

**Alzheimer's Australia**  
**Consumer Medication Survey**

**April 2005**



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## Executive Summary

Alzheimer's Australia commissioned the Rehabilitation Studies Unit, University of Sydney and Dr Susan Kurrle to survey people with dementia and their relatives and carers about their experience with drug treatments for Alzheimer's Disease. The project was funded by Alzheimer's Australia Research Ltd.

This report presents the initial analysis of data from more than 1,200 completed surveys. This includes surveys returned from people diagnosed with forms of dementia other than Alzheimer's disease.

### Key findings:

- Of the 1,226 people who responded to the survey, 90% (1,104) reported receiving a drug for the treatment of dementia.
- Of the 1,104 respondents reporting some experience with a dementia drug, 798 (72%) reported that they were currently taking one of these treatments at the time of survey completion.
- The most commonly reported cholinesterase inhibitor medications used, were Aricept, Reminyl and Exelon. 14% had tried Ebixa, even though it is not subsidised under the Pharmaceutical Benefit Scheme (PBS).
- There was an average treatment duration of between 17 months and 23 months for the cholinesterase inhibitors (Aricept, Exelon and Reminyl) and a 9 month average duration of treatment for Ebixa.
- 70% of those who had experience of drug treatments for dementia felt they were effective.
- 76% of all respondents (including those who have never used dementia medications) would advise family or friends with Alzheimer's disease to take the dementia medications.
- The most commonly reported benefit of the dementia medications was that they improved/helped memory loss, whilst the most commonly reported side-effect of the medications was that they caused nausea/sickness.
- 27% of respondents reported receiving medications that were privately prescribed and therefore not subsidised.
- 12% of those who had some experience with dementia medications had obtained their drugs at some point through participation in a research study.
- 65% of respondents reported waiting less than four weeks for an assessment by a specialist to access drug treatments.
- For the 291 respondents who reported waiting four weeks or longer for an assessment, the average waiting time was 20 weeks.

- Very few people (78 or 7%) reported losing access to medications because the PBS eligibility criteria were not met.
- People with a range of diagnoses responded to the questionnaire. However, 75% of respondents reported obtaining a diagnosis of Alzheimer's disease.
- Many respondents reported the use of support services. The total number of types of services used was 4620, which is an average of 4 per person.
- Medical specialists were the most common source of information that drug treatments for dementia were available.
- A number of respondents commented on the high cost of drug treatments.
- Further analysis from this survey will be undertaken over time to look into the experiences of different consumer groups. This will be complemented, by an analysis of the take-up of Alzheimer medications under the PBS guidelines for 2002-03 and 2003-04, which will look at questions such as
  - Who benefits from PBS/Repatriation Pharmaceutical Benefits Scheme (RPBS) supplied Alzheimer medications?
  - Who prescribes Alzheimer medications under PBS/RPBS?
  - How long do people stay on Alzheimer medications supplied under PBS/RPBS?
  - Do prescribing patterns under PBS/RPBS vary across Australia?

#### Conclusion:

- This is the first time that consumers in Australia have been surveyed about their experience of Alzheimer medications. These initial results reflect the diversity of consumer experience, while providing an interesting insight into consumer views of the usefulness of these medications.
- Consumer views are in accord with the Alzheimer's Australia's policy position that
  - it is important that subsidised Alzheimer medications are available under reasonable restrictions as they provide some benefit to some people for a period and
  - a person with dementia merits a well-managed medication trial if this is appropriate after considering their personal preferences and other medical conditions.
- The key findings of the survey are similar to those of a 2003 UK survey.
- Care should be taken in interpreting the findings of the survey, as they may not be generalisable to all people with dementia in Australia. Currently some 25,000 scripts are dispensed for Alzheimer medications under the PBS or RPBS each month.

## Comparisons to the UK survey

As this survey was based on the 2003 survey conducted by the Alzheimer's Society (UK), it is interesting to make comparisons between the two reports. Some of the similarities and differences between the results of the two surveys are highlighted below:

- Whilst the percentages of respondents that had used Aricept, Exelon and Ebixa were similar in each report, the number of respondents reporting the use of Reminyl was significantly lower in the UK report (18% vs. 31%).
- The average length of time that respondents had taken Aricept, Exelon and Reminyl were again very similar in the two reports. However, in this report the average length of time for Ebixa was 13 weeks longer than that reported in the UK report (39 weeks vs. 26 weeks).
- In this report, the percentage of respondents obtaining drug treatments with a private prescription was 10% higher than that reported by the UK paper (27% vs. 17%).
- In the UK report it was found that 29% of respondents had to wait for an assessment, which is similar to the 26% of respondents that were found to have waited 4 weeks or longer for an assessment in this report. For those who had to wait the average waiting times for an assessment were very similar in both reports (20 weeks vs. 21 weeks).
- In the UK report 76% of respondents with experience of drug treatments felt they were effective, which is similar to the 70% reported in this report.
- Alzheimer's disease, followed by vascular dementia, were the two most common diagnoses reported by both reports.
- In both reports the average age of the person with dementia was 77 years, and there was only a one year difference in the average age of the main carer (67 years vs. 68 years).
- Whilst the percentage of female carers was similar in each report (62% vs. 63%), in the UK report 57% of those with dementia were female compared to the 44% reported here.

## Methods

Permission was obtained to base the survey on a similar survey that was developed and used by Alzheimer's Society (UK). Results of the United Kingdom survey are available on the Society's website ([www.alzheimers.org.uk](http://www.alzheimers.org.uk)).

The United Kingdom survey was modified to suit Australian conditions through consultation with Alzheimer's Australia and a number of clinicians involved in the management of dementia. These modifications were made to reflect the systems and services available in Australia. The Australian survey questionnaire is shown in the Appendix.

Research ethics committee approval was obtained from the Ethics Committee of the Royal Rehabilitation Centre Sydney, which is the host hospital of the Rehabilitation Studies Unit.

Survey forms were distributed mainly through the State/Territory member organisations of Alzheimer's Australia. About 25% were distributed via medical specialists, general practitioners and aged care services. There was also an online version of the survey available on the Alzheimer's Australia website.

Distribution of the survey commenced in September 2004. This report presents findings from the 1,226 completed surveys that were returned before the closing date of 14 March 2005.

# Results

## Experience of dementia drugs

**Question: Have you, a person you care for, or a person you cared for in the past, ever received a drug treatment for dementia?**

- 1,104 (90%) respondents reported receiving a drug for the treatment of dementia, and it is the responses from these 1,104 people that deliver the main results of interest from the survey.
- 122 (10%) respondents reported no drug use.

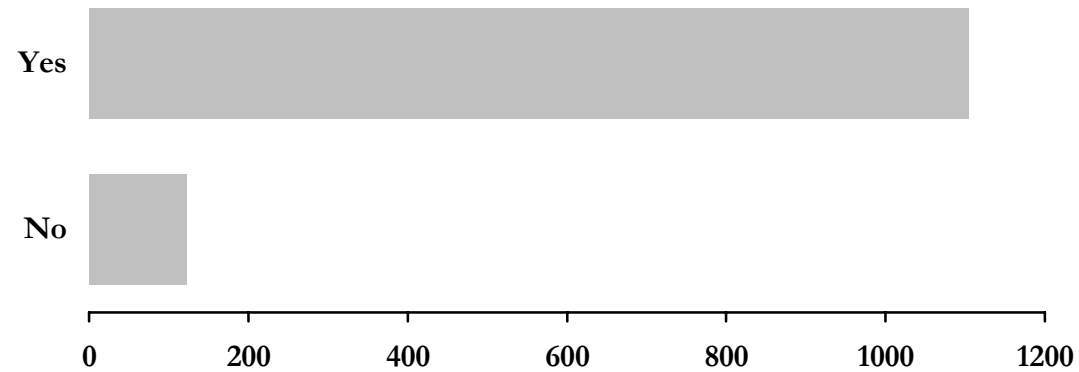


Figure 1. Use of drug treatment for dementia

**Question: Which of the following drugs were prescribed? (please tick all of the boxes which apply to you)**

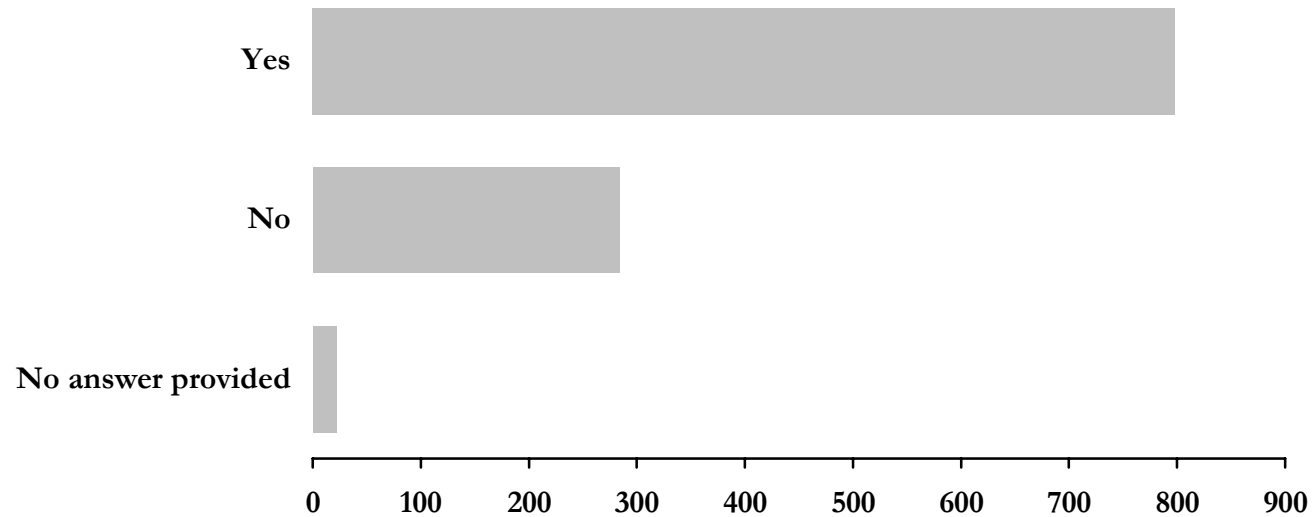
Aricept	Exelon	Reminyl	Ebixa	ONE DRUG USED
540	55	184	13	
76		76		MORE THAN ONE DRUG USED
68				
37	37			
			26	
20		20	20	
14	14		14	
13	13	13		
9	9	9	9	
	9		9	
	9	9		
	1	1	1	
<b>777</b>	<b>147</b>	<b>338</b>	<b>160</b>	TOTAL USE

- Of those 1,104 respondents reporting the use of drug treatments for dementia, 777 (70%) had tried Aricept, 338 (31%) had tried Reminyl, 160 (14%) had tried Ebixa and 147 (13%) had tried Exelon.
- However, as Figure 2 demonstrates many respondents had tried more than one of the drug treatments.
- 16 (2%) respondents reported using an alternative drug for the treatment of dementia, whilst 14 (1%) were unable to recall the name of the drug used.
- The frequency of use of Ebixa (memantine) is of note as it is not subsidised through the Pharmaceutical Benefits Scheme.

**Figure 2. Prescribed medications used for treatment of dementia**

**Question: Are you, or the person you care for, currently taking one of the drugs?**

- Of the 1,104 respondents reporting some experience with an anti-dementia drug, 798 (72%) reported that they were currently taking one of these treatments.
- 284 (26%) respondents reported that they were not currently taking one of the drugs, whilst 22 (2%) respondents did not provide an answer to the question.



**Figure 3. Current use of dementia medications**

## Duration of treatment

**Question: For how long was treatment prescribed, or for how long has it been taken so far?**

- The duration of treatment varied for each drug and was on average 85 weeks (median 56 weeks).
- There was an average treatment duration of between 17 months and 23 months for the cholinesterase inhibitors (Aricept, Exelon and Reminyl) and a 9 month average duration of treatment for Ebixa.

	<b>Mean</b>	<b>Standard deviation</b>	<b>Median</b>	<b>Interquartile range</b>
<b>Aricept</b>	100	87	78	26 - 156 (130)
<b>Exelon</b>	86	79	56	13 - 156 (143)
<b>Reminyl</b>	71	59	56	26 - 104 (78)
<b>Ebixa</b>	39	35	30	13 – 52 (39)
<b>All four drugs</b>	85	78	56	26 – 130 (104)

**Figure 4. Duration (weeks) of treatment with dementia medications (up to time of survey completion)**

## Funding the drug treatments

Question: How was/is treatment provided? (please tick all of the boxes which apply to you)

PBS	RPBS	Private	Clinical Trial	ONE SOURCE
579	100	100	45	
145		145		MORE THAN ONE SOURCE
48				
26		26	26	
	16	16		
			9	
7	7			
	4		4	
	3	3	3	
1	1	1	1	
1	1	1		
<b>807</b>	<b>132</b>	<b>301</b>	<b>136</b>	<b>TOTAL</b>

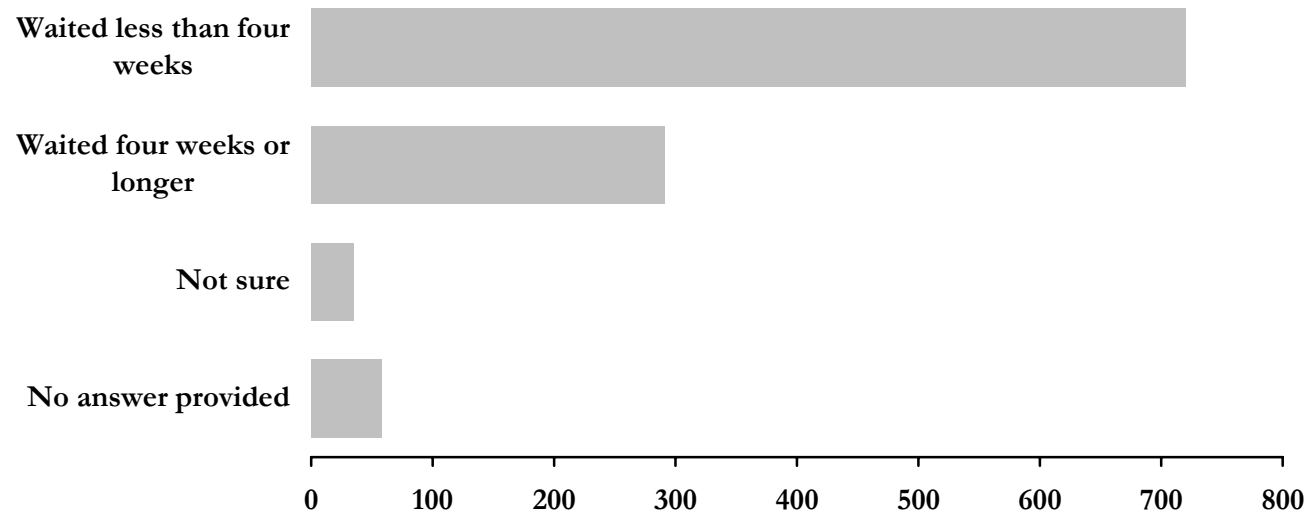
- The Pharmaceutical Benefits Scheme (PBS) provided the medication for 807 (73%) people, and the Repatriation Pharmaceutical Benefits Scheme (RPBS) provided it in 132 (12%) cases.
- A private prescription, which means that the full cost of the medication was borne by the person with dementia, was used by 301 (27%) respondents, whilst the medication was provided by a research study in 136 (12%) cases.
- However, as shown in Figure 5, for a number of people treatments were provided by a variety of sources.

Figure 5. Sources of funding for dementia drugs

## Waiting for treatment

**Question: Many people have to wait some time for an assessment by a specialist to access the drug treatments. What was your experience?**

- 720 (65%) respondents reported a waiting time of less than four weeks for an assessment by a specialist to access drug treatments. For the 291 (26%) respondents who had to wait four weeks or longer for an assessment, the average waiting time was 20 weeks (median 13 weeks, range 4 to 156 weeks, standard deviation 24 weeks).
- 35 (3%) respondents were not sure how long the wait had been, whilst 58 (5%) respondents did not provide an answer to the question.

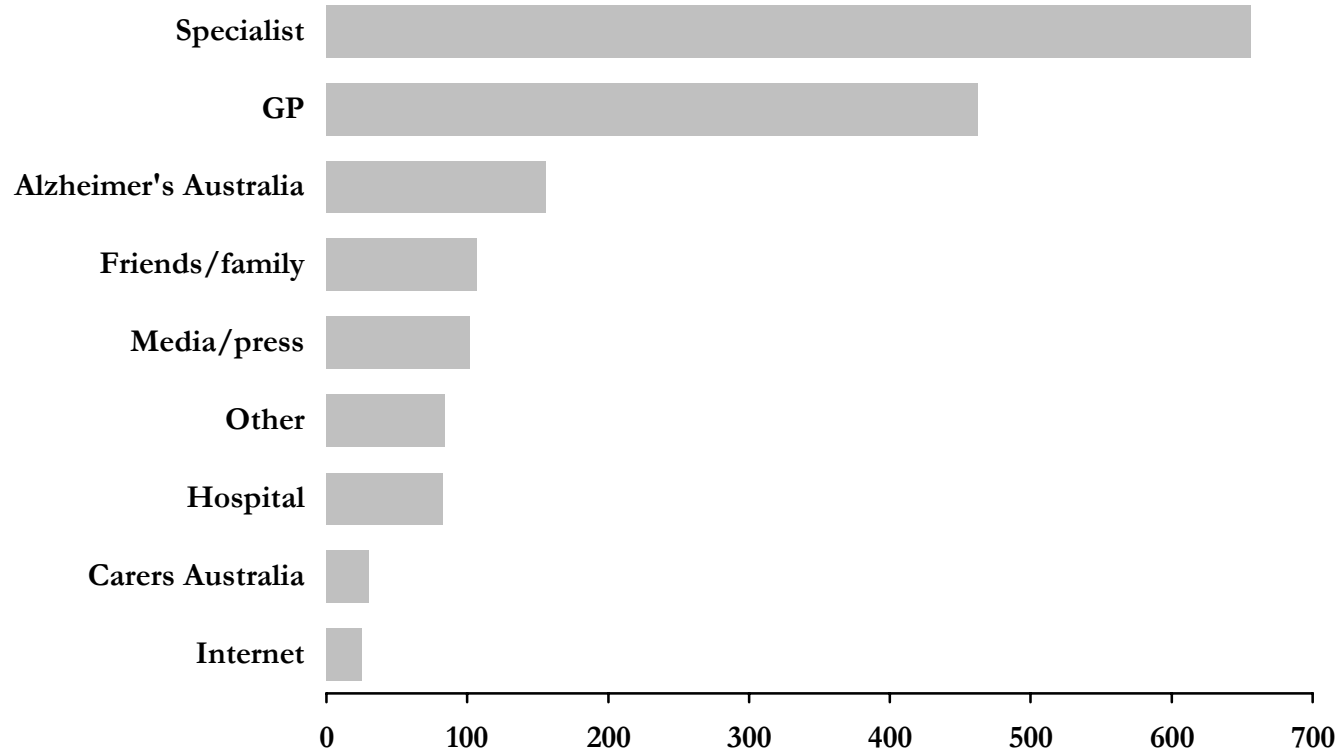


**Figure 6. Waiting time for assessment about drug treatment**

## Finding out about drug treatments

**Question: How did you find out that drug treatments were available for dementia? (tick all which apply)**

- These results are shown in Figure 7.
- A number of respondents reported more than one source of information. However, medical specialists were the most common source of information that drug treatments for dementia were available, and were reported as a source of information by 656 respondents.
- GPs were reported as a source of information by 462 respondents, whilst 156 people reported obtaining this information from Alzheimer's Australia.
- 107 respondents reported friends and family as their source of information, whilst 102 respondents obtained the information from the media/press.



**Figure 7. Source of information about dementia drug treatment**

## Does the treatment work?

**Question:** Taking everything into consideration, do you feel that the drug treatment has worked for you or the person for whom you care?

- 775 (70%) of respondents reported that the drug treatment had worked, whilst 227 (21%) reported that they had not.
- 102 (9%) respondents did not provide an answer to the question, including a number who commented that they did not know how progression might have varied without medication.

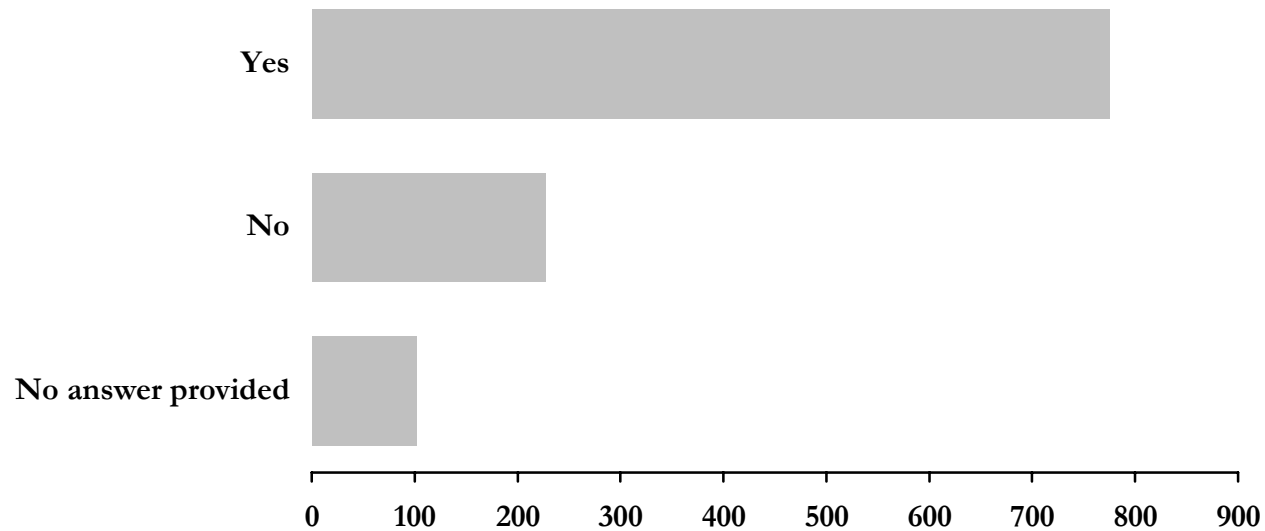


Figure 8. Impression of drug treatment effectiveness

**Question: Please list up to five ways in which the treatment has been helpful.**

- A variety of responses were provided for this question and are shown in Figure 9.
- 353 respondents reported that the drug treatment improved/helped memory loss, whilst 230 respondents reported that they slowed symptoms down.
- 151 people reported that the drug treatment made the person more active/livelier, whilst 136 respondents reported that they were happier/brighter.
- Improved/controlled behaviour was reported by 126 respondents, whilst calmer/less aggressive behaviour was reported by 93 people.
- 60 respondents reported that the drug treatment helped the person with dementia to be less confused.

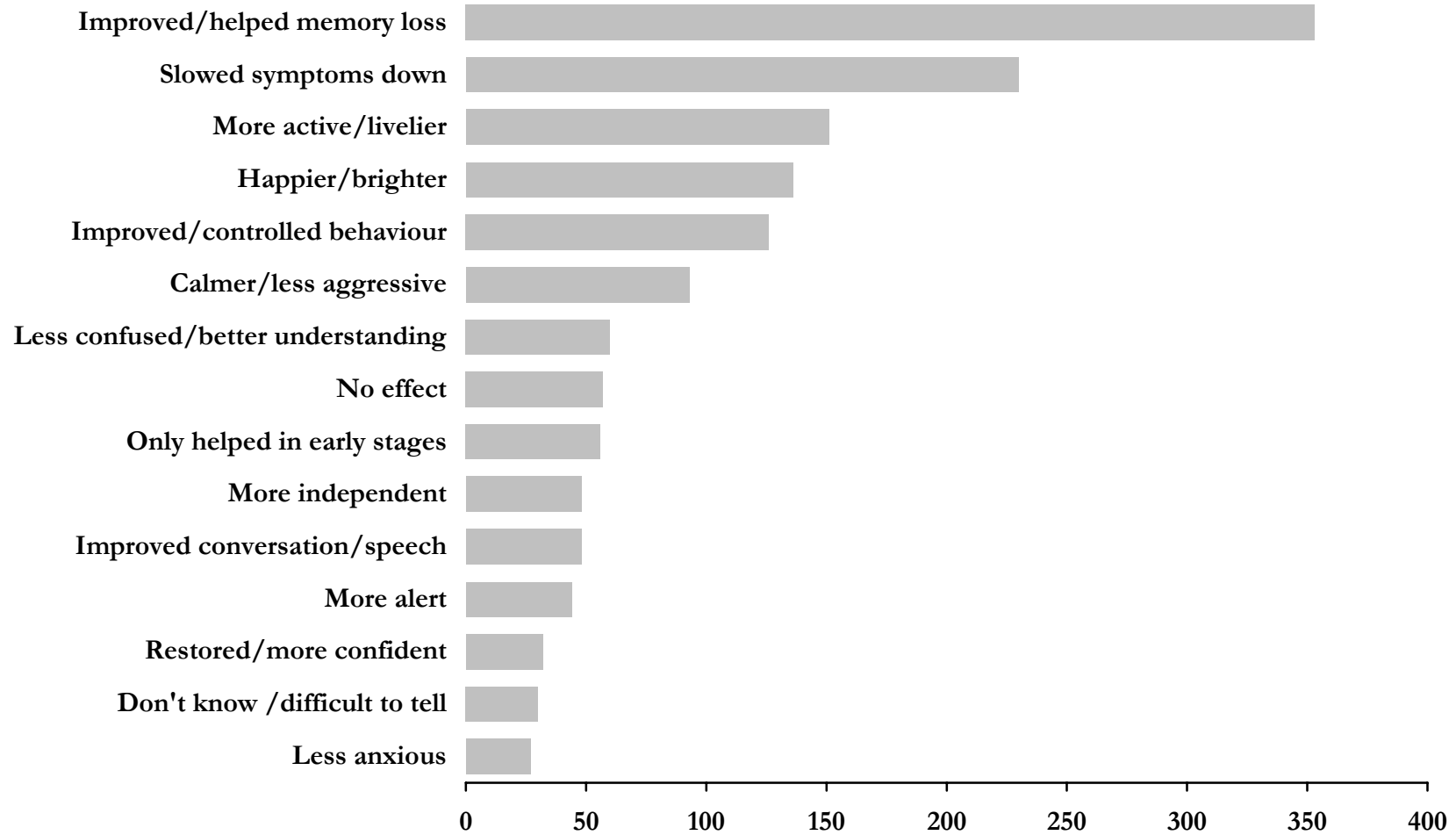


Figure 9. Benefits of drug treatment

## **Problems with the treatment**

**Question: List up to five problems, difficulties or side effects related to the treatment.**

- A variety of responses was provided for this question and are displayed in Figure 10.
- 302 respondents reported no problems, difficulties or side effects related to the drug treatment.
- 130 people reported nausea and sickness as a side effect of drug treatment, whilst bowel problems were reported by 82 respondents.
- Nightmares and bad dreams were reported by 64 respondents, whilst 58 respondents reported tiredness as a side effect of the treatment.
- Headaches and aggressive behaviour were reported by 35 and 36 respondents respectively.
- A number of respondents reported multiple drug use and an inability to attribute side effects.

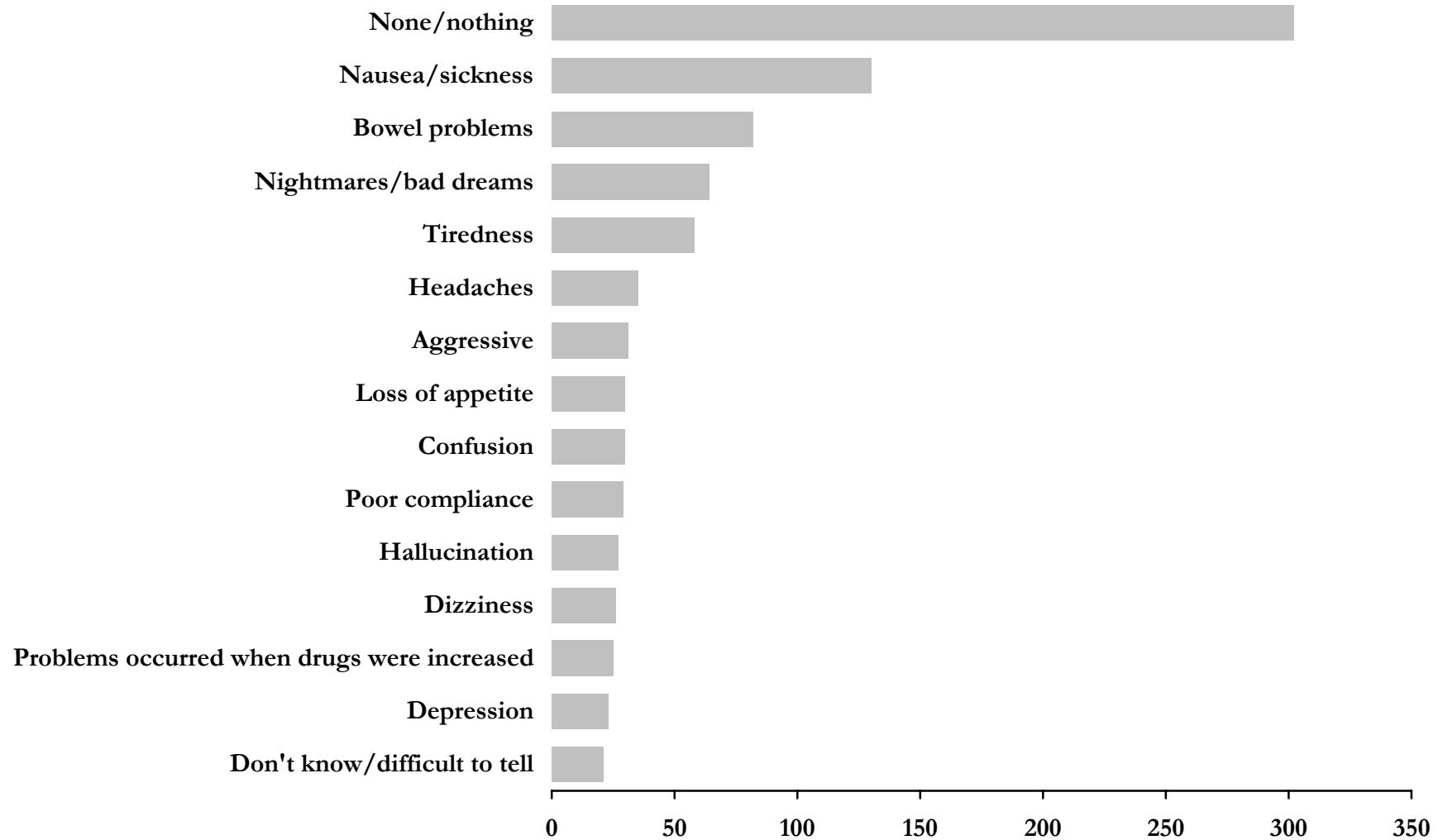
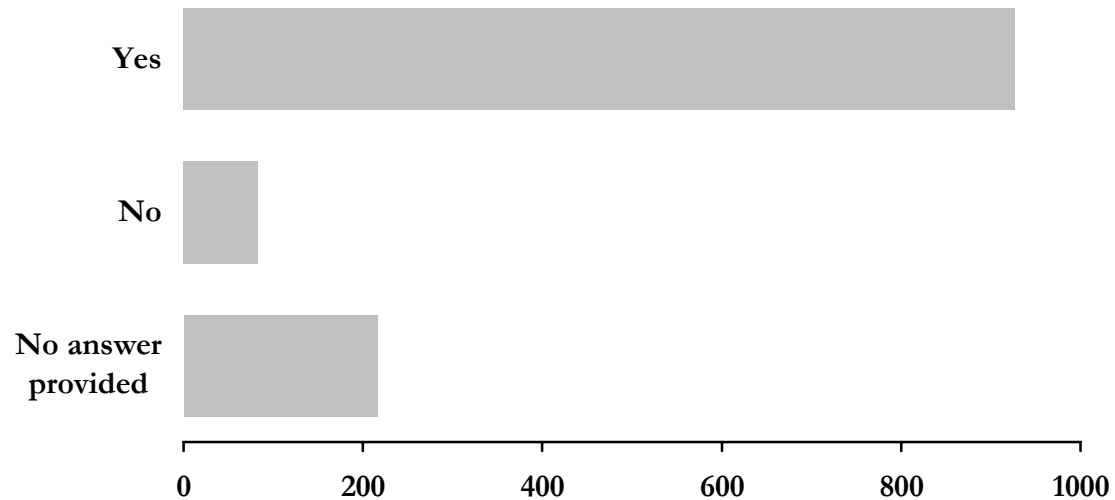


Figure 10. Side effects/difficulties with treatment

## Recommending treatments to others

**Question: Would you advise a family member or friend suffering from Alzheimer’s Disease to take these medications?**

- 76% (927) of all respondents (including those who have never used drugs for the treatment of dementia) would advise family or friends with Alzheimer’s disease to take the dementia medications, whilst 7% (83) of respondents would not advise others to take the medications.
- 216 (18%) respondents did not provide an answer to the question.
- A number of those who answered no or who didn’t provide an answer to this question indicated that they were “not qualified to offer such advice.”



**Figure 11. Recommending drug treatment to others**

## Getting access to treatments

**Question: Have you, or the person you care for, lost access to drug treatment because the eligibility criteria were not met?**

- Of the 1,104 people who had some experience of dementia medications, 78 (7%) respondents reported losing access to drug treatments because the eligibility criteria were not met.
- 467 (42%) reported no loss of drug treatment eligibility, whilst 559 (51%) respondents did not provide an answer to the question. By comparison, see Figure 3 where 72% of respondents reported that they were currently taking one of the medications.

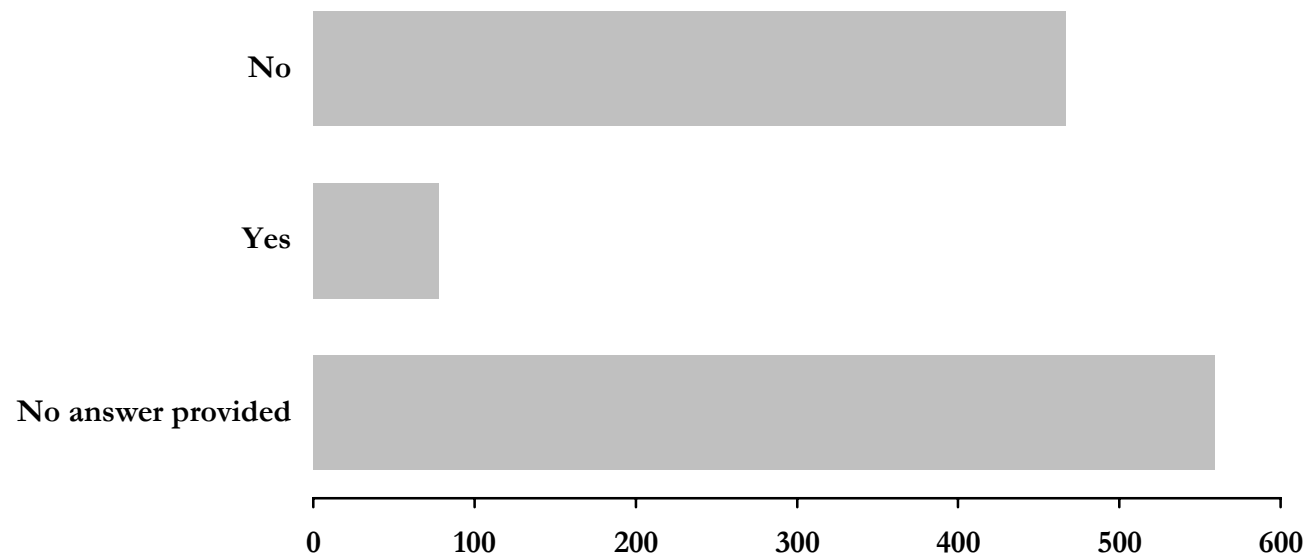
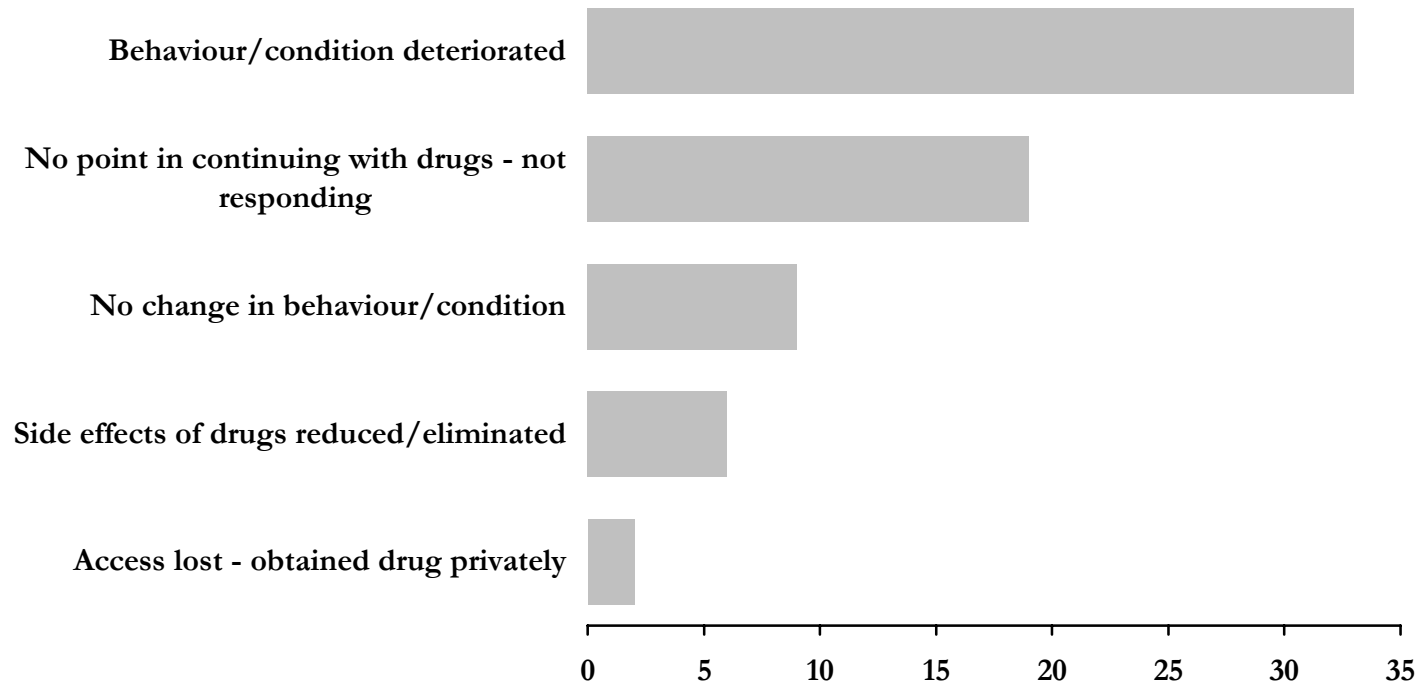


Figure 12. Loss of drug treatment eligibility

**Question: Please tell us briefly about what happened when the drug treatment was stopped.**

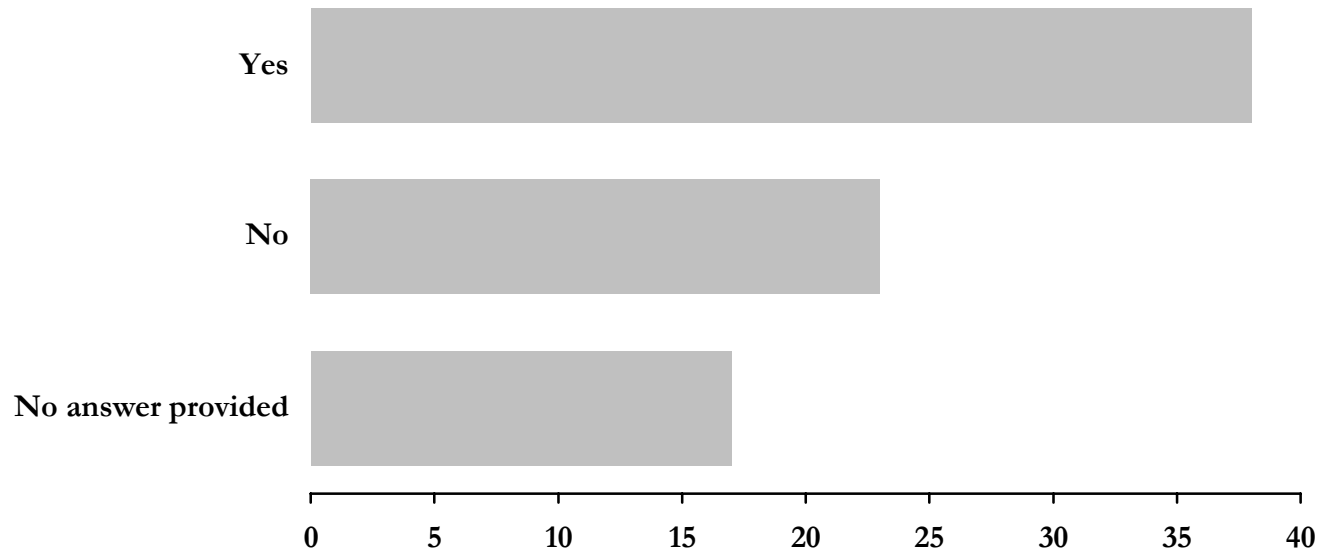
- The 78 respondents who reported losing access to drug treatments provided a variety of responses to this question. The five most commonly reported responses are displayed in Figure 13.
- The commonest response from 33 people was that the behaviour/condition of the sufferer deteriorated when treatment was stopped. 19 respondents reported that there was no point in continuing with the drugs as the patient was not responding to treatment.



**Figure 13. Changes after stopping drug treatment**

**Question: Were you adequately consulted about the process of stopping treatment?**

- Of the 78 respondents who lost access to drug treatments, 38 (49%) reported that they were adequately consulted about the process of stopping treatment, whilst 23 (30%) respondents reported that they were not.
- 17 (22%) respondents did not provide an answer to the question.



**Figure 14. Adequate consultation about stopping drug treatment**

## Diagnosis

Question: What is the diagnosis that you have been given?

- People with a range of diagnoses responded to the questionnaire.
- Alzheimer’s disease was the most commonly reported diagnosis (917 (75%) respondents).
- However, as shown in Figure 15 a number of respondents had either a mixed disease or had been given more than one diagnosis.
- 87 (7%) respondents were not sure of their diagnosis and 19 (2%) did not provide an answer to the question.

Alzheimer’s Disease	Parkinson’s with dementia	Vascular dementia	Fronto-temporal dementia	Dementia with Lewy bodies	Other	SINGLE DIAGNOSIS
825	27	93	34	33	10	
48		48				MULTIPLE DIAGNOSIS
	25					
2	2					
			2			
1	1	1				
		1	1			
	1					
	1		1			
					1	
<b>917</b>	<b>57</b>	<b>146</b>	<b>48</b>	<b>40</b>	<b>14</b>	<b>TOTAL</b>

Figure 15. Dementia diagnoses

**Question: Who originally made the diagnosis?**

<b>GP</b>	<b>Specialist</b>	<b>ACAT</b>	<b>Other</b>	
238	718	6	13	<b>ONE SOURCE</b>
176	176			<b>MORE THAN ONE SOURCE</b>
	17		17	
10				
8	8		8	
6		6		
	5	5		
3	3	3		
1		1	1	
<b>442</b>	<b>927</b>	<b>21</b>	<b>49</b>	<b>TOTAL</b>

**Figure 16. Source of diagnosis of dementia**

- With 927 (76%) respondents providing this answer, a medical specialist was the most common source of a dementia diagnosis.
- General practitioners were also reported as commonly making the diagnosis (36%).
- However, as shown in Figure 16 many respondents reported obtaining their diagnosis from more than one source.
- 25 (2%) respondents did not provide an answer to the question.

**Question: When the diagnosis was made, who was told about the diagnosis? (tick all which apply)**

- In most cases (1060) the carer was the person reportedly told of the diagnosis. The person with dementia was also commonly told (881).
- However, as shown in Figure 17, this was often in combination with other people.
- 30 (2%) respondents did not provide an answer to the question.

<b>Person with dementia</b>	<b>Carer</b>	<b>Other family member</b>	
32	161	42	<b>ALONE</b>
412	412	412	<b>TOGETHER</b>
375	375		
	112	112	
62		62	
<b>881</b>	<b>1060</b>	<b>628</b>	<b>TOTAL</b>

**Figure 17. Who was told about the diagnosis?**

## Information provided at time of diagnosis

Question: At the time of diagnosis, were you provided with enough information about....

- Most respondents felt they were provided with sufficient information but this varied with the type of information considered.
- 363 (30%) respondents reported that they were not given sufficient information about Alzheimer's Australia organisations and support services. 348 (28%) respondents reported that they were not given sufficient information about the possible side effects of medications.
- 231 and 232 respondents reported they were not given sufficient information about the treatment and diagnosis respectively.

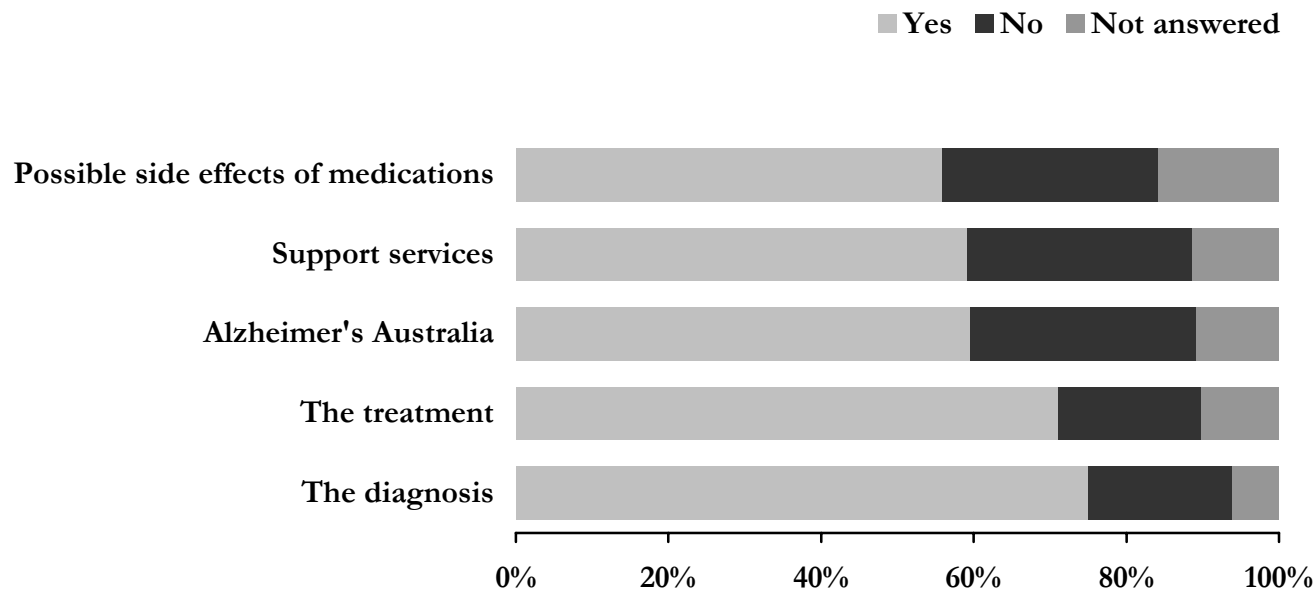


Figure 18. Provision of adequate information

## Supports and services

**Question: Have you received any of the following supports or services....**

- These results are shown in Figure 19.
- The total number of kinds of services used was 4620, which is an average of 4 per person.
- Aged care assessment (717 respondents) and Alzheimer's Australia services (627) were those most commonly used supports and services.
- 525 respondents reported using carer support groups, whilst 516 reported the use of day care/ day centres.
- Home care service was reportedly used by 428 respondents, and residential respite care was used by 378 people.
- 285 respondents reported using memory clinics, whilst 238 people reported the use of transport assistance.

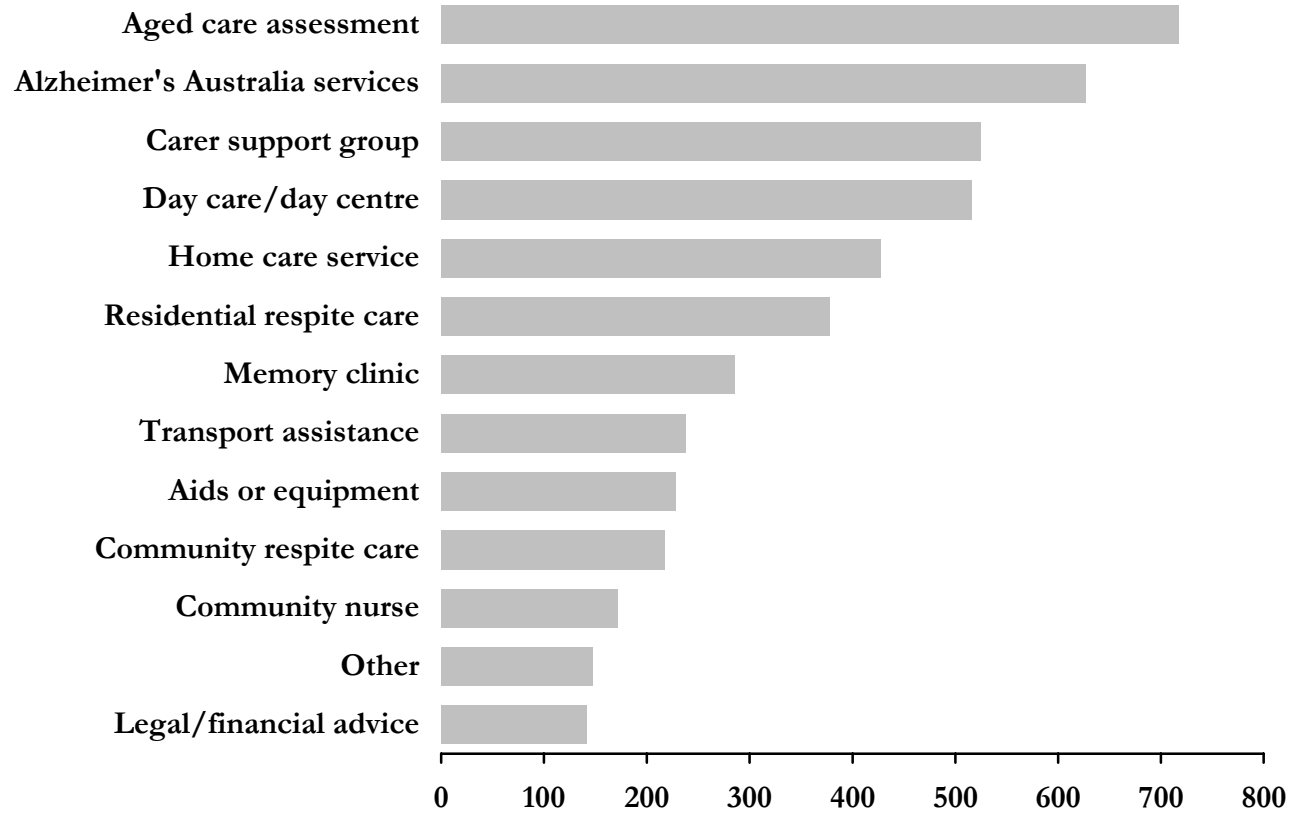


Figure 19. Type of support services used

## **Additional information about treatment and access**

**Question: Please give any additional information or views that you have on the Alzheimer medications and how they are provided through the Pharmaceutical Benefits Scheme or Repatriation Pharmaceutical Benefits Scheme.**

- A large variety of responses were provided for this question. These responses were initially coded during the data entry process, and later some categories were further collapsed.
- The responses have been divided into the following categories:
  - benefits of drug treatments,
  - problems/difficulties with drug treatments,
  - the cost of drug treatments,
  - access to medications and scripts,
  - problems with clinicians,
  - the range of care required,
  - the importance of support groups,
  - respite and day care,
  - the problems with supports and services, and
  - the need for more information.
- These responses are reported in the following pages (Figures 20-28).

- 154 respondents reported that drug treatments were important/beneficial.
- 23 respondents reported that drug treatments should be started as soon as possible.

Comments	Number of respondents
Drugs important/beneficial	154
Drugs should be started as soon as possible	23
Drugs enabled patient to stay at home	14
Would be unable to cope without drugs	3
Drugs at least offer some hope	1
Drugs gave us extra time to make changes etc	1
Drugs delay need for outside intervention and support	1

**Figure 20. Comments made regarding the benefits of drug treatment**

- 27 respondents reported that they were unsure of the benefit of drugs for the treatment of dementia, whilst 8 people reported that drug treatments might not be beneficial to those in the later stages of dementia.

Comments	Number of respondents
Unsure of drug treatment benefit	27
Drugs not beneficial to those in later stages	8
Drugs don't work	4
Drug treatment may not be suitable for all	4
Drugs with no side effects would be helpful	3
Was told drugs would not be beneficial	3
Urgently need more research on Alzheimer drugs	2
Preference for natural medication	1
Drug companies give false impression that dementia can be treated	1
Have never been offered drugs	1
Need to be careful of polypharmacy	1

**Figure 21. Comments made regarding the problems/difficulties with drug treatments**

- A number of respondents commented on the high cost of drugs for the treatment of dementia.
- 31 respondents reported that dementia drugs are expensive and/or they needed financial assistance to continue with their use.

Comments	Number of respondents
Drugs are expensive/need financial assistance	31
Ebixa needs to be on PBS	25
Can only afford drugs on PBS	10
Drugs should be available to all – not just wealthy	7
PBS is a great help	3
Wish we could be involved in latest trials	1
Trial finished – would now like assistance to stay on Aricept	1
Would like to have tried Aricept – but could not afford it	1
Only the rich can afford these drugs	1
Patient is lucky to be able to afford Ebixa	1
Drugs on PBS is more economical than institutionalisation	1
Over charging by pharmacy contracted by hostel to provide blister packed drugs	1
Have to pay full price for Aricept to treat dementia with Lewy bodies	1
Now Aricept on PBS have more money for care and support	1
Cannot get Risperdal on PBS – very expensive	1
Vet Affairs will not subsidize Ebixa until more research is done	1
Would like Phosphatidylserine to be on PBS	1
Patient refused drugs due to price	1

**Figure 22. Comments made regarding the cost of drug treatments**

Comments	Number of respondents
No delays/problems	187
Delays in receiving scripts	63
Diagnosis took a long time	11
Test not fair/accurate	9
Access to PBS problematic/difficult	8
Drugs should be available irrespective of test result	7
Authority was lost and had to be replaced	3
There hasn't been a review of drugs since first prescription	2
Delay in being reassessed	2
Sometimes chemist does not have drug in stock	2
Should wait longer than 6 months before reviewing patient	2
GPs should prescribe drugs without referring to specialist	2
Patient deteriorated significantly whilst waiting for assessment	2
Having to sit MMSE made patient very anxious	2
Continued drugs depends on ACAT	1
Receptionist of GP would block calls for scripts	1
Improvement should be a criterion for continuation of drug	1
Difficulty accessing drugs when admitted to hospital	1
Clinician decided drugs were not working so we now get them privately	1
Patient dislikes visiting specialist and being asked questions	1
Script renewal should be automatic	1

**Figure 23. Comments made regarding access to medications/scripts**

- A wide variety of comments were made regarding access to medications and scripts.
- 187 respondents reported having no delays or problems with receiving their scripts and medications, whilst 63 respondents reported experiencing such delays.

- Some respondents reported experiencing difficulties whilst dealing with clinicians.
- 6 respondents reported that the carer’s opinion is important and should be listened to by clinicians.
- 4 respondents reported experiencing difficulties with their doctor, particularly in relation to obtaining the relevant information.

<b>Comments</b>	<b>Number of respondents</b>
The carer’s opinion is important and should be listened to by clinicians	6
Difficulty dealing with doctors and obtaining information from them	4
Carer had to ask GP about possible drugs	4
GPs lack attention for diagnosing and treating dementia	2
Doctors should be more aware	1
GP/specialist did not inform me of the services/support available	1
GP refused to write script – had to wait for psychiatrist to visit nursing home	1
Initial doctor did not think Aricept would work – so we changed GP	1
Drugs altered when in hospital – was not informed	1

**Figure 24. Comments made regarding problems with clinicians**

- 95 respondents commented that drug treatments, carer support and respite are all important when caring for people with dementia.
- 39 respondents reported that drug treatment in combination with other support services is preferable to drug treatment alone.

Comments	Number of respondents
Drugs, carer support and respite are all important	95
Drugs combined with support is preferable	39
Patient should feel that everything possible is being done to help	1
TLC is also required	1

**Figure 25. Comments made regarding the range of care required**

- 81 respondents reported that carer support groups are important/beneficial.
- 33 respondents reported that respite care is important.

<b>Comments</b>	<b>Number of respondents</b>
Carer support groups beneficial/important	81
Respite care important	33
Home help important/beneficial	3
Social activities are important	2
All possible help has been given/offered	2

**Figure 26. Comments made regarding the importance of support groups, respite and day care**

- 12 respondents reported needing more carer support, respite and/or home help.
- 2 people reported that no other help had been offered.

Comments	Number of respondents
Need more carer support/respite/home help	12
No other support offered	2
Carer feels exhausted and helpless	1
Carers may feel guilty for using day care/respite	1
Very long wait for aged care assessment	1
Need careful monitoring of patients living alone	1
ACAT was a waste of time and money	1
Patient refuses respite, home and day care	1
Husband had to sell home to afford wife's nursing home care	1
Some nursing homes do not provide the appropriate care	1
Availability of hostel care was a problem	1
Patient resistant to help and assistance	1

**Figure 27. Comments made regarding the problems with supports and services**

- 12 respondents reported needing more information on drug treatments for dementia and their side effects.
- 7 respondents would like more information on Alzheimer’s disease and dementia.

<b>Comments</b>	<b>Number of respondents</b>
Need more information about drugs and their side effects	12
Would like more information on Alzheimer’s disease and dementia	7

**Figure 28. Comments made regarding the need for more information**

## Who responded to the survey

- Among the respondents, 1001 (82%) indicated that they were carers or former carers and 200 (16%) were people with dementia. These figures may underestimate the actual number of surveys completed by carers. In 25 (2%) cases the respondent did not report whether they were a carer or a person with dementia.
- The average age of the carers was 68 years (range 21 to 96 years, standard deviation 12 years), whilst the average age of the person with dementia was 77 years (range 43 to 100 years, standard deviation 8 years).
- The genders of the carers and those with dementia are shown in figure 21. 44% (539) of those with dementia were female, whilst 63% (775) of the main carers were female.

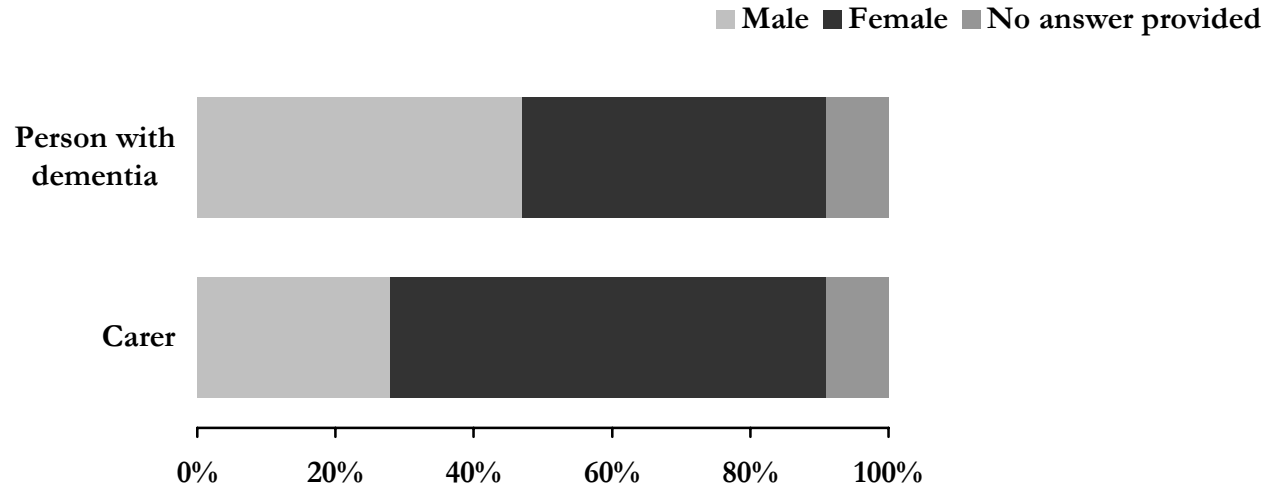


Figure 29. Who completed the questionnaire?

- 137 (11%) respondents reported speaking a language other than English at home.
- 132 (12%) respondents reported receiving medications under the Repatriation Pharmaceutical Benefits Scheme (RPBS).
- About one third of respondents recorded postcodes outside the major urban areas.
- Figure 22 shows the distribution of responses from each Australian State.

<b>State</b>	<b>Number of responses (%)</b>
<b>NSW</b>	372 (30)
<b>VIC</b>	252 (21)
<b>WA</b>	237 (19)
<b>SA</b>	188 (15)
<b>QLD</b>	80 (7)
<b>ACT</b>	42 (3)
<b>TAS</b>	19 (2)
<b>NT</b>	13 (1)
<b>Unknown</b>	23 (2)
<b>Total</b>	1226

**Figure 30. Response rate by State/Territory**

## **Acknowledgements**

The authors gratefully acknowledge the involvement of people with dementia, family members and carers in completing this survey. Thanks are also due to the staff of the Alzheimer's Australia National and State/Territory organisations, and to those medical practitioners, memory clinics and aged care services who assisted in survey distribution.

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# Appendix



**Alzheimer's  
Australia**  
Living with dementia

## **Alzheimers Australia Questionnaire on Drug Treatments for Alzheimers Disease<sup>1</sup> Participant Information Sheet**

This information sheet is provided for you to keep after you have sent back the questionnaire. It gives further information that may be of use to you.

Drug treatments for Alzheimer's Disease have been available in Australia since 2000. Three drugs (Aricept, Exelon and Reminyl) have been made available in a restricted way to patients through the Pharmaceutical Benefits Scheme. In 2003 a new drug treatment for people with more severe dementia, Ebixa (memantine) was launched. It is currently available on private prescription only.

Alzheimers Australia would like to learn more about the use and benefits of these drugs from the point of view of people with dementia and their families and carers in order to determine our position towards providing better access to these medications. If you are a person with dementia, a carer, or a former carer who has any experience of these drugs, we need to hear from you.

Thank you for completing and returning the questionnaire. The information obtained will be of benefit to people with Alzheimer's Disease and other forms of dementia, and the families and carers of people with dementia.

If you have questions about drug treatments, please contact your doctor or call the Dementia Helpline on 1800 639 331. Telephone interpreter services can be accessed on 131 450.

If you have any questions or concerns about the questionnaire, you may contact Alzheimers Australia (Anne Eayrs) on 02 6254 4233.

If you have any complaints about this questionnaire, you may contact the Secretary of the Ethics Committee, Royal Rehabilitation Centre, Sydney on 02 9807 1144.

*Please return the completed form in the reply paid envelope provided or mail to Alzheimer's Australia Medication Survey, Reply Paid 4019, Hawker, ACT, 2614.*

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<sup>1</sup> *This project is supported by Alzheimer's Australia Research Ltd.*

## Alzheimers Australia Questionnaire on Drug Treatments for Alzheimers Disease

Drug treatments for Alzheimer's Disease have been available in Australia since 2000. Three drugs (Aricept, Exelon and Reminyl) have been made available in a restricted way to patients through the Pharmaceutical Benefits Scheme. In 2003 a new drug treatment for people with more severe dementia, Ebixa (memantine) was launched. It is currently available on private prescription only.

Alzheimers Australia would like to learn more about the use and benefits of these drugs from the point of view of people with dementia or their families and carers in order to determine our position towards providing better access to these medications. If you are a person with dementia, a carer, or a former carer who has any experience of these drugs, we need to hear from you.

Please complete the questionnaire below. There are no right or wrong answers in this questionnaire. Most of the questions only need short answers. However, there is also space for you to tell us anything else that you want to. You do not need to answer all the questions. The responses will be analysed by an independent organisation based at the University of Sydney. Your information will be kept confidential.

If you have questions about drug treatments, please contact your doctor or call the Dementia Helpline on 1800 639 331. Telephone interpreter services can be accessed by ringing 131 450.

**1 Have you, a person you care for, or a person you cared for in the past, ever received a drug treatment for dementia?**

Yes

No  - (if No – please go to question 13)

**2 Which of the following drugs were prescribed? (please tick all of the boxes which apply to you)**

Aricept (also known as donepezil)

Exelon (also known as rivastigmine)

Reminyl (also known as galantamine)

Ebixa (also known as memantine)

I do not know the name of the drug

Please specify other drugs e.g. ginkgo biloba .....

**3 For how long was treatment prescribed, or for how long has it been taken so far?**

Name of drug	Years	Months	Weeks	Not sure

**4 How was/is treatment provided? (Please tick all of the boxes which apply to you)**

Pharmaceutical Benefits Scheme

Repatriation Pharmaceutical Benefits Scheme

Private prescription

Clinical trial (research)

**5 Many people have to wait some time for an assessment by a specialist to access the drug treatments. What was your experience?**

No waiting (less than four weeks to wait)

Waiting for an assessment

Length of wait ..... years ..... months ..... weeks Not sure

**6 How did you find out that drug treatments were available for dementia? (Tick all which apply)**

GP

Carers Australia

Specialist

Media/press

Alzheimer's Australia

Internet

Hospital

Friends/family

Other, please specify .....

**7 Taking everything into consideration, do you feel that the drug treatment has worked for you or the person for whom you care?**

Yes

No

**8 Please list up to five ways in which the treatment has been helpful (eg. improved memory, return of ability to perform some activities, change in behaviour or personality).**

1 .....

2 .....

3 .....

4 .....

5 .....

**9 List up to five problems, difficulties or side-effects related to the treatment.**

1 .....

2 .....

3 .....

4 .....

5 .....

**10 Are you, or the person you care for, currently taking one of the drugs?**

Yes  (go to question 13)

No

**11 Have you, or the person you care for, lost access to drug treatment because the eligibility criteria were not met?**

Yes

No

**12 Please tell us briefly about what happened when the drug treatment was stopped.**

.....  
.....  
.....

**Were you adequately consulted about the process of stopping treatment?**

.....  
.....

**13. What is the diagnosis which you have been given?**

Alzheimer's Disease

Parkinsons Disease with dementia

Vascular dementia

Fronto-temporal Dementia (Picks Disease)

Dementia with Lewy bodies

Other Dementia (please specify) .....

Not sure

**14. Who originally made the diagnosis?**

GP

Specialist

Other, please specify .....

.....

**15. When the diagnosis was made, who was told about the diagnosis? (tick all which apply)**

Person with dementia

Carer

Other family members

**16. At the time of diagnosis, were you provided with enough information:**

About the diagnosis Yes  No

About possible treatment Yes  No

About possible side-effects of medication Yes  No

About community support services Yes  No

About Alzheimer's Australia Yes  No

**17. Have you received any of the following supports or services?**

- |                          |                          |                               |                          |
|--------------------------|--------------------------|-------------------------------|--------------------------|
| Memory clinic            | <input type="checkbox"/> | Day care / day centre         | <input type="checkbox"/> |
| Home care service        | <input type="checkbox"/> | Community respite care        | <input type="checkbox"/> |
| Community nurse          | <input type="checkbox"/> | Carer support group           | <input type="checkbox"/> |
| Aids or equipment        | <input type="checkbox"/> | Legal/financial advice        | <input type="checkbox"/> |
| Residential respite care | <input type="checkbox"/> | Transport assistance          | <input type="checkbox"/> |
| Aged care assessment     | <input type="checkbox"/> | Alzheimers Australia services | <input type="checkbox"/> |

Other, please specify .....

**18. Please give any additional information or views which you have on the Alzheimer medications and how they are provided through the Pharmaceutical Benefits Scheme or Repatriation Pharmaceutical Benefits Scheme. (eg. Have you experienced delays or other problems in receiving scripts? How important do you think drug treatments are compared to other types of support or intervention such as respite care, carer support groups etc?).**

.....  
.....  
.....

**19. Would you advise a family member or friend suffering from Alzheimers Disease to take these medications?**

Yes

No

**20. Please tell us a little about yourself and your carer**

I am a person with dementia  My age is .....years.

I am..... Male  Female

My carer is .....years old, and is ..... Male  Female

I speak a language other than English at home. Yes  No

My post code is

**If you would like information about the final report please give us your name and address (below) and tick here  Your name and address will not appear in the final report.**

**Name** .....

**Address** .....

**State** ..... **Postcode**.....

**Email** .....

**We are keen to make the information that is provided in this questionnaire available as quickly as possible. Please return the questionnaire within one week of receiving it.**

If you have any questions or concerns about this questionnaire, you may contact Alzheimers Australia (Anne Eayrs) on 02 6254 4233. If you have any complaints about this questionnaire, you may contact the Secretary of the Ethics Committee, Royal Rehabilitation Centre, Sydney on 02 9807 1144.

*Thank you very much for your time and effort in completing this questionnaire.  
Please return completed form in the reply paid envelope provided or send to  
Alzheimer's Australia Medication Survey, Reply Paid 4019, Hawker, ACT, 2614*