Alzheimer Scotland
Action on Dementia

Three Into One

How the organisation evolved
1980 - 1994

By Evelyn McPake

Acknowledgements

This account combines the memories of many people, some of whom allowed me to record their recollections, while others helped me revise the text and fill in details that I either did not know or had forgotten. I am particularly grateful to:

Glenda Watt: not only shared her memories with me over some glasses of wine, but organised my papers (and me!) at the onset of the project to record this history.

Dr Bill Boyd: undoubtedly the unsung hero of this whole story; put me in the picture regarding the management of dementia patients before, and at the time, the Alzheimer organisations came into existence and so provided the background to the whole movement.

Alison Glen and Maureen Rasbash: with whom I shared enjoyable sessions reminiscing about the early years.

Angus Mitchell: gave me his perspective on the early days of Scottish Action on Dementia from the point of view of one with no personal experience of the illness.

Jan Killeen: for much useful information from her extensive records and for filling out many details of my chapter on Scottish Action on Dementia.

Dr Alan Jacques: for more than I can list here but especially for many helpful suggestions (without the benefit of a glass of wine) and moral support throughout.

Ewan Davidson: for taking time out from his ever busy schedule to discuss with me his ‘Alzheimer’ days.

Representatives of the Falkirk, Dumbarton, Lochaber and Stirling Branches: for responding to my requests for information regarding their activities.

Mary Hope and Jim Jackson: for their comments on the final days of Alzheimer’s Scotland and the beginnings of the new organisation.

Alexander McCall Smith: for generously agreeing to provide the Preface.

Preface

Being alone in the face of suffering is not an easy thing. Not having a name for the cause of the suffering and not knowing how widely it is shared is not easy either. And worst of all must be the thought that nobody cares very much.

Alzheimer Scotland is a comparatively young organisation that has, in a relatively short time, done a great deal to reduce the loneliness of those who have to deal with Alzheimer’s Disease in the family. The story of its foundation and its progress is an interesting one, and is related here by Evelyn McPake with clarity and hope. Her account of the activities of the organisation shows us not only how a widespread, common problem can fall between the cracks of state provision, but also how a volunteer civic organisation can combat this through targeted pressure and determination to make sure that those who feel voiceless should be heard.

The history of human disease shows us how the scourges of individual disease may be reduced if there is sufficient determination to face up to and tackle them. Miracle cures are usually elusive, but the lives of those afflicted may be considerably improved by the work of individuals who insist that suffering should not be ignored. There have been many such people involved in the work of Alzheimer Scotland, and this booklet is a fine tribute to them.

Alexander McCall Smith

Contents

Introduction

The Scottish organisation now formally known as Alzheimer Scotland - Action on Dementia is an amalgamation of three earlier bodies, hence the title of this history. First there was the Edinburgh Branch of the Alzheimer's Disease Society with its headquarters in London, which almost imperceptibly metamorphosed into Alzheimer's Disease Society, Scotland. This is turn became Alzheimer's Scotland after the separation took place, and in due course, with the amalgamation with Scottish Action on Dementia, the present title came into being. Some might say there were four stages involved, but I prefer the idea of three. Someone remarked that "three into one won't go". In this case they did! This account is an attempt to chronicle and commemorate the efforts of the pioneers and volunteers who brought this all about.

It will probably come as a considerable surprise to many current members of the Alzheimer's Society in England, and indeed to a number of the newer members of Alzheimer Scotland - Action on Dementia, to hear that the 1985 annual conference of the Alzheimer's Disease Society of London was held in Edinburgh. On this occasion a well-known public figure, one of the principal speakers, referred to events "occurring here in England", to the lasting indignation of the late Irene Fisher, secretary of the Edinburgh Branch of the Alzheimer's Disease Society at that time. This 'slip of the tongue', as we must charitably refer to it, and the underlying attitude it represents, was inevitably one of the factors which led to the separation of Scotland from that organisation later on in the Eighties. By 1994, with the Scottish organisation firmly established in its own right, the time came to amalgamate with Scotland's other well-established dementia organisation, Scottish Action on Dementia, and Alzheimer Scotland - Action on Dementia came into being. This publication will show, it is hoped, how all this came about.

Chapter One

In the Beginning: Three Pioneering Women

The first stirrings of the Alzheimer movement in the UK were felt in 1979 when Cora Phillips, SRN, whose husband had recently died after a long illness diagnosed as 'pre-senile dementia', heard a broadcast on Alzheimer's disease by a professor researching this illness. She wrote to him proposing the formation of an Alzheimer's Disease Society the aims of which were to be:

1. to give support to the families of those affected,
2. to widen knowledge of the illness among the public and professionals,
3. to ensure adequate nursing care in its final stages.

Twenty-five years later, all three of these aims remain on the agenda of current organisations in this field.

Meanwhile, another carer for a husband diagnosed with 'pre-senile dementia', Morella Fisher, later Mrs Kayman, had written letters to a number of newspapers about her experiences and, as a result, an article entitled 'The Sad Quiet Epidemic' appeared in The Observer in December 1979. Mrs Phillips contacted Mrs Fisher and they joined forces in the steering committee of what was to become the Alzheimer's Disease Society. There were, of course, many others involved in the formation of this society, but as this is a history of what took place in Scotland it is to be hoped that they will understand, and forgive, their omission from this account.

Writing in 1986, some eight years after the death of her husband, Cora Phillips was still lamenting the dearth of respite care, nursing and supportive therapist care.

Scotland's part in the Alzheimer story begins in 1980 when Glenda Watt, the sister in charge of the psycho-geriatric Day Hospital held in Ward 5 of the Royal Edinburgh Hospital, read an article by Cora Phillips in the Nursing Times and made contact with her. Glenda had already seen the need for a method of encouraging and informing the relatives of people suffering from this distressing illness and was running a support group for relatives of patients in the hospital. This gave her a base from which to proceed when the committee in London invited her to become the Scottish representative. In this capacity, with the help of newspaper and radio announcements, Glenda arranged a meeting which took place in Ward 5 of the Royal Edinburgh Hospital on a Saturday afternoon in November 1980.

At this time, due to increasing awareness of the needs of confused elderly patients placed in general psychiatric wards, the time had come to set up a specialist service for them apart from the mainstream patients. Dr W D ('Bill') Boyd, consultant psychiatrist in the Royal Edinburgh Hospital, was able to make use of separate accommodation which by chance became available at this time. This marks the point in time when the term 'Alzheimer's Disease' began to be used in place of 'senile dementia' with the realisation that the two were synonymous. It should be understood that the successive organisations have always been concerned with all forms of dementia, but this is not the place for medical considerations.

Dr W D ('Bill') Boyd who was at the time consultant psycho-geriatrician in the Royal Edinburgh Hospital and himself much involved in the setting up of the Branch, says that his main claim to fame in the matter was his appointment of Glenda Watt as the sister in charge of Ward 5. He describes her as "a quite exceptional girl with energy, who always smiled and was cheerful"

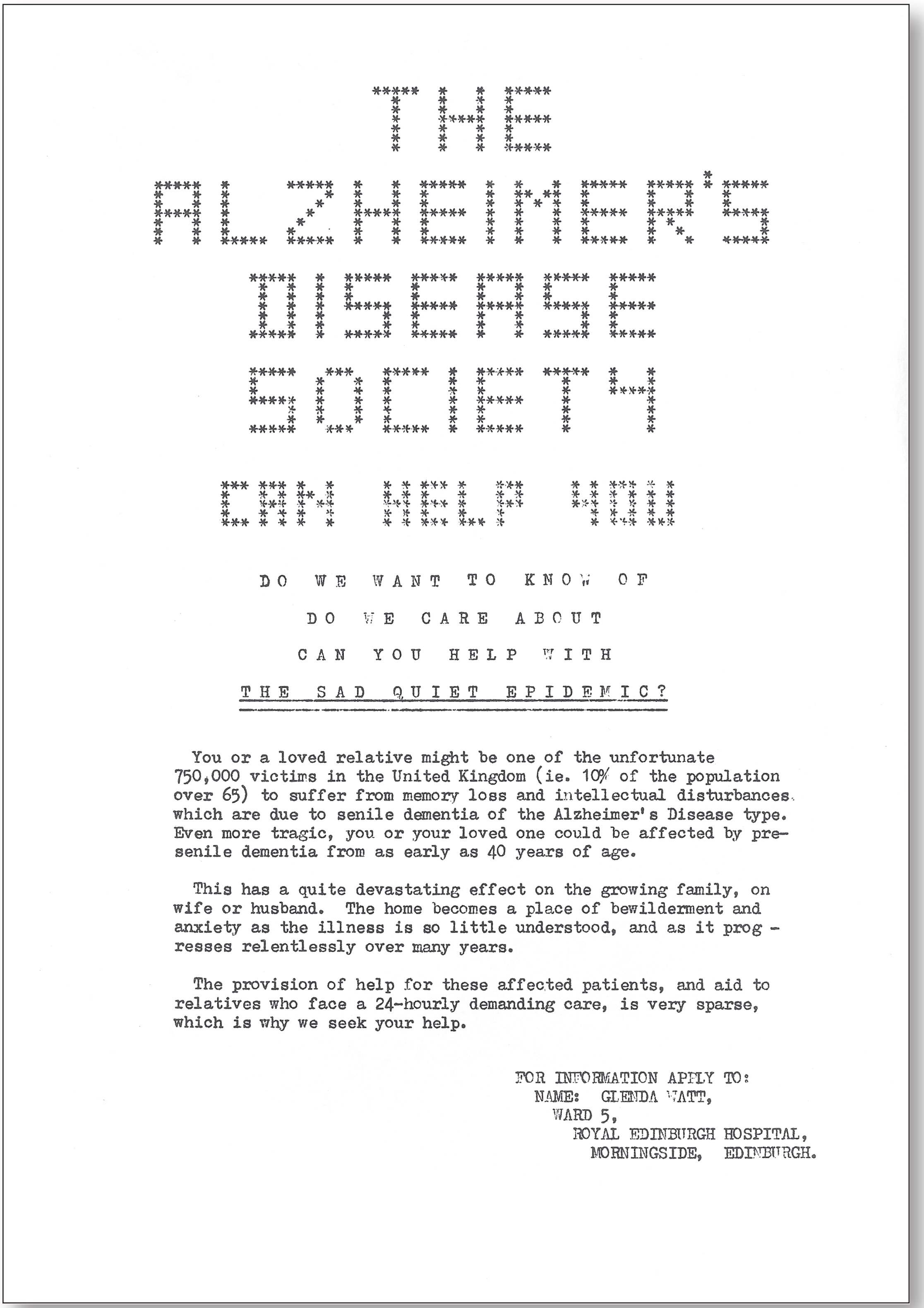
My own involvement began when, as I drove to work one morning, I heard a trailer for one of Glenda's broadcasts and prevailed on my bosses to allow me to listen to it in working hours. My mother was then in care suffering from what I thought was something quite unique, and the idea that this might represent a known disease was a revelation. I decided to attend that first meeting to find out more, and so began an involvement which has now lasted for nearly a quarter of a century.

Some 30 other people also attended, and we were treated to a series of talks by a number of professionals in the field of dementia, explaining the ways in which they could assist both the relatives and the person with dementia. Greatly encouraged, those present expressed their determination to form a group for mutual assistance, and to press for improvements in the inadequate services then available. A monthly meeting would also be held. In effect, the Edinburgh Branch of the Alzheimer's Disease Society was under way, but it remained to set this up in a formal manner in accordance with the constitution of the Society. In May 1981, meetings took place, with Glenda in the chair, while I became minute secretary. A committee was appointed and procedures instituted which led to the formal constitution of the Branch. A few of the original 30 who attended are still active to this day and many others gave valuable assistance in the early years. Among these is Myra Smyth, who has given unstinting service to the developing organisations as committee member and a befriender. She also took charge of the Saturday Break in its early stages, was a representative of the Edinburgh Branch on the council of Alzheimer's Scotland and, on a lighter note, was much involved in the Christmas parties arranged for members.

One member who was present at that first meeting still reflects on "the enormous relief it was to have a name for the devastating behaviour and the condition into which my mother had sunk". Until then she felt she was the only person in the world enduring this experience.

Another early member has said that attending meetings and talking to others with similar problems to her own helped to dispel the feeling of isolation from which she suffered as a carer, and gave her something in which she could participate on her own account.

In the words of yet another carer, whose wife was diagnosed with 'senile dementia' in 1982 or 83, "the meetings were brilliant: I met people who knew more than me and shared their knowledge and experience".



THE

ALZHEIMER'S

DISEASE

SOCIETY

CAN HELP YOU

DO WE WANT TO KNOW OF

DO WE CARE ABOUT

CAN YOU HELP WITH

THE SAD QUIET EPIDEMIC?

You or a loved relative might be one of the unfortunate 750,000 victims in the United Kingdom (ie. 10% of the population over 65) to suffer from memory loss and intellectual disturbances which are due to senile dementia of the Alzheimer's Disease type. Even more tragic, you or your loved one could be affected by pre-senile dementia from as early as 40 years of age.

This has a quite devastating effect on the growing family, on wife or husband. The home becomes a place of bewilderment and anxiety as the illness is so little understood, and as it progresses relentlessly over many years.

The provision of help for these affected patients, and aid to relatives who face a 24-hourly demanding care, is very sparse, which is why we seek your help.

FOR INFORMATION APPLY TO:
NAME: GLENDA WATT,
WARD 5,
ROYAL EDINBURGH HOSPITAL,
MORNINGSIDE, EDINBURGH.

The first poster of the Alzheimer's Disease Society in Edinburgh

Chapter Two

Edinburgh Branch of the Alzheimer's Disease Society: Feeling the Way

The history of the Edinburgh Branch is inextricably entangled with that of the Alzheimer's Disease Society, Scotland. This chapter attempts to deal mainly with Branch affairs. In the early days, minutes were variously headed 'Edinburgh Branch of Alzheimer's Disease Society' and 'Edinburgh Committee of Alzheimer's Disease Society' but the matters dealt with were the same. For a time, the two appear interchangeable.

Once the branch had come into being, the committee met and the monthly support meetings continued to be held in the day hospital until January 1982, when a move to the welcoming and more homely surroundings of the new Jardine Clinic at the Royal Edinburgh Hospital took place.

The first printed syllabus covers the programme for the monthly meetings in the year 1981-82 and shows that the first formal meeting in August 1981 was addressed by the Rev. Murray Leishman, then chaplain to the Royal Edinburgh Hospital, on the 'Spiritual needs of dementia patients and their families'. This was followed in succeeding months by a series of talks on practical, psychiatric and research matters which set the tone for the years to come. As a solicitor, I soon found myself giving a talk on legal matters affecting people with dementia, although the subject was not one I knew too much about at the time. At least, however, I had access to the relevant books! A session with a panel to answer carers' questions and address problems was introduced in 1983, although informal sessions of this nature had been among the early activities of the group (especially on the occasions when the invited speaker failed to appear!). Events or outings for carers and sufferers were tried out for the first time in 1984, proving most popular with members, and continuing so to this day. In contrast, with the increase over the years of information, advice and assistance to carers from alternative sources, the need for the monthly meetings diminished and only occasional members' meetings now take place.

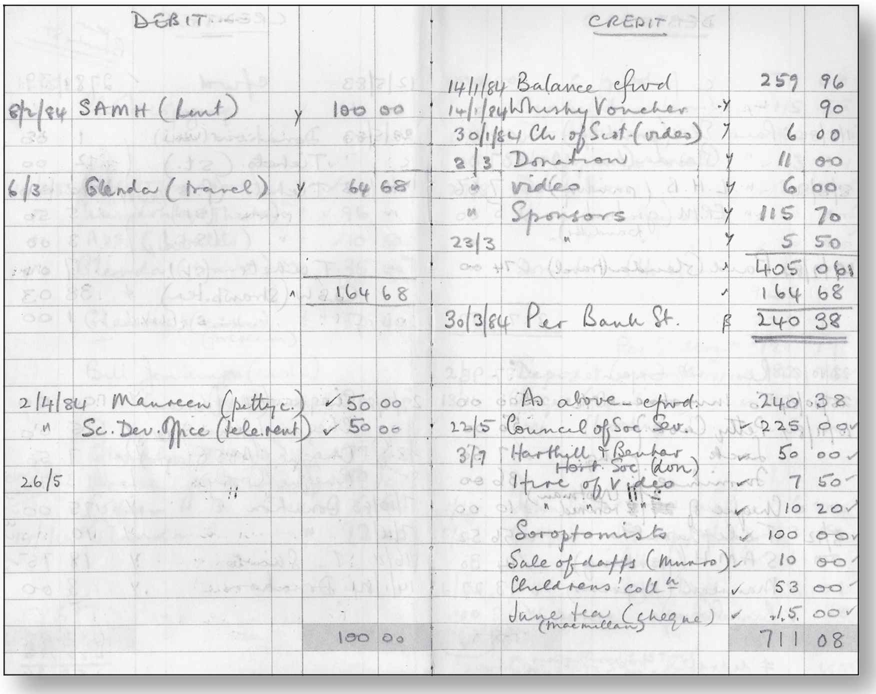
Among popular speakers at the early monthly meetings were two general practitioners. The first in 1985 was Dr Ian Fraser, who gave 'A GP's perspective', followed by Dr Bill Mathewson on a similar topic in 1986 and again in 1987 on 'Management of Alzheimer's Disease'. These occasions gave members an opportunity to air the many grievances they had at that time regarding the apparent indifference of many GPs towards the problems carers experienced. Most GPs were disinclined to admit that any good could come of a society concerned with an illness for which there was no known cure, and it was at this time that the syndrome which came to be known as "just waiting for a crisis" was first referred to. The branch spent much time, energy and, indeed, hard-won funds in attempting to win over to the cause these somewhat recalcitrant members of the medical profession. Tempting food and drink were provided on one occasion, but few attended, and written information supplied to local practices seemed to sink without trace.

A current GP (2004) has said that at the time she knew little about the illness and did not see the significance of the Society. Only after attending a lecture by Dr Alan Jacques did she understand how wrong she had been!

One method of communicating with members and professionals alike was the Newsletter, the first of which appeared in November 1983, and was aimed to be the first of monthly issues. However, this proved over-ambitious, and the next did not appear until March the following year. Significantly, the first two appear on the official paper of the Alzheimer's Disease Society but thereafter a succession of addresses appears from which, in themselves, the progress of the Branch can be followed. Early members will remember 14/16 Frederick Street, 40 Shandwick Place and 6a Albyn Place. The first editors of the newsletter were Maureen Rasbash and Eileen Robinson.

> *Committee members will recall with a smile (it is hoped) the evening we became locked in at Shandwick Place, and had to appeal to passers-by to release us!*

Funds, as always, were scarce. In the earliest days all funds collected had to be transmitted to London, which also collected all membership dues. Eventually, however, agreement was reached that Scotland, rather than the Branch, might have its own account. At the end of 1982 I took over as treasurer, and the cash book started at that time shows a balance of £2,644.36 at the Bank. From this payments of £1,000 and £1,200 were almost immediately made to the Scottish account in London and to a new savings account with the Trustee Savings Bank respectively. Approximately a year later the balance in the Edinburgh current account amounted to £278.39 only. Fund-raising was a matter of constant concern as expenses were mounting, largely for administration, but also to fund Glenda's required attendance at committee meetings in London and other costs. The idea that there might eventually be funds with which to provide services for carers was considered to represent "pie in the sky" at that time. The main sources of funding were donations, events and, eventually, the hire and sale of videos (of which more later) but there were also copper collections (including one of the half penny coin which was withdrawn from circulation at that time and raised £3.62 for the Branch!), my sponsored 'swim and slim', a sale of daffodils, sales of used postage stamps collected by members and collections made at talks given by office-bearers. The TSB account eventually turned into a share-holding in the company, the sale of which boosted the funds at a later date.



DEBIT

8/2/84	SAMH (Lent)	y	100	00
6/3	Glenda (travel)	y	64	68
			164	68
2/4/84	Maureen (petty c.)	✓	50	00
"	Sc. Dev. Office (tele. rent)	✓	50	00
26/5	"			
			100	00

CREDIT

14/1/84	Balance c/fwd		259	96
14/1/84	Whisky Voucher	y		90
30/1/84	Ch. of Scot. (video)	y	6	00
2/3	Donation	y	11	00
"	video	y	6	00
"	Sponsors	y	115	70
23/3	"	y	5	50
			405	06
			164	68
30/3/84	Per Bank St.		240	38
	As above – c/fwd.		240	38
22/5	Council of Soc. Serv.	✓	225	00
3/7	Harthill & Benhar Hort. Soc. (don)	✓	50	00
	Hire of video	✓	7	50
	" " "	✓	10	20
	Soroptomists	✓	100	00
	Sale of daffs (Munro)	✓	10	00
	Childrens' collⁿ	✓	53	00
	June tea (cheque) (macmillan)	✓	15	00
			711	08

Page of cash book - note the £0.90 "Whisky Voucher"!!

The fund-raising events most fondly remembered by early members are the pantomime, the ascent, by car, of Ben Nevis and a fashion show. The first of these took place in the theatre at the Royal Edinburgh Hospital, more accustomed to serious lectures given by professors and consultants for students of psychiatry. The indefatigable Glenda assembled a cast from the staff of the hospital and put on a memorable performance attended by patients and public, not to mention those members of the branch who were not otherwise involved.

The projected ascent of Ben Nevis by a group of young men in a Renault car probably attracted the greatest attention of these events, although the outcome was somewhat disappointing as the participants were stopped by the police before reaching the summit, because the amount of scree being dislodged was creating a danger to on-lookers.

The fashion show, in turn, was held in the George Square theatre, the models and clothes being supplied by British Homes Stores, and it proved to be a glamorous evening in aid of a cause with rather the reverse reputation.

A raffle was held at the fashion show and I vividly recall appearing on the platform to draw the winning tickets, feeling anything but fashionable in a rather mundane tweed suit, with my pockets weighed down with all the small change I had collected in payment.

The committee members, in agreeing to these projects, had to have the courage of their convictions, greatly boosted by Glenda's encouragement, since in each case outlays for expenses were required before any returns were assured. I can record with satisfaction, however, that in each case a profit resulted to the Branch.

A much more serious enterprise was the production in 1983 to 84 of two videos. While not primarily intended as fund-raising projects these in due course turned into money-earners for the branch, with distribution on hire or sale throughout the UK, and sales to Japan and Canada. One of the videos, entitled 'Suffer the Carers', featured an Edinburgh Branch member, Bet, who looked after her husband, Harry, with incredible devotion, and a Mr Falconer from Falkirk who was in the unenviable position of looking after, at the same time, his mother and his wife, both of whom suffered from dementia. He revealed that, on leaving for work each day, he locked them in together, an indication of the extreme lack of provision for such cases at that time.

I wrote the following article for the Branch Newsletter, but Bet, at that time, would not allow its publication. Sadly, Bet died shortly after Harry over 10 years ago and this is the first time this tribute has seen the light of day.

Harry may harry Bet, but Harry can bet on Bet

Bet has looked after Harry for longer than we have known her. Harry has Alzheimer's Disease and Bet, with Harry, joined the Edinburgh branch of the Alzheimer society in its early days, and has been a faithful attender, often with Harry, ever since. As a result we have been saddened to see him change from a lively and upright, if slightly muddled, individual into the silent and huddled figure he now is. Bet has never wavered in her resolve. Harry comes first, and we know she will look after him for as long as she has the strength, in spite of ever *increasing difficulties. At our meetings she is an encouragement to others who are facing up to the disease. She never minimises the problems and speaks plainly about her own difficult situation, but it is notable that she never actually complains. "He does this" and "He does that", she will tell us, but never "I can't cope with this (or that)". While Bet must have her bad days, we are not allowed to know about these, but rather, on group holidays, she is able to enjoy herself and share her enjoyment with others.*

In the early years, Harry was sometimes hard to follow - in more ways than one. We didn't always know what he was trying to say but, more to the point, once a great walker, Harry used to take off at great speed and Bet couldn't keep up with him, until she thought of attaching herself to him with a dog's lead, enduring with humour the gibes of onlookers who misunderstood the situation. There is no doubt, however, that the act hardest to follow is Bet's own!

As mentioned in a Newsletter of the period "It [the video] is very revealing about the illness and seems to provoke keen discussion". The second, for which two American doctors, Sid and Shura Saul, were responsible, was a set of three tapes entitled 'Communication and Dementia'. This again involved Edinburgh members and their relatives and was made in the Jardine Clinic. These tapes were much used for the information of professional groups, including field workers from social work departments, as they vividly conveyed the many problems associated with the disease. Earlier films had been made about Alzheimer's disease in the Jardine Clinic, but in a minute of the branch from December 1982 it was remarked on that these films would not "now" be seen on TV as the material was thought too alarming for the public!

Mention was made earlier of the various addresses at which the Branch was situated. Not referred to then were the first shared premises from which the Branch functioned. These were in a York Place basement and it was there that the first steps were taken towards providing an information service to members and the public. Staffed entirely by volunteers, this service expanded from about one hour a week in the beginning until, by 1985, there was a daily service provided by Irene Fisher, Maureen Rasbash, Toni Meechan, Anne Cullen and Bill Garlick, each with their own field of expertise, much valued by colleagues and callers. In a report of 1986 the telephone service was described as "the most popular form of communication" and may perhaps be seen as the first step towards Alzheimer Scotland's much praised Helpline available today.

In 1986, thanks to a grant from the Manpower Services Commission, it became possible to employ a co-ordinator of volunteers. This was Bob Erskine, who devoted 20 hours a week to promoting volunteer activities, including recruitment and identification of appropriate activities. Fortunately, fund-raising was keeping pace with this development, with money coming in from various charitable trusts, other appeals and increased efforts by members. It was at this time that Bill Jenkins inaugurated the '100 Club', with its monthly draw, which he continues to administer today.

At the same time, while the monthly meetings continued in the Jardine Clinic, further meetings were held in the Royal Victoria Hospital involving carers from the north of the City and adding to the membership of the Society. In these early years, Alan Jacques, consultant psycho-geriatrician in that hospital, was always a popular and hugely innovative speaker both at these and other venues.

> *One lecture I particularly recall was an attempt to give an impression of what it must be like to suffer from dementia. I was not alone in finding this a stunning revelation.*

At the AGM in 1986 Glenda Watt gave up her position as chair-person of the Branch, due to her many other commitments. Maureen Rasbash took over from her, to be followed a year later by Alison Glen who had joined the committee in 1983 and has served with distinction in various capacities ever since. She subsequently demitted office as chairperson of the Branch when appointed first chair of Alzheimer's Scotland itself and she has since resumed her position in the branch (though finally now stepping down after twenty-one years of sterling service). This period, from 1986-87, possibly represents the time of the greatest introduction and expansion of services ever experienced by the Branch. At the time of the move to extended premises at Albyn Place in 1987 the existing services were listed as follows:

1 Information and support services
2 Telephone/face to face counselling
3 A monthly relative support group meeting
4 A limited home visiting service
5 An assessment service to determine how the Branch might meet the needs of the carer and sufferer.

To these were shortly to be added a Shopping Break, the forerunner of the popular Saturday Break. The latter came into being at Christmas 1989, after a considerable period of gestation, its purpose being to cover weekends and Monday holidays, when there was a lack of other respite care. A 'care centre' is first mentioned in a minute of the branch dated January 1987, when a sub-committee was formed to develop the idea. In the following months, the need for volunteers was stressed and the costing carefully gone into. A number of schemes by other organisations sprang up at this time, which also delayed the introduction of the branch's plan. However, as has been seen, the scheme finally got under way under the guidance of Myra Smyth, and from its small beginnings continues to this day, with a paid organiser.

In the same year, 1989, the holidays to Strathyre were inaugurated. Previously, Alison Glen had initiated the idea when she and a volunteer accompanied one carer and her husband to a cottage in Argyllshire to which she had access. This led Alison and her committee to realise the potential of such a scheme. When the Strathyre accommodation owned by the Order of St John and already run as a holiday home became available, the branch had the confidence to book this and the holidays began. Two volunteers, three carers and three people with dementia enjoyed reasonable weather, trips to Ben Lawers with views of snow-covered mountains and above all, for the carers, a period of relaxation and the pleasures of company.

> *The first three dementia sufferers to go on holiday to Strathyre were, by sheer chance, Tom, Dick and Harry, a coincidence still remembered by all who took part.*

Later still, in the era of Alzheimer's Scotland, the Branch was able to finance a further form of respite care. In spite of being denied funds from a bequest to Headquarters for the purpose of respite services, the Branch decided in 1992 to go it alone, and money from its own funds was allocated for sitting, or overnight services, supplied by a nursing agency. These services were offered to carers on a 'one-off' or regular basis up to a given maximum cost, to provide the opportunity to the carers for regular or occasional relaxation. No volunteers or premises were involved in this undertaking, which still continues.

One other accomplishment of the Edinburgh Branch deserves mention. This was a display of aids, suitable for people with dementia, which was pioneered by Alison Glen, herself a retired occupational therapist. It proved very popular, and was only discontinued when the space it occupied at Albyn Place was required for other purposes.

After 7 years in Albyn Place, the Branch moved briefly to an office in the General Post Office then still in Waterloo Place and the North Bridge, and finally came to rest in 1995, thanks to a generous legacy specifically to the Branch, at its present premises in St Leonard's Street, where it still continues the work which it had pioneered. The amalgamation with Scottish Action on Dementia in 1994 introduced many new rules to the organisation as a whole, and has entailed many changes, but the Branch has managed in many ways to maintain its independence and its high profile among the carers and the cared-for of Edinburgh.

It is no doubt the case that the other Scottish branches and groups could report in similar terms on progress and prowess in the story of the Alzheimer movement in Scotland, but it is not possible to include here a history of each one. However, it is clear that the impetus towards the creation of a branch differed considerably from place to place. To take but two examples: in Falkirk, the encouragement and preliminary planning arose from the volunteer committee and professionals jointly overseeing a local project, who arranged a public meeting in the town, at which the need for action was aired, and this was followed up by the formation of a branch in 1992. Prior to this initiative there had been little action in the town since the days of the earlier mentioned Mr Falconer. By contrast, the Dumbarton Branch, formed in February 1994, stemmed from a carers' group set up as long ago as 1984 by one individual carer, Betty Currie. Both of these branches, although coming into existence quite late in the period covered by this history, have continued to flourish under the modern regime. Both branches have been successful in fund-raising and have made a point of involving the church as a way of raising awareness locally.

Chapter Three

Alzheimer's Disease Society, Scotland: The End of the Beginning

At the same time as the Edinburgh Branch of the Alzheimer's Disease Society was developing, other support groups were opening up in other parts of the country, notably in Glasgow and Aberdeen. Once again, Glenda Watt was to the fore in getting these groups off the ground, but as time passed and the work became more onerous, it became apparent that professional help was required. In 1983 the national Society had appointed 8 part-time development officers, on an experimental basis, throughout the UK, sited in London, Bath, Guildford, Luton, Leeds, Cardiff and Edinburgh. As a result, the framework of a national organisation was set up. The first person to be appointed in Scotland, and known as the Scottish Co-ordinator was Annette Forster, soon to be joined by Maitland Simpson as secretary and group worker.

The first mention in the minutes of a separate Scottish (as distinct from Edinburgh) 'Management' committee occurs on 12 December 1984 when its formation and constituents were discussed by the Edinburgh committee. The aims were to monitor development in Scotland, to administer the Scottish account, and to advise, guide and support the staff. Two representatives from each support group were to form the committee. Myra Smyth and Maureen Rasbash were the first members from Edinburgh, along with Andrew Learmonth from the Stewartry, who attended Edinburgh meetings, and had considerable experience as a carer. Glenda also attended and I served as the treasurer.

During the first year of operation, the need of carers for more practical and psychological help was identified, membership and support groups increased, and in January 1985 the Scottish Co-ordinating Committee came into being. It consisted, in theory if not always in practice, of two elected members from each Branch or Support Group who met every three months and became the decision-making body for the society in Scotland. That year also a Scottish Headquarters office was set up in Edinburgh, sharing premises with the Edinburgh Branch at 40 Shandwick Place. Funding for this enterprise was now obtained from the Scottish Office and was therefore much more secure than the previous temporary arrangement with the Manpower Services Commission. Accounts for the year to 31 March 1986 show income received of £19,902 and expenditure of £18,522, salaries for the two members of staff accounting for £12,488 of this total, rent for premises and communication services being the other main items.

Improved, but temporary, funding also made possible a move into service provision, with two projects starting up in 1985, in Paisley and Kirkcaldy and, by 1986, a third underway in Motherwell. In Paisley, under the inspired leadership of Linda Lee, a day centre was established and soon expanded from one day per week to three, catering for some 30 people with dementia. Linda also ran an enquiry service for carers from her office, which played an important part in providing local information. A year later, a day centre manager joined the team and a sitting service was inaugurated. In Kirkcaldy, the project's main activity was a respite care scheme providing respite in people's own homes and general advice and support for families caring for dementia sufferers. In addition, along with the towns and cities already mentioned, there were relative support groups in Bathgate, Cupar, Dundee, Dunfermline, Inverness and Stirling, with plans in hand for two more, in Peebles and Galashiels. In writing this account, it has been interesting to note how some branches across Scotland have come and gone as the need has grown, and waned again as other services have been provided, whereas some, such as the Edinburgh, Falkirk and Dumbarton Branches, and others, have remained steadfast in their local endeavours.

Writing at the very end of 1986, Annette stated her objectives for the future:

1. To be more effective in pressurising the government to provide more and better services.
2. To start more care projects.
3. To have more support groups in areas where the society was not very active.
4. To be more visible to the general public.

From to-day's point of view these aims seem modest but at the time many members, while greatly encouraged, had their reservations.

By the middle of the following year, with the new project in Motherwell officially opened and day centre services functioning there, and with a new support group operating in Ayrshire, the hopes expressed in objectives 2 and 3 above were showing signs of fulfilment, and in a sense objective 1 was being superseded. So far as this aim and that of objective 4 are concerned, the growing activities of Scottish Action on Dementia, with which a number of Alzheimer's Disease Society members were co-operating, were already serving to raise the issues concerned.

By July 1987 the idea of a society in Scotland, separate from the London society, was under consideration. The topic first came to the fore at a meeting of the Scottish Co-ordinating Committee after a few of the delegates, in private discussion, found that they had each been thinking along these lines. So far as Scotland was concerned, the matter was dealt with very democratically. A discussion paper was circulated to all groups, seeking their views on the idea of separation itself and, if this were agreed, on what links should be maintained with the Alzheimer's Disease Society. A vote of every member was eventually called for, and in the event, the majority in favour of separation was impressive.

The main reasons for separation were:

1. *Fund-raising difficulties. Members in Scotland did not care to see their donations disappearing to the south.*
2. *Differences in the law, local government and health service provision, usually neglected by London.*
3. *Failures in communication, which had led to a waste of time and money.*

It fell to me to intimate this development to the council in London, where I had replaced Glenda as Scottish representative, along with Andrew Learmonth from the Stewartry and the late Carsewell Jones from Fife. It has to be said that the proposal was not well received in the south, indeed much 'shock-horror' was expressed and many attempts at dissuasion made. However, matters proceeded as the vote had indicated, and at the Alzheimer's Disease Society Annual General Meeting in Sheffield in 1988, attended by a posse of representatives from Scotland "just in case of a hitch", a resolution was passed, agreeing on certain terms, to the separation:

1 A small sum of money was to be returned to Scotland.
2 A close liaison between the original body and the new Scottish one was to be maintained.
3 A representative from the Alzheimer's Disease Society was to sit on the committee about to be formed for the purpose of setting up the new organisation in Scotland.

The first of these terms was no doubt met, the Scots' reputation with money being what it is! It is left to others to offer an opinion on the second, although there is no doubt that in the end the arrangements were amicably received on both sides. The third, which was a temporary measure, quickly fell into abeyance, but an exchange of council members continued for a while. Once the new Scottish organisation came into existence, the respective executives met quarterly and members' attendance at each others' annual meetings was encouraged. Meantime, the 'separation committee', as it might be termed, laboured manfully over many months to bring into effect the separation members had voted for. It was decided to form a company limited by guarantee with, of course, charitable status, and to this end much legal activity was involved. In addition, much heart-searching took place over the name for the new society, as it was felt necessary to choose something to distinguish it from its antecedents. For this reason the obvious 'Alzheimer's Disease Society, Scotland' was rejected. Eventually, the simple 'Alzheimer's Scotland' was decided upon, for better or for worse, and a new era for Alzheimer activity in Scotland inaugurated.

'The Alzheimer's Society of Scotland', on the model of The Alzheimer's Society of Ireland', (ASI) was ruled out on the grounds of the unfortunate initials! The name favoured by a majority of members was actually 'Scottish Alzheimer and Dementia Society' (SANDS), but we discovered that the initials were already in use by another charity, the Stillbirth and Neonatal Death Society.

Before all this was achieved, however, Annette Forster and Maitland Simpson had moved on to pastures new, leaving a considerable gap in the administration in Scotland. A new group worker and secretary was recruited in Maitland's place in the person of Lorna Arnott, who held the fort admirably until the appointment of Ewan Davidson as the new Scottish co-ordinator in September 1987. He joined the committee setting up the constitution of the new Scottish organisation, as its scribe and recorder, and his multiple versions of the proposals are well-remembered. When Alzheimer's Scotland came into existence, Ewan then became its first director.

Chapter Four

Alzheimer's Scotland: Aspirations and Activities

In retrospect, the initiation of Alzheimer's Scotland appears to have given a tremendous fillip to the development of the organisation in Scotland, although many difficulties remained. In particular, the uncertainties of funding were a constant source of concern to the director and to members of the council and executive set up under the new constitution. Alison Glen took the chair, and I became company secretary, with Ian McLeish as treasurer. The annual turnover at the time was in the region of £200,000 only, with much of the funding due to expire at the end of the financial year, and strenuous efforts were required to improve matters. At one time, even the salaries of the staff were in doubt and other debtors had to be asked to hold off. Two out of the three then existing local projects fell into the danger zone and great difficulty was experienced in obtaining the funds to continue them. In Fife, headlines appeared in the press about the service being closed, but in the event the Council relented and offered replacement funding. In Paisley, funds were eventually guaranteed by Fred Edwards, then Strathclyde's Director of Social Work, on behalf of the Council. The third project of that time, Motherwell, was always in a better position with funding from the Unemployed Voluntary Action Fund.

Inevitably, the setting up of a new association led to much debate about function, focusing on whether to be solely a voice for the carers or to continue attempting to provide services. It was decided to continue with service provision, a decision which further differentiated Scotland from the London society, which was not at that time in favour of directly offering services (a directive which, it may be noted, had already been ignored by Annette Forster, to her great credit). One other difference from London, which became apparent as matters proceeded, was that London was concerned only with the carers whereas Scotland's efforts were directed equally to the carers and to those with dementia.

At the time when Ewan Davidson and Lorna Arnott took over from Annette Forster and Maitland Simpson, the Society had eight employees including five in the field, and the administration of the Society was based in two rooms at the Shandwick Place offices. With the appointment of Edwin Wilkinson as Development Officer and Joyce Dodds (who were to become two of the organisation's longest serving employees), and later of Roz Farnese as Training Officer, it had become urgent to find larger premises. It was fortunate that at the same time Age Concern Scotland was vacating its accommodation at 33 Castle Street, now the prestigious Oloroso Restaurant, and Alzheimer's Scotland was able to take over the balance of their lease on very favourable terms, a welcome consideration in the light of the financial situation. At that time the building consisted of a warren of small rooms, none of which was large enough to contain the full Council and we had to move elsewhere for our meetings. This is, no doubt, one of the factors which led the organisation to make the subsequent move to premises at 8 Hill Street in the winter of 1992/93.

> *It was at this point that Ewan's famous dining room table, too large for his own use, entered the inventory of Alzheimer's Scotland's property. Although no longer in the board room, the table is still in use at Drumsheugh Gardens to this day --- thank you, Ewan.*

When Age Concern moved away, Jan Killeen, of Scottish Action on Dementia, remained behind and began her long association with the other dementia organisation which was to be eventually amalgamated with her own. Moira Stratenburger, who had managed the Motherwell project, also joined the team at this point, as a development officer for branches, a post which was eventually discontinued.

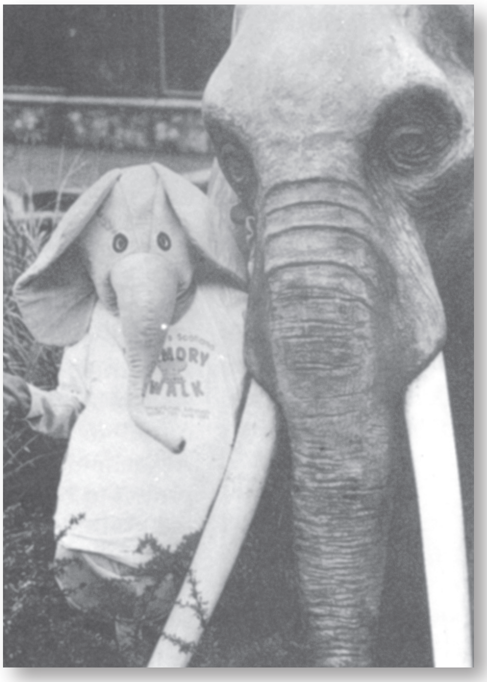
Financial difficulties began to be alleviated with funding from the Scottish Office from the Mental Illness Specific Grant. This Grant had been allocated 70% to mental illness and 30% to dementia, and Alzheimer's Scotland received half of all that 30% nationwide. This was the springboard for a period of considerable expansion. Projects were initiated all over the country.

Although not entirely funded in the way just described, one project which I particularly remember because of the legal intricacies in which I was involved was the Woodlands Centre in Inverness. It was custom built on to the existing Mackenzie Day Centre for the elderly and leased back to Alzheimer's Scotland for 30 years (if I remember correctly), at a peppercorn rent. It was the organisation's first capital project, costing in the region of £200,000 provided jointly by the local health board and social work department, the Scottish Office and the Highlands and Islands Development Board. Much thought went into the design and legal considerations, and at the time it was thought likely that this would form the standard for future projects of this nature. This has not actually proved to be the case, although the centre has been a success in itself. With pleasure, I also remember the splendid hospitality offered when I flew to Benbecula one weekend to perform the opening ceremony for the new centre there, and, with regret, my inability to utter even one word in Gaelic on such an important occasion.

The author performing the opening ceremony at a new centre in Benbecula

While the projects launched in this period are too numerous to mention in detail (a note of recent achievements made in 1994 refers to over 30 day care centres, some including evenings and week-ends, and to many flexible home care schemes, some offering overnight care), I feel the need to add some words regarding those people, many of them volunteers, who worked unstintingly to bring these schemes into existence. I know from my own involvement with the Falkirk project just how much time and energy was required from, in many cases, a comparatively small group of dedicated people.

Fund-raising became a preoccupation for the Society, and with the appointment of Fred Chatterton in 1990 as the first paid fund-raiser became much more structured. Events were organised and sponsorships obtained from companies, such as the Ladbroke's betting chain, and from industry, trusts and other bodies. Christmas cards were introduced at this time and proved popular in spite of the difficulty of choosing a suitable range. More fund-raising events than can possibly be mentioned here have been organised over the years. The vast majority of these have been a success, from the Holbein art exhibition in Edinburgh and the performance of 'Macbeth' with Iain Glen in Dundee, to the Memory Walk featuring an elephant (which never forgets) during the 1993 Dementia Awareness Week. Occasional disasters have occurred but it would be best to draw a veil over these.



Zelmer and friend launch the memory walk at Edinburgh Zoo

At the same time as the expansion of services was proceeding, two campaigns of great importance were entered upon. The first of these was the movement to have people with dementia included among those exempted from the Poll Tax. When first introduced the exemption applied only to those who lacked capacity from birth, and the tax was felt to impact greatly on the carers, who already had much to contend with. So the campaign was launched to extend the exemption to people who had acquired incapacity later in life. The late Donald Dewar and the Secretary of State, Iain Lang, were involved on opposing sides of the debate, the latter contending that people with dementia "sometimes recovered" and therefore should not be included in the exemption! Success in this campaign represented a significant achievement for the fledgling society. Another campaign, in which Alzheimer's Scotland became involved along with Scottish Action on Dementia at about this time, lay in what eventually came to be passed as the Adults with Incapacity (Scotland) Act 2000, which has greatly improved the legal provisions for people with dementia, but the outcome of which lies outwith the period of this account.

Many other enterprises of importance were planned and launched in the period of Alzheimer's Scotland. One of the most influential is the telephone helpline for carers, people with dementia and professionals in the field. It was begun with funding approved by the Scottish Office and the start coincided with the move to Castle Street in 1989. At first, there were times, especially at weekends, when it was not always possible to provide cover, and an answering machine was employed. The full 24-hour service began in 1991, the first of its kind in the United Kingdom. This was made possible, with funding from British Telecom, through the purchase of a remote call diversion machine which connected the calls without the need for someone to be in the office. The system was elaborated by Kate Fearnley who had been appointed to the post of Information Officer in that year. She was joined at a later date by Catherine Cockburn as Helpline Assistant. As will be seen later, the Scottish system became the model for other helplines throughout Europe, and I recall giving a talk about setting up a helpline to members of Alzheimer Europe, with collaboration from Kate Fearnley, in which seven points of good practice were enumerated. The last of these was "An answering machine is no answer"! The helpline was staffed by volunteers, who were, from the beginning, put through a quite rigorous training, kept up to date by frequently issued information sheets and subject to regular refresher courses. It was certainly no sinecure to serve on this project. By 1994, over 3,000 enquires were dealt with per year, many involving further action by means of personal letters or printed information. A record was made and statistics kept of the nature of every call received. Many letters of gratitude were received from callers regarding the benefits of this service.

A current member, still caring for a parent after many years of doing so, went out of her way to say how much the helpline is appreciated. "Not just a helpline - a lifeline", and "wonderful to know that there is someone at the end of the line when you're at the end of your tether".

Other services inaugurated in the time of Alzheimer's Scotland include the Lothian Carers' Panel, set up by Helen Tyrrell, who had been charged with identifying gaps and overlaps in the services provided. The carer members of the panel worked to raise awareness of the illness and provided speakers for conferences, seminars and talks. There was also a Welfare Rights project in the West of Scotland which increased benefits to carers by over £200,000 in 1992, and a Carers' Education programme which provided training in groups for those caring informally for a relative with dementia, and did much to improve the lives of both carer and cared-for.

Another undertaking worthy of mention is the opening of the St John's Respite Holiday Home at Cramond in Edinburgh. Unfortunately, this did not enjoy the sustained success of the Strathyre holidays pioneered by the Edinburgh Branch, but it did at least provide a wonderful venue for the opening social function of the tenth Annual Conference of Alzheimer's Disease International, held in Edinburgh in 1994.

This event took place on a beautiful sunny evening in September. Intending a compliment on the kindness of the hosts, one of our foreign visitors remarked to me "The people here is so varm". To my subsequent embarrassment, my response was to ask if the windows should be opened!

The last events in the era of Alzheimer's Scotland to be mentioned are the preliminary arrangements for the 1994 international conference, and the negotiations for the proposed merger of dementia organisations, which are both described later. In the middle of these proceedings Lorna Arnott emigrated to South Africa and Ewan Davidson resigned in the interests of a prolonged stay in Australia. Edwin Wilkinson admirably held things together in the interim until in due course Jim Jackson was appointed to manage the organisation, including the realisation of the above events. In Ewan's own words "the entrepreneur gave way to the statesman" and the road to the present successful organisation that we know today lay open.

Chapter Five

International Involvement: Scotland in the Wider World

Alzheimer's Disease International

Scotland's involvement in the international aspect of the Alzheimer movement began when Annette Forster, our Scottish co-ordinator, Linda Lee, project manager in Paisley, and I attended the third Alzheimer's Disease International conference in Paris in 1986. The first conference had been held in Washington in 1984, when representatives of no more than four countries met with a view to setting up an international organisation. The United Kingdom was among those sending a delegate, in the person of Ann Brown, a member of the council and a vice-president of the Alzheimer's Disease Society. Also present then were delegates from the United States, Australia and Canada. All met again in Chicago in 1985, and there a formal structure was put in place, which began the process which led to the international organisation we know to-day, with 66 member countries, links with other important international bodies and a secretariat in London with a staff of five.

Scotland's voice at that 1986 Paris conference might be said to be non-existent as we were still part of the UK Alzheimer's Disease Society and had no chance to speak up for ourselves. However, our presence there laid the groundwork for our eventual independent position in the international organisation. The by-laws, as the Americans designate the constitution of the organisation, state in no uncertain terms "one country, one vote", and Scotland's entitlement to independent representation was a long time in coming. It was in Jerusalem in 1996 that we became so entitled on the grounds of "grandfather" status (i.e. we had been there from the beginning) and we were dubbed "the historical anomaly". No other member country has been afforded the privilege of more than one voting member, although Spain and Belgium, for example, would have liked to follow our lead. Despite our inability to contribute, the Paris Conference made a lasting impression on at least one of those who attended, inspiring my life-long interest in the welfare of Alzheimer's disease patients (as we certainly referred to them at that time) and creating contacts and friendships which persist to this day.

The 1987 conference was again in Chicago, but our colleagues in London failed to give notice of the event until rather late in the day, and no duly appointed representative from Scotland was able to attend. However, the late John Heaney, an Inverness member, already in the United States on holiday, was contacted and was able to put in an appearance on our behalf. He literally 'flew the flag' for Scotland at this meeting and his enthusiastic antics with the Saltire gave rise to some adverse comments from his English colleagues. This in turn led to some consternation among the Edinburgh Branch committee members, but it should be recorded that John Heaney was held in high regard by overseas members, and his skill in welcoming visitors to the 1994 international conference, held in Edinburgh, was much valued by the organisation.

The result of the 1987 events, however, was a determination that we be kept informed of international events and official Scottish representation provided. In 1988 the conference was held in Brisbane, Australia, and with some financial assistance from the Edinburgh Branch I was able to attend as a delegate. At this meeting I took the first steps to becoming the chair of the by-laws committee, a cunning move with reference to Scotland's independent voice.

At the Brisbane conference a whirlwind blew in the shape of Lilia Mendoza from Mexico, by this time, not the first non-native English speaker to represent a country, but the first to plead the cause of an under-developed country with little cognisance of the illness and even fewer facilities for dealing with it. In no time at all she had persuaded the meeting to hold the 1990 conference in Mexico City, an event which took the members to an unlooked for venue, and raised the awareness of the illness in Mexico beyond all expectations. I recall a demonstration, with placards, held in the street outside the Conference centre in an attempt to influence the Mexican Government to recognise the problem.

At this meeting, the death earlier that year of Ann Brown was greatly lamented, and her contribution to her own society, and to the international body, recognised. At the same time, Dr Nori Graham of the Alzheimer's Disease Society was appointed as her successor on the Alzheimer's Disease International executive.

It was also at this meeting that I was able to make the case that the international conference be held in Edinburgh in 1994, against claims by some other members. The 1989 Conference was to be held in Dublin, our equally small sister-nation having, of course, no problem with independent status. Ireland, in the persons of Winifred Bligh and the late Michael Coote, was from the early days an influential and enthusiastic member of the Alzheimer's Disease International. It will be noted that the Mexican whirlwind achieved her aim with only two years' notice, whereas we required four. The competition to hold the conferences was hotting up. The 2004 conference took place in Japan, after some nine or ten years' campaigning and planning for the event.

Before 'our' 1994 Conference took place in Edinburgh we had been to the Netherlands in 1991, Belgium in 1992 and Canada in 1993. At each of these conferences Scotland continued to be represented at the international committee tables in spite of her continuing 'unofficial' status in the organisation. As the years went by more delegates from Scotland were attending and returning home with new enthusiasms and ideas, as well as "promoting the lessons learnt in Scotland", as my citation for Honorary Life Membership was eventually to say.

Much hard work went into the planning of the 1994 Edinburgh Conference, by successive directors, the local committee formed for the purpose, and the professional conference organisers that were appointed. At one time financial worries were predominant but, in the event, these were unfounded, and Scotland was the first country to return a profit to the parent organisation. The conference, under the practised leadership of Brian Moss from Australia, then Chairman of Alzheimer's Disease International, was voted an outstanding success and is still fondly remembered by those from all over the world who attended. Around 800 participants were present, most of whom assembled in the McEwan Hall to hear Princess Yasmin Aga Khan (President of Alzheimer's Disease International and daughter of film actress Rita Hayworth who had succumbed to Alzheimer's disease) give the opening address. This high note set the tone for the proceedings of the next few days of debate, lectures and workshops. The conference evaluation form reveals that few complaints and great praise were registered, much to the satisfaction of the organisers. It is gratifying to end this account of the period relating to the final days of Alzheimer's Scotland and to the emergence of Alzheimer Scotland - Action on Dementia on such a high note.

Brian Moss and Princess Yasmin Aga Khan outside the McEwan Hall

Alzheimer Europe

Alzheimer Europe came into being in the early years of the 1990s. Those proposing its foundation were from Ireland, the Netherlands and Belgium, in response to the feeling that funds and other benefits might be forthcoming from the European Community to counter the ever-increasing costs of caring for an ageing population and to further the cause of those suffering from Alzheimer's disease. The first meeting was held in the Netherlands in January 1991 and Alan Jacques and I attended on behalf of Alzheimer's Scotland, along with some eight other countries, including Poland, the first non-member of the European Community to join. There were also representatives from Malta and Gibraltar. As before, the procedure entailed the writing of by-laws or a constitution, proposals for a newsletter and the setting up of various committees. Scotland has always been well represented on the latter, I having been briefly the newsletter editor, the vice-chair and subsequently the honorary secretary, a post now occupied by Alan Jacques. One of the highlights of Scotland's involvement stems from the adoption of our helpline system, demonstrated by Kate Fearnley, as the model system of Alzheimer Europe. Although in its early days Alzheimer Europe was organised mainly by volunteers, like all the organisations in which Scotland is involved it now has a professional secretariat with its headquarters in Luxembourg. Its conferences have also been held annually in many European cities from Madrid to Warsaw.

The first meeting of Alzheimer Europe represents one of the coldest experiences of my life. We were accommodated in empty rooms in a nurses' home with little heating, bare floor boards and inadequate bedding. The only hot water was in the shower. Fortunately I had travelled with a hot-water bottle, but try filling that from a shower! I slept in most of my clothes with the rest piled on top. It was gratifying to be seated later in the warm house of Henk ter Haar, Chairman of the Netherlands association, but disturbing to be watching the first Gulf War unfolding on the TV.

Chapter Six

Scottish Action on Dementia: Awakening the policy makers

The third member of the three which became one was inaugurated in 1985 with a view to raising matters relating to dementia in high places, unlike Alzheimer's Scotland and its predecessors, which were in their early days dedicated solely to helping the carers. The genesis of Scottish Action on Dementia was completely different from the somewhat haphazard way in which Alzheimer's Scotland came into being. It was the brainchild of Age Concern Scotland, where Jan Killeen was training officer and Mary Marshall was director. Mary is now director of the Dementia Services Development Centre in Stirling, while Jan remains with Alzheimer Scotland to this day as public policy director. It must be recorded that it was Mary Marshall's prescience in allowing Jan Killeen to follow her own instincts in this matter that created the environment in which the movement was able to develop so successfully.

Following the outcome of the first big Scottish conference on dementia, 'Coping with the Care of the Ambulant Person with Dementia', held by Age Concern Scotland in Glasgow in June 1984, the group that had planned the conference agreed that there was a need for a campaign body to press for:

1 specialist services for dementia,
2 better standards of care,
3 training and public awareness, and
4 adequate benefits to meet the hidden costs of care.

A steering group was formed to look at how such a campaign might be taken forward, which included Annette Forster, the development officer in Scotland for the Alzheimer's Disease Society. A 'Dementia Action Forum' was held in February 1985, chaired by the indefatigable Dr Bill Boyd, where the above topics were again explored with the addition of the topic of legal implications for those suffering from the illness.   A commitment from over seventy relevant professional associations, voluntary and statutory organisations was achieved and the title 'Scottish Action on Dementia' adopted for the campaign. Jan Killeen became part-time co-ordinator of the campaign, and later director of the established organisation, Scottish Action on Dementia.

> *"Over 400 people wanted to attend this conference - only 200 places so we had to turn people away. The final plenary session was like opening up a can of worms - participants were very angry that people with dementia were being tossed around like hot potatoes between residential homes and hospitals because no one wanted to care for them, and there was little or no support for carers to continue caring at home"*
>
> *Sarah Colles, Conference Planning Group member 1984*

This organisation was fortunate that from the beginning it had funding from the Mental Health Foundation and the Scottish Office, later increased by funding from a number of trusts and local councils. A national co-ordinating committee and five sub-committees were formed to take the issues forward. Dr Boyd had many other duties to perform in his professional life and Angus Mitchell became the first chair of Scottish Action on Dementia at its first formal meeting in June 1985, remaining in that post until the amalgamation in

1994. As a recently retired civil servant of the Scottish Office and author of the 'Mitchell Report' (1977, on joint planning between the NHS and local authorities), he was skilled in the art of dealing with ministers and prepared to tackle them on issues relating to dementia, qualities which proved of inestimable value to the organisation. Under his tutelage, an influential document 'Dementia in Scotland: Priorities for Care, Strategies for Change' was issued in January 1986. It was agreed, because of the extent and impact of its work, that Scottish Action on Dementia should become a voluntary organisation in its own right, leading to its formal inauguration in April 1986. The first AGM took place early in 1987 and the first Dementia Awareness Week shortly after that.

Many other influential people were involved in the early days of what came to be known as SAD. Professor Fred Edwards, then Director of Social Work in Strathclyde, and in due course a member of the Scottish Action on Dementia council, had great influence in persuading local authorities to give greater priority to the problems of the elderly, and in particular those with dementia. At the time, considerable weight was given to issues relating to child care, a factor greatly detracting from attention to those of the older generation. (In passing, it might be mentioned that the rise of AIDS and AIDS-related dementia created fears of a similar reaction, which fortunately proved more or less unfounded). Professor Edwards spoke at and chaired a number of Scottish Action on Dementia conferences, and his much-respected views there expressed were of huge importance in spreading its messages to local authorities and the wider public.

> *"This event, represents a 'watershed' in the provision of services for people with dementia and their carers, attended as it is by those at a top level in health and social work - it must make an impact, people must sit up and take notice, we must all work together for this most neglected group"*
>
> *Professor Fred Edwards, 'Developing Innovative Services in the Community' Conference 1987*

Fred Edwards becomes carer for the day, Dementia Awareness Week 1990

Other early members who provided inestimable service to the organisation are the chairs of the four sub-committees created by Scottish Action on Dementia, all of whom were also on the original co-ordinating committee:

1 Dr Peter Murdoch, consultant geriatrician at Falkirk Royal Infirmary, was chair of the Education and Training sub committee. This committee organised the first Scottish Action on Dementia conference 'Dementia: Action on Training' (May 1986), at which a commitment was gained from the Scottish Health Education Board to produce the booklet 'Coping with Dementia: a handbook for carers' which, with regular revisions, is still reproduced today. Later a report on training was published which identified the need for a national resource centre to support the provision of specialist dementia care. It was quite beyond the scope of Scottish Action on Dementia to provide this. Hence the Training sub-committee developed the concept which became the Dementia Services Development Centre at Stirling. Peter Murdoch subsequently became one of its first trustees. The committee also conducted a survey of what specialist dementia care training was being provided by authorities and training establishments. Needless to say, the lack of specialist training was alarming.

2 Dr Brian Ballinger, then consultant in old-age psychiatry at the Royal Liff Hospital at Dundee, who chaired the Standards of Care sub-committee. The achievements of this committee included the organisation of the conference and publication, 'Dementia, Positive Approaches to Care' (1987) and a rather more critical conference on standards for long terms care, 'Bed, Bored, Ignored?' (1989). One contentious issue which the group tackled was staffing levels; the core argument being that there should be 'therapeutic' levels of staffing and not merely enough for the 'maintenance' of residents or patients. In addition, following a consultation by the Scottish Office, the committee produced a document for the government called: 'Principles for the Planning of Residential Environments for Dementia Sufferers'.

3 Dr Lindsay Burley, followed by Dr Alan Jacques, chaired the Patterns of Service sub-committee. The achievements of this committee included the publication of a number of research-based reports which recommended: dedicated dementia joint planning groups; collection of dementia specific data on needs and service use; and specialist dementia services. This work provided the foundation for a series of conferences, responses to Scottish Office consultations, and meetings with Ministers. The most notable event took place at the two-day conference, 'SHARPENING Local Plans' at Crieff Hydro in November 1988, at which Angus Mitchell sent an encouraging fax to Peebles Hydro, where Malcolm Rifkind, the Secretary of State for Scotland was, very belatedly, releasing the SHARPEN Report (Scottish Health Priorities for the 80s and 90s) to the Health Services General Managers conference. In this report health boards and local authorities were asked to give highest priority to services for older people with dementia, and to develop appropriate services, including home support and small, homely, local facilities for long-term care.

4 Dr Bill Boyd, already mentioned in this history of dementia organisations, and Alexander McCall Smith, Professor of Medical Ethics at Edinburgh University, and now more widely known as a celebrated novelist, in turn chaired the Rights and Legal Protection sub-committee. This committee dissected the current

> legal provisions for the protection of people with dementia and found them woefully wanting. Its first report 'Dementia and the Law: the challenge ahead' was used as the basis for a joint World Health Organisation and Mental Welfare Commission conference held in 1988. The report and the conference debated the pros and cons of 'tinkering' with the legislation, or going for radical reform and came down in favour of the latter. This policy was rigorously campaigned for by Scottish Action on Dementia and subsequently by Alzheimer Scotland until our goal was achieved with the passage of the Adults with Incapacity (Scotland) Act 2000, the first piece of major legislation to be passed by the new Scottish Parliament. The committee also identified the lack of information on legal and ethical matters for carers. Funding was obtained for the production of the first edition of 'Dementia: Money and Legal Matters' in which I became heavily involved. It was revised by others on a regular basis thereafter, and is still much in demand to-day.

No account of the work of Scottish Action on Dementia could possibly proceed without mention of the numerous roles filled by Dr Alan Jacques, consultant in old-age psychiatry at the Royal Victoria, now retired, who has dedicated much time and energy to the promotion of the cause of those with Alzheimer's disease and other dementias. It is at this point that I can add a personal reminiscence to this chapter which relates that part of the Alzheimer story in Scotland in which I played relatively little part. However, I can now recount how I, as a solicitor, had the opportunity, along with Dr Jacques, over several years of addressing students of psychiatry in Edinburgh regarding the legal problems facing those with dementia and their carers. This experience gave me the courage to further this project by later on lecturing to classes of social work students at Stirling University (one of which by chance included Glenda Watt, then pursuing a change of career), and even to a meeting of qualified social workers, also in Stirling. In this way Alan Jacques' message was spread into areas where it could be most useful.

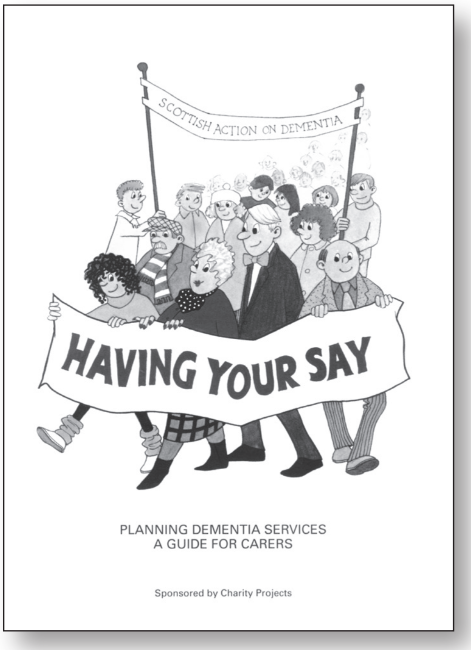
Two former vice-presidents of the organisations also deserve mention here: Ruth Wishart of the Scotsman newspaper provided vital publicity for the campaign and Mary Marquis, television personality, gave invaluable help with fundraising.

Also to be placed in the roll of honour is Lord Taylor of Gryfe who successfully raised the issue of dementia in the House of Lords and chaired the Scottish Dementia Appeal Committee. Readers may have noticed that no mention has been made of any members of the House of Commons. However, Rachel Squire, MP for Dunfermline West, who took a particular interest in dementia, used every opportunity she could to highlight issues. Most importantly she raised an hour and a half debate in the House of Commons in February 1994 on NHS long-stay care on behalf of Scottish Action on Dementia, Alzheimer's Scotland, the Dementia Services Development Centre and Age Concern Scotland. Scottish Action on Dementia was represented by Jan Killeen at a cross-party meeting on Mental Health and at back-bench meetings on carers issues. However the majority of politicians showed little interest, somewhat reflecting the problems that the Alzheimer societies had in their turn with the general practitioners in the medical profession.

Lord Taylor with Edith Rifkind at the launch of the Scottish Dementia Appeal

Last but not least in this account of significant personalities in the life of Scottish Action on Dementia is Min Inches. She was the first person with dementia in Scotland to speak out about her own condition, and her advice to the caring professions about the importance of being given the diagnosis and about her support needs, at the Crieff conference of 1990, made an outstanding impact.

Two of the many campaigns initiated by Scottish Action on Dementia were of outstanding significance. First is the campaign which led to the setting up of the Dementia Services Development Centre, which obtained funding of £85,000 from the Scottish Office in 1988. The University of Stirling was chosen as the venue for this department and the Dementia Services Development Trust was set up with Scottish Action on Dementia and the University as joint trustees, and with Jan Killeen as honorary secretary. Mary Marshall became the first, and so far the only, director with the title of Professor. The purpose of the centre was, and still is, to provide a consultation and advisory service for service providers, to carry out evaluative research and initiate innovative training procedures. This proved to be the start of the dementia services development centre movement across the UK and elsewhere. Scottish Action on Dementia played the central role in getting this important part of the world Alzheimer movement off the ground.



SCOTTISH ACTION ON DEMENTIA

HAVING YOUR SAY

PLANNING DEMENTIA SERVICES
A GUIDE FOR CARERS

Sponsored by Charity Projects

Another campaign of importance was 'Getting Local Action on Dementia' (GLAD). The objective was to form local action groups that would gather data about services and needs in order to lobby their own health and social work authorities. Funding was received from Comic Relief to employ a GLAD resource worker, Fiona Shaw, who produced a 'Getting Local Action on Dementia Resource Pack', full of advice on how groups could find their way through the maze of bureaucracy to hit the right target. This complemented another of Scottish Action on Dementia's publications 'Having Your Say' which was written for carers' groups who wanted to have their voices heard. GLAD groups were formed in several areas across the country.

Chapter Seven

Alzheimer's Scotland and Scottish Action on Dementia: Joining forces

By 1990 there were three thriving organisations in the dementia field in Scotland: Scottish Action on Dementia, Alzheimer's Scotland and the Dementia Services Development Centre. Each had clearly identified roles and remits, spelt out in a leaflet to help avoid confusion. There was much co-operation between the three, with Scottish Action on Dementia and Alzheimer's Scotland sharing accommodation and equipment, and all three benefiting from the Scottish Dementia Appeal. However it became apparent that in the minds of the public there was some confusion and there were inevitable overlaps and duplications. Scotland is a small place for three specialist dementia organisations to exist and fundraise. So, after an exchange of letters and a lot of informal discussion, it was agreed by all to seek the advice of a consultant to look at the roles, remits and organisational structure of the three and to advise on whether there would be advantages in merging. The outcome, after long and friendly deliberations, was that there would be much to be gained from the amalgamation of Scottish Action on Dementia and Alzheimer's Scotland, with the Dementia Services Development Centre remaining a separate body. As Angus Mitchell points out, Alzheimer's Scotland would inevitably be the "big sister" in the new organisation, in terms of its financial weight and range of services, but it was from the first agreed that the aims and objectives of Scottish Action on Dementia were of equal importance and that this should be reflected in the structure of the new organisation.

A constitutional committee was set up, chaired by Alan Jacques, who was in the lucky or unenviable position of being vice-chairman of both organisations, and it laboured long and late to give effect to the intentions and ambitions of both constituents. Mary Hope, whose background was in housing, had been introduced to Alzheimer's Scotland through Mary Marshall of Age Concern Scotland. She took over as interim chairman, but stayed for seven more very successful years as convener of the new organisation. She saw her role in the merger discussions as emphasising important themes, with Angus Mitchell as the constitutional expert. The task of ensuring that all the Branches, projects and members were 'on board' was important, as was the maintenance of the wide representation of professional, regional and carer interests in the council. Most of the Scottish Action on Dementia sub-committees continued as committees of that new council (and still do, with some of the original members still serving). Mary Hope remembers that one of the most convincing arguments for the merger was that "the best way to run an effective campaign is to base it on an intimate knowledge of the services and those who use them". Among other important factors were: ensuring a good management and sound financial structure; and being in a position to seize opportunities for future developments.

Mary Hope recalls being approached by Alison Glen outside the Hill Street office and "had my arm twisted" so see if she might like to become chairman of Alzheimer's Scotland. It was only after she agreed that she realised that she would be involved in complicated negotiations over the constitution of the new organisation, and that her chief executive would be disappearing at the same time.

Once again, the name of the new association caused much anxiety. It was, however, obvious from a canvass of members' opinions that both 'Alzheimer' and 'dementia' had to be included, and so, the somewhat lengthy formal title that we know today came into being.

162 different names for the new organisation had been suggested, including lots of catchy but meaningless single words!

Jim Jackson, who had come to his new post from the Scottish Council for Voluntary Organisations, remembers that some members and staff of the organisations were passionate about the name, others a lot less so. His role at that time was to make sure that a new constitution was agreed and approved by the Inland Revenue by 1 April 1994. The final Memorandum and Articles were prepared at great expense by an Edinburgh law firm. At the same time as drafting the Rules of the new organisation, Jim had to work quickly on the 'Agenda for Dementia Care' which was to set out its practical aims and aspirations. Angus Mitchell has summed up the results of all these deliberations as "overdue, friendly and well-worthwhile".

Each organisation held its own AGM in 1994, at which resolutions were passed confirming the details of this happy outcome, followed by the first general meeting of the new one. Mary Hope become the first convener, with Alan Jacques as vice-convener, while Ian McLeish and I continued as treasurer and company secretary respectively. Jim Jackson, having earlier in the year taken over from Ewan Davidson at Alzheimer's Scotland, became executive director, and has continued in that post (now with the title Chief Executive) to this day, with Jan Killeen as public policy director.

The success of Alzheimer's Scotland and its predecessors had been based on the commitment and enthusiasm of the early pioneers, followed by its effective transformation into a fully professional organisation. Scottish Action on Dementia worked because it embodied so successfully the principle of collaboration between all those involved in dementia care. The aims of both organisations were combined in those of Alzheimer Scotland - Action on Dementia and will continue to be carried forward:

- to be the national and local voice of and for people with dementia and their carers in Scotland
- to improve public policies for the benefit of people with dementia and their carers in Scotland
- to provide and to secure the provision of high quality services for people with dementia
- to provide and to secure the provision of high quality services for the carers of people with dementia.

Conclusion

What of the Future?

We have now seen how the most recent and highly successful chapter in the history of the Alzheimer movement in Scotland came about. For me, it has been a privilege and an inspiration to have been part of a movement which has achieved so much in a comparatively short period of time and I look forward to see, as an observer only, what happens next. No doubt, in the future, someone will have something to say about what happened in the next twenty, fifty or more years. Ten of these have already elapsed and there is still no cure in sight. Would it be fair to say that the best result that we can look for is that the organisation will have been disbanded in the light of the success of those searching for that elusive cure?

Evelyn McPake
Edinburgh, 2004

Postscript by Alan Jacques

Ten years have now passed since the merger negotiations between Alzheimer's Scotland and Scottish Action on Dementia were brought to a successful conclusion. Under the leadership of Jim Jackson, supported by a Council and Executive of many talents, with conveners Mary Hope and me, the staff and volunteers who are at the heart of the organisation have striven towards the comprehensive goals we set.

In our strategic planning the organisation early on made a conscious decision that we could never hope to provide everything for everybody with dementia all across Scotland. What we could hope to do was to continue with our effective programme of successful national campaigns (as we did on Incapacity legislation, free personal care and post-code prescribing); provide some important national services (such as our 24 hour Helpline and carer education programme); and, in locations spread across Scotland, provide a wide range of services, concentrating on pioneering, high quality and specialist services that no-one else would be likely to provide (to give only a few examples - services for younger people with dementia, for those for people at the earliest stages, and for those from ethnic minorities, and work on dementia friendly communities). To support all that range of effort, we have tried to ensure that we have a wide membership, a well trained and supported team of staff and volunteers, an effective national system of administration and support services, and, underneath it all a sound financial base, built on an effective fund-raising team and prudent budgeting and financial controls.

Recently our emphasis has been on enhancing the involvement of people with dementia and their carers, and on ensuring help for people at the earlier and the later stages of the illness, but all the other aims and objectives have been carried forward at the same time. It is a big and complex undertaking. The key to it all has been effective collaboration at all levels within the organisation and with our partners - the Scottish Executive, health and local authorities planners and providers, other provider and campaigning organisations, and most of all carers and people with dementia throughout Scotland.

It will be for others to judge whether we have been successful in living up to the hopes of those dedicated pioneers of the Edinburgh Branch of the Alzheimer's Disease Society, and the enthusiasts who were at those early meetings that led to the setting up of Scottish Action on Dementia. They were united by their determination that future generations of people with dementia and their carers should not be faced with the walls of ignorance, lack of service, poor standards, indifference and stigma which made it so difficult for anyone to get effective assistance twenty to twenty five years ago.

It is a long haul. Some may feel disappointed that we cannot claim that any of those original aims have been achieved. Others will know the lessons of a history like this - progress comes slowly; history repeats itself; some things change, making old ideas redundant, other things never change; and some things that look like progress turn out to be false dawns. Thank you, Evelyn, for helping us see more clearly where we come from, so that we can look more wisely towards the future.

Where are they now?

Glenda Watt	After re-training as a social worker and filling several posts in the local social work department, now masterminding Edinburgh's 'City for All Ages' project. First Honorary Life Member of Alzheimer's Scotland.
Maureen Rasbash	Still Strathyre holiday organiser and attending group support meetings. Helpline volunteer and once a week office volunteer at the Edinburgh Branch.
Alison Glen	Newly retired as chair of the Edinburgh Branch but still on the committee and once a week office volunteer at the Edinburgh Branch. Honorary Life Member of Alzheimer Scotland.
Irene Fisher	Deceased.
Myra Smyth	Still doing sterling work for the Edinburgh Branch, as a volunteer, and involved with the Strathyre holidays.
Dr Alan Jacques	Convener of Alzheimer Scotland - Action on Dementia.
Dr Bill Boyd	Retired.
Jan Killeen	Still with the organisation as Public Policy Director.
Mary Marshall	Professor in the Dementia Services Development Centre.
Angus Mitchell	Retired
Mary Hope	Retired
Jim Jackson	Chief Executive of Alzheimer Scotland.
Evelyn McPake	Retired but wrote this book! Honorary Life Member of Alzheimer Scotland
Ewan Davidson	Now Planning and Innovations Co-ordinator with the Richmond Foundation.

Alzheimer
Scotland
Action on Dementia

Alzheimer Scotland
22 Drumsheugh Gardens,
Edinburgh EH3 7RN

Telephone: 0131 243 1453

Fax: 0131 243 1450

Email: alzheimer@alzscot.org

Website: www.alzscot.org

24 HOUR
Dementia
Helpline

Alzheimer
Scotland
Action on Dementia

Freephone 0808 808 3000
Email helpline@alzscot.org

Registered in Scotland 149069 • Scottish Charity No. SC022315