor can, in theory, write a private prescription for you if they think the treatment would help you and if the doctor is willing to accept responsibility for the decision to prescribe the drug. A private prescription can be obtained through a consultant or other specialist, a private hospital, or general practitioner (GP). However, hospital doctors may not be allowed by their health boards to write private prescriptions for patients after assessing them at an NHS consultation. This

could mean you have to pay for a private consultation.

You may decide to ask your family doctor (GP) for a private prescription. GPs are not allowed to charge or accept a fee for writing a private prescription if you are registered for NHS care with that GP or another GP in the same practice.

There is nothing preventing a patient from approaching a GP in another practice to ask for a private prescription. In that case the GP is free to ask for and accept a fee. However, if you are not registered with that practice, you are unlikely to receive ongoing monitoring of the drug's effects. In addition, not all GPs are willing to issue private prescriptions, and some may feel they do not have the right expertise to prescribe the Alzheimer's disease drugs, as they are normally only prescribed by hospital specialists.

There are other advantages to staying within the NHS system for dementia care, other than reduced cost and ongoing monitoring of your condition, such as getting access to other NHS services like community nursing, continence services and various therapies.

If you get a private prescription you take it to a pharmacy or chemist. You will have to pay for the drug in full. Private prescriptions are not covered by the prescription charge and are not supplied free to people who do not pay prescription charges. You will also have to pay a dispensing fee on top of the cost of the drug.

### **Private consultations**

Private specialists will write private prescriptions if they consider the drugs would be beneficial. However, it is unlikely that they would wish to do so without arranging to monitor you for the effects of the drug. If you have arranged to see a specialist privately ask for a written estimate of any additional on-going costs associated with the prescription.

### **Dispensing charges**

The pharmacy will charge you the full cost of the drug you are prescribed plus a dispensing charge. It may pay to shop around if you can, as dispensing charges can vary from pharmacy to pharmacy and even between branches of the same company. There is no standardised formula for the pricing of private prescriptions. Alternatively, online pharmacies such as Boots may deliver to you at home and save you money.

### **Buying prescription drugs online**

Some recognised high street retailers have online dispensaries and these are subject to UK regulations. The prices they charge for dispensing may be lower than their own high street pharmacies and therefore worth investigating. This type of online dispensary supplying drugs only on prescription should not be confused with overseas online pharmacies or websites offering internet consultations and drugs supplied without prescription.

The sale of medicines is controlled in the UK by the Medicines Act 1968. However, overseas suppliers are not subject to these controls and many have websites which advertise the supply of drugs which are only available on prescription in Britain.

Avoid buying prescription drugs from unregulated suppliers. Not only are you potentially putting your health at risk by taking drugs without a medically supervised prescription, there is also no guarantee that the "drug" is, in fact, what it claims to be. It could also be contaminated by other substances.

### **Costs of the Alzheimer's drugs**

NHS boards can negotiate lower drug costs because they buy in bulk. The costs below are taken from the British National Formulary (<http://bnf.org/bnf/>) but are based on the cost to the NHS. These figures are provided as a guide but what you pay will vary, depending on the dispensing pharmacy.

### Aricept (donepezil)

Licensed in the UK at a dosage of 5mg/day and 10mg/day. Prices are £63.54 for 28 tablets of 5mg and £89.06 for 28 tablets of 10mg (excluding VAT). This equates to £828.29 and £1160.96 per year of treatment, respectively.

### Reminyl (galantamine)

The maintenance dosage is 8-12mg twice daily. Prices are £68.32 for 56 tablets of 8mg and £84.00 for 56 tablets of 12mg (excluding VAT). This equates to £890.60 and £1095.00 per year of treatment, respectively.

### Exelon (rivastigmine)

The usual maintenance dosage is 3-6mg twice daily. Prices are £68.04 for 56 capsules of 1.5mg, 3mg, 4.5mg and 6mg (excluding VAT). This equates to £886.95 per year of treatment.

### Ebixa (memantine)

The recommended maintenance dosage is 10mg twice daily. Prices are £69.01 for 56 tablets of 10mg (excluding VAT). This equates to £899.59 per year of treatment.

### Your experiences

Alzheimer Scotland is continuing the campaign to make drug treatments for dementia available on the NHS at all stages of the illness. We need to know your experiences.

Please email [alzheimerscot@alzscot.org](mailto:alzheimerscot@alzscot.org) or write to Kate Fearnley, Policy Director, Alzheimer Scotland, 22 Drumsheugh Gardens, Edinburgh EH3 7RN if you have difficulty in obtaining treatment a doctor has told you is appropriate.



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