

Postcode prescribing still persists

1 Background

The first drug for Alzheimer's disease was licensed in the UK in 1997. There are now four licensed treatments: donepezil (Aricept), rivastigmine (Exelon) and galantamine (Reminyl) for mild to moderate Alzheimer's disease and memantine (Ebixa) for moderate to severe Alzheimer's disease. All can help to improve or stabilise the symptoms of Alzheimer's disease in many, but not all, people with the illness who try them.

Alzheimer's disease is a progressive illness, affecting memory, understanding and behaviour. People with Alzheimer's disease gradually lose their ability to carry out the activities of daily living, such as shopping, handling money, personal care and cooking. Eventually, over several years, even basic activities such as dressing and going to the toilet become impossible without help.

It is therefore vital that people are diagnosed and treated as early as possible, so that they can retain maximum independence. A delay of even a few months means the person with Alzheimer's disease loses skills he or she may never regain. Family members' lives change too as they cope with the changes in the person they love, and devote increasing time and effort to caring tasks, often having to give up work and seeing their own social lives dwindle.

From the moment the first drug was licensed, many people with Alzheimer's disease and their families have faced difficulty in accessing the new treatments. Despite guidance in January 2001 from the National Institute for Clinical Excellence (NICE) recommending that treatment be funded by the NHS, and the subsequent positive recommendations in April 2001 from the Health Technology Board for Scotland (HTBS), a survey in summer 2001 by Alzheimer Scotland showed that very significant variation in availability still existed.

The fourth drug for Alzheimer's disease, memantine (Ebixa), was licensed for moderate to severe Alzheimer's disease in October 2002. No recommendation on memantine has yet been made by the Scottish Medicines Consortium, which will report in August on its findings.

2 The survey

In January 2003, we wrote to the Chief Executives of all NHS boards in Scotland, asking:

1. What is the Board's current policy on the prescription of:
 - 1.1 Aricept (donepezil)?
 - 1.2 Exelon (rivastigmine)?
 - 1.3 Reminyl (galantamine)?
 - 1.4 Ebixa (memantine)?
2. If the Board is awaiting the report of the Scottish Medicines Consortium (SMC) before funding the prescription of Ebixa, how soon after any positive conclusion by the SMC would Ebixa be made available to patients?

3. How much has the Board allocated for drug treatment for Alzheimer's disease in its budget for the current and next financial years, and how is this amount broken down between costs of diagnosis and assessment, costs of prescribing and costs of monitoring patients on treatment?
4. How many patients with Alzheimer's disease were already on or were started on one of the four available drug treatments from April – September 2002? If possible, please provide the figures for each drug.
5. Is there a waiting list for these treatments, and if so, how many patients are on it, and how long will they have to wait for treatment?
6. Are there other constraints on how many patients can receive treatment, such as lack of consultant time for diagnosis, or of staff resources for monitoring?

3 Results

11 of the 15 NHS boards replied to the survey. The full results are in Appendix 1.

3.1 Prescription policy

Some NHS boards outlined the protocols surrounding prescription. The pattern outlined¹ was that a GP refers a patient to a specialist (a geriatrician / psycho-geriatrician) who is then responsible for the assessment (and review) of the patient; after this process the GP prescribes the drugs. Forth Valley specifies that patients are monitored by specialists, and that there are protocols for monitoring and discontinuation of the drugs (as there is for prescription). Greater Glasgow has specific outcome criteria which need to be met within 3 months.

In most places the choice of cholinesterase inhibitor is down to clinical judgement. Ayrshire & Arran and Greater Glasgow explicitly expressed their preference for donepezil, and 7 other NHS boards² demonstrated through the figures they provided that this was the drug most frequently used.

3.2 Memantine

At the time of the survey, Lundbeck had yet to submit its evidence concerning Ebixa to the Scottish Medicines Consortium (SMC); and the majority of replies from NHS boards indicated that they were awaiting the decision before proceeding. Dumfries & Galloway replied that while it would not recommend memantine until the SMC's decision, but this will not prevent it being used in "exceptional circumstances".

All NHS boards replied that – post-SMC decision – the issue would be discussed locally, mostly by Area Drug and Therapeutics Committees. Four³ NHS boards explicitly mentioned the need to consider the cost implications, whilst others alluded to budgetary factors by reference to 'competing priorities'⁴, or the need to consider the evidence of memantine's efficacy, and relative importance compared with other new drugs. The most positive response was from Western Isles, who stated that memantine could be prescribed two weeks after recommendation by SMC.

3.3 Budget allocations

The likelihood of receiving treatment is still heavily dependent on where a person with Alzheimer's disease lives.

Table 1 compares spending per head of the estimated number of people in each area suitable for treatment. In order to allow comparison between NHS boards, we have extrapolated some figures (shown in italics)⁵. Figures in bold represent information directly supplied by the NHS board.

There is a remarkable range: from £551 per person likely to benefit to £136. The highest spenders per head are Argyll & Clyde, Fife and Dumfries & Galloway; with the lowest spending boards being Greater Glasgow, Western Isles and Lothian.

<i>NHS boards</i>	<i>People with dementia⁶</i>	<i>Estimated number of people suitable for treatment⁷</i>	<i>Annual AD drugs budget/ expenditure</i>	<i>Drugs budget per person likely to be suitable for treatment</i>
Argyll & Clyde	5,050	1,000	<i>£551,028⁸</i>	£551
Ayrshire & Arran	4,702	931	£65,000⁹	not comparable
Borders	1,583	314		
Dumfries & Galloway	2,104	417	£150,000	£360
Fife	4,334	858	<i>£420,436¹⁰</i>	£490
Forth Valley	3,179	630	£170,000	£270
Grampian	6,052	1,199	£250,000	£209
			£275,000¹¹ (02-03)	£136
Greater Glasgow	10,221	2 024	£300,000 (03-04)	£148
Highland	2,605	516	<i>£137,000</i>	£266
Lanarkshire	5,555	1,100		
Lothian	8,918	1,766	£300,000	£170
Orkney	254	51	<i>£13,000</i>	£255
Shetland	247	49		
Tayside	5,428	1,075		
Western Isles	430	86	<i>£14,000</i>	£163

Table 1: NHS board spending on Alzheimer's disease drug treatments, per head of estimated number of people with Alzheimer's disease suitable for treatment

3.4 Numbers receiving treatment

Table 2 compares the numbers of people reported as receiving treatment between April and September 2002, and shows these figures as a percentage of the estimated number of people suitable for treatment. However, many NHS boards found it impossible to provide specific patient numbers, and where these were provided they were sometimes for different periods of time. Figures provided by NHS boards are shown in bold, with extrapolated figures, based on annual expenditure and an estimate of £1,000 cost per patient per year, in italics, although variation in how long patients continue with treatment makes accurate extrapolation difficult.

Figures from the previous survey, in July 2001, are also shown. The majority of these were extrapolated from budget figures on a similar basis.

Although direct comparison is difficult as the previous survey covered a year and the new survey covers six months, it can be seen that while some NHS boards appear to have made significant improvements in the proportion of people treated, others appear to be treating a lower percentage of people than before.

Notable changes include:

- seven NHS boards are treating more people than in 2001, with four treating four times the proportion they were before: Argyll & Clyde, Dumfries & Galloway, Fife and Highland
- Grampian and Orkney are treating five and six times more respectively than their low figures in 2001, but remain in the bottom half of the league table
- two NHS boards appear to be treating significantly fewer people than in 2001: Lothian and Greater Glasgow. Lothian reported a delay in patients receiving treatment due to the redesign of services.

NHS boards	People with dementia	Estimated number of people suitable for treatment	2001 survey		2003 survey	
			People being/ likely to be treated (whole year ¹²)	% of people likely to be suitable being treated	People being treated April – Sept 02	% of people likely to be suitable being treated (6 months)
Argyll & Clyde	5,050	1,000	130	13%	551	55%
Ayrshire & Arran	4,702	931	460	47%	170 (366) ¹³	18% (39%)
Borders	1,583	314	60	18%	-	-
Dumfries & Galloway	2,104	417	40	9%	160	38%
Fife	4,334	858	100	11%	420	49%
Forth Valley	3,179	630	100	15%	208	33%
Grampian	6,052	1,199	50	4%	265 *	22%
Greater Glasgow	10,221	2,024	407	20%	223	11%
Highland	2,605	516	40	7%	137 *	27%
Lanarkshire	5,555	1,100	321	28%	-	-
Lothian	8,918	1,766	650	36%	250	14%
Orkney	254	51	2	4%	13	25%
Shetland	247	49	-	-	-	-
Tayside	5,428	1,075	70	6%	-	-
Western Isles	430	86	-	-	14	16%

* Figures cover April 02 - January 03

Table 2: Percentages of people with Alzheimer's disease likely to be suitable who are receiving treatment; 2001 and 2003 surveys

3.5 Waiting lists & other constraints

Nine¹⁴ NHS boards stated that there was no waiting list for the drugs. However, waiting lists often existed for the clinic or specialist appointment: this varied as demonstrated in the table below. The shortest waiting periods (apart from the three boards which stated that there were no waiting lists at all) appeared to be in Greater Glasgow, with the longest in the acute sector of Ayrshire & Arran. 2 areas were committed to seeing assessing patients within a month, with a further 4 seeing patients referred within 2 months.

NHS boards	Waiting time for appointment / assessment	relevant factors & constraints
Argyll & Clyde	6 weeks	4 consultant psychiatrists have recently left
Ayrshire & Arran	Within primary care: 4 weeks average (9 weeks maximum) Within acute care: 90% are seen within 19 weeks	Redesign opportunities are being explored
Borders		
Dumfries & Galloway	8 weeks maximum	Community mental health teams are "stretched"
Fife	8 weeks maximum	
Forth Valley	5 weeks maximum	A "previous" waiting list of 14 patients who had been waiting for months is being "addressed gradually". Insufficient clinic time
Grampian	"no waiting list for treatment"	If prescription numbers increase, there will be staffing implications; and the prescribing budget is finite.
Greater Glasgow	2 - 3 weeks	
Highland	No waiting list for Old Age Psychiatry list	Are developing case for creation of dedicated memory clinic.
Lanarkshire		
Lothian	"there is a delay in patients receiving treatment due to the redesign of services"	
Orkney	No waiting list	Patients are referred to consultant psychogeriatrician in Aberdeen. Monitoring happens locally.
Shetland		
Tayside		
Western Isles	95% of patients are seen within 4 weeks	The greatest problem is the "very low" level of referral from GPs.

4 Conclusions

Despite improvements in the numbers of people receiving treatment in seven NHS boards, it is clear that a 'postcode lottery' remains.

- Greater Glasgow and Lothian NHS boards are treating fewer people than they were eighteen months ago.
- A person living in Argyll & Clyde in the mild to moderate stage of Alzheimer's disease is five times more likely than a person living in Glasgow to receive drug treatment with cholinesterase inhibitors.
- The size of Alzheimer's disease drug budgets varies very significantly – spending per head in Argyll & Clyde is four times that in Greater Glasgow.
- Whilst there are no reported waiting lists for receipt of the treatments, there are delays in receiving the assessment necessary for treatment to commence. Several NHS boards reported problems encountered due to gaps in staffing, with others foreseeing difficulties in the future as prescription demand rises.
- Despite the introduction of the Scottish Medicines Consortium in order to tackle the issue of postcode prescribing, most NHS boards have declared their intention to make the final decision locally, which is likely to perpetuate the problem.
- Some of the under-prescription may be a result of lack of awareness leading to people with memory problems and their families not seeking early assistance from their GP and/or GPs not referring patients for diagnosis and treatment.

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¹ By (for example) Highland, Ayrshire & Arran.

² Fife, Argyll & Clyde, Western Isles, Orkney, Highland, Grampian and Forth Valley

³ Argyll & Clyde, Grampian, Highland and Lothian.

⁴ Forth Valley

⁵ Where no figure was given, we have extrapolated based on an assumed cost of £1000/person/year.

⁶ To estimate the population of each NHS board, we used the 2001 mid-year population estimates from GROS. To calculate the number of people with dementia in each NHS board, we used prevalence rates from Harvey (1998) on the population 30 – 64, and the EURODEM (1991) prevalence figures for the population 65 and above.

⁷ This figure is an estimate for the number of in each NHS board in the mild to moderate stage of Alzheimer's disease who are suitable for treatment with donepezil, rivastigmine or galantamine. This is based on the following assumptions (see *Planning Signposts* (2000)): 55% of people with dementia have Alzheimer's disease; 72% of those with Alzheimer's disease are in the mild to moderate stages; with a conservative estimate that only half of those with mild to moderate Alzheimer's disease will be suitable for treatment, due to other illnesses or treatments incompatible with these drugs. We have excluded people with more advanced Alzheimer's disease who might be suitable for treatment with memantine, as this treatment was not in common use at the time of the survey.

⁸ Extrapolated from reported spending on drugs between July and September 2002 of £137 757.

⁹ Excludes costs of prescriptions in primary care, which accounts for a large proportion of those treated; includes allocation for the acute setting (£45,000) plus a projected overspend of £20,000.

¹⁰ Extrapolated from reported spending of £210,218 between April and September 2002).

¹¹ Figures for both years exclude GP prescribing costs.

¹² Many of these figures were extrapolated from other information.

¹³ Figure in brackets is number being treated at March 2003.

¹⁴ Argyll & Clyde, Fife, Forth Valley, Grampian, Greater Glasgow, Highland, Lothian, Orkney, Western Isles.