

## **Anger as NICE says no to Alzheimer's appeal**

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People with dementia have been told their lives are not worth £2.50 a day as five appeals for access to dementia drugs were today turned down. The National Institute for Health and Clinical Excellence (NICE) has ruled treatments are too expensive for a cash-strapped NHS.

An internal NICE hearing rejected appeals from patient and professional groups vehemently opposed to its decision to deny treatment in the early and late stages of the disease.

The decision will force patients to wait until their condition deteriorates into a state of fear and confusion before receiving drugs that work. There is evidence that these drugs work at all stages of the disease yet NICE proposes to restrict their use on grounds of cost. Clinicians will also be banned from prescribing Ebixa, the only licensed drug available to treat distressing symptoms of late dementia such as aggression.

The Action on Alzheimer's Drugs alliance, representing over thirty charitable and professional organisations, responded in outrage:

Neil Hunt, chief executive of the Alzheimer's Society, says,

'What sort of society have we become when the health of hundreds of thousands are sold to save just £2.50 a day? This blatant cost cutting will rob people of priceless time early in the disease and later clinicians will have no choice but to use dangerous sedatives that increase the risk of heart disease and stroke. This is victimisation of the most vulnerable in society.'

Dr David Anderson, Chair Faculty of Old Age Psychiatry. Royal College of Psychiatry,

'This is a terrible decision based on a deeply flawed process. I am astonished that the appeals against this guidance have been disregarded.

Implementation of this guidance will set the treatment of Alzheimer's Disease back 10 years while the number of sufferers continues to increase rapidly. It is extremely short sighted to deny these people access to effective treatment.

'As a nation we should be ashamed that the quality of life of a person with such a serious medical condition is valued at less than £2.50 per day.'

Keith Turner, a person with Alzheimer's disease says,

'I am disgusted that NICE has rejected these appeals. What right do they have to say that relief from this terrible disease is not worth £2.50 a day? They are hiding behind processes, committees and models but I know that these drugs have given me precious time with my family. It is wrong to deny people newly diagnosed the chances that I have had. People should remember this devastating disease can strike anyone, and until we have a cure treatment is our only hope.'

Attacking NICE's findings, Neil Hunt continues,

'Psychiatrists, nurses, patients and carers all agree that NICE has got it so wrong and yet the internal appeal panel refuses to acknowledge this. NICE is allowing a hugely harmful decision to stand because they won't admit fundamental flaws in its appraisal process. It is time the government stepped in.'

Pauline Ford, Royal College of Nursing (RCN) advisor for gerontological nursing, says,

"Nice's decision removes hope and places nurses in the very difficult position of telling patients and their families that they can no longer have the drugs which we know make a big difference to their quality of life. It is also likely to

result in the increased use of sedatives as there will be no pharmaceutical alternative.”

“Nice says these drugs aren’t cost effective but many of the costs, including the human cost of stress, anxiety and depression, are being ignored. This is likely to lead to an increase in the number of people needing long term care at an earlier stage of the disease – and that cost will far outweigh the £2.50 a day for an anti-dementia drug.”

## NOTES

- The National Institute for Health and Clinical Excellence (NICE) recommends three anti-cholinesterase drugs (Aricept, Exelon, Reminyl) only be funded for people in the moderate stages. Ebixa will not be funded.
- The decision contradicts current government policy in improving access to care and commitments to improve older people’s mental health services.
- NICE has received the biggest ever response to a consultation with over 9000 people writing to protest. NICE has refused to listen.
- The only alternative to treat distressing behavioural symptoms in late dementia is unlicensed neuroleptics. These are dangerous sedatives that increase the chance of heart disease and stroke.
- NICE guidance applies to England and Wales. People currently on the drug treatments will continue to receive them.
- There are approximately 381,920 people have Alzheimer’s disease in England and Wales. Approximately 72,565 people would be in the mild stages of dementia and 309,355 people are in the moderate to severe stages.
- Dementia affects one in 20 people over the age of 65 and one in five over the age of 80.
- For information and advice on Alzheimer's disease or other forms of dementia call the Alzheimer's Society national helpline on 0845 300 0336 or visit [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

For further information please contact :

Alzheimer’s Society – 020 7306 0813