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# MailOnline

## Fury as NICE refuses to lift restrictions on drugs for Alzheimer's sufferers

By [Jenny Hope](#)

Last updated at 2:20 AM on 11th June 2009



**Reminyl: One of the drugs for Alzheimer's sufferers that NICE has refused to fund**

Outraged doctors have condemned the Health Service's rationing body for refusing to lift restrictions on drugs for Alzheimer's sufferers.

They claim new evidence showing the drugs are cost effective for patients with mild symptoms has been ignored by the National Institute for Health and Clinical Excellence.

Since May 2006, NICE has refused to fund three drugs – Aricept, Exelon and Reminyl – for those with mild or severe forms of the disease.

Although NICE admits the drugs work on those with mild symptoms, it claims that, at £2.50 a day per patient, they provide value for

money only in 'moderate patients'.

It means many sufferers in the early stages of the disease face having to wait until their symptoms are classified as moderate to receive treatment – only to have it withdrawn again as their condition worsens.

Last October, NICE was forced to review its guidelines after a landmark legal challenge – funded by Daily Mail readers – resulted in the High Court ruling its decision to withhold treatment was 'procedurally unfair'.

Despite this, NICE will announce today that its guidance remains unchanged even though there is growing evidence that giving the drugs to patients with mild Alzheimer's could save the NHS money in the long-run.

Professor Roy Jones, of the Research Institute for the Care of Older People in Bath, said evidence, published in the journal *PharmacoEconomics*, found savings of at least £4,000 a patient could be made over ten years if treatment began in the mild stages of the disease.

'NICE got their calculations wrong according to those who devised the model used to justify the ban, but they did not want to lose face,' he added. 'I believe it is unethical to say to patients, "Come back when you've got worse" when doctors in the rest of the western world use them for patients with early symptoms.'

It is thought up to 100,000 newly diagnosed patients are being denied drug treatment each year while others – including bestselling-author Terry Pratchett – pay privately.

NICE will now carry out a routine review of Alzheimer's drugs, probably starting in September, which could take two years.

Dr Gaby Silver, of Eisai, licence holder of Aricept, said: 'This is massively frustrating for patients. Many could have been helped to retain their ability to lead a normal life for longer if scientific evidence that the drugs are cost-effective had been accepted by NICE.'

'It failed to use the opportunity it had to do the right thing.'

Neil Hunt, chief executive of the Alzheimer's Society, said: 'It is completely unacceptable to deny people with dementia the only treatments that could improve quality of life for them and their carers.'

'The glimmer of hope is that NICE has finally committed to a full review to address these concerns.'

Andrew Dillon, NICE's chief executive, said its independent advisory committee had considered its critics' statistics and had concluded 'these were not enough to make these treatments a cost-effective use of NHS resources in the mild stages of the disease'.

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My husband has been having tests for early onset Alzheimer's for two years, and as he is considered to be "borderline" specialists will not give definite diagnosis. I have been told he needs to deteriorate further. One Consultant, whom I had asked if he could prescribe medication to help slow down the illness, told us that medication does not work despite all the evidence to the contrary. I now understand why, after reading this article, that there is a reluctance to diagnose Alzheimer's as then they might I have to do something about it.

- toots, southport uk, 11/6/2009 23:21

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Just to set the record straight, NICE doesn't pay committee members. Those who make these decisions receive no pay or bonuses. And the answer to "If the doctors say that there is evidence this medication works and is cost effective..." is that doctors

don't all say that, and hard evidence doesn't back it up. I've rarely met a doctor who passes a comment on cost-effectiveness one way or the other. I didn't play any part in this decision but I've worked with NICE in the past on other things - they're decent people trying to do a very difficult job and very much aware that it's other people's money they're spending.

- Anonymous, Cornwall, 11/6/2009 16:58

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Only a government approved body could come to such a stupid and vile decision.

- paul caspari, Edgware U.K., 11/6/2009 15:09

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Of course they're not going to let people have these drugs. That would cut into their bonus money, wouldn't it.

- paul, Milton Keynes, UK, 11/6/2009 09:58

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Another Labour "jobs for the boys". These people run roughshod over our health. I myself have suffered because of their jobsworth attitude to drugs and treatment. Like Labour if they want to pass a rule that is unpopular they do it on the quiet without informed comment

- Brian, Brentwood, 11/6/2009 09:48

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Are the cost calculations holistic taking into account the impact of the sick patient on the socio-economy and not just the NHS. Where do human values fall into the calculations?

- Gabriel Alexander Khoury, Bury St Edmunds, Suffolk, UK, 11/6/2009 09:00

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Published by Associated Newspapers Ltd  
Part of the Daily Mail, The Mail on Sunday & Metro Media Group

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