Policy

Work on the Access Economics Report The Dementia Epidemic: Impact and Positive Solutions for Australia and particularly its national launch helped to raise the profile of Alzheimer’s Australia substantially.

The Department of Ageing, Disability and Home Care has initiated quarterly meetings with Senior Executives from Alzheimer’s Australia NSW. These focus on the relationship between the two organisations, both in terms of government funded programs and also a wider policy and advocacy perspective.

We participate in a number of other networks: a metropolitan dementia service providers network, an NESB Dementia Network and the Professional Dementia Network for regional positions funded by the Department of Ageing, Disability and Home Care as well as those we sponsor through Commonwealth funding for the Dementia Education and Support Program.

Policy Submissions

There are a large number of Commonwealth reviews underway in the aged care area. A significant contribution was made to the Commonwealth initiated conference in February 2003 on The 21st Century Hospital – Innovative Care for Older People, with a paper by Lewis Kaplan focussing on quality dementia care.

Alzheimer’s Australia National Position Paper No. 2, Quality Dementia Care was published in February 2003. There is every reason to believe that this work contributed to a decision by the Commonwealth to include specific requirements in relation to dementia care in this year’s Aged Care Approvals Round. At year end, Alzheimer’s Australia was negotiating with the Commonwealth to provide formal briefings on quality dementia care to prospective providers around Australia.

Other submissions by Alzheimer’s Australia NSW during the year included a draft Social/Community Planning and Reporting Guidelines and Manual 2002 and a review of Guide to Handling of Medication in Nursing Homes in NSW, requested by the Pharmaceutical Services Branch, NSW Department of Health.

National submissions with Alzheimer’s Australia NSW contribution included a review of General Guidelines for Medical Practitioners on Providing Information to Patients (we were the lead agency); a submission on Residential Aged Care Application Form; an Inquiry into Long Term Strategies to Address the Ageing of the Australian Population over the next 40 years; a review of the operations of Divisions of General Practice; Draft Palliative Care Guidelines for Residential Aged Care Facilities; and A New Strategy for Community Care Consultation Paper, Department of Health and Ageing.

Achievements

Strengthening Recognition

Objective – Strengthen recognition of Alzheimer’s Australia NSW by Government, service providers and the community as the peak consumer body and a source of expertise on dementia issues
Media

Our media profile continues to grow. Barely a day goes past without some new development, be it research or service related. Our aim of being the first port of call for media covering dementia issues has not yet been fully achieved, but we are heading in the right direction. On many occasions during the year we have been required to provide comment to the media on current issues and research. This has resulted in additional media coverage to that which we proactively seek.

Throughout the year we consistently targeted media with information about dementia, our work, and the services we provide. Our greatest media opportunities arose during National Dementia Awareness Week and through the launch of the Access Economics Report. We received extensive media coverage during the year including television interviews on the 7.30 Report (ABC TV), Today (Ch. 9), Sunday (Ch. 9), Sunrise (Ch. 7) and news stories on each of the five major channels in Sydney – Channel 10, Channel 9, Channel 7, ABC and SBS; numerous radio interviews on 702 ABC Sydney, Radio National, Radio 2UE and Radio 2GB and on community, regional and rural radio stations; and feature stories in the Sydney Morning Herald, Daily Telegraph, Australian Financial Review, The Australian and numerous suburban and rural newspapers and weekly and specialist magazines.

Special Events

All special events during the year were aimed at increasing community awareness and generating fundraising income. During National Dementia Awareness Week we hosted Opera on the Harbour to recognise the importance of funding for both Alzheimer's Australia NSW and Alzheimer's Australia Research Ltd. It attracted a sell out crowd on Captain Cook Cruises. Professor Henry Brodaty gave a thought provoking speech about the need for increased funding into dementia research, which resulted in a pledge from Pfizer Australia of $15,000 at the event.

The inaugural Dementia Symposium, held as the lead event for National Dementia Awareness Week, attracted 200 participants, largely sector professionals. It incorporated presentations and workshops focused on the needs of people with dementia from culturally and linguistically diverse backgrounds, Aboriginal and Torres Strait Islander communities and rural and remote areas.

In January we partnered Ryde City Council in their established Australia Day Concert with the aim of raising funds and awareness in our local area of Ryde. Ita Buttrose spoke about dementia and Alzheimer's Australia NSW and encouraged the audience to dig deep in support of those living with dementia.

The ASX Reuters Charity Foundation selected Alzheimer’s Australia NSW as one of fourteen charities to benefit from its annual Golf Day and Dinner in 2003. Through this we received $24,000.

The Hordern Pavilion was again the venue for Corporate Countdown. Corporate Australia was represented with bands from AON, Arnott’s, Belgiovane Williams Mackay, DDB, ING Direct, Julia Ross Personnel, McKinsey & Company, Nestle Peters, Prince of Wales Medical Research Institute, Microsoft, Sydney City Lexus and Upstream. Luminaries in the audience included Neville Wran, Kevin Jacobson, Channel Seven’s David Leckie and chef Jason Roberts. This year we shared the proceeds with the Prince of Wales Medical Research Institute.

Events where others kindly raised funds and awareness for us included a Swimathon organised by Rotary Club of North Sydney Sunrise, SKAL Ball and a Melbourne Cup Calcutta organised by the firm de Vries Tayeh.

Achievements

Changing Attitudes

Objective – Contribute to changes in attitude in the community leading to: decreased stigma, improved understanding and increased respect for people living with dementia, their carers and families
National Dementia Awareness Week

National Dementia Awareness Week, which took place from the 15 – 21 September, was bigger and better in 2002. Through publicity, advertising and a program of special events we were able to achieve our main objective which was to increase community understanding of dementia as a major health issue.

This year we were generously supported by the state government through the Department of Ageing, Disability and Home Care which enabled us to run an extensive media awareness campaign on television, in print media and at selected cinemas. Research conducted pre and post campaign indicated a high degree of success with unprompted awareness of the organisation increasing by 33%.

During the week, special events were held across New South Wales. Support groups across the state held information sessions, expos, community displays and carers events. Education Services hosted a carer training session in Newcastle, a community information session in Port Stephens, a family carers workshop in Wollongong and a seminar with Dr Helen Creasey in Mittagong. In Newcastle, the Hunter Network held a memorial church service.

Coinciding with this year’s Dementia Awareness Week was an innovative collaboration between Alzheimer’s Australia and the Photographic Imaging Council of Australia (PICA). Based on the theme Thanks for the Memories – frame a memory for Alzheimer’s on World Alzheimer’s Day, the initiative provided the public with the opportunity to purchase a $4 magnetic photo frame from participating retailers, with proceeds going to Alzheimer’s Australia. Over 22,500 photo frames were sold around Australia and $64,178 was raised.

National Dementia Awareness Week was made possible through the support of the Commonwealth Government together with the NSW Government, National Museum of Australia, Pfizer, Janssen-Cilag, PICA and Hills.

Advertiseing

In conjunction with the Photographs & Memories campaign, Thanks for the Memories – frame a memory for Alzheimer’s on World Alzheimer’s Day, PICA and their advertising design company Stand Alone Design produced an attention grabbing television commercial based on the synergy between photographs and memories. It was used nationally as our television advertisement during National Dementia Awareness Week.

In January we also developed a new corporate video, She Misses Him, which was produced by Anvil Media. It follows a day in the life of a family touched by dementia. The reaction to it, whenever screened, is profound. She Misses Him won an international Silver Summit Award for charity advertising in Portland, Oregon this year.

Publications and Promotional Material

Four editions of intouch and Fundraising News were published during the year. All of our promotional material and stationery was upgraded and redesigned to incorporate our new corporate identity. New promotional material produced and distributed during the year included a Statewide Dementia Support Services brochure; a Dementia Services brochure for the Bega Valley Mobile Respite Team; Life Doesn’t Stop When Dementia Starts posters for the Chinese and Arabic communities funded by the Department of Ageing, Disability and Home Care; a poster for Dementia Awareness Week; posters for the PICA Photographs & Memories promotion; and other giveaway material.
Corporate Identity
Our new corporate identity, which was launched during National Dementia Awareness Week, has given us a real national perspective and profile both internally and externally. We are working on an expressed desire within the organisation to become more nationally focused both in terms of raising awareness and fundraising. There has been a definite and positive response from our business and community partners who see our proactive approach in this area as a sign that we are an organisation on the move. To prospective sponsors, we have established a greater image of professionalism. Being more unified in our image has also given us much more buying power in national advertising.

Although some stakeholders were apprehensive about change, and being a member driven organisation it is important we acknowledge these opinions, the new corporate identity has largely been embraced to a point where members feel an ownership and pride in it.

At the Alzheimer’s Australia National Conference in Melbourne, international delegates from Alzheimer organisations around the world gave positive feedback about the symbolism and meaning of the new identity.

Policy and Research
New South Wales is the only State member of Alzheimer’s Australia Research Ltd., which conducts specific fundraising activities for research. We are also the largest member contributor of funding to Alzheimer’s Australia Research Ltd. The Research Foundation is aiming to increase its profile substantially but is aware of the need to do so in collaboration with rather than in competition with Alzheimer’s Australia state and national offices.

Policy development in New South Wales has been slower than hoped for, mainly due to the non-implementation of a decision as part of the strategic plan to create a position of policy officer. This is only due to financial constraints. A submission for a policy officer to the NSW Department of Ageing, Disability and Home Care has yet to be funded.

National Program Management
National programs are reaching a critical phase in the cycle of our four year contracts for Carer Education and Workforce Training (CEWT) and Living with Memory Loss, which finish in June 2004. After a slow start, demand has now clearly outstripped supply. External evaluations point to all programs being successful. We will be developing bids for new contracts with the Commonwealth Government in a changing environment being driven by the New Strategy for Community Care Review and Consultation, to which we have contributed.

National Resources Committee
Two staff members represent us on the National Resources Committee. This year a partnership with the Australian Chinese Community Association was developed and six Help Sheets were identified, produced and distributed in both Mandarin and Cantonese. Six Help Sheets were also translated and distributed in Polish, Greek, Italian, Vietnamese and Arabic.

National Education Initiatives
Education Services continue to relate closely to interstate counterparts through meetings and regular teleconferences. The primary issues of the year related to national review of the Dementia Care Competency, the CEWT Project and the exchange of ideas around pilot projects for small isolated residential facilities. Also on the agenda were strategies for addressing issues and barriers when training and assessing students from Culturally and Linguistically Diverse Backgrounds (CALDB) and Aboriginal or Torres Strait Islander (ATSI) communities.

The Dementia Care Competency CHC99ALZA was reviewed by the Australian National Training Authority, which consulted widely across the industry and found strong support for it. The result yet to be announced is a strong probability that this competency will become compulsory for the Certificate 3 Aged Care and Community Care qualifications. These are the primary training qualifications being offered in residential care and community service organisations. This is a significant gain for dementia care across Australia.

The CEWT project continues to grow in reputation and demand, and in many States waiting lists and priority systems apply. National moderation of assessments remains an issue to be addressed, however through the CEWT project each State and Territory now has an active and viable dementia education program for both family carers and dementia care workers.

National Website
During the year a new national website was developed for Alzheimer’s Australia. It was launched at the National Conference in March. The site was made possible through the generous support of the Macquarie Bank Foundation, and additional support through the Commonwealth Government. It includes all the information that is generic to each State and Territory, and also a separate section for each.
Dementia Helpline
The Dementia Helpline is the first point of call for many carers, people living with dementia and those concerned about memory loss. The Dementia Helpline exists to meet the needs of this state with its widely dispersed and multicultural population. During the year over 5,200 callers accessed the Dementia Helpline. To meet this demand, we now operate four Dementia Helpline booths. As the graph below demonstrates, the majority of calls to the Dementia Helpline are from carers of people living with dementia. Their calls related to managing stress and challenging behaviours, grief and loss, legal issues and placement in residential care.

A new initiative for this year was the launch of a Chinese Dementia Helpline. The first of this kind of service in Australia, it operates on the first Thursday of each month and both Cantonese and Mandarin are spoken. Carers of people living with dementia in the Chinese community have received the Chinese Dementia Helpline enthusiastically and have primarily been making requests for information, particularly for the recently translated Help Sheets.

Living With Memory Loss Program
Living with Memory Loss is an education and support program that aims to maximise the health and well being of people living with early stage dementia and their support persons. In a group format, program participants have the opportunity to tell their story of memory loss; gain a greater understanding about dementia; reflect on the impact of the diagnosis on themselves and their family; and learn the importance of better communication and problem solving skills, as well as self care. They also hear a solicitor speak about financial planning, wills, enduring power of attorney and guardianship.

During the year 22 Living with Memory Loss programs were delivered for people in early stage dementia and their support persons. This year they were held in the Sydney metropolitan areas of North Ryde, Hornsby, Baulkham Hills, Northern Beaches, Eastern Suburbs, Kogarah and Penrith; and in the rural areas of Bega, Wollongong, Central Coast, Armidale, Tamworth, Wagga Wagga, Northern Rivers and Nelson Bay.

Support Groups
Across New South Wales there are approximately 225 support groups. At monthly group meetings, those looking after people with dementia come together to assist one another by mutual problem solving, and learning new ideas and skills. Each group generally has its own leader and program. In some areas, there are groups exclusively for multicultural carers, male carers, and adult children of people with dementia and teleconference groups for current and former carers. The graph below illustrates the dramatic growth in this field.
Achievements

Counselling
Free professional counselling is available for people needing support in dealing with issues relating to dementia. People with dementia and those in a caring role often benefit from a confidential consultation at strategic points in the progression of dementia. This can be done either face-to-face or by telephone. Counselling provided at North Ryde is fully booked with a two week waiting list.

Some of the issues encountered when working with clients this year have included intergenerational conflict; people with dementia having only one adult child caring; conflict amongst siblings and management of a relative’s dementia; denial of the condition by family members; migrants with a Holocaust and war background with dementia reliving trauma; lack of appropriate community resources and facilities like day care and respite; the ramifications of younger onset dementia; and lack of understanding about dementia.

Library & Information Service
The Library & Information Service has continued to grow its collection of books, videos and audio materials for loan to members. An inter-library loans service is used to meet any resource requests that are not available in-house, in particular journal articles. Information queries and loan requests are received via telephone, in person and increasingly via email directly to the library, or through the website.

Collection development has continued to focus on resources for carers and people with dementia; however increasingly healthcare workers and students are finding these resources beneficial in the provision of their service to people with dementia and their families.

The extension of hours of the library to cover four days has resulted in an increase in people visiting and using the services in person. We are grateful to the Department of Ageing, Disability and Home Care for their partial funding that led to the extended hours.

Professional Dementia Network
The Professional Dementia Network grew rapidly over the past year with the integration of 14 new Dementia Advisory Services. During the year two face-to-face workshops were held, one at our North Ryde offices and one linked to the Alzheimer’s Australia National Conference in Melbourne. Alzheimer’s Australia continued to provide support for the four Dementia Education and Support Program rural positions to participate in this Network. Our contract for this project is now complete, and the Department of Ageing, Disability and Home Care will undertake the supervision of the Network. The Network will continue to expand with the release of four additional Dementia Advisory Services in metropolitan Sydney.

Dementia Advisory Services
We have received funding for four Dementia Advisory Services: Bega/Eurobodalla, St George/Sutherland, Wingecarribee and Mid North Coast.

The Bega/Eurobodalla service has been operational since early this year and is co-located with the Mobile Respite Team in Bega. Achievements for this service include a needs analysis for both Bega and Eurobodalla Shires; participation in a steering committee for Southern Area Health Service for dementia planning and mapping; commencement of a counselling service for both Shires; commencement of a *Living with Memory Loss* program for Bega Valley in partnership with the Dementia Networking Group for Bega Valley; and organising for the geriatrician to speak to General Practitioners about dementia.

The St George/Sutherland position commenced in March. The service is made possible through a partnership with Southcare where the position is situated. Achievements to date include a needs analysis for the St George and Sutherland regions and development of numerous relationships across the region.

The Wingecarribee position has been filled and the position holder will commence in the new financial year. Negotiations with Mid North Coast Area Health Service are underway and it is envisaged that this position be operational by the end of 2003. This position will also be responsible for the Local Dementia Services Mapping Exercise for which we received funding for the region.
Carer Education

‘Felt very relieved and more supported to have those details and information making life easier.’

‘It helped me get over that guilty feeling, and know that I am not alone.’

‘The information presented about how the brain and memory work and the different stages of dementia helps me to better understand about the disease and what to expect.’

Carer education continues to grow in response to the needs of carers of people with dementia across New South Wales. The Carer Education program aims to educate, support and inform family carers and to assist them with the often stressful role of carer.

During the past year 1,569 carers and family members attended sessions, 191 of these were carers attending a new carer’s course focusing on Challenging Behaviours through the Carer Education and Workforce Training (CEWT) project. Eighty five separate carer education sessions and extended courses were provided from Tweed Heads to Bega, Broken Hill to Canowindra to Wollongong. Attendance figures are climbing with some sessions reaching capacity. In general, Carer Education was able to meet all requests to provide sessions for local service providers.

Carer Education continues to expand with a broader range of topics, day and evening options, increased rural access, longer course options and the opportunity to attain the Dementia Care Competency becoming available through the CEWT project. The various options complement one another to offer a wide range of education and training alternatives to family carers of people with dementia.

Number of Carers Attending Separate Education Sessions
Education Services

During the year Education Services focused strongly on increasing delivery to clients located in rural or remote areas. As a result we have been extraordinarily successful in increasing our reach into rural New South Wales within one year. Overall Education Services provided education and training sessions for family carers or dementia care workers in 38 different rural locations, covering all rural Area Health Service regions of New South Wales. This represents a more than 100% increase on the previous year.

The Carer Education and Workforce Training (CEWT) project delivered 25 courses in rural locations including courses for carers and workers. This represents more than 58% of the total number of CEWT courses, up 14% on the previous year. Family Carer Education provided 25% of all sessions in rural areas in addition to the carer programs under CEWT, and the Experiencing Dementia Workshop exceeded its target by providing 60% of the ten subsidised workshops in rural and regional New South Wales.

Demand for dementia training remains extremely high from rural areas of New South Wales. The addition of four sessional trainers, three of whom are regionally located, has also significantly increased our rural delivery capacity. More funding is being sought from a number of sources and a priority system based on location has been implemented for some programs to improve equity.

Fourteen different dementia education and training sessions for clients from culturally and linguistically diverse backgrounds (CALDB) were provided. Four CEWT courses specifically for groups from CALDB and two carer sessions in Cantonese for the Australian Chinese Community Association and Blacktown Migrant Resource Centre were held. A submission for the development and delivery of a carer course using interpreters and translated materials for both Italian and Vietnamese carers was successful as a pilot under the CEWT project. Aboriginal and Torres Strait Islander (ATSI) students participated in a range of education and training sessions.

Achievements

Improving Equity

Objective – To improve equity in service provision and access to appropriate services for people in targeted groups, including: people living with any dementing illness; people in regional, rural and remote areas; people within culturally and linguistically diverse communities; and Aboriginal and Torres Strait Islander people.

Education Services

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Publications
The quarterly *Dementia Educator* remains a significant support resource for workers and support group leaders across New South Wales providing topical information and practical skills for those regularly involved in family carer education.

Mobile Respite Team
This innovative short term service for people living with dementia and their carers residing within the Bega Valley Shire continues to provide interventions to up to six families per week. The carer support group run monthly by the Mobile Respite Team continues to attract twelve carers per month. Specialist supervision for the leaders of the support group is provided through the Group Development Unit of Alzheimer’s Australia NSW. During the year the team members successfully completed and were accredited via CEWT Respite Workers course and have attended a business planning day in Sydney with other members of the Family Services Team.

Support Groups
The Group Development Unit continues to offer a range of workshops, consultations and resources to rural and regional New South Wales. The Unit also provided a range of short term telephone support groups specifically to the Maltese and Korean communities. Each was evaluated, showing that this group program can meet the needs of those who could not attend a face-to-face support group.

Living with Memory Loss Program
Of 22 programs delivered this year, 41% were in rural areas. These programs, at Armidale, Bega, Central Coast, Nelson Bay, Northern Rivers, Tamworth, Wagga Wagga and Wollongong, catered for 51 people with dementia and 62 carers. After completing the initial 7 week program, 26 people with dementia and 30 carers attended ongoing monthly support meetings in five rural locations. All rural programs and meetings were planned and led in partnership with staff from other agencies.

Dementia Education and Support Consultants
We continue to provide funds towards the employment of staff in rural areas. We currently have partnerships and staff in Orange, Warilla, Wagga Wagga and Armidale. Funds are provided to contribute to salary costs for these positions, in addition subsidies for participation in the Professional Dementia Network are also provided. The positions provide counselling, support groups, carer education, community awareness and *Living with Memory Loss* programs in these areas.

Hunter Network
The Hunter Network has had another successful year servicing the needs of the people of the Hunter area. Their office is now staffed three half days a week. A partnership with the Newcastle Welfare and Pension Officers Network RSL sub-branches and Department of Veterans’ Affairs provided a grant that enabled them to offer their expertise to organise and present six seminars throughout Newcastle, Lake Macquarie, Port Stephens and Hunter areas. The very active Speakers Bureau has seven members who gave 35 talks to Probus, Rotary and Lions Clubs, Support Groups, WEA Educare, Nursing Homes and a Ladies Golf Club. In June they had a stand at the Newcastle Seniors Expo where over 5,000 people attended. A successful memorial Church Service was held on World Alzheimer’s Day for the third successive year.
Achievements

Education and Training
Objective – To provide a comprehensive, flexible, accessible range of education and training services on dementia issues

This year has been one of high activity and achievement for Education Services with a number of concurrent projects being conducted for different target groups and aims. We have significantly increased numbers of carers and workers attending dementia education sessions, achieved extensive coverage of rural areas, completed and delivered the Family Carer course under the Carer Education and Workforce Training (CEWT) project, and increased training and initiated policy collaboration in the intellectual disability field. Education Services has grown rapidly over the past few years and now offers a wide range of training options that vary in length, complexity, location, and time to both carers and dementia care workers.

The Education Unit delivered a total of 345 different training sessions and courses to carers, dementia care workers, health professionals, volunteers and the general community. These sessions varied in length from one hour to a four day program. There were 4,460 attendances at dementia education sessions during the year, an increase of almost 30% on the previous year.

Education staff presented papers at the Alzheimer’s Australia national conference in Melbourne. Anne Sammut’s article, Developing an appropriate response to emotional pain, was published in the UK Journal of Dementia and Marleina Hoschke’s article, Challenging Behaviours, was published in The Lamp. A number of invitations to consult on dementia care philosophy, policy and education program development for various organisations were received. Education staff represented the organisation on a number of committees and working parties including the Faculty of Psychiatry of Old Age – NSW Institute of Psychiatry, the NSW Transcultural Aged Care Service and the Dementia Education and Training Working Group – Future Directions for Dementia Care and Support in NSW 2001-2006.

Alzheimer’s Australia NSW remains a Registered Training Organisation (national code 5929) recognised by the Australian National Training Authority, and all training staff have a clinical background in dementia care as well as training qualifications and experience. The positive reputation of the unit and our training continues to result in ongoing and repeat business.

Fee for Service and Calendar Courses
A total of 408.5 hours of dementia specific training was provided to 2,290 dementia care workers and health professionals through fee for service training and our calendar courses. This is a slight increase on the previous year, however this is close to our maximum output with current staff resources and program requirements. At our North Ryde training facility 74.5 hours were delivered, in the Sydney metropolitan basin 232 hours, evening courses at Baulkham Hills and Merrylands 16 hours, through the Dementia Assessment and Management course with Sydney University Continuing Professional Education Unit (CPEU) 28 training hours, and in the rural and remote areas of Kootingal, Buladelah, Katoomba and Bega, 58 hours.

The evening seminar series goes from strength to strength with Fresh Insights into Dementia held at Baulkham Hills and New Frontiers in Dementia Care in Merrylands. A range of specialist guest speakers shared their expertise, and then facilitated an interactive question and discussion time. The series was also offered in an intensive two day format to enable rural workers to attend. Especially popular was our presentation on Challenging Behaviour with more than 80 people in attendance. We also facilitated a powerful session on Treading the rocky road... Carers’ Stories by interviewing Jack and Grace, spouses and carers of a person with dementia.

Our program on Challenging Behaviour was a popular request and was delivered from Bulahdelah to Sutherland, Pagewood to Glenfield. We continue to attract interest from a relatively new area with workers in the intellectual disability (ID) field who recognise the impact of ageing in their services. Four courses were provided to ID workers – psychologists, therapists, trainers, nurses and residential staff – covering topics including assessment, diagnosis and responding to changed perceptions. We continue our partnership with Sydney University CPEU and have provided several sessions in courses by the NSW Nurses Association.
Carer Education and Workforce Training (CEWT) Project

The CEWT project is a Commonwealth funded national dementia training initiative now in its third year of a four year contract. Carers NSW is a partner in this project. The project focuses on training for community based dementia respite workers and family carers of people living with dementia in the community who demonstrate challenging behaviours. The project has two primary components: the Respite Workers Course and the Carers Course.

Forty three CEWT courses were delivered during the year. Our pool of sessional trainers has significantly increased our rural reach and overall output capacity. Overall, 638 participants attended, comprising 191 carers and 447 workers from community based dementia respite services. Of the students who chose to pursue the assessment procedure, 276 respite workers were successful in achieving the National Dementia Competency.

The Respite Worker Course and assessment procedure for the Dementia Care Competency is at Certificate 3 level and is quite demanding, especially for those with language and literacy difficulties. This is the case for many workers in the community based dementia care industry and appears more so in New South Wales than any other State or Territory due to our cultural mix. The national competency framework of training recognises that practical caring skills are not necessarily a reflection of written or spoken language capacity. Our training staff have worked hard to support these students and to develop a range of assessment options including audio tape and face-to-face interviews to assist.

Outcomes and feedback from participants of CEWT have been overwhelmingly positive and many practical gains in interacting with people with dementia are reported back from both participants and service supervisors. The funding for this course has facilitated many people attending who would not otherwise have been able to access such a substantial dementia training course due to cost or location. Demand has grown to the point where it greatly outstrips funding resources and a waiting list and priority system have been implemented.

Experiencing Dementia Workshop Project

The Experiencing Dementia Workshop is an interactive workshop for aged care workers based on an innovative simulation exercise. This project was funded by the Department of Ageing, Disability and Home Care to subsidise 10 workshops, 8 of which were delivered in this financial year with 169 participants to date.

The Experiencing Dementia simulation exercise aims to provide deeper insights into the experience of dementia, through enabling participants to enter into ‘the world’ of a person who has dementia. Through this experiential workshop, participants are challenged to not only understand dementia with their heads, but also with their hearts. This opportunity leaves participants with fresh insights, greater compassion and a new motivation and ability to improve care for their clients with dementia.

Dementia Educator

The Dementia Educator newsletter continues to produce four issues annually with a theme for each edition. As a benefit for professional and organisational members it has now reached a circulation of 950 and continues to grow. It aims to provide information, resources and skills development for workers and group leaders whose role includes carer education and support. Informal feedback remains very positive, especially in regard to the simple concrete tools that can be easily utilised.

“As a caregiver I have learned to look and listen... Since I am using new strategies in communicating with Mrs Smith I realised she is more relaxed around me... my understanding about dementia is at a higher level than before, I am using different techniques, and focusing on the person, not on her illness, the purpose to restore Mrs Smith’s dignity as a person. Making her happy will be one of my satisfactions.”

“I had never really thought about restraints and had considered them a necessary evil, now I understand that there are alternatives.”
Achievements

Improving Service Delivery and Activities
Objective – To continuously improve our service delivery and activities

Home and Community Care (HACC) Program Validation
The successful passing of the NSW HACC Validation process for the Carer Education and Chief Executive / Advocacy programs required extensive cross-departmental collaboration. Home and Community Care Validation of our Core Operations grant produced a score of 20 out of 20. The knowledge gained from this process will be passed on for the next validation process of the Library and Information Service in 2004.

Education Services
Education Services continues to maintain Registered Training Organisation status and provide nationally recognised training. A quality management cycle is embedded into Education Services planning and activities.

Specific quality improvement initiatives for the past year have included passing HACC validation, an in-house train the trainer program, a full evaluation of the CEWT Respite Worker course based on more than 12 months’ feedback, assessment moderation and development of assessment standards guidelines, updating of the Education Policies and Procedures manual and a review of processes against the upgraded national training standards.

A comprehensive report analysing our CEWT project performance against contractual requirements and outcomes was completed by the project manager and reviewed by the external Quality Outcomes Committee. The national CEWT project has been evaluated externally by Australian Aged Care Solutions with initial results indicating highly significant learning gains for participants, particularly carers. A full report of this national evaluation is due late in 2003. The Experiencing Dementia Workshops series funded by Department of Ageing, Disability and Home Care is also subject to an independent evaluation with results due by September 2003.

The CEWT project has achieved a significant goal in catching up output requirements from the current and previous year. In 2003, we achieved 78 output points from a target of 80. The variation was due to a late course cancellation by a client and will be easily redressed in the coming year.

Dementia Helpline
The Dementia Helpline booths, which now total four, are all now equipped with computers, and resource databases have been compiled for Aged Care Assessment Teams and Support Groups. The new Chinese Helpline is operational on the first Thursday of each month. A new telephone monitor, which collects data on calls coming into the Dementia Helpline, has been installed. The Vincent Fairfax Family Foundation has provided a grant of $20,000 to initiate an intranet pilot for the Dementia Helpline. A separate server has been purchased and installed and software to build the intranet is being evaluated.

Living with Memory Loss Program
Clinical staff in NSW ran three workshops to train a total of 31 health professionals in the principles of group leadership and how to deliver Living with Memory Loss programs for people with dementia and their carers. This enabled more clients in more locations to benefit from this early intervention program.

The clinical staff provided weekly telephone supervision, to extend the expertise of the health professionals delivering these programs and to maintain clinical standards. Telephone supervision also helped to identify and resolve any problems quickly.

Library & Information Service
A review of the Library and Information Service has been completed. One of the aims of this review was to improve our services to our remote and rural clients and members. Some recommendations, particularly involving technology, will be acted on in the next financial year.

Support Groups
As support groups are a critical resource for the field of dementia, the Group Development Unit has initiated a research project, Alzheimer’s Australia NSW Quality Support Groups Research Project. This project has the support of NSW Health, the Northern Sydney Health Human Research Ethics Committee and Macquarie Research Limited. The purpose of this research project is to become better informed about the operation and structure of support groups in New South Wales. In order to do this there will be an investigation into the needs of both support group leaders and carers. It is envisaged that the outcome of this research will be a clearer understanding of what constitutes quality support groups and how this can be achieved.
Expanding Annual Income
Objective – To expand our annual income to support our growing services and our longer term financial security

Fundraising
The past year has been one of consolidation with our Direct Mail donor file growing, thanks to a successful acquisition campaign.

Corporate Countdown again rocked corporate Australia with some of Australia’s leading business leaders performing alongside Glenn Shorrock, Richard Clapton, Margaret Urlich, Lee Kernaghan, Tim Webster, Michael Tierney of Human Nature and Murray from the Wiggles. It was hosted by Richard Wilkins and Toni Pearen. It also marked the reformation, at least for one night, of Jono & Dano, radio’s former dynamic duo. The amount raised was well down on the inaugural year and was shared with the Prince of Wales Medical Research Institute for Alzheimer’s research. Our thanks to Harrow Productions, Hausmann Communications and John Doumani for their support of this event.

Creative Memories supported us via their Home Class consultants in raising $20,000 for the organisation nationally. During National Dementia Awareness Week, the Photo Imaging Council of Australia (PICA) launched Photographs & Memories through many photographic outlets across Australia. This national program was initiated and managed by Alzheimer’s Australia NSW. This raised $64,178 for the organisation nationally.

For the first time we were a beneficiary of the ASX – Reuters Charity Foundation Golf Day and Dinner, the biggest event of its kind in the Southern Hemisphere. This raised $24,015.

The swimathon organised by the Rotary Club of North Sydney Sunrise took place in November and raised $1,260.

During National Dementia Awareness Week we partnered with Alzheimer’s Australia Research Foundation in presenting Opera on the Harbour on World Alzheimer’s Day. The event raised almost $28,000.

The growing acceptance of dementia as a burgeoning ‘health epidemic’ has seen a definite increase in corporate interest with approaches from companies wanting to establish community partnerships with Alzheimer’s Australia including Kimberly-Clark Australia, One Steel and AGL.

The recognition that our donors and supporters are our greatest asset resulted in the establishment of a Donor Development Coordinator position to oversee the development of a membership strategy which includes recognition of our donors, members and bequestors.

Trusts and Foundations contributed $30,650. Rotary’s Community Chest raffle contributed $4,538, which was down 29% on the previous year.

Membership is on the rise, following a review of the program to ensure we recognise the contribution our supporters are making to the organisation long term.

Direct Mail raised $142,948, up from $132,740 the previous year. This 8% increase of income is due to the magnificent support we have received from our membership, regular donors and people with a long time association with the organisation. We acknowledge that much of this support has been forthcoming in difficult times for some and it has been an awe-inspiring experience for us.

In Memoriam, in which people donate to us in lieu of flowers, raised $46,032 this year. It is humbling to think that at a time of grief people still think of others. This sort of generosity is almost without equal.

Bequests saw $157,455 being left to us. For these donations, and all of the others, we are eternally grateful and we will continue to see that this collective generosity is put to maximum use.
Hunter Network
Through their fundraising efforts the Hunter Network of Alzheimer’s Australia NSW have raised $36,138 towards their resource centre appeal.

Training Income
Fee for service and calendar course income generated $68,387 over the past 12 months.

Subsidised fees for funded projects provided $34,065 towards the Carer Education and Workforce Training Project and $8,600 for the Experiencing Dementia project. These contributions enable these programs to remain financially viable, provide discounted registrations for participants, and support training provision right across New South Wales.

Commonwealth Grants
Commonwealth grants have remained stable with four programs being funded by the Department of Health and Ageing under this umbrella: Dementia Education and Support Program, Living with Memory Loss, Mobile Respite Team, Bega Valley Shire and Carer Education and Workforce Training.

State Grants
Funding for recurrent State grants funded by the Department of Ageing, Disability and Home Care increased by approximately 75% during the year and included four Dementia Advisory Services: Bega/Eurobodalla, St George/Sutherland, Wingecarribee and Mid North Coast

The Department of Ageing, Disability and Home Care also approved two Service Development and Planning grants for the Mid North Coast and Wingecarribee.

The Department of Ageing, Disability and Home Care also provided a one off grant for Dementia Awareness Week in the amount of $115,000.

A partnership with the Newcastle Welfare and Pension Officers Network RSL sub-branches and Department of Veterans’ Affairs provided a grant that enabled the Hunter Network of Alzheimer’s Australia NSW to present seminars throughout the Hunter region.
Volunteers continue to be a vital and valuable support for the organisation. A wide range of tasks are now undertaken by both our regular and casual volunteers. Our volunteers provide us with much needed support in all areas including general administration tasks such as bulk mailing or collating information packages, data entry, member call backs and assistance in the Library & Information Service. The member call back scheme has developed strongly with many members now requesting telephone contact with one of our representatives.

Volunteers continue to be an essential component of the Dementia Helpline team. Education Services has a number of casual volunteer roles for carers presenting personal stories or being interviewed for various education programs. This builds on the initiative of the Community Awareness Partners who continue to promote awareness through their own stories presented to clubs, community groups and nursing homes. This group also regularly set up and answer questions at stands at different community events.

Volunteers played an important role in the success of our events including Corporate Countdown, Australia Day Concert, Opera on the Harbour and the ASX Reuters Charity Dinner.

Our volunteers were excellent media spokespeople especially during Dementia Awareness Week, for the launch of the Access Economics Report and when other media opportunities arose. Often sought by the media, they offered an invaluable insight into dementia through their stories and personal experience.

Advocates

Alzheimer’s Australia NSW has a consumer group called ‘The Advocates’ comprising people who have shown an interest in supporting the organisation’s policy work. Advocates assist with lobbying Governments, industry and community organisations to improve services for people living with dementia and their carers. They are invited to participate in discussion groups, review and comment on draft discussion papers, participate in forums, attend Government and industry meetings as consumer advocates, write letters of support to Members of Parliament and assist with delegations to Government Ministers. During the year we asked our Advocates for input on a number of policy issues.

We wish to thank the team of hardworking, skilled and dedicated volunteers who contribute so much. We could not continue to deliver the high level of our activities and quality services without you.
Policy & Procedures Manual
A complete update of the Policies and Procedures Manual was undertaken during the year with several information sessions for all staff to further their understanding and provide feedback. This was a vital part of the Home and Community Care accreditation process, which was completed at the end of June 2003.

Continuing Education
All staff have taken part in a range of skill enhancing workplace training programs. This included undertaking at least an intermediate course in Word or Excel, depending on what they used more and an introduction course on the other.

Lynn Shaw, Manager Education Services, graduated from Macquarie Graduate School of Management with a Masters Degree in Management in September 2002.

The majority of service staff attended the Alzheimer’s Australia National Conference held in Melbourne in March 2003, where new information was obtained, networks built and contacts made across Australia.

Internal Communication
We continue to develop an environment of open communication between staff, volunteers, Board members and members. Various systems are in place to support information flow such as bi-monthly staff/volunteers meetings, the weekly Revelations staff newsletter, fortnightly Managers Communications meetings with minutes distributed to all staff and regular team meetings within various departments.

Communication to our members is provided through the quarterly newsletter intouch which includes Fundraising News.