A lot of good things have happened at Alzheimer’s Australia New South Wales over recent months. We have finalized a strategic plan and throughout the organisation we are working towards implementation of its elements. We have settled a good budget which allows for pursuit of our mission and allows the Chief Executive Officer to work towards the achievement of its elements.

About that strategic plan it was developed first by officers within the organisation. Only when they were satisfied with the product did the Board have input, changing some things here and there and making it a document to which everyone could support.

At the AGM in November it is the intention of Geoff McIntyre and Ern Alchin to retire. Each of those two has made considerable and significant contributions to our organisation over much time. Geoff maintained the important and valued association with the Rotary Club of Sydney to whom we owe so much. He has been a President of the Association during turbulent times and moved it from an Association to a Company. He found us the sponsorship for the van we have, and of which we are so proud.

He is a wise and valued advisor who will be missed.

So thank you Geoff.

Ern Alchin, with his particular personality has driven the finding, the purchase and the renovation of Percy St in Hamilton in Newcastle. Thanks to him we will have a home and a living presence in the Hunter. Alterations and improvements are being completed as you read this and we have so much to thank Ern for.

But his task is now complete and he feels that he can retire and watch it work well for the people of the Hunter. Incidentally, we held the launch of Dementia Awareness Week in Newcastle this year. We also “launched” the memory van there – thanks go to the staff who managed the many parts of that event so well.

We continue to look at ourselves on the Board and to recruit “high flyers” who have reached commercial retirement age – they look for more activity and we value the skills they bring to us. We are aiming at a balance between experience in the sector with more general management skills and are amazed constantly at the numbers of skilled people who have been touched with dementia and want to help us.

Now on to next year!

Peter Baume AO
“To give something back” is the common reason given for doing volunteer work, but to me it is just being part of the community, and that brings a lot of pleasure. This may be taking part in a Mother & Toddler group as I did when our daughters were young, or organising a study group for new mothers, which was a new development for me in our village in England, or helping by listening to children read in our local Primary school. Just a rewarding part of life. Certainly as a family we also received from others: from the Brown Owl, the leader of our daughters Brownie pack, from the leader of the Girls’ Brigade, an organisation of the Baptist Church, from the trainer of our daughter’s softball team, and from the trainer of our second daughter’s hockey team. Like many families the list just grows once you start to think about it.

So when I retired from full-time employment in 2002 it was natural for me to look for a new avenue and I responded to a request in the Sydney Morning Herald from Alzheimer’s Australia for ‘helpers’. I felt especially interested in the Helpline service since it would be such a contrasting experience from my professional work as a computer software developer in a manufacturing and distribution environment.

The training for our group was organised by Anne Hall who was then the Helpline Co-ordinator. It lasted over two months and introduced me to the services and resources of the organisation and most importantly to the concept of active listening, an action of querying what you have heard in order to verify your understanding. Many of our calls to the Helpline cover several issues and we try to help rather than simply act as a call centre channelling the call to services.

Training did not finish at the end of the two months and our group meets on a regular basis for on-going education sessions. I have also found it very useful to attend some of the professional education sessions held at the Alzheimer’s Australia NSW Vincent Fairfax Family Resource Centre in North Ryde and in my local council area. In this way I have made up for my lack of prior knowledge of medical matters in relation to dementia and my ignorance of health services. I can confidently recommend families, especially those who have recently received a diagnosis of dementia, to take advantage of our education services and the Living with Memory Loss programs.

I did not expect that this new found knowledge would become very personal. Following the sudden death of my father my brothers and I slowly realised that my mother could not safely take care of herself, we had not known how extensively my father had looked after her, like many people of his generation you “just get on with things”, pride and loyalty did not allow him to reveal how things were. The situation was not helped by the fact that the three of us siblings were living in three different countries. Our situation is similar to so many other families; distance brings its own set of problems.

Each family is unique and dementia does bring many problems but caring can have moments of pleasure. I am proud to be part of the community of Alzheimer’s Australia NSW.
Injectable Antibody for Alzheimer’s

Source: ScienceDaily

Researchers recently showed that an injectable antibody with the ability to bind to the toxic amyloid-beta protein in the brains of Alzheimer’s patients could provide the basis for a new Alzheimer’s therapy. This research represents a breakthrough in that this large antibody has the ability to cross the blood-brain barrier that often prevents therapeutic agents from reaching targets in the brain.

Fewer Teeth may be Linked to Dementia Risk

Sources: Newswise
http://www.newswise.com/articles/view/534090/
American Dental Association news release
http://www.ada.org/public/media/releases/0710_release03.asp

New research has indicated that deterioration of oral health might be a potential risk factor for dementia. Scientists compared dental records and mental assessments to conclude that low numbers of teeth (zero to nine) are associated with an increased dementia risk, and therefore may be a predictor for the development of dementia late in life. Suggested reasons for the association include altered diet (lacking in essential brain vitamins) as a result of tooth loss, adverse impact on brain health caused by increased oral infection/inflammation, or unidentified early-life causal factors leading to both tooth loss and brain damage.

It should be noted that this study cannot indicate whether tooth loss is causative or plays any direct role in dementia onset.

Testosterone may Reverse Alzheimer’s Progression

Source: ScienceAlert

Scientists at Edith Cowan University in Western Australia have discovered that beta-amyloid levels responsible for Alzheimer’s symptoms can be lowered in both animals and humans by testosterone replacement therapy. A comprehensive literature review examining evidence on hormone levels and Alzheimer’s pathology indicated a strong association between testosterone and beta-amyloid levels. Subsequent animal and human pilot studies have indicated that restoring testosterone to the body can lower beta-amyloid levels in the brain, which might help in delaying or preventing Alzheimer’s disease. Researchers point out that one therapeutic advantage of testosterone is that it would be quickly available to Alzheimer’s patients, should the treatment prove effective.

New Potential Marker for Early Alzheimer’s Diagnosis

Source: Newswise
http://www.newswise.com/articles/view/534026/

Researchers report that decreased levels of ethanolamine plasmalogen, a vital brain compound, could be a potential bio-indicator for diagnosing Alzheimer’s disease. A decrease of ethanolamine plasmalagens in the blood is observed even in the early stages of the disease, with the decline becoming more noted as the disease progresses. Scientists hypothesise that the reduced levels may result in decreased release and activity of acetylcholine, a compound important for memory formation that is known to be deficient in Alzheimer’s patients. This discovery suggests new possibilities for accurate early diagnosis of Alzheimer’s, which has previously been notoriously difficult. However, further research will be required to demonstrate if restoration of the compound could prevent or reverse Alzheimer’s symptoms.

The above news stories will be posted shortly on the Alzheimer’s Australia website under Research | Dementia News (http://www.alzheimers.org.au/content.cfm?topicid=400).

Also, these stories will be made available on the Alzheimer’s News website (http://alznews.blogspot.com/), along with more news items covering a broad range of topics relating to dementia. This news service site is fully archived and searchable. You can also set up your own email alert or news feed to Alzheimer’s News at http://alznews.blogspot.com/2007/03/how-to-set-up-email-alerts-to.html
So you’ve got the diagnosis. In this case Alzheimer’s Disease, but it could just as easily be Asthma, Breast Cancer, Diabetes, MS, or Parkinsons.

You’ve gone through the shock, the ‘why me/us’, the terror of what is to come. Where to go from here?

Alzheimer’s Australia NSW. Through it you will find information, knowledge, support and above all how to go down the networking path… particularly local support groups.

The general profile of an Alzheimer’s support group starts with the organisers. They can be social workers, dementia trained specialists, technical people, and are often former carers. Former carers are people who have lost family members or friends to this condition. They’ve come through the other side with sanity and comfort to offer others traveling the dementia path. One such group, through Alzheimer’s Australia NSW is ADHOC (Alzheimer’s Disease Help Our Carers).

ADHOC meets socially on a Saturday every month at the beautiful and dementia-specific built Vincent Fairfax Family Resource Centre in the grounds of Macquarie Hospital at North Ryde.

On offer are afternoon teas, lunches, barbeques, candlelit dinners, entertainment and a fabulous Christmas lunch.

The Vincent Fairfax Family Resource Centre also houses a very extensive library, and counseling and meeting rooms. Nick Hayward-Wright, the librarian and her staff are extremely knowledgeable and approachable and the counselors are available and free of charge for the first few sessions.

Another life-line is a local support group. Our local group is the Alzheimer’s Discussion Group Turramurra. We have a guest speaker every month, ranging in topics from aromatherapy for carers, to music therapy, physiotherapy, through to advice on technical matters.

Then there are the other self-support groups which have come through from the ‘Living with Memory Loss’ programmes run by Alzheimer’s Australia NSW. These groups are a continuation of the programme. They are wonderful for sharing of ideas and experiences, networking, letting off steam and general support of each other. And of course you already know each other and have gone through the early grieving stage together.

Networking, sharing, support…. I know it’s hard sometimes to even contemplate getting out of the house. But I cannot too strongly recommend that you do get out there and find a group, it brings sanity back into your life. If you can’t find one already existing, start one. It’s a great help and in the case of dementia the saying ‘trouble shared is trouble halved’ is absolutely right.

Patsy Templeton

Patsy and Ron Templeton are passionate advocates for people with dementia and their carers. Here Patsy shares some of her experience and advice in ‘Alzheimer’s: A–Z’

For a full range of support and education services offered by Alzheimer’s Australia NSW call the National Dementia Helpline 1800 100 500
Arts and Dementia: the creativity of the individual was the theme of this year’s Dementia Awareness Week activities and we can report that it was a wonderful success.

Thanks to everyone who attended the events and the speakers who gave their time in particular.

Overall there were 6 major events throughout the State during the week, including the one day Newcastle symposium and a special World Alzheimer’s Day afternoon tea at the Vincent Fairfax Family Resource Center at North Ryde.

All the events had very strong arts and dementia themes and the venues reflected this. We had the support of some wonderful art galleries and enthusiastic staff including the Newcastle Region Art Gallery, the Orange Regional Art Gallery, New England Regional Art Museum, Coffs Harbour City Gallery and the Bega RSL.

The artistic efforts of people with dementia and their carers were a major feature of the week. In Coffs Harbour the audience heard from Robyn Lawrence who is an artist in her own right and who spoke very movingly of her artist husband Neil and how his career as an artist and his abilities changed considerably during the progression of dementia in his life.

The World Alzheimer’s Day event at Cox’s Road highlighted the marvellous work of Barry Trengove, another artist with dementia who painted through the progression of his condition. Barry died last year and his partner Kay Barnes spoke very emotionally and bravely about what Barry went through and what each of his paintings, which were on show that day represented. It was a very special moment for all who listened as this was the first time Kay had spoken publicly about what she and Barry had gone through. An edited version of Kay’s speech and black and white photos of Barry’s work are featured in this edition.

In Bega, Orange, Coffs Harbour and Armidale significant collections of art which had been produced by people with dementia and their carers were on show. In Coffs Harbour 250 people saw the art and dementia exhibition while 120 works were on show at the Bega event.

To hear these very personal stories and to see heartfelt works of art and experience such creativity was a rare and real privilege.

A special tribute should also be made to the wonderful array of speakers who gave their time during Dementia Awareness Week 2007. This included Professor Kenneth Rockwood; Marily Cintra who spoke at four events around the State and who inspired audiences with her talk about unlocking the creativity of the individual; and the team from the National Gallery of Australia who spoke about their wonderful work engaging and interacting with people with dementia as they toured the gallery. The NGA has produced a very moving video about the gallery access project which they, with the help of Marily Cintra, Dr John Zeisel, Dr Mike Bird and Alzheimer’s Australia NSW and ACT have been running. There are many more people we would like to thank and many more activities which local DAS workers and support groups have conducted.

And a special thank you again to the NSW Department of Disability, Ageing and Home Care for its continued generous support of DAW.

DAW remains the showpiece of what Alzheimer’s Australia NSW is all about- showing the wider community that people with dementia and their carers are human beings who enrich and contribute to our society.
Listening to People with Alzheimer’s Disease and Those Who Care For Them

Each of us will have taken something different away from Professor Rockwood’s key message about why listening to patients and family carers is good medicine, good science and good public policy.

Dr Rockwood challenged us to think about the way in which governments currently measure the cost effectiveness of dementia medications. This is important because we understand that there may be around 140 different compounds at various stages of trial at the present time. Subject to the necessary safeguards about safety and efficacy, Australians need subsidised access to new and effective dementia medications as quickly as possible through the Pharmaceutical Benefits Scheme.

The current approach to testing potential medications is through random controlled trials which compare outcomes on psychometric scales for those receiving medications and those who do not. Dr Rockwood’s key message is that while this provides useful information for the study group about the particular medications, when it comes to the treatment of individuals, there may be better approaches.

Rather he suggests that treatment outcomes should be measured against the goals set by consumers themselves in terms of those issues that impact most on their quality of life.

When the Pharmaceutical Benefits Advisory Council considered listing the anti-cholinesterase medications, anecdotal evidence was provided of how those who had been involved in the trials had experienced improvements in their everyday lives. Some of this was captured by the observations of family carers that “their mum or dad had come back to them”. These types of positive outcomes were not able to be objectively measured in the trials as they were run.

Dr Rockwood’s research suggests that it is possible to set consumer goals for treatment and measure outcomes scientifically to assess if a treatment has assisted a particular individual.

The challenge for Alzheimer’s Australia will be to find ways of supplementing the group information that comes out of those large trials with individually focussed approaches that have scientific credibility and provide perhaps better and faster access to medications for people with dementia including for those with the less common causes of dementia.
A successful designer and art director, Barry Trengove was also passionate about painting. His exhibitions attracted critical acclaim, then he was diagnosed with Alzheimer’s Disease. But he painted on producing some of the finest work of his life…..

This is an edited version of Kay Barnes’ tribute to her partner Barry Trengove which she gave at the World Alzheimer’s Day event at the Vincent Fairfax Family Resource Centre at North Ryde during Dementia Awareness Week 2007

I was Barry Trengove’s partner for 30 years – and carer. It was Barry who created these paintings you see here today. Barry died from Alzheimer’s in June last year.

Barry was a very complex person. He came over as a very gentle man - he was never overbearing or pushy. But he was absolutely passionate about “painting” – it was his life, and he approached his paintings with joy, energy and determination.

The period in the early 1990s was his most productive and joyful. As with most painters I think, Barry would sometimes work night and day producing a flood of paintings - only to be followed by a period of drought and reflection.

Mid-to-late ‘90s and the momentum started to disappear. Barry struggled more with each individual painting, often spending days agonising in front of it, only to paint over it and start again. I’d get up in the morning and find he’d been in the studio for hours, totally obliterating a painting he’d been working on for weeks. He could paint out a painting 5 times and still not be happy with it.

His confidence, which had always been so strong, started to fail. Painting itself had become hard, even though the passion was still there. But I think the paintings got stronger.

This now brings us to the late 90s and it was obvious that Barry had a problem with his memory. However we (or basically I, because by this time Barry was totally dependent on me for all decisions) – were in denial.

After those months of inactivity there’d suddenly be a couple of wonderful days in the studio. It was as if Barry was fighting an internal battle, with his lack of confidence competing with his determination to paint the best painting ever.

I think these, and the remainder of his paintings, were the best he every produced – his inner conflict producing amazingly strong and thought-provoking images.

About this time we finally went to the doctors and got the confirmation of Alzheimer’s.

His last painting took maybe a year to complete. It’s an enormous piece, too large to show here. How he fought over that one. He described it to the Community Care people as trying to show “What’s going on in my head”.

In the talks we had over these latter stages, he said how throughout his working life he had always felt smug, that when he retired he would have a pastime, a passion that few others had. He was so angry that at last, when he had the time to paint as much as he wanted to… it had got so hard. In the end he wouldn’t even go into the studio – it was obviously too depressing for him.

In summary, all I can say is that before the Alzheimers’, Barry’s work was free-flowing, adventurous and individual. Afterwards it was drawn out with barbs, and as a result I think it was the most creative, emotional and vibrant work he did.

One thing I’ve learned in this Dementia Awareness Week is that creativity and Alzheimers can, and do, co-exist. I believe Barry’s work is an example of this.
Congratulations to long time volunteer Pat Larsen who has been given a volunteer’s award for her work helping people with dementia and their carers and especially for her association with the Ad Hoc group. The Federal Member for Bradfield The Hon Dr Brendan Nelson presented the award making special reference to Pat’s piano playing and love of sharing music with people.

Many thanks to the Hills Rural Lions Club which has raised $3,000 for Alzheimer’s Australia NSW. The generous donation came from proceeds from the annual Garden Competition & Open Gardens scheme which was part of the Baulkham Hills Shire Council, Orange Blossom Festival. The Lions Club would like to thank the public and local businesses for their support.

Also a big thank you to some generous athletes! Thirteen people ran in support of Alzheimer’s Australia NSW in the City to Surf earlier in the year. Collectively they raised $5,350 which is fantastic. Also 5 people ran in the half marathon in the Sydney Running Festival and raised almost $1,000. Thanks for your support and well done for keeping fit!

The Hunter Dementia and Memory Resource Centre at Hamilton in Newcastle is fast becoming a reality. Work has commenced at the Centre with the demolition of the rear of the building and the laying of the slab for the building extension. The NSW Department of Disability, Ageing and Home Care has become a partner in the re-development project with a commitment of $150,000. We are pleased to advise that the Newcastle Permanent Foundation has also committed $60,000 to the project. A number of other organisations and local companies are considering our proposal of support. As reported we are indebted to the Rotary Club of Newcastle which raised the capital sum to purchase the property.

Our Information and Library Service would like to mention that with Christmas fast approaching why not go to our online bookshop www.alz.seekbooks.com.au and purchase a book! The bookshop not only has a selection of dementia titles, but over 1.5 million general titles to choose from. For an additional discount during the month of December include the following code at checkout: ALZNSW25

As part of Dementia Awareness Week Alzheimer’s Australia NSW produced a TV and Radio Community Service Ad. These have been sent out to all radio and TV stations in NSW promoting the National Dementia Helpline 1800 100 500 so keep a look out!

Santa’s coming to the next Ad Hoc lunch at the North Ryde RSL on Friday 30 November. For bookings please call 9449 3576.

A successful night was held at the Ariel Bookshop at Paddington to help promote ‘Remember Me Mrs V? Caring for My Wife: Her Alzheimer’s and Others’ Stories by Tom Valenta. Tom’s seen here with Alzheimer’s Australia NSW Chief Executive Bill Northcote on the night. Proceeds from the sale of the book will go to Alzheimer’s Australia. Thanks Tom!

Finally, one of our favourite Alzheimer’s Australia NSW couples Jack and Daphne Lamont will be honoured in a very special exhibition entitled, Eternity at the National Museum in Canberra. Jack, whose wife Daphne has dementia, will feature in the section on ‘devotion’ and includes the muffin tin which carried the famous muffins he would make the nursing staff every time he visited Daphne. You’re an inspiration Jack!

Win a new car for Christmas?
By supporting Alzheimer’s Australia NSW this could become a reality by buying tickets in the Rotary Christmas Treasure Trove Raffle.

We retain 80% of proceeds – so every ticket you, your family of friends buy helps us provide services and foster dementia awareness and understanding. Buy a $20 book and be in the draw for a special book seller’s prize. Just complete the order form for your chance to win or call Brian Daniels on 02 8875 4612 with your phone order. Brian can also arrange for tickets for you to on sell.

1st Prize – Toyota Corolla, valued at $22,000
2nd Prize – Jewellery, valued at $3,000

Tickets just $2 each and entries close January 9, 2008

Good Luck!
We offer our sympathies to the families who have lost their loved ones. We also thank the friends and families who have donated to Alzheimer’s Australia NSW in their memory.

Marcia (Abby) Abbot
Maria D Aloia
Olga Ellen Armitage
Mair Ash
Doris Ida Ashenden
Una May Bailey
Domenica Barbaro
Giovanni Barnaba
George William Blair
John Bowen
Elizabeth Brady
Tom Brooks
Rae Bruce
John Bylart
Isabella Caccetta
Phil Chain
Mabel Jane Chapman
Lloyd Childs
Giuseppe Ciocci
George Claydon
Kathleen Conomy
Brenda Coppock
Brigid Corby
Leila Crawford
Sheila Curran
Edward William (Ted) Cuskelly
Evelyn Daizell
Brian Davis
Dixie Dean
Alma May Deans
Frederick Dobson Dures
Heather May Folpp
William Tom Francis Foskett
Lance Foster
Yvonne Garisyne
Concetta Garozzo
Melanie George
Joseph Ghata
Barnaba Giovanni
Jean Gowan
Mario Grava
Ray (Tubby) Green
Rita Edna Guinness
Dorothy Margaret Haggart
Betty Harvey
Mavis Hawkins
Reta Hayes
Gerard Michael Healy
Jenny Hersee
J Hickey
Jack Hilder
Myra Hogan
Eileen Holmberg
Patricia Clare Hooton
Mignonnette Louisa Horn
Joan Phyllis Howard
Winifred Humphries
Betty Crombie Jobson
Edith Johnson
Edwin H Johnston
Betty Jones
Stanley Philip Jones
Joe Kane
Ronald Kirkwood
Michael Koutsourais
Dorothea Long
Ann Lynch
Elise Winifred (Pat) Mackay
Helen Mangioni
Patricia Maynard
Pat Mills
Sheila Molloy
Trevor Malcolm Moore
Efstratia Moraitis
William John (Bill) Nadin
Nawzar Ostowari
Pauline Parkinson
Mona Patterson
Eric Arthur Perriam
Jean Phillips
Vittorio Piscicelli
Joy Margaret Porter
Gladyd Puddy
Pamela Laidlaw Pywell
Daphne Patricia Reynolds
Jack Rigg
Stephanie Riley
Jose Romo
Vivienne Rowe
Esme Jean Ruddy
Muriel Hilary Ryan
Roger Sydney Sheppeard
Max Edward Silva
Elwyn Joyce Sloggett
Len Smalley
Lily Smith
Edie Spain
Vivienne Straube
Patricia Bernice Sweeney
Asvero Taverniti
Evelyn Alma Tolhurst
Mimi Torsh
Paul Traynor
Maria Vaccarella
Ada Robina Vale
Thelma Gwen (Sally) Venables
Daphne Eleanor Vernon
Chan Yee Hing Wong
Joseph Allen (Brigham) Young
Albert Young
Margaret Rose Zorbas
Library & Information Service

New Resources for Loan
The following is a small selection of new books for loan to members.

Recipes for a Healthy Mind: With a Large Selection of Recipes by Celebrity Chefs showcases a range of healthy recipes. Additional resources on diet, nutrition and dementia are available to borrow.

Memories are made of this. Reminiscence Activities for Person-Centred Care produced by Alzheimer’s Society (UK) is full of reminiscence based activities. Each activity includes a list of what you need for the activity and also a case study. Additional resources on reminiscence, life stories and activities are available to borrow.

New audio CDs include Learning to Meditate and Overcoming Stress. Additional resources on stress management and relaxation are available to borrow.

Other new titles available to borrow cover activities, behaviours of concern, spirituality, carer stories, stories written by people with dementia, stories and information for children, depression, about dementia and writing to name a few.

Not sure what you need then visit our online catalogue https://catalog.nsw.alzheimers.org.au/Liberty3/opac.htm for a full list of titles available to borrow or contact the Library staff between 9am and 5pm Monday to Friday on (02) 9888 4218 who will assist you in selecting the most appropriate resource for your needs.

Book Review

Communication Activities with Adults by Jayne Comins, Felicity Llewellyn and Judith Offiler

This convenient pocket sized book is a gem! It is great for activity staff to have this on hand to do some mental callisthenics with a group. It is a book of quick quiz-like questions that can be used as is, or easily adapted to the Australian culture. Games and activities would also work with people who have dysphasia. The book would also be excellent for group work in education for warm-up mental exercises. Easy and fun games are described. My favourite is one of the miming games – give every one a piece of newspaper which is then scrunched up into a stick. Each person takes a turn to use it to describe an action that the others have to guess for example – conducting an orchestra. Lauretta Kaldor, Diversional Therapist.

Are you interested in doing a book review? For further information contact the Library on (02) 9888 4218.

Research Briefs
Keep up to date on various topics relating to dementia including: care practices, drugs and drug therapy, research, risk reduction, therapeutic interventions, personal stories, and more by visiting Alzheimer’s News at: http://alznews.blogspot.com