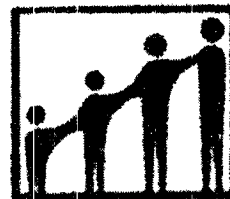


**THE
Institute of Human
Ageing**



**EVALUATION OF THE
ALZHEIMER'S DISEASE SOCIETY
SOUTH CLEVELAND PROJECT**

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SUMMARY

The need for services

An analysis of specialist service provision in South Cleveland suggested the following:

- The scale of 'need' within the community is very large in terms of numbers of people with dementia and people caring for them.
- There is a relative lack of specialist community-based EMI services in the South Cleveland area.
- There is a relative lack of specialist nursing-home accommodation.

Given these considerations, it is clear that ADS plays a vital role in terms of community support services for carers of dementia sufferers in South Cleveland. The development of the specialist EMI nursing home should also be welcomed as an essential part of local service provision.

Awareness of Alzheimer's Disease in South Cleveland

A random survey of 370 local people was undertaken to establish the level of awareness of Alzheimer's disease within the local community. The main results were:

- A large majority of the population have heard of AD and/or dementia, but much smaller number have a reasonable idea of what AD actually is.
- Interviewees mentioned TV as the most important medium for gaining awareness of AD.
- Two-thirds of people who had heard of AD had also heard of the ADS, but only a third of these had a reasonable idea of what AD do.
- Local media and ADS facilities, such as the minibuses and the nursing home have raised the profile of ADS in South Cleveland.
- Certain groups within the population have a greater awareness of AD and the ADS, particularly middle-class women.

Survey of carers supported by the ADS project

On average carers had been involved in a caring capacity for about five years, with the longest being 11 years.

Nearly all carers reported that the task of caring had significantly affected their lives.

Most carers expressed satisfaction with their contacts with GPs and the social services department, although a few were very critical of the help they received.

There was usually a considerable period of time between the first symptoms of dementia, contact with a GP and eventual contact with the ADS, probably in the region of two years. Significantly, a majority of carers (59%) said that they would have benefitted from getting in touch with the ADS earlier.

The major source of contact with ADS was through workers in the formal services, particularly GPs and hospital staff.

Half the carers said that they would not have been able to carry on without the help of the ADS, while only a fifth said that they would have been able

Two thirds of respondents felt that they were getting enough help to carry on for the foreseeable future.

Most carers (75%) received direct support from a number of sources other than the ADS. But it should be remembered that for a quarter of the carers, the ADS was the only source of direct support.

Carers were very appreciative of the support they received from the ADS. For most of them, the various ADS services were essential if they were to carry on caring for their relative.

The key strengths of the ADS were seen as its Flexibility in responding to carer needs and the Caring attitude of the ADS and its workers.

Carers did feel that the ADS was limited by the voluntary nature of the organisation. Carers were unwilling to ask 'too much' of the ADS and felt that the major responsibility should lie with the statutory sector.

Evaluation of day care service

The day centres offered a friendly, relaxed and non-routinized environment for sufferers. Carers were generally very satisfied with the day care and felt that both they and the sufferers benefitted considerably from the service.

The research indicates that the day centres provide a stimulating environment, where a high level of activities and social interaction enhance the quality of life of clients.

The day centres were able to cope with a wide range of client needs, from very confused, anxious and active people, to less confused people who treated the centre as a 'club'.

Transport is a perennial problem with day centre care and clients may be involved in relatively long journeys of up to an hour.

The physical environment of the day centres were not ideal, and problems of restricted space and facilities is a limiting factor.

Evaluation of other ADS services

Counselling: About half the carers interviewed said that they had not received any counselling. About one third of interviewees felt that counselling had been important in helping them to come to terms with their situations.

Advocacy: The ADS tries to help carers in their dealings with the authorities, benefits, the law, etc. About half of the respondents said they had been helped in this way.

Publicity: An important role of the ADS is to raise public awareness of AD and the problems facing carers. About two-thirds of carers felt that South Cleveland ADS had made a big impact in terms of raising public awareness, through posters, fund-raising events, local press, etc.

Sitting service: Although the service is available to all carers, they appear reluctant to make use of it. Only two of the survey respondents said that they made use of the sitting service.

Relative support groups: As with the sitting service, the relative support groups appears to be an ADS activity in which carers are reluctant to engage.

Information and education: The ADS provides an information and education service for carers, covering rights and benefits, information about AD and its effects, and details of other services available. Most carers (71%) said they had had enough information to enable them to cope with the task of caring.

1. INTRODUCTION

The South Cleveland branch of the Alzheimer's Disease Society (ADS) asked the Institute of Human Ageing of the University of Liverpool to undertake a comprehensive evaluation of their project in South Cleveland. In South Cleveland the ADS has a well-developed programme of day care and carer counselling, together with a range of other support services, such as a sitting service and information service. The evaluation focused on the following issues:

What is the impact of the project on the lives of the carers? Are carers coping longer and what is the effect on their quality of life? What aspects of the service have had the most impact? Are the services meeting the needs of all carers? Where could improvements be made?

Assessment of the care provided for sufferers: Are sufferers being provided with a high quality of care? What are the implications of different levels of disability?

What effect has the project had on other services in South Cleveland? What is the level of need for services in the local community? Does the ADS project play a significant role within the overall pattern of care in the district?

Public awareness of Alzheimer's Disease: Are members of the public aware of AD and its effects? What profile does the ADS have within the local community? Has the ADS had any effect on raising public awareness of AD?

The evaluation touched on a wide range of issues, which demanded a range of methodologies. Interviews were conducted with carers, ADS staff and with professionals from other organisations that deal with care of the elderly and the elderly mentally ill. A self-completion questionnaire was also sent to carers, which provided essential background information on their experiences of being a carer and their attitudes towards available services. All the ADS day centres were visited during the course of the research. On these visits, observational research was undertaken, together with interviews with volunteer workers and sufferers and dependency assessments of clients. Public awareness of AD in South Cleveland was assessed by undertaking a street survey in Middlesbrough, which generated a random sample of some 300 respondents. The field research was undertaken over a 12 month period in 1990 and 1991.

Finally, I would like to acknowledge all the help and assistance given to me throughout the evaluation. In particular I would like to thank all the carers who agreed to be interviewed and who completed questionnaires, the staff and volunteers of South Cleveland ADS and the staff from other organisations who were interviewed in the course of the study.

2. THE SERVICE CONTEXT

It is important to examine the ADS project within the wider context of service provision in South Cleveland. Three specific issues have to be addressed:

- What is the level of need within the community?
- Does current provision (from whatever source) match the level of need?
- Are the available services appropriate to the specific needs of the Elderly Mentally Ill and their carers?

It should be pointed out that these are all very difficult questions, both conceptually and methodologically. Given the scope of the present research project, only a very limited analysis was possible.

The Level of 'Need'

It is possible to roughly estimate local 'need' by applying the results of various research studies to the basic population data for South Cleveland. Two issues are examined:

- how many dementia sufferers are there likely to be?
- how many carers are there in the community?

It should be emphasised that it is only possible to make very crude estimates and that the figures presented in this section should be seen as rough indicators of the scale of dementia and caring.

A number of community surveys since the early 1960s have provided a reasonable idea of the prevalence of dementia within a local area. Thus, it is possible to estimate the numbers of dementia sufferers by applying these prevalence rates to local population data. Table 2.1 shows the population data for South Tees broken down by age, together with prevalence rates from two well-known studies. The table indicates that within South Tees Health Authority (Middlesbrough and Langbaugh local authority districts) there is likely to be between 1668 and 1738 cases of dementia. It should be noted that this does not estimate the level of dementia amongst the under-65 population. Moreover, the total number includes people living in nursing homes and residential homes as well as people living in the community. A proportion of these people would be in the early stages of dementia and would not have been diagnosed as sufferers.

The General Household Survey of Informal Carers (Green, 1988) provides a rough idea of how many people are likely to be carers in the community. This survey indicated that, nationwide, one adult in seven provided informal care and three per cent of adults devoted at least 20 hours per week. By using the data from this data it is possible to build up a picture of informal caring in the South Cleveland area.

Table 2.1 Estimated levels of Dementia in South Cleveland

	65-74	75+	65+	Estimated Cases
South Tees Population (thous)	23.8	15.0	38.8	
Prevalence 1				
1% of people 65-74	238	-	-	} 1738
10% of people 75+	-	1500	-	}
Prevalence 2				
4.3% of people 65+			1668	} 1668

Sources: pop data- OPCS (1990) Key Population and Vital Statistics HMSO

Prevalence 1- Ineicheh 1987

Prevalence 2- Copeland et al 1987

It should be emphasised that this exercise is very crude and the figures that are derived are only indicators of the scale of caring in the community and not hard and fast 'facts'. The actual prevalence of caring will depend on a number of local factors which cannot be adjusted-for in the present study:

- the age structure of the population
- local service provision
- local cultural attitudes
- local socio-economic circumstances, such as the availability of informal carers

Table 1.2 shows the estimated numbers of informal carers in the area covered by South Tees Health Authority. As can be seen about 10% of the adult population are likely to be involved in caring for an older person. This gives a total of over 23,000 carers in South Tees, of which the majority are involved with caring for an elderly person who is physically infirm. The table shows that around 683 people will be looking after someone who is mentally infirm, while nearly 3000 will be looking after someone who has both mental and physical disabilities.

These estimates cover carers that are involved to varying degrees in the task of caring. However, it is possible to look at the impact of the caring task on the community. Of all carers, about 24% spend over 20 hours per week in caring for a dependent person. Of these 'intensive' carers, 12% have difficulty in arranging alternative care for a 2-hour break, 44% have difficulty in arranging cover for a 2 day break, while 52% have not had a break of 2 days or more since they took on the task of caring. In Table 2.3 these percentages are applied to the estimated numbers of EMI carers in South Tees.

If we look at carers who are looking after older people with mental disability, about 164 would be involved in over 20 hours caring per week. About 20 would have difficulty in arranging cover for 2 hours, while over 70 find difficulty in organising longer breaks. If we include the figures for carers who look after older people with mental and physical disabilities, the level is much greater. Of the estimated 3644 carers, about 875 carers would be involved in caring 20 hours per week or more and about 100 of them would have difficulty arranging cover for 2 hours. A high number of people find it very difficult to arrange longer breaks.

Service Provision in South Cleveland

The previous section gives an indication of the level of service need within the community. This section provides a review of services for elderly people with dementia and their carers in South Cleveland.

i. Health Authority

Until recently, Health Authority EMI services were based at St Lukes Hospital in Middlesborough. St Lukes provides 24 elderly assessment beds and 16 beds for acute admissions of elderly people suffering from functional disorders. In April 1990, 52 long stay beds were allocated for EMI clients, although at the time only about 30 beds

were occupied. It was felt that the mushrooming of private sector nursing homes had reduced the effective demand for health authority places. By September 1991, long-stay accommodation had been transferred to community hospitals in Redcar and Middlesbrough, providing a total of 18 long-stay beds and 2 respite beds. A day care unit is based at St Lukes hospital, providing places for about 15 people. There is an elderly person's day unit in Guisborough, but this is not specifically for EMI clients.

ii. Social Services

In Middlesbrough District there were 6 Part III homes providing 266 residential places and 18 day places. Three day centres provided 100 day care places. In Langbaugh District, there were 8 homes providing residential accommodation for 406 people. There were five day centres providing 95 places. A further 21 day places were available at the various Part III homes. Two social centres for elderly people provided day places for 180 people.

Cleveland Social Services and South Tees Health Authority jointly operate a family Support Unit at Eastbourne Lodge in Middlesbrough. This provides short-term care for 5 people at a time and 10 day care places (7 days a week). Evening care and special occasions care can also be arranged. Referrals are made through the Psychogeriatric Department at St Lukes Hospital.

Specialist domiciliary services are fairly limited. The home help service covers the whole spectrum of dependent elderly people and provides cleaning and shopping etc. Grove Hill Carers is a project run by Cleveland Social Services and funded by the Inner Areas Programme. The aim is to support carers in the local community, particularly to relieve the build-up of stress that can lead to the breakdown of family care. Care is available seven days a week at any time of day or night. The service is geared to the specific needs of the carer. The support is available to anyone who is caring for a dependent person and the dependent person is not necessarily old or mentally infirm. The support workers are paid employees of the social services department. At the time of contact, 31 families were supported by the scheme. Although the scheme is not age limited, 26 of the dependent persons were aged over 65 years. Of these, only 5 carers were looking after an elderly person with dementia.

Table 2.2 Estimated numbers of carers in South Tees

	prevalence	pop 15+	estimated no. of carers
'old age'	0.5%	227,800	1139
physical and mental disab	1.3%	227,800	2961
mental only	0.3%	227,800	683
physical only	7.7%	227,800	17541
other	0.2%	227,800	456
TOTAL	10.2%	227,800	23121

nb. population figures are for the over-15 population and not the over-16s. This means that the figures in column 3 will be slight over-estimates, because the GHS survey gives data for adults over-16.

Table 2.3 Effects of caring in South Tees

	mental only	mental & Phys/mental
numbers of carers	683	3644
20hrs+ per week	164	875
2-hour break difficult	20	107
2-day break difficult	72	384
no break of 2 days or more	85	453

iii. The Voluntary Sector

Age Concern is actively involved in the welfare of older people in South Cleveland. In terms of services, they operate a visiting scheme in East Cleveland. In Middlesbrough, there is a pop-in centre and also a hospital after-care service. Day centres are operated at Redcar, Southbank and Hemlington. Other elements of Age Concern is their advocacy role and their advice and information service.

Age Concern is currently in the process of reorganisation. The strategy will emphasise a role of enabler, rather than as a direct provider of services. Development teams will help and support local schemes and initiatives. Age Concern will also refer-on people with dementia, who will be more appropriately helped by ADS. Other voluntary organisations include Crosslink and an Institute for blind people, many of whom are elderly.

iv. The Private Sector

In the area covered by South Tees Health Authority, 20 nursing homes provide 727 beds, mainly for the physically frail elderly (some homes also cater for younger chronically sick clients. In the Middlesbrough and Langbaugh Districts of Cleveland there are 36 registered residential homes providing 618 places.

The private sector, however, is primarily concerned with long-term residential and nursing home care. Very little day care or short-term/respite care is provided. The development of private sector domiciliary care has also been very limited. Furthermore, there are relatively few specialist EMI homes. This is surprising given the prevalence of dementia amongst older people and the high level of stress associated with caring for people with dementia. However, there are indications that the Private sector will diversify in response to changes in service provision and funding at the local level and the 'bottoming-out' of the residential and nursing home market.

In South Cleveland there are three registered nursing homes for the elderly mentally ill. However, it should be remembered that most residential and nursing homes will have clients with some degree of mental impairment. Two of the EMI homes are located in Guisborough, Graceland and Four Seasons (phases 1&2), and one in Middlesbrough, Southend. These were contacted to assess the current situation regarding Private Sector EMI care:

In total, 143 residential places are provided in the three homes.

There is currently 6 bed vacancies (5, 1 and 0 in the three homes).

Currently, no day care is provided by any of the three homes. However, one home does have plans to offer three day places in the near future.

None of the homes offer short-term care on a regular basis. One home did occasionally take short-term clients if there was a vacancy and the need was desperate.

None of the homes currently had any short-term residents

None of the homes offered regular respite care.

The contacts in the homes were asked to estimate the current demand for respite services. This was assessed as very limited, although one interviewee felt that their home was known specifically for permanent care and that it would be unlikely that they get many enquiries about respite care. One of the three homes did occasionally admit people on a short-term basis.

The survey of the private EMI homes would indicate that current demand for specialist EMI nursing home accommodation is high. The three homes are operating more or less at maximum capacity (96% overall), although one of the homes had 5 vacancies (operating at 88% of capacity). None of the homes had major plans to diversify (eg day care or short-term care).

Conclusions

A number of issues need to be borne in mind:

The level of need within the community is large

The private sector is relatively buoyant

There is a relative lack of community-based specialist EMI services in the public sector

There is a relative lack of specialist nursing-home accommodation

There is a lack of demand for alternative forms of care, such as respite care. This could reflect the channelling of clients into permanent residential care and inadequate information to potential users.

Given these considerations, it is clear that the ADS plays a vital role in terms of community support services for carers of dementia sufferers in South Cleveland. The development of the specialist EMI nursing home should also be welcomed as an essential part of local service provision.

3. AWARENESS OF ALZHEIMER'S DISEASE AND THE ADS IN SOUTH CLEVELAND

There were two main areas of concern. Firstly, what was the level of awareness of Alzheimer's Disease (AD) amongst the public. Secondly, what was their level of awareness of the Alzheimer's Disease Society (ADS) and their activities in the South Cleveland area.

A street survey was carried out in Middlesbrough centre on various dates from January to April 1991. A small survey was also carried out in Durham to provide comparison data. A total of 370 interviews were carried out; 277 in Middlesbrough and 93 in Durham. Interviewees were selected at random and the aim was to provide a cross-section of the Middlesbrough public.

The questionnaire was in three sections. The first looked at people's awareness of AD and dementia. Interviewees were asked whether they had ever heard of these conditions. A 'lie' question was also included, using a fictitious disease, to see whether people were responding appropriately to the questionnaire. Interviewees were asked questions about what AD is and who it affects. A question also looked at where people had heard about the disease.

The second section asked people if they had heard of the ADS, where they had heard about it and what it did. Finally, background questions were asked about the interviewee; age, sex, marital status, occupation (socio-economic group) and where they lived (postcode). Interviewees were also asked if they knew anyone with AD and whether they cared for a sufferer.

It is important to point to some of the limitations of street interviewing. It is likely that there will be some sample bias, ie. the sample is not entirely representative of the population of Middlesbrough. For example, much fewer informal carers of elderly people were interviewed than might have been expected from a sample of nearly 400 people. However, the focus of the survey is on the awareness of AD amongst people who are not necessarily involved in supporting an elderly person. It can be assumed that any bias in the sample will not invalidate the general findings of the survey to any great extent.

Have people heard about Alzheimer's Disease?

In total, 77% of the Middlesbrough sample claimed that they had heard about AD. However, a further 6% said that they had heard of dementia, but not AD, indicating that just 17% of the people interviewed were unaware of either AD or dementia.

It is worth mentioning definitions at this point. AD has become a catch-all phrase amongst the public. People may use the term AD to refer to any organic brain disease.

The "lie" question asked people if they had heard of a fictitious disease. This was included to test if people were answering automatically 'yes' to questions. Only 3% of the Middlesbrough sample answered 'yes' to this question. This low figure means that we can confidently conclude that the questionnaire results are a good reflection of the level of awareness of AD.

Where had people heard about AD?

Table 3.1 indicates the main sources of hearing about AD. The most frequently mentioned medium was TV, with 29% of people mentioning this as where they had heard about AD. A significant proportion of the sample said that they had become aware of AD because they knew someone with it, or knew of someone through a friend or relative.

16% of interviewees mentioned a range of sources, which are classified as 'other' in Table 1. These include: seeing a notice in a surgery/hospital; and being told about it by someone else and hearing about a famous personality with AD.

Some 17% of interviewees said that they were unsure about where they had heard about AD. It is probable that an individual's awareness derives from a number of sources and that the identification of a specific source of their knowledge is likely to be a little contrived. However, the results should give a reasonable picture of the key sources of information.

Do people know what AD is?

Although a large proportion of people interviewed had heard the term AD, this does not mean that they knew very much about it. Those interviewees who had heard of AD (n=228) were asked to define AD/dementia in their own words and their responses were examined in detail during the data analysis. Table 3.2 lists the key definitions that were mentioned.

For the purposes of data analysis interview responses were put into three categories: accurate, vague and don't know. Responses were classified as 'accurate' if they mentioned a common symptom of AD- memory impairment, loss of mental faculties, confusion, inability to look after yourself- or described AD as a disease led to the progressive degeneration of the brain. Obviously, people were not expected to provide text-book definitions; to be classified as 'accurate' they needed to have at least some idea of what AD implied. Responses were classified as 'vague' if interviewees could only give very limited responses. For example, a number of people described AD as a 'nervous disease', indicating an illness that is in some way related to mental functioning. Responses were classified as 'don't know' if interviewees said that they were unsure or if they provided an answer that was wrong, such as 'AD is muscle-wasting disease'.

On the above basis, 51% of respondents who had heard of AD were classified as 'accurate' and had a reasonable idea of what AD was. 12% could only give very vague definitions while 37% could not give a definition. Taking the sample as a whole (n=277), 42% of all those interviewed could give a reasonable definition of AD.

Interviewees who had heard of AD were also asked the question 'who does AD affect'. 15% said that AD only affected old people while 39% said that AD usually, but not necessarily, affected old people.

Table 3.1 Where people had heard about Alzheimer's Disease

know someone with AD	16%
know of someone with AD through friend/relative	11%
TV	29%
newspaper/magazine	11%
professionally involved	6%
school/college course	4%
publicity event	2%
other	16%

Table 3.2 People's definitions of AD

memory loss
loss of mental faculties
nervous disorder
debilitating disease/condition
brain deterioration
mad/insane/lose marbles/lose senses
senility
confusion
cannot look after self
going back to childhood
muscles wasting away
Downes Syndrome

Had people heard of the ADS?

Of those interviewees who had heard of AD, 68% had also heard of the ADS. The remaining third said that they were not aware of the ADS or were unsure. This means that out of the total sample of 277 people, just over half (56%) had heard of the ADS. Did people know what the ADS was involved in?

Did people know what the ADS was involved in?

People were asked to say in their own words what they thought the ADS was doing. Table 3.3 summarises the main responses to this question. As with the question on the definition of AD, responses were classified as 'accurate', 'vague' and 'don't know'. 'Accurate' responses were those which mentioned one or more of the activities of the ADS in South Cleveland. 'Vague' responses were those such as 'helps the sufferer'. During the interviews it became clear that people could surmise the role of the ADS from their general understanding of the role of voluntary organisations, rather than 'hard' knowledge of ADS activities. Quite often people would respond by saying 'I suppose that they do....etc'.

Based on the above classifications, around 30% of those people who had heard of the ADS had a reasonable of the ADS's activities. 35% only had a vague idea, while 35% were unsure. Of the total sample of 277 people, only 17% could be said to have a reasonable idea of the role of the ADS in South Cleveland.

Where had people heard about the ADS?

While many people's awareness of AD itself was attributed to TV programmes, awareness of the ADS appears to originate from more local sources. Table 3.4 summarises the responses. Local media, such as public service announcements on regional TV and articles in local papers were frequently mentioned. Local ADS facilities, such as the Poplars Day Centre, the ADS minibus and the ADS shop were the most frequently mentioned sources of people's awareness. Other Day centres were not mentioned. This may be due to the relatively low profile of the other centres, although it is not possible to say this with any confidence. In the 'other' category, people mentioned conversations with others, personal knowledge of a sufferer, posters and publicity events.

The results indicate that the best publicity is not publicity at all! Seeing the day centre and the minibus appears to have the greatest impact on people.

TABLE 3.3 What people thought the ADS did

helps sufferers
helps carers/relatives
helps both sufferer and carer
organises meetings
puts people in touch with each other
runs day centre
does research
fundraising

TABLE 3.4 Where people had heard about the ADS

TV feature	6%
TV public service announcement	6%
Local radio	1%
National radio	1%
Local newspaper	13%
National paper/magazine	8%
Professional involvement	4%
Seen ADS day centre	18%
Seen ADS minibus	17%
Seen ADS shop	1%
Other	33%
Unsure	9%

Comparison with another locality

To see if the activities of South Cleveland ADS has had any impact in terms of raising local awareness of AD and the ADS, a comparison survey was undertaken in Durham. The initial piloting of the questionnaire indicated that the presence of ADS day centres and minibuses had an impact on public awareness. Also South Cleveland ADS was often mentioned as having a high local profile.

The sample of interviewees in Durham and Middlesbrough were very similar in terms of their demographic structure. Thus, the survey results from both towns could be directly compared.

The results indicate very little difference between Durham and Middlesbrough in respect to awareness of AD, the source of their knowledge of AD and their ability to reasonably define the disease.

However, there were differences in respect to awareness of the ADS. In Middlesbrough 68% of the sample claimed that they had heard of the ADS, while the equivalent figure for Durham was 49%. Also, a very large proportion of those people in Durham (54%), who had heard of the ADS were unable to say what the ADS did. The equivalent figure for Middlesbrough was only 35%. In Durham the major sources of people's awareness of the ADS was the TV and professional involvement. In Middlesbrough, people frequently mentioned local ADS facilities.

One can conclude that ADS activities in Middlesbrough has resulted in a high profile and raised public awareness of the organisation. However, local activities have less impact on the public's awareness of AD itself.

Overall Awareness

Out of the 277 people interviewed in Middlesbrough, 23% had never heard of AD and had never heard of the ADS.

A further 34% had only minimal knowledge, that is they had heard of AD or the ADS, but were not able to say what either were.

Only 14% of the sample could be described as knowledgeable, that they had heard of AD and the ADS and were also able to give adequate definitions.

Some 20% were had heard of AD and the ADS and were able to adequately define AD, but were unable to say what the ADS was involved in.

Is awareness of AD Related to the background of the individual?

Background data (age, sex, occupation, postcode) were collected for all interviewees. It is possible to look at awareness of AD and ADS according to these socio-demographic characteristics:

The most knowledgeable group of people were middle-class women, especially those aged over 30.

Overall, women were more aware of AD and the ADS than men.

Overall, middle-class people were more knowledgeable than the working class.

Not surprisingly, children aged 11-16 had generally little awareness.

Although young adults (18-29 years) had marginally lower levels of awareness, age was not a factor in determining level of awareness.

Although quantitative data is not available, a high number of students said they did not know what AD was. This is surprising as one might expect higher levels of awareness amongst people with a good education.

People who had personal knowledge of someone with AD were much more likely than others to have heard of the ADS. However, only about half of them had a reasonable idea about what the ADS does.

Summary of Key Findings

A large majority of the population (83%) have heard of AD and/or dementia, but

A much smaller number (42%) have a reasonable idea of what AD actually is.

Interviewees mentioned TV as the most important medium for gaining awareness of AD.

Two-thirds of people who had heard of AD had also heard of the ADS,

but
only a third of these had a reasonable idea of what AD do.

Local media and ADS facilities have raised the profile of ADS in South Cleveland.

Certain groups within the population have a greater awareness of AD and the ADS, particularly middle-class women.

ATTITUDES TO CARING

All the carers interviewed were very committed to the task of caring. The aim was to support the sufferer at home rather than to resort to residential care. Data from the questionnaire survey indicates a fairly long time lag between diagnosis of dementia/AD and making contact with the ADS. This suggests that the people who approach the ADS have already made the decision to be a carer and that the ADS service itself has relatively little impact on this decision-making process, although this conclusion is fairly tentative.

There are different types of carer, an issue that has not been fully explored in research into caring. This is an important issue as different services may be needed to meet the specific needs of carers. The interviews suggested a range of different 'types' of carer:

The obsessive carer- for these individuals, the task of caring dominates their lives. Caring may become an obsession, where even when they are not actually be looking after the sufferer, this still preys on their minds. Such people usually feel that no-one else could look after the sufferer and when they are away from the sufferer they are constantly worrying.

Boundary setters- the carer is able to put the task of caring into a more practical perspective. Unlike the 'obsessive' carers they are able to define fairly clearly what can be reasonably expected from them as carers. These people are more willing to share the task of caring. However, they should not be seen as any less 'devoted' because of this.

Little difference- the person just accepts the role of carer, and their existing pattern of life is not significantly disrupted. This may be a situation where the sufferer is 'pleasantly confused', and does not cause significant stress.

The unwilling carer- Some people who were interviewed appeared to see caring in wholly negative terms. For these people, the task of caring is seen primarily as a nuisance. However the disruption to their lives would not be enough to warrant residential care. Caring is taken on out of a sense of duty, rather than loyalty or love. Family relationships prior to Alzheimer's Disease may have already been poor. They may be caring 'at a distance', rather than living with the sufferer and the actual caring may be jobs such as housework and shopping. Some carers may be unwilling to resort to residential care because of possible financial implications.

IMPACT ON HOME LIFE

Almost all the respondents (86%) said that they were closely involved in caring, providing care ranging from general household duties, such as cleaning and shopping to the '36-hour' day situation of total care for the sufferer. About half of the respondents said that the task of caring had significantly affected their lives. Table 4.1 summarises the kinds of effects on the carer.

The demands of caring for an Alzheimer's sufferer can have a tremendous impact on the carer's life at home. The following quote expresses the sense of isolation experienced by many carers, particularly the spouses of sufferers:

"I feel like a nursing home with no time off. I can never just drop off in the afternoon at all. I feel like I am trapped at home. I hate it- so isolated. It can be like a prison. He paces up and down. he is so bored and there is nothing I can do, he just paces a lot

For most people, 'home' is a place to relax in the privacy and comfort of the house. However, for this person 'home' is a place of anxiety and entrapment. The isolation is often compounded by the breakdown of social contact. For example:

"You soon realise who your friends are. My husband's family just don't want to know. Friends stop coming to see you".

But can carer isolation be solved simply by offering respite services? To illustrate:

"People say that they would like a sitting service, but there is no take-up. But where do you go without your husband? Also people are too knackered, physically and mentally. And if you are bound up with life at home, you get out of the habit of going out".

Isolation is a problem for carers. However, it is a problem that is not easily solved. The contributory factors of the demands of caring and the breakdown of social opportunities can lead to increasing social disengagement amongst carers.

THE SITUATION BEFORE THE CARER CAME INTO CONTACT WITH THE ADS

On average, carers had been involved in caring for about five years. However, there was a wide range, with the longest period being eleven years.

For most people the first point of contact with the caring services was their local GP, accounting for two-thirds of respondents. Other first contacts were either the ADS or local social services. There was usually a considerable delay between the first symptoms of dementia and approaching someone for help and advice. On average, this delay would be about 18 months. Most people (53%) said that this initial contact was very helpful to them. Only three people said that they found their first point of contact unhelpful. GPs have been often criticised as being unhelpful and lacking in understanding. These results indicate that generally people are very satisfied with their local GP.

Prior to contacting ADS, most people had contact with other services. Obviously GPs were frequently mentioned. About half of the carers mentioned input from social workers. However, relatively few mentioned active help in terms of day centres (20%) and psychiatric hospital (20%). Only two respondents said that they had had no contact with other services prior to getting in touch with the ADS. Again most people expressed satisfaction with the services they had been receiving.

Most carers (75%) received direct support from a number of sources other than the ADS. But it should be remembered that for a quarter of the carers, the ADS was the only source of direct support. The large majority of carers (79%) said they were satisfied with the services they were receiving (39% very satisfied, 39% quite satisfied). Table 4.2 shows the other services carers were receiving.

Just over half the carers (56%) said that they were receiving help in caring from other members of the family or from neighbours. However, it should be remembered that nearly half (44%) of the respondents were caring on their own, and that any support would have to come from organised services. Many carers find themselves in financial difficulty. The large majority of carers (79%) said that they experienced no financial difficulties. About 11% said that they experienced some difficulties, while another 11 said they were experiencing great difficulty.

Table 4.1 The effects of care

loss of companion
sufferer is mmody and aggressive
stress
stress leading to high blood pressure
trying to keep a job and 2 households going at once
isolated from family and friends
did not like to see deterioration in husband
whole life and that of family revolves around caring
loss of sleep
irritableness- eg. due to having to repeat things
husband completely dependent on me
felt upset that no one could understand
I feel I cannot do enough for the sufferer
could not come to terms with AD- hoped doctors were wrong
could not go out shopping etc.
worried mother would fall

Despite the overall level of satisfaction with statutory sector services, some respondents felt that these were inadequate. Specifically, they felt that the statutory sector was:

- unresponsive and slow
- do not keep clients informed of what is happening
- bound by red tape

In addition, several carers related episodes where contact with the statutory sector had been wholly unsatisfactory. Some of the complaints related to GPs. For instance some GPs offered virtually no help or advice once a diagnosis of dementia had been made. One carer had been very unhappy about their contact with a social worker:

"I won't have anyone from the social services. I have banned them. When she was still able to understand things, a social worker came out of the blue to talk to my wife. She asked my wife if she had made a will and told her to cancel her holiday. She told her she was going to die. My wife was in tears and I was furious. The social services denied it, but I banned them".

It is important, however, to put these observations into perspective. The questionnaire survey indicated that, on balance, carers were satisfied with the services they received from the health and social services. Moreover, most people were happy with the level of services they were receiving from all sources. Indeed, some carers felt that they were receiving very high levels of services and that the South Cleveland area was well served. However, problems were raised by carers in respect to the statutory services:

- the way information is channelled to carers is patchy- the fragmented nature of services makes consistency difficult. Thus some carers will get very good support, while others will miss out.
- the way in which carers are often dealt with by statutory services- ie they are processed as a client, rather than helped as another human being.

MAKING CONTACT WITH THE ADS

Most people had been involved with the ADS for less than two years. Clearly there is usually a considerable period of time between the first symptoms of dementia, contact with a GP and eventual contact with the ADS, probably in the region of two years. Significantly, a majority of carers (59%) said that they would have benefited from getting in touch with the ADS earlier. Only a quarter of the carers said that they would not have benefited from earlier contact. The rest were unsure.

The ways people found out about the ADS are summarised in Table 4.3. The major source of contact was through staff in the formal services, particularly GPs and hospital staff. Relatively few people found out about the ADS through informal channels, such as posters, leaflets etc.

Information is the key to service provision. Without information and knowledge of what is available, a carer cannot gain access to the service. The questionnaire survey indicates a significant time lag between the diagnosis of dementia and contact with the ADS. Interviewees were asked about their experiences at the onset of Alzheimer's Disease. A typical pattern emerged:

- Initially, people do not realise that the sufferer has dementia. They recognise problems such as wandering and memory failure, but do not know the underlying cause.
- When problems become significant, they approach their GP, who recognises the problem.
- They contact social services, which usually involves a long wait. Social services mention the ADS.
- Carer contacts the ADS

Some interviewees felt that the available services were too fragmented and that liaison between the different organisations- GP, hospital, social services, ADS- was very patchy. The lack of coordination means that the whole process of getting information and appropriate services takes longer than it should do. Meanwhile, the carer has to cope without really knowing what is going on. The GP was seen to play a key role in providing information, as they are usually the first point of contact for carers:

"Information at the start is very patchy. Sometimes help is very good, but in general it is very poor. For example GP help can be very poor. The first thing the GP should do is to refer you to the ADS. They should advise everybody that X is available for advice".

Some interviewees talked about carers being reluctant to find things out for themselves:

"I was lucky. I got the help I needed without really asking for it. But there are people who are not getting the services they need. They might not know what is available or they may not be asking for it. Some people are their own worst enemies when it comes to asking for help. They try to do too much for themselves. Paradoxically, I think the ADS needs to sell its services more".

Table 4.3 How carer made contact with the ADS

	Frequency of mention
GP	7
leaflet	1
poster in surgery	1
national ADS	1
social worker	3
consultant	4
staff at hospital	4
staff at local authority day centre	1
friend	3
local newspaper	2
sufferer had been ADS volunteer	1

HOW DOES THE ADS HELP THE CARER?

Half the carers said that they would not have been able to carry on without the help of the ADS, while only a fifth said that they would have been able. The remaining people (about a third) said that they were unsure. Of the people who said that they could have carried on without ADS support, several mentioned that this would have only been with considerable difficulty. The conclusion to be drawn is that the ADS service plays an important part in maintaining the carers' ability to cope with their situation.

Two thirds of respondents felt that they were getting enough help to carry on for the foreseeable future. Of these, a little under half felt they were receiving plenty of support, while a little over half felt that support services were 'just adequate'. The remaining third felt that they were not receiving adequate support in their task of caring. The package of care that people were receiving did NOT appear to depend so much on:

stress felt by carer
or
dependency of sufferer

but on:

awareness of what was available
(information and knowledge of available services)

willingness to accept help
(some people are fiercely independent)

appropriateness of service

(services may not be exactly what the person needs or may be inconvenient)

attitudes towards accepting support
(some people do not want to be a burden- they see services as a favour, rather than as a right)

The vast majority of carers (89%) felt that the ADS service benefited them. The benefits are summarised in Table 4.4. The majority of respondents (71%) felt that the ADS service had no disadvantages for them personally. However, 25% did feel there were some problems. These included:

- mother will not attend, as she gets bored and does not like being with people who are more demented than her
- wife does not like ADS transport
- problem getting wife ready in time for transport
- have to take time off work to get sufferer ready for day centre

CARERS EXPECTATIONS OF THE ADS

Generally, carers expected a lot of the ADS in respect to:

- information about AD
- respite care
- individual support
- legal and welfare advice and advocacy

Carers were very grateful for any help that they got and invariably talked about the ADS in positive terms. However, carers were aware that the ADS is a voluntary organisation. Although carers praised the ADS highly, they saw the ADS as inherently limited in what they could offer. The fact that the service was based on volunteer help was seen as a limiting factor:

- There was a widespread concern that volunteers do not have the 'medical expertise' required to look after someone with dementia.
- The hours where a service could be available would be limited by the availability and willingness of volunteers. As one person put it: "You are asking a lot from a voluntary service. It is nice to have it, but it is very limited. With the sitting service, you get half a night out, but never a full night. You are always clock watching".
- The turnover of volunteers is high, making it difficult to maintain continuity of relationship between sufferer and carer and the volunteer.
- Many of the interviewees said they were unwilling to ask 'too much' of the ADS, as they did not want to impose on the goodwill of volunteers.

In contrast, there was a very common feeling that the statutory sector was not doing enough for carers and that far more should be provided by social services and the health authority (although people were fairly vague about what they wanted). People felt that too much was being expected of the ADS. In this situation carers can feel uncomfortable because they are ' beholden' to the goodwill of the ADS. Alternatively, they feel resentment because they feel they have some 'right' to support from the statutory services. People felt that carer support should be the Government's responsibility.

However, the volunteer aspect of the service remains important. The following quote is illustrative:

"...people appreciate that volunteers are doing it out of the goodness of their hearts. It is a feeling that there is someone else who cares and is not just doing a job in order to get paid".

Table 4.4 Benefits of ADS service to carers

	Frequency of mention
a few hours of peace/breathing space	3
a break	2
relaxed/free form stress	2
feel refreshed	1
feel able to cope if I know I get some free days	1
don't have to worry about sufferer	3
confident husband is being well looked after	4
look forward to free time	1
time for myself	4
time to be with family	1
able to go and do shopping	5
only place where people really understand	1
able to carry on working	2
useful advice	2

CONCLUSION

Carers were very appreciative of the support they received from the ADS. For most of the carers interviewed, the various ADS services were essential if they were to carry on caring for their relative. The strengths of South Cleveland ADS were seen as:

Flexibility- the ADS is quick to respond to requests from help, whereas the Statutory services are seen to be slow and bound by red-tape.

Caring- the fact that the volunteers offer support 'out of the goodness of their hearts' means a lot to carers

However, certain limitations were highlighted, related to the voluntary nature of the ADS: limited hours where a service is available, and the unwillingness of carers to ask 'too much' of volunteers. Many carers felt that the main responsibility for supporting carers at home should lie with the health and social services.

The interviews gave important insights into the "consumer perspective". What are the key attributes that make a service right from a client's point of view. It should be remembered that success depends not just on WHAT is delivered, but on HOW it is delivered. The following principles are suggested as the basis for quality assurance procedures in community-based services. The service should be reviewed regularly in terms of:

Visibility- People need to know that the service is there. Good communication and advertising is essential.

Approachability- It needs to offer a non-threatening, relaxed, supportive, non judgmental contact. This applies to telephone contact and face-to-face contact. An office would be an inappropriate place for such contact.

Availability- The service needs to be available when the person themselves wants it.

Appropriateness- The service has to fit in with each person's unique needs and circumstances.

Flexibility- Care and support needs to be flexible as the clients needs change over time.

Effectiveness- It is important to look at outcomes; is the service really making a difference, or is it just delivering care? For example, does respite care remove the carer's worries or does it substitute different ones? Is it improving the quality of life?

Responsiveness- To be effective, services need to be responsive and immediate for critical events and for longer term care.

Caring- Clients do not just want help. They want to feel that someone cares about

them. The service needs to exist for people and NOT for its own perpetuation.

In the UK a lot of effort is being put into developing respite services to give carers a break from the task of caring. However, the support needed by carers is not just social but psychological. For some people this feeling of security may be more important than the social respite services. From interviewing carers, it was apparent that a major strength of the South Cleveland ADS was the feeling that 'you are not on your own' and that 'there is always someone there to listen'. Indeed, voluntary organisations, such as the ADS are perceived to be more caring than the statutory services. This issue was raised by many of the carers who were interviewed. Thus, it is important that this aspect of the ADS's work in South Cleveland should remain at the forefront and should not be compromised by any developments in respite services and residential care.

5. EVALUATION OF ADS DAY CENTRES

A major part of the South Cleveland ADS efforts in supporting carers is the day centres that are operated in various part of the locality. The evaluation of the day centres was approached in two ways. Firstly, the consumer's viewpoint was provided by the questionnaire survey of carers and through face to face interviews. The second approach was to observe directly the care provided in the day centres.

South Cleveland ADS offers daytime respite care in six centres in South Cleveland. The questionnaire contained questions which were aimed at finding out the benefits and disadvantages of the day centres for the sufferer. The great majority of carers (93%) mentioned benefits for the sufferer and these are summarised in Table 5.1.

Most carers could not think of any disadvantages with the day centres. however, a few problems were raised:

- sufferer uncomfortable in presence of more advanced AD sufferers
- sufferer sat all day if little is going on
- sufferer sometimes afraid of others
- sufferer becomes aware of their problems
- better communication- not enough feedback to carers
- sufferer arrives back home when carer is at work

When asked to evaluate the day centre service, 72% said they were very satisfied, with 26% saying they were quite satisfied. Nobody said that they were dissatisfied with the day centre service. Respondents were asked if there were any changes they would like to see in the day centre provision. Only one person said there was. The others were equally divided between 'no changes' and 'unsure'. A number of respondents mentioned that they had very little actual knowledge of what went on in the day centres.

Dependency level of clients

In order to get a more thorough picture of who the ADS was caring for in the day centres, a dependency assessment scale was used to look at physical frailty, mental functioning, mood and cooperation, and capacity to look after oneself. The particular schedule used was the Chrichton Royal assessment scale, which has been used in many studies of services for physically and mentally frail elderly people. In total, 43 individuals were assessed, with the leaders of the day centres acting as key informants. The scale gives a very crude, but useful, measure of dependency- the higher the score the more dependent the person is. The range of scores is 0 (not dependent) to 38 (maximum dependency, where the person is profoundly physically and mentally disabled, uncooperative, and unable to perform any simple tasks of living).

The following observations can be drawn from the data:

- i. Clients varied considerably in terms of their level of dependency. For example, when the assessments were done at Poplars, two out of 14 clients were rated more or less

as maximum dependency, while 3 others were minimally dependent, perhaps only showing a problem of forgetfulness.

- ii. Because of the wide variation, there is no such thing as a 'typical' ADS client.
- iii. Overall, however, ADS cope with a moderate level of dependency. A fair degree of confusion, including short-term memory loss, disorientation in time and place and, to a lesser extent, communication problems, are common. On average, clients are fairly mobile and retain a fair degree of autonomy in respect to feeding, washing, ability to cope with clothing and going to the toilet.
- iv. Although the overall dependency level was moderate, ADS is dealing with some clients who would typically be found on high dependency psychogeriatric wards.
- v. Some day centres had a higher level of dependency than others, with Poplars and Coulby Newham having the most dependent clients.

The 'mixing' of severely mentally impaired people and people who are relatively unimpaired has been the subject of considerable debate. Some people have argued that the more seriously impaired people benefit, while others argue that the less impaired people find this mixing unacceptable. Similarly, the age of clients ranged considerably, from people in their early 50s to people in their mid-80s. Interviews with carers and the questionnaire survey did indicate that these are issues about which some carers are concerned.

Overall, workers in the day centres were able to cope with a wide range of needs:

- very confused people
- people who just want to be quiet
- active people
- some people with aggressive tendencies

Table 5.1 Perceived benefits of day centre care

	Frequency of mention
change of environment for sufferer	8
sufferer comes back in happier frame of mind	2
sufferer's mind is stimulated	4
activities	3
comes home tired and has good nights sleep	1
get company	17
gets attention	2
friendly staff	2
sufferer sleeps all time at home	1
being with people who understand the problems	2
nice food	2

Day centre facilities

Transport: This can be a problem in the provision of effective day centre services. It is the kind of things that carers complain about most. Situations where a sufferer is picked-up at regular times in the morning, spends 2 hours in an ambulance and a few hours at the day centre before another long journey home is commonplace. On a relative basis, South Cleveland ADS is well-endowed in terms of transport. However, some sufferers have to be transported quite long distances and an average trip is estimated to be just under an hour.

Buildings: The Poplars is the only dedicated day care unit. The other day centres make use of available local facilities, such as a communal lounge in a sheltered housing complex and local community centres. Although the ADS is obviously restricted in terms of what is available for use, a number of problems were highlighted in respect to the buildings.

- not enough space
- not enough different areas
- facilities, such as toilets, not ideal

Observation study of day centres

The evaluation of the day centres included observation studies at Coulby Newham and Poplars. The study involved observing all clients in the centres at regular intervals and noting their activities each time. The observation study was limited in scope and does not allow sophisticated statistical analysis. The observation study classified client activity in four ways:

Positive activities: These are activities which generally enhance the quality of life and well-being of sufferers. Two types of activity are included: leisure activities and social interaction. Leisure includes groups activities and informal leisure pursuits. Social interaction is any activity (verbal or non-verbal) where the primary objective is communication for its own sake rather than some instrumental reason.

Passive behaviour: One of the criticisms of institutional-type care of the elderly is the low level of activity that is often encountered. This may reflect lack of stimulation or lack of resources. Passive behaviour includes 'doing nothing' and 'asleep in chair'.

Negative activities: This includes behaviour such as aimless wandering, agitation, anti-social and deviant behaviour. A high level of negative activity could indicate boredom or inappropriate care.

Care activities: This is any care activity, either independent or dependent on a care worker. This would include going to the toilet, eating and drinking, washing etc.

Table 5.2 summarises the results. The key conclusions from the data on client activities are:

- a high level of positive activities
- a relatively low level of passivity

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Table 5.2 summarises the results. The key conclusions from the data on client activities are:

- a high level of positive activities
- a relatively low level of passivity

- minimal negative activity

Although we do not have any comparative data for EMI day centres, the usual pattern for residential care is that passivity is the most common 'activity'. The data from the observation study of the ADS day centres would indicate a stimulating environment, where a high level of leisure activities and social interaction enhance the quality of life of clients.

Table 5.2 Client Activity

	C. Newham	Poplars	Total
Positive activity	13	11	24
Passive behaviour	7	21	28
Negative activity	0	2	2
Care activities	1	7	8

(Table shows observed frequency of different activities)

In conjunction with the client observation study, staff were observed at regular intervals and a not was taken of their activities. Worker activities were classified in five ways:

Social care: This is worker activity that is aimed to stimulate or engage clients. This includes organised activities, such as singing or informal activities such as social conversation.

Functional care: This is care that is aimed at helping clients with their everyday tasks of living, such as going to the toilet, feeding, or just generally helping the client.

Domestic: Domestic activities includes food preparation, cleaning, setting tables, etc.

Administration: Administration includes paperwork involved with running the centre or with the care of clients. It also includes discussion between staff about clients.

Miscellaneous: This is a catch-all category, but in particular includes moving around the day centre from one location to another and non-caring activities such as tea-breaks or social chit-chat between workers.

Table 5.3 summarises the worker data. The main conclusions are:

- A large proportion of time spent on social care.
- A high level of 'miscellaneous' activity

The high level of social care indicates a stimulating environment for clients. There was relatively little time spent on domestic work, administration and functional care. The emphasis appears very much on the client. However, a considerable proportion of worker activity was classified as 'miscellaneous', mainly social talk between workers.

General observations

The observation study also allowed more 'qualitative assessments of the care provided in the day centres. A number of points are made:

Role of day centre leader. The running of the day centres appeared very dependent on the leaders and a few key people who take the lead and set the tone of the day centres. This is a delicate balance, but appears to work and a day centre can be very good with a good leader. However, the situation may be fragile.

Differences between workers: From our observations we felt that there were certain differences between volunteer workers and those who were employed on the Youth Employment Scheme. Training scheme workers appeared less motivated and perhaps approached sufferers as elements in their job rather than as people.

Distressed sufferers. On a few occasions it was observed that no attempt was made to cope with sufferers who were in distress. For example, one man at Poplars was in a constant state of anxiety for a long period of time during the observation study. It may have been

possible to alleviate this with diversional activity, but nobody attempted to help during this time.

What the clients think: Sufferers appeared to be generally happy, although there was inevitable a few who were restless and 'wanted to go home'. In general, sufferers enjoyed going to the day centres.

Table 5.3 Worker Activity

	C. Newham	Poplars	Total
Social care	7	14	21
Functional care	0	5	5
Domestic	3	0	3
Miscellaneous	11	11	22
Adminsitration	0	6	6

(Table shows observed frequency of different activities)

They enjoyed the company and the activities and liked the staff. An interview with two ladies with mild dementia at the Poplars was typical. These ladies really enjoyed going to the Poplars and said that it was the highlight of the week. They said that they liked to join in with the games and activities, but they said that the main thing was having a chat. Certainly, they did not see being at the Poplars as something to give their carers a break, but as something for their benefit. They seemed to cope with the very confused clients, probably because they did not seem to relate them to their own condition.

No routine: Sometimes care of elderly mentally ill people can take on a 'conveyor-belt' style, characterized by the block treatment of clients and a strict daily routine. In this situation the clients are made to fit the system, rather than vice versa. The observation of staff and sufferers emphasised the pleasant, relaxed and informal atmosphere of the day centres. There appeared to be little set routine apart from meal times. The researchers were struck by the spontaneity of activities at the day centres. For example, one lady burst into song with a verse of "She'll be coming round the mountain". Three other sufferers joined in for the rest of the song.

Workers activity: The observation study indicated that workers spend a very high proportion of their time chatting to one another. In one sense, this can be construed as a bad thing, because workers are spending less time with sufferers. In another sense, however, this contributes to the happy and relaxed atmosphere in the day centres. As volunteers, this is a legitimate activity, whereas paid staff need to demonstrate that they are 'working'.

How could day centres be improved

Workers in the day centres were asked how client care could be improved? The following issues were the most frequently raised:

- Better accommodation and facilities
- More training
- More outings for sufferers
- Someone with occupational therapy training
- More volunteers

Views of volunteers

Training: Some volunteers had prior experience with confused elderly people. However, others were totally unfamiliar. Volunteers felt that they did not have enough training. Most learn to cope with AD through experience. They felt a training officer would be beneficial, especially with a rapid turnover of workers.

Why volunteer? Volunteers fell in two main types. Firstly, those who were unemployed and either wanted to fill in time or felt that their volunteer work would help them with finding work. The second group was those people who had a social objective of 'wanting to help'.

Volunteers got a lot of satisfaction from doing something to help sufferers and their families. Sufferers were their prime objective however.

Dedication: Volunteers said that dedication was essential, otherwise they would not be involved.

Disadvantages to volunteers: Volunteers mentioned three problems associated with their work:

- organising their family life
- getting attached to sufferers
- work is sometimes stressful

Some problems associated with respite care

Respite care aims to give the carer a break; even loving and dedicated carers need support in the everyday task of caring. However, many respite services often do not fulfil this role properly. For instance, one carer mentioned that the actual time that the sufferer is at the day centre is quite short and did not really allow that carer to do the things he wanted to: 'you spend the day waiting for her to come back'.

The main respite service offered by the ADS is day care. However, there are a number of different ways of providing respite care; residential, sitting service, etc. However, carers pointed to a number of problems associated with these services. Residential respite can be highly disruptive to the sufferer, often leading to higher levels of confusion and behavioural difficulties after the sufferer returns home. Carers were generally suspicious of the idea of sitting services, where a volunteer comes into the home of the individual. Carers felt that the sufferer would be suspicious of a stranger in the house. Carers may also be wary about the possibility of abuse taking place, although this was not specifically mentioned in any interview.

For many carers, accepting help and support is not worth the effort, hassle and aggravation that often accompanies the service. Day care is perhaps the most 'hassle-free' kind of care.

Thus it is important that a service should be reviewed in terms of outcomes: is the service really making a difference to the life of the carer? How can it be made better for individual carers?

6. EVALUATION OF OTHER ADS SERVICES

As well as the day centres, the ADS provide a range of other services in the South Cleveland area. This section presents the results of the evaluation of these services, covering:

- counselling
- advocacy and publicity
- sitting service
- relative support groups
- information and education

Counselling

South Cleveland ADS provides trained counsellors who help carers to come to terms with their feelings towards the sufferer and the illness and to aid carers in making decisions about their situation. Respondents were asked how important counselling had been to them. The majority of carers (53%) had not received any counselling. About 17% said that counselling had been fairly important in helping them as carers. A further 17% had found counselling very important in coming to terms with their situations. Counselling was seen as important by carers because:

- ADS is the only place where carer feels s/he is understood
- ADS really try to listen to what you say
- makes me feel better
- nice to be able to discuss problems
- helps with peace of mind
- did not know what to expect when first diagnosed
- when I go to hospital they do not seem to care
- helping me to sort out my mind

Some people who had never made use of the counselling service said why this was the case:

- only had initial visit, but would like more contact in my own home
- prefer to talk things over with my family
- ADS is based in Middlesborough- inconvenient

Respondents were asked whether the counselling service could be improved from their point of view. Only a few comments were forthcoming:

- would like someone to come and see carer more often
- need more time/sessions
- need more help and information right at the beginning

Advocacy and Publicity

The ADS tries to help carers in their dealings with the authorities, benefits, the law, etc. About half of the respondents said they had been helped in this way. The ADS also acts as

a local pressure group, trying to improve the situations of carers in the South Cleveland area. In the main, carers referred to the help they received in claiming benefits, particularly attendance allowance.

An important role of the ADS is to raise public awareness of AD and the problems facing carers, and this has been dealt with in detail in section 3. About 70% of carers interviewed felt that the ADS had made a big impact in terms of raising public awareness. The remainder felt that the ADS had made only a marginal impact. The kinds of activities that carers felt were effective were:

- minibus, which is seen on the streets
- articles in local press
- publicity from new residential home
- printed information on collection envelopes
- posters in surgeries and hospitals
- fund-raising events
- video shown at work

However, one person made an important point; that you only really know what it means to be a carer of an AD sufferer when it happens to one of your family.

Sitting Service

As well as the day centres, the ADS offers some respite care through a sitting service in the carer's or sufferer's own home. Only 2 out of the 28 carers said that they had made use of the sitting service. Of those two, one was a regular user and the other just made use of the service now and again.

The 26 remaining respondents were asked why they had not made use of the sitting service. The main reasons given were:

- friends/family sit with sufferer if I go out
- reluctant to approach sitting service because volunteers are already doing a lot
- sitters do not always have a car, making organisation difficult
- not aware of service
- I prefer to do it
- prefer sufferer to go to a day centre
- never felt the need
- sufferer would resent someone sitting with him

Non-users of the service were also asked if they would be interested in using the service in the future. 38% of these people said they were interested, 23% said they were unsure and 31% said they were not interested. Thus, it would seem that the potential demand far exceeds the actual take-up of the sitting service. The take up of the sitting service has been surprisingly limited. The possible reasons for this are:

- lack of awareness that service is available
- unwillingness to have a 'stranger in the home'
- difficulty in organising sitters
- unwillingness to impose on volunteers
- time and hours may not be ideal for carer
- carer may have limited social opportunities

Relative Support Groups

Support groups are arranged informally to allow carers to meet and to talk about their common problems and experiences. Of the 28 carers, 6 (21%) said that they had attended a support group meeting. All but one of these people had found the meetings useful to them. The benefits of the support groups to carers were seen to be:

- helpful in finding out about AD
- talking to other carers -learn about other people's experiences of how to cope
- can talk about feelings and fears
- feel empathy with other people going through same experience
- carers can learn a lot from each other

The other 79% of the carers were asked why they had never attended a support group meeting. The main reasons given were:

- time taken up with work and home life
- need someone to look after husband
- inconvenient, at work when meetings take place
- never invited to attend
- not been involved with ADS very long
- have to take several buses
- get all the support I need from family
- never given it a thought
- too depressing
- find it inconvenient to attend at night
- in Middlesbororugh- too far away
- unable to leave sufferer at night
- prefer top get away from AD if I have the opportunity
- advised to wait until my emotions are more stable
- attend Parkinson's support group
- unaware of support groups
- the groups are not very lively
- carer finds it difficult to talk about their situation
- carer finds the sessions depressing

Carers were also asked whether there were any problems which made it difficult for them to attend support groups. Problems mentioned were:

- time factor
- shift work

- look after a young daughter
- clash with work
- transport
- wife would not stay with anyone else
- meetings difficult because of public transport
- can't leave husband alone
- don't like going out alone at night nowadays
- poor attendance at support groups is disappointing

Carers were asked whether they would attend support groups in the future. A few (18%) said they would not, 36% said they were unsure, while 43% said they would attend. As with the sitting service, there appears to be less take up of the service than would be expected.

Information and education

The ADS tries to provide an information and education service for carers. A library has been built up and information is provided about AD and its effects, the roles of the different services and the availability of benefits. Specialist speakers are invited to give talks. Overall, most carers (71%) said they had had enough information (from whatever source) to enable them to cope with the task of caring.

Information on rights and benefits: 43% of carers had found the ADS very helpful in providing information on rights and benefits, while a further 25% found the ADS information service fairly helpful. About a third of the carers had either not used the service or had not found it helpful to them.

Information about AD and its effects: 46% of carers found the information very useful, while a further 25% found it fairly useful. 29% had not made use of the service.

Information about other services: 37% had found the ADS a very useful source of information about other services available to them and a further 21% said the ADS had been fairly useful. 39% had not used the ADS as a source of information about other services.

Specialist talks: The large majority of carers (81%) had not attended a talk by a specialist speaker. The four carers who had attended talks had found them useful.

Conclusion

Overall, carers were very satisfied with the range of services provided by the ADS in South Cleveland. As we have seen in Section 4, most carers feel that the ADS has been an essential factor in coping with a sufferer of AD. However, the sitting service and the carer support groups have been relatively unsuccessful in terms of usage by carers. Two reasons for this are suggested. Firstly, many of the reasons given by carers appear to be minor 'hassles' for not utilising a service. However, carers are often caught in a trap of the daily routine and are unwilling to disrupt this pattern. A second reason is that the 'flavour' of the ADS has changed over time. For example, the carer support groups were very strong initially, but as the day care services developed, it may be that the need for support groups has declined.

7. AREAS FOR DEVELOPMENT

As part of the evaluation carers were asked about the kinds of services (from whatever source) they would like to see developed in the future. Questions were asked about the how the current ADS service could be enhanced and what services they would like to see in an ideal world. Carers were also asked for their opinions about possible alternatives to day care and residential respite care.

Carers' Suggestions

In the questionnaire survey, carers were asked about what kinds of services they would like to see developed. They mentioned a number of possible areas where carers could be offered more help and support:

Training to cope- emotionally
physically
medically

Evening respite- a domiciliary sitting service may not be acceptable to the sufferer. Some opportunity for evening care at a centre should be available. Equally, weekend care is very limited.

Longer hours- day centres should be open longer, to give the carer a break for a full day.

Support services- some carers want more access to home care, such as nursing, toileting, bathing and washing.

Pre-senile sufferers- in general, there is very little support available for this group from the various caring services. Clearly they should be targeted for special support.

Social events for carers- social isolation can be a problem. Even if carers had the free time, they often have nowhere to go to socialise.

Aftercare- some people felt that there was little continuity after the sufferer had died or gone elsewhere. Ongoing support is needed through this period of transition.

Intervention- at routine critical times, such as morning help and bedtime help

Emotional counselling- on a regular basis for carers

An ideal world

Respondents were given the opportunity to say what they would like to see done to help people such as themselves in the task of caring. In an ideal world, carers said they would like to see the following:

- respite care
- residential care when required
- daily support
- speech therapy
- longer day care hours to allow carers to continue working
- flexible time for day care
- day care at weekends
- properly established sitting service
- help and practical advice- lifting, feeding, incontinence, etc
- a carers group in my locality
- yearly holiday at reduced price, with a bit of spending money
- more education of carers and public
- more local day centres

Generally, carers ideas were pretty modest and suggest that they want more of the same, perhaps provided in a more flexible manner, for example, day care at weekends.

Carer attitudes to possible services

As well as evaluating existing ADS services, it was thought important to include some questions about other possible services. The responses of the carers not only provide feedback on these specific schemes, but also gives some insight into the receptiveness of carers to other forms of care in general. Two potential services were included. Boarding-out is where a sufferer goes to stay with a paid carer for a period of time as part of their household. Boarding-in is where a paid carer comes to live in the home of the sufferer from time to time, to relieve the carer from the task of caring for a few days. Both schemes have been successfully implemented by a charitable organisation in Liverpool (Personal Services Society).

None of the carers questioned received this kind of care from any source in South Cleveland. The majority of carers said that they were not interested in these kinds of service (70% not interested in boarding-in; 46% not interested in boarding-out. One person said they were interested in boarding-in, while three persons (13%) expressed interest in the boarding-out scheme. The remainder said they were unsure. The reasons why people said they were not interested in the schemes were:

Boarding-out

- son helps me out
- mother prefers to be in own home
- sufferer would probably not go
- I prefer to look after sufferer
- I would not be happy to leave sufferer with strangers
- sufferer has a difficult nature
- would disturb/confuse sufferer even more
- sufferer goes to Eastbourne Lodge
- sufferer would feel abandoned
- sufferer would not settle in a strange house

Boarding-in

- mother likes her privacy
- sufferer would resent someone in the house
- sufferer would be too difficult to handle

Overall, the carers were not very receptive to these possible schemes. Carers appeared to be concerned about the reaction of the sufferer to this kind of care and were also suspicious about having other people care for their relative in a domestic setting.

8. CONCLUSIONS

The South Cleveland branch of the ADS must be congratulated for their considerable contribution to the support of carers of elderly mentally ill people in the local community. Overall, the carers contacted as part of the study were very appreciative of services and support provided by the ADS. The day centres are the major component of the ADS's efforts in South Cleveland. These are effective in coping with a wide range of client needs in a friendly and relaxed atmosphere. In respect to the specific services offered by the ADS, the report highlights a certain problems and also some areas for service development, but on the whole these are of a minor nature.

Bearing in mind the key criteria for evaluating the project, which were outlined in the introduction, then the ADS has largely been successful in all these respects.

Firstly, in terms of its role within local service context then it is clear that the ADS plays a central part in providing essential specialist care for AD sufferers and their carers. The ADS has had a good relationship with the statutory sector and the different services complement each other.

Secondly, the key strengths of the ADS is the responsiveness of the service and the humanity and caring attitude of the workers. Carers gain considerable psychological benefit from feeling that someone cares about them and understands their problems.

Thirdly, most carers feel that the ADS services are an essential factor in being able to carry on caring for their relative. Carers were generally receiving an appropriate package of support to meet their needs.

One should also consider that public awareness of AD has grown considerably in recent years and the ADS, at both national and local levels, has played key role in this process.

The evaluation, however, did uncover some areas of concern:

The level of need is very high and local specialist service fairly restricted. Although the ADS provides support for many people in South Cleveland, it should be remembered that there will be considerable number of people who will still be caring for a sufferer with little or no support.

The research indicated that there is a considerable time lag between the onset of symptoms of AD and contact with the ADS and often this can be a matter of years. Most carers said that they would have benefitted from earlier contact with the ADS.

Although the ADS offers a range of services and activities, such as the sitting service and organises relative support groups, these are not well used by carers. The carers who were interviewed appeared to be happy with day centre care and limited in terms of what alternative types of care they might want. However, the development of alternative forms of care is important if the potential needs of all carers are to be met.

The role of charitable organisations in the provision of services was also raised by carers. At a practical level, it was suggested that a service based on volunteer workers is limited, for example in the hours provided for day care. At a more fundamental level some carers said that they were unwilling to make too many demands on volunteers, who were 'helping out of the goodness of their hearts'.

Finally, it is recognised that the development of the nursing home in Middlesbrough will have a major effect on the nature of ADS services in South Cleveland. and that many of the limitations of the current service will be overcome. For example, the purpose-built day centre will offer much better facilities for providing care. The nursing home and the qualified staff will also provide an excellent resource for the training of volunteer workers.