



newsletter

National Newsletter of the Alzheimer's Society

OCTOBER 2003

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Question time

What does this medicine do? How long will I need to use it? How and when should I take it? What are the possible risks and side-effects?

These are just some of the questions people using medicines are being advised to ask health care professionals as part of Ask About Medicines Week (AAMW) 2003.

AAMW – being held from 12 to 18 October – is a UK-wide event that aims to enable people to make better use of medicines by helping them get involved in decisions about medicine taking. It also aims to encourage health professionals to help us ask questions about medicines.

The week will give people who take medicines and their carers the opportunity to:

- have their views, experiences and preferences taken into account in prescribing decisions
- know that health professionals will listen to their experiences and that their questions will be answered
- gain greater understanding and safer, more appropriate use of medicines.

To raise public awareness, the AAMW executive is issuing an Ask About Medicines Week patient medicines card. This credit card-size resource features key questions for people to ask about medicines. Cards will be distributed through every pharmacy in the UK and to primary care trusts (PCTs) around the country. Ideally, PCTs will pass these cards on to GP surgeries.

The Alzheimer's Society will be using the week to highlight its campaign for Ebixa (memantine) to be provided free on the NHS for all those

with a clinical need for it. Julia Cream, the Society's head of public affairs, said: 'Ebixa was licensed in the UK in October 2002 and is the first drug for people with moderate to severe Alzheimer's disease. However, many members of the Alzheimer's Society have reported that they are being refused NHS prescriptions for Ebixa.'

During the week, the Society will also be highlighting its concern that neuroleptic drugs, otherwise known as antipsychotic or sedative drugs, are being inappropriately and over-prescribed to people with dementia. There are particular worries about their use in hospitals and care homes. In one Society survey (1997), over half of all carers said that they were not consulted on the use of drugs in residential and

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The Ask About Medicines Week logo which you may see in your local pharmacy

Alzheimer's Society
Gordon House
10 Greencoat Place
London SW1P 1PH
Tel: 020 7306 0606
Fax: 020 7306 0808
email: info@alzheimers.org.uk
www.alzheimers.org.uk

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direction

I cannot help feeling that this time of year is the real new year. It is that 'new school year' feeling, reinforced for me as my son started 'big school' just last week.

The Society's annual conference marks the start of our official new year and this year's event held in York had a definite 'all change' feel about it. Over 450 people joined us over the weekend to say a final goodbye to Harry Cayton, who has been our chief executive for the past 12 years. Laughter, love and appreciation abounded, and there was more than the odd tear!

Although we were sad to say farewell to Harry, we were delighted to welcome Neil Hunt, our new chief executive. The baton has been well and truly passed on, and although there is change in the air it shouldn't be something that worries us. The conference was about embracing change rather than mourning it and the sheer energy, passion and commitment on display by members, volunteers and staff certainly made everyone feel optimistic about the future.

Managing change while ensuring continuity, building on the past while looking to the future, growing while working out how to manage the consequences of growth – these are all conundrums that the Society has to address these days. But the fact that these challenges come as a result of success, achievement and growth should also make us glad and excited.

After his first day at school my son told me that going to school is 'better than Star Wars' – praise indeed. Back at my desk after the invigoration of our conference I am sharpening my pencils in that 'new school year' way and looking forward to the autumn term as much as he is!



Jane Bell, deputy chief executive

in the press

by Sarah Quick, press officer

Shock at US Alzheimer's figures

The August release of statistics predicting a 300 per cent increase in the number of people with Alzheimer's disease in the US by 2050 caused a flurry of press activity in a normally quiet season.

The Society's press office received a steady stream of calls from media outlets wanting our response.

Harry Cayton, the Society's former chief executive, was quoted on BBC Online: 'In the UK we estimate a 150 per cent increase by the year 2050...but the important message is that in the next 50 years there will be huge advances in research...so the likelihood is there will be effective treatments, prevention or even a cure...'

But he added: 'For this to happen we need a real increase in funding for research into dementia, which lags well behind that into other major health problems such as cancer and heart disease.'

Harry was also quoted by the Press Association and The Independent Online. The Sun, Therapy Weekly and the Evening Standard also ran the story and included quotes from the Alzheimer's Society (with the exception of The Sun, which referred to us as 'British experts').

Question time

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nursing homes.

Carers often say that it is only by asking questions about the use of neuroleptic drugs that their use is reviewed and people with dementia are taken off them.

Neuroleptics can have adverse side-effects, and are often used to compensate for poor training or lack of staff.

What is happening in Walford?

Those readers who follow Eastenders will probably be aware that the character Nana Moon is currently involved in a dementia – related story line.

During the last month she has become increasingly confused, forgetting her way home and going missing on her way to bingo. She has also been frustrated at not being able to remember things such as where she went on holiday as a child.

This story line will continue to develop over the next few months. While we are not able to reveal any details, we can say that a BBC helpline number is scheduled to be broadcast after several episodes. People who call the helpline will be given the contact details of a number of organisations, including the Society.

Nana Moon's plight has also generated some press interest, with Margery Magee, manager for Northern Ireland, appearing on the BBC's six o'clock news during September.

Margery spoke on the prime time Northern Ireland bulletin about Eastenders and the Society's local billboard campaign for its helpline. The interview featured a shot of one of the billboards and the helpline number.

AAMW is an initiative of the Medicines Partnership, the Doctor Patient Partnership and the Promoting Excellence in Consumer Medicines Information working group and is being supported by many patient groups.

Further information can be found at www.alzheimers.org.uk or www.askaboutmedicines.org



caring

Robert and Julie Breckman

In memory of Julie

by Robert Breckman

My dear Julie died on Friday 31 January 2003 at 11 in the morning. She was 64 and had had Alzheimer's disease for some ten years. For the last six years she had been at the Meadbank nursing centre with Brian, our ever-faithful pug, at her side.

I had been warned that when it happened, it would happen quickly. I received the dreaded call in my office on the Monday morning of that week. I went straight to the Meadbank and sat by her side as she slept, her breathing strong but strained.

Unbeknown to me, my children had been preparing themselves for this eventuality, too. When they heard that I was not in the office, they feared the worst. Trilby set off from Bath, and Sam and Thomas both stopped work and came to the Meadbank.

We spent most of that week with Julie, arriving at 6.30am and sitting with her for as long as we were able. She was put to bed at 5pm – after we had all left, as I did not want the memory of seeing her laying there. As the week progressed, so dear Julie faded until that Friday when she leaned forward in her chair, opened her blue eyes wide, looked at me and died.

The Meadbank staff were wonderful – stoic and calming. I was told to leave and come back in an hour. The children and I walked into Battersea Park and the four of us sat

with Brian on the bench that Julie and I had donated to the park, inscribed 'In memory of memories'. We just sat there and cried – oblivious to all.

When we returned to Meadbank, Julie had been laid out on the bed, peaceful and beautiful. I spent some time alone with her, holding her hand, and then I left. The Meadbank arranged for the collection of the death certificate and they made contact with the undertakers.

I had made plans for everything a couple of years previously. I had drawn up a list of those who would want to be told and my friends, Robin and Keith, rang everybody on it. I had chosen a non-religious ceremony to be held at the Putney Crematorium. The speakers who were to read selected poems and a eulogy had been sent their pieces two years previously.

The music had also been arranged two years before with my friend, John. It was a selection of Julie's favourite classics. One of the song's that particularly moved me was

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In memory of memories

***In memory of Julie* is the ninth article by Robert Breckman that has appeared in the *Society's Newsletter*. The other eight, which chronicle Robert's experience of caring for his late wife, Julie, can be read in the *Society's* new book *In memory of memories*.**



In memory of memories is a collection of 26 articles, first published in the *Newsletter*, by people whose lives have been affected by dementia. Most are by carers, although there are two contributions from people with dementia.

In memory of memories is available from the Society, priced £5.99 including P&P. You can order your copy using the flyer enclosed with this *Newsletter* or by sending a cheque, payable to Alzheimer's Society, to the address on the front page. Please remember to indicate which publication you are ordering.

In memory of Julie

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Irvin Berlin's 'What'll I do?' sung by Johnny Mathis. This had the whole congregation in tears. The last piece was James Brown's 'Sex machine' – a very loud and raucous piece. I loathed it but Julie loved it and we used to laugh at our respective reactions to it.

I had organised the flowers so that a carnation would be given to each person attending and, at the end of the service, we all put one on Julie's coffin while Mahler's 'Adagietto' from his Symphony No.5 played in the background.

I had wanted to be alone after the funeral but had been told that we would have to have a party. So, again, several years before, I had arranged for it to be held in Richmond Park and Patisserie Valerie would organise a cake. Victor and Robert had very cleverly transposed the picture of Julie that I had used on the funeral programme onto the cake.

I will give our friends a copy of the music from the service, together with a book of articles from the Society's monthly newsletter. This contains experiences of those touched by this terrible illness including several of my own articles. I felt the book, designed by my friend, Cliff, would be useful for others to see that they are not alone.

I really do feel that all the planning I did prior to my dear Julie's death helped me to cope. I am told by my friends that time will heal the hurt and sadness of her premature death. I don't believe it. It gets worse – but I have to go forward, I know not where.

good practice

Food for thought

by Simon Crompton



Food is a big issue for those caring for people with dementia. An Alzheimer's Society survey indicated that around 80 per cent of you have concerns that the person you care for is not eating or drinking properly.

'My grandmother slowly but surely went off her food. This was the biggest stress associated with caring,' said one carer from Northern Ireland who responded to the survey. Another, from Wales, said: 'Hospital staff took food away when my mother needed time and encouragement to eat, and sometimes interpreted no reply as 'I'm not hungry'.'

For the Alzheimer's Society too, the challenge of food has become an increasingly apparent one. The startling response to its 1999 survey, which found that only half of respondents felt that

people they cared for were given enough food in hospital, led to the Society publishing a high-profile report* calling for action from hospitals and care homes, and more practical help for carers in their homes. Last year, with Department of Health backing, it launched its Food for Thought project to try to encourage action on both fronts, educating professional caregivers and supporting carers.



'I've been surprised by the demand for the service already,' says Gwen Coleman, the state registered dietitian who co-ordinates the project.



People with dementia often eat better if they are offered additional snacks throughout the day

The issue is an important one, primarily because eating badly can reduce general physical health, energy, concentration and independence. But eating and drinking also have social and emotional associations which, for people with dementia, can provide vital opportunities to interact and links with normality and the past.



Unfortunately, the physical and behavioural changes that dementia brings often mean that people lose interest in food. Sometimes drugs affect a person's ability and desire to eat. Physical changes may make chewing or swallowing difficult. And some people with dementia overeat because they have lost the sense of when they have had enough.

But there are successful strategies that can help overcome such problems, as one carer recently testified following a training session given by a dietitian. 'It was a breakthrough,' she said. 'If only I had met her three years earlier. She was full of practical suggestions.'

What Gwen is trying to do is make such knowledge more widely available, not just to individual carers but to the hospitals and care homes which all too rarely accommodate the specific eating needs of people with dementia.

'People with dementia often eat better if they are offered additional snacks throughout the day, and we want to see hospitals and care homes offering those more. Providing pictures on menus can make choosing meals easier. A noisy and hectic environment can distract people from eating, so we'd also like to see hospitals and care homes allowing people more time to eat, and more flexible ways of eating.'

Staff can see food as a source of conflict with patients who have behavioural problems. 'My experience in training

sessions in care homes is that you need to help staff understand challenging behaviour,' says Gwen.

'A person could be unwilling to eat or drink because they don't like the way the food is presented to them. It's easy to assume that if someone can't use a knife and fork, they want to be fed. But that's not always the case. You can give people finger foods, for example, which allow people to eat as and when they want, and can often improve confidence and self-esteem. They may not want to eat because food all of one colour can look unappetising, or patterned crockery may be distracting.' Sometimes, she says, there may be a simple physical reason why a person won't eat – for example, they may have sore mouth ulcers.

The project is a resource for such insights. It has already produced three information booklets for carers, and is now working on practice guides and educational seminars for health professionals. Gwen has also found herself becoming something of an ambassador on food and dementia issues, being invited to speak at meetings organised by the Hospital Caterers Association, the NHS Better Hospital Food Programme and the British Dietetic Association. If nothing else, she hopes the project is finally helping to put eating and dementia into the spotlight.

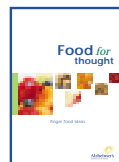


'I think the work that has already been done with hospitals and care homes is beginning to help bring the issue to the fore,' says Gwen, 'but there's still an awful lot to do.'

* *Food for thought, Alzheimer's Society, July 2000. This report is available to order from the Society, priced £3.50 including P&P. To order please send a cheque, payable to Alzheimer's Society, to the address on the front page. Please remember to indicate which publications you are ordering.*

Food for Thought publications

The Society has produced three Food for Thought leaflets on eating and nutrition for people with dementia.



Finger food ideas

Finger foods are prepared in a way that makes them easy to pick up and eat with the hands. They are ideal for people with dementia who have difficulties using cutlery or for people who like to leave the table and walk about at mealtimes. This leaflet gives examples of finger foods and menu suggestions. 8 pages, A5.



Top tips for carers

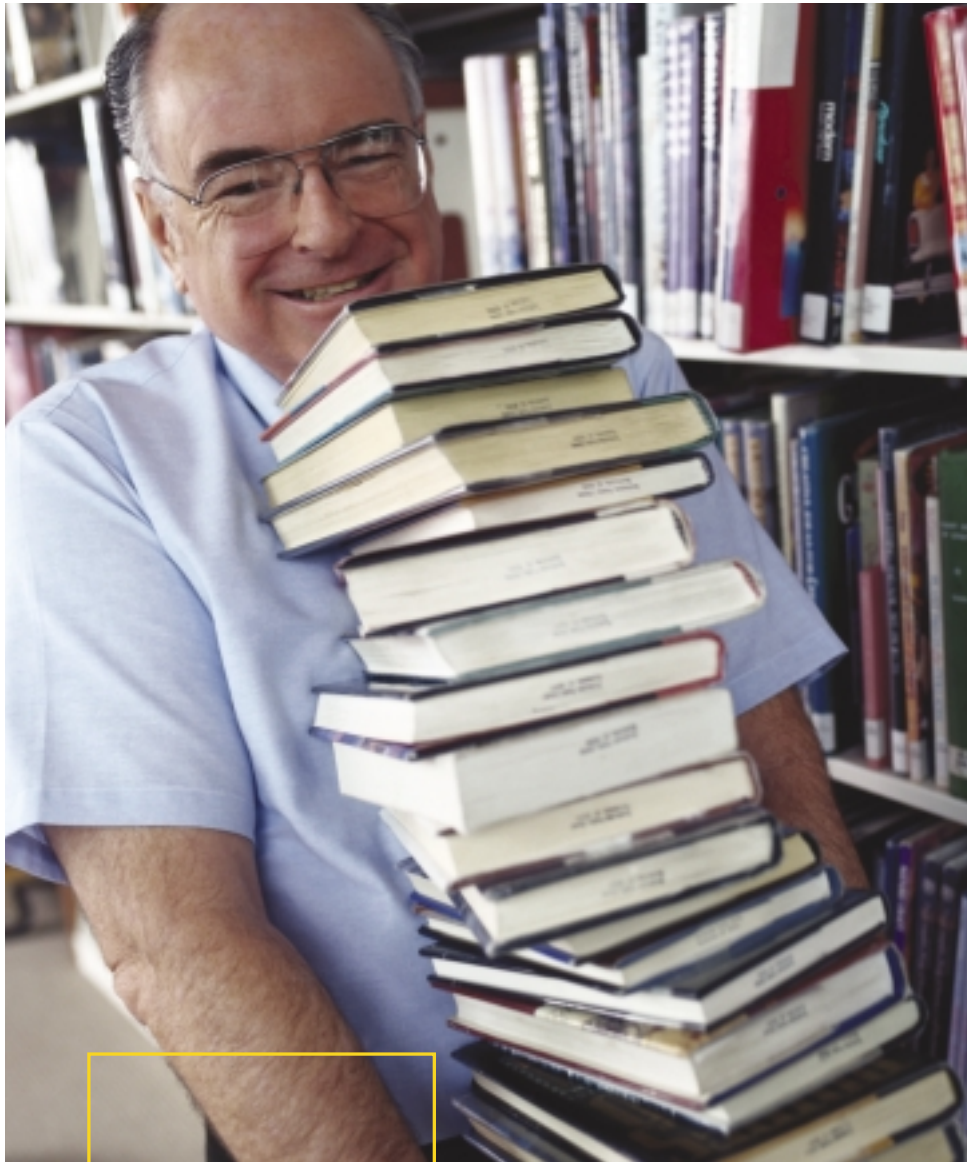
Some of the biggest challenges of caring for a person with dementia involve eating and drinking. In this leaflet, carers share their experiences and offer tips and suggestions to help overcome some of these difficulties. 16 pages, A5.



Eating and nutrition

As dementia progresses, changes in a person's eating habits and ability to eat often take place. Difficulties swallowing, changes in taste or a poor appetite can make it increasingly difficult to ensure that an adequate amount of nutritious food is eaten. This leaflet gives information about nutrition and advice on helping people with dementia eat healthily. 12 pages, A5.

Food for Thought leaflets are available from the Society, priced £2 including P&P for the set of three. To order please send a cheque, payable to Alzheimer's Society, to the address on the front page. Please remember to indicate which publications you are ordering.



research

Learning to avoid Alzheimer's disease?

Sophie Petit-Zeman

The 'use it or lose it' theory of Alzheimer's disease received a boost in June, when American researchers reported that people educated for longer are at reduced risk of developing severe dementia.

Dr David Bennett, director of the Alzheimer's disease center at Rush-Presbyterian-St Luke's Medical Center in Chicago led the research team, which examined the brains of 130 people who had died. All had previously been diagnosed with Alzheimer's disease and had also taken tests of cognitive function – essentially, their brain's agility – on average eight months before death.

When looking at the brains in detail, the researchers measured the number and extent of amyloid plaques, which are clumps of protein thought to clog up the brain and cause Alzheimer's disease. They then compared the changes in the brains with the results of the mental agility tests and found that men and women with more years of education had less decline in mental ability, even when the extent of changes in their brain characteristic of Alzheimer's disease were identical.

To make this assessment, the researchers used a clever scoring system, in which the average participant scored 100 on mental agility. They found that the presence of 18 plaques – more than enough for a diagnosis of Alzheimer's disease – lowered the score of someone who had only had a little college education to 82. People with the same number of plaques in their brain, but who had done postgraduate study, had maintained an impressive score of 96.2.

Dr Bennett said, '[The research shows] there is something about education that allows the brain to tolerate a much larger burden of Alzheimer's disease without depressing cognitive functions.' One possible explanation is that education somehow increases the number of synapses, which are connections between cells in the brain and via which they communicate during mental activity. Indeed, Neil Buckholtz, who is chief of the dementias of aging branch at the National Institute on Aging which funded the latest study, is optimistic that further examination of the brain tissue may give useful clues as to the processes underway in the brain. He says, 'What we have to do now is look at a greater range of education, as well as try to figure out what the mechanisms are.'

Dr Bennett commented that while 'there is fairly good evidence that education and things related to education protect against getting the clinical signs of Alzheimer's disease', many types of mental activity seem to be good for the aging brain. Indeed, a study reported just a week earlier had found that playing musical instruments, cards, board games and dancing were linked to reduced risk of

developing Alzheimer's disease. Dr Bennett says, 'It's a question of information processing, and even playing games is information processing.' He also cites the possible value of simply having conversations with people.

This is not the first time that levels of education have been linked to the risk of developing dementia. A study of almost 900 pairs of Swedish twins, reported at the World Alzheimer's Congress in 2000, pointed to a higher incidence of Alzheimer's disease and other forms of dementia among study participants with six years or fewer of schooling.

It remains unclear just what protective effect education might be having within the brain, and how and why this becomes apparent so many years later. There will also always be exceptions to any finding. Many highly educated people, such as the late Iris Murdoch, a prolific author and successful academic, succumb to the ravages of the condition, while many who have received less extensive formal education do not.

Susanne Sorensen, the Society's new head of research, also points out that while mental activity may help to build up a brain reserve which can protect against the changes of Alzheimer's disease in later life, 'Static mental exercise alone may not be enough.' As she points out 'Maintaining physical activity has been linked to better general health as people get older, preventing cardiovascular disease and falls. This latest research should not be taken as a recommendation to concentrate only on cerebral exercise.'

If education really boosts brain function and reduces the risk of dementia, we need to know more about the stages in life when it can have this impact. Alternatively perhaps, education simply acts as a marker for people with what Margaret Gatz refers to as 'A higher cognitive reserve'. Put another way, maybe it is most often those people whose brains already have more cells and connections who tend to go on to higher education, and it is this innate property rather than any effect of their education which is in fact protective. Whatever the answer, it seems that doing the crossword puzzle and then taking a stroll round the block may well be a good idea!

The pension credit

This month sees the introduction of a new type of income for people aged 60 or over – the pension credit. The government says that up to half of all pensioners will benefit from the pension credit.

The pension credit guarantees everyone aged 60 and over an income of at least £102.10 a week for single people or £155.80 a week for those who have a partner. The person who applies for pension credit must be at least 60; it does not matter if their partner is under 60.

There will be higher amounts for some disabled people, carers and homeowners with certain housing costs. And for the first time, people aged 65 and over will be rewarded for having income and savings by being given extra money.

How is the pension credit made up?

The pension credit has two parts: the guarantee credit and the savings credit. Some people will get both the guarantee and savings elements, while others may receive either one or the other.

The guarantee credit replaces the current minimum income guarantee (MIG – income support for people over 60) and will work in the same way, by topping a person's income up to a set level.

The savings credit is extra money for people aged 65 or over who have income above the basic retirement pension level or who have savings or investments. It is based on the total amount of income a person has, including income received from private or occupational pensions.

How to apply

People who are already getting MIG/income support do not need to make a claim for pension credit – they will automatically be transferred. Those who do not receive MIG will need to claim.

Between April 2003 and June 2004, the pension service is writing to all people aged 60 and over to help them decide whether to apply for pension credit. Those who have not yet claimed will not lose out – so long as they claim before October 2004, their pension credit will be backdated to October of this year.

People can provide the details needed to work out their pension credit claim over the telephone. The pensions service will then send them a statement of the details given, which should be signed and returned to confirm that these are correct.

To apply for pension credit, ring the pension service on 0800 99 1234 (Monday to Friday, 8am-8pm; Saturday 9am-1pm). The textphone number is 0800 169 0133.

You will need the following details when you phone:

- Your national insurance (NI) number. You can get this from your pension book, payslips, tax papers or letters from the benefits agency
- Information about any income you have
- Information about any savings and investments that you have.

I wish to become a member

of the Alzheimer's Society and receive the monthly newsletter

Mr/Mrs/Miss/Ms _____

Address _____

Postcode _____

Telephone _____

I enclose my payment for: £10 £25
 £50 Other £_____

There is no fixed subscription – please give generously (thank you). If you are a person with dementia or carer and would appreciate free membership, please tick the box:

I would like to pay by cheque (payable to Alzheimer's Society)

I would like to pay by Visa/Mastercard/Switch

Card number _____

Expiry date _____

start date (Switch only) _____

Issue number (Switch only) _____

Signature _____

Date _____

I agree to abide by the Society's rules (copy available on request)

Gift aid

I would like the Alzheimer's Society to treat all my donations from 6 April 2000 (until I notify you otherwise) as Gift Aid donations:

This makes your donation worth nearly a third more, at no extra cost to you. You must be a UK taxpayer and pay enough income tax or capital gains tax to cover the amount we reclaim from the Inland Revenue. Please remember to let us know if your tax status changes or if you change address.

Thank you

Please return this slip to:

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NE118



In the August 2003 issue, Helen Clegg asked whether developing drugs for the moderate stages of dementia was merely prolonging the distress for the person with dementia and their carers. Here four readers respond:

I agree with Helen Clegg [letters, August 2003] that it is pointless to use drugs to prolong the moderate stage of dementia if it is a period of unhappiness. My mum was tormented for three years with imaginary fears which could not be pacified. Now that she is severely affected, she is quite content.

Janet Goodwin, Oldham

I take the opposite view to Helen Clegg. My husband has dementia and recently I started paying for Ebixa privately for him. It is too early to tell whether it will help him. I hope that, by prolonging the moderate stage, a cure may be found before he gets to the final stages.

Yes, it is probably too late for Helen's father but, if we took the attitude of not using these drugs, we would not get anywhere.

Sandra van Eeden, Southsea

My husband is 67 and has had Alzheimer's disease for four years. He is now considered to be at the moderate/severe stage. Although I had been told that Ebixa would not be available to NHS patients until next spring, I asked the consultant if there was any possibility of obtaining the drug. He agreed to trial my husband on it provided that I monitored his progress very carefully. Before going on the new medication, however, he had to come off Aricept and was without any drugs for three weeks. He became a person who could barely utter a sound or do anything for himself other than mooch around or sleep.

I started him on Ebixa with dramatic results. He began to formulate sentences and interact during conversation. And he smiled – something he has not done for a very long time. He was also able to help with his personal hygiene and dress himself, and his walking skills improved. He still slept for long periods during the day.

On our next visit to the memory clinic, I asked about reintroducing Aricept to run alongside Ebixa as they work on different parts of the brain. The consultant agreed to do this but, due to financial constraints, our GP had to fund one

of the drugs. Earlier the practice had refused to prescribe Aricept as my husband's mental score was so low. However, he did agree to fund Aricept for two months. The result is that my husband is much more alert.

I agree with the writer that these drugs are not a cure for the disease but they do enable us to do more together and that makes my task as a sole carer much easier. Without medication, I don't think I would be able to cope effectively with the result that he would probably not be in my care but in a home.

PA Payne, Camberley

I agree with Helen Clegg. To watch someone with dementia deteriorate over a period of ten years is truly heartbreaking.

My wife had a series of falls and mini-strokes and is now in a nursing home. It was difficult enough to find a home that would take her but circumstances are such that the home is far from happy. She wanders from chair to chair, sometimes falls asleep. There is little or no stimulation except for a TV and there is hardly any conversation there.

My wife is no longer able to converse – even if she were able, I am almost deaf. As we cannot talk, we hold hands and I tell her how much I love her.

I visit my wife frequently but somehow it does not seem to be enough. Flowers sometimes help. Each night I stand at the foot of an empty bed and say a few prayers, asking our Lord to keep her safe and saying how much I love her and miss her terribly. It gives me a feeling that I have at least tried in some small way – I have remembered her.

Vic Blackie, Rugeley

*We welcome your letters. Please write to:
Newsletter Editor, Alzheimer's Society,
Gordon House, 10 Greencoat Place,
London SW1P 1PH or email:
newsletter@alzheimers.org.uk*

Letters may be edited.

We regret that we are unable to forward letters on to correspondents without their prior consent.

*Articles and letters for December/January issue of the Newsletter to arrive by
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The views expressed in this Newsletter are personal and not necessarily those of the Alzheimer's Society.

*Editor: Janice Brown
Assistant editor: Sandra Fletcher*