



32nd International Conference of Alzheimers Disease International

Report from the Alzheimers NZ Delegation

June 2017

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The Conference – Overview

The 32nd International Conference of Alzheimers Disease International (ADI) was held in Kyoto, Japan from 25 to 29 April 2017. The theme was Together towards a new era and the Conference attracted around 2,000 attendees from around the world.

Alzheimers NZ delegation

The Alzheimers NZ delegation comprised Jan White (Board member, Alzheimers NZ), Anne Schumacher (CE, Alzheimers Wellington), and Catherine Hall (CE, Alzheimers NZ).

The Alzheimers NZ delegation sought to achieve as much coverage as possible of the conference programme and all members of the delegation have contributed to the preparation of this report, based on the conference sessions that they attended.

Conference Highlights and Messages

Particular highlights for the delegation were:

- The **strong presence** of people with dementia (again) presenting in all plenary and concurrent sessions;
- The focus on **engaging with people living with dementia**
- **Human rights** and **dementia-friendly** initiatives were again a major focus
- The focus on **quality of Life, dignity** and **person-centred** care;
- **Technology** opportunities are also starting to be a focus internally;
- The value of **engaging with children** and interacting with schools
- The importance of **partnership and collaboration** across social, health and community organisations to enable people to remain at home longer.

In terms of the current state of play in the international dementia community:

- There have been significant achievements over the past few decades including the network of strong Alzheimers organisations, the growth in self advocacy groups, and the strong relationship with the WHO and, as a result, there is much that can now be done
- Major disappointments are the continued stigma, the lack of a cure, far too few people still receive a diagnosis, Alzheimers associations are reaching far too few people within their countries, not enough money, and OECD's conclusion that dementia is the area where the health system performs worst of all diseases
- The major challenge ahead is that health systems around the world will collapse under the weight of the numbers of people expected and the growing cost without a stronger focus on prevention/risk reduction and treatment and different models to support people living with dementia - Governments must accept this challenge and the Global Action Plan is a major tool for that to happen.

Overall, the Conference content **supported our current direction of travel** in particular our advocacy goals, our focus on rights and standards, and our dementia-friendly initiatives.

Conference Programme – Thursday 27 to Saturday 29 April

Each day the Conference opened with a 15-min presentation from a person with dementia.

Plenary Session 1 – Global Aspect of Dementia

Overview of dementia movement from early 1980s to 2017 – Marc Wortmann

Marc is the outgoing CE of ADI, having been in the role for 10 years. Marc provided an overview of progress in the international dementia movement over the past nearly 40 years.

His observations included:

- The international movement started in 1984 with a vision of collaboration amongst 7 countries and has since grown to 90 countries;
- Major achievements are the network of strong Alzheimers organisations, the growth in self advocacy groups internationally and within countries, the growth in specialists and primary care professionals, media and officials now starting to pay attention, the dedicated researchers and policy experts, the strong relationship with the WHO
- And, as a result there is much that can be done – early warning signs, timely diagnosis, appropriate care and support following diagnosis, reducing risk, the relationship with other chronic conditions, training and education, and working with stakeholders and partners
- Major disappointments are the continued stigma, the lack of a cure, far too few people still receive a diagnosis, Alzheimers associations are reaching far too few people within their countries, not enough money, and OECD's conclusion that dementia is the area where the health system performs worst of all diseases
- Challenges ahead – health systems around the world will collapse under the weight of the numbers of people expected and the growing cost, we urgently need a stronger focus on prevention/risk reduction and treatment, and one different models to support people living with dementia.
- Governments must accept this challenge and the Global Action Plan is a major tool for that to happen.

Takeaways for the Alzheimers NZ and Members

- the international dementia movement has moved forward through hard work, a preparedness to get back up every time its been knocked down, solid facts and figures, and strong Alzheimers organisations
- we need to look at how we can expand our reach (the number of people living with dementia we support and provide services to and for)
- the direction of travel for our advocacy activities is pitched in the right place and the Global Action Plan on the public health response to dementia provides a boost
- Members have an opportunity to claim the prevention/early intervention space and deliver comprehensive community education programmes
- Push for timely diagnosis using dementia pathways
- Collaboration with stakeholders is the key.

Dementia movement in Japan from 1980 to 2017 – Kunio Takami

Kunio Takami, has been the President Alzheimer's Association Japan since it was established in 1983.

He provided a personal history of the movement starting with his experience as a carer of someone with dementia, and including setting up one of the first carer support groups and the process of slowly building that into a national network.

He spoke about how important the carer support group was to him at a time when he thought he was alone – discovering he wasn't was a revelation.

He also talked about the 5 dementia groups that exist in Japan and the way they had gone about finding a way to work collaboratively together, noting this was a slow process that required hard work and commitment by all parties.

Takeaways for the Alzheimers NZ and Members

- don't lose sight of the value of our services
- our history and development follows a similar path and occurred at around the same time as Japan
- we are not alone in having to find a way to work with multiple organisations in the sector.

What kinds of knowledge and wisdom can we propose for the next generation? –Kyoshi Kurokawa

Kiyoshi Kurokawa is Professor Emeritus of the University of Tokyo, Chair of the Health and Global Policy Institute and of the Global Health Innovative Technology Fund and a member of the World Dementia Council

Kiyoshi Kurokawa summarised his involvement with the work of the World Dementia Council and the work of the G7 over the past four years.

He introduced Pepper an interactive robot that had been working with people with dementia in Japan encouraging physical and cognitive exercise.

He also introduced four areas where he saw developments in the digital technology area:

- Big data and artificial intelligence – introducing change based on the analysis of facts
- Social robots – supporting people living with dementia
- Frontier of neuroscience – using technology to study the brain
- Dementia PPP (Public Private Partnership) – integrating research, care and support and data.

Takeaways for the Alzheimers NZ and Members

- The significant global focus on dementia over the past 3 years continues with active engagement from G7 countries and the WHO
- Whilst robots never will take the place of human interaction, it would be foolish to ignore this development of using robots as an engaging and fun adjunct to providing care.
- Technology advances rapidly (think smart phone development) therefore, it is important to keep abreast of developments and be ready to embrace and/or lead adoption of new technology.

Plenary Session 2 – Equity and access in dementia care

Dignity in care in the heart, mind and actions – Faizal Ibrahim

Faizal Ibrahim is a geriatrician based in South Australia with an interest in dementia and delirium. He is also lead clinician for the South Australia National Dementia Care in Hospitals Pilot Programme and the lo-lead champion for the caring for Cognitive Impairment campaign.

He spoke passionately about why dignity in care is so important arguing that with 40% of people going into hospital with a dementia diagnosis there is an urgent need for a dignity in care revolution.

He described the dignity in care programme that has been implemented in South Australia over the past 7 to 8 years, including the focus on changes in physical layout and food, and the role of champions and education, and the value of a collaborative network.

He also described the benefits including reduced use of restraints and drugs, and reduced hospital acquired complications.

He noted they are about to start an evaluation of the programme through a PhD student.

Takeaways for the Alzheimers NZ and Members

- How can we not address this issue and be part of a dignity in care revolution?
- Focus on creating lots of small changes, start engaging now with local hospitals
- Make it part of everybody's job and success
- Engage children to raise awareness and understanding of dementia at a young age.

Human Rights for people with dementia – Kate Swaffer

Kate Swaffer is Chair, CEO and co-founder of Dementia Alliance International (DAI), a World Dementia Council member, a Board member of ADI and Chair of Alzheimer's Australia's Dementia Advisory Committee

Kate argued that the system grossly underestimates the capacity of people with dementia and has been demanding full rights and inclusion in Society since she appeared at the Ministerial Conference on Dementia in March 2015.

She described the role and purpose of DAI as a by and for people with dementia organisation leading advocacy and provide digitally based support groups.

She also described the contribution DAI has made to the human rights agenda through the UN over the past two years.

She described the rights she is demanding as:

- Timely diagnosis;
- Care that is proactive and rehabilitate to support independence for longer;
- Research into cure and into care;
- Education for all health staff engaging with people with dementia; and
- Living independently and being included in community.

Takeaways for the Alzheimers NZ and Members

- People with dementia have to be at the centre of everything we all do
- Adopting a rights based approach is challenging for all of us
- Build our capacity to provide high quality education to stakeholders (? via Services and Standards work)
- Zero tolerance to all forms of abuse
- Human rights based approach to living beyond a dementia diagnosis.

Equity and access through collaboration in dementia care – Li Ling Ng

Li Ling Ng is a senior consultant psychiatrist at Changi General Hospital in Singapore. She has been Vice-President of Alzheimers Singapore since 1993 and is an active member of the Asia Pacific region.

She described an example of collaboration in community based support for people living with dementia in Singapore. This programme was developed in response to a situation where community based support services were uncoordinated and disconnected from the hospital services.

The programme sought to improve access to services by integrating the various healthcare disciplines, acute services with long term care, hospital and community services, and the health and social services. It relied on commitment and leadership so all parties are pulling together, education and a willingness to share, strong communications and ongoing review.

She also described their National Dementia Network working with new models of care and with the support of government agencies, noting that establishing this network required hard work from a committed group of people over a number of years.

Takeaways for Alzheimers NZ and Members

- Collaboration has significant rewards but requires real commitment and hard work over a long period
- Trust, transparency and shared goals are necessary for a successful partnership
- New Zealand Dementia Network has the potential to achieve greater collaboration, e.g Wellington Network could go to the next level and work on developing new models of care.

Plenary Session 3 – The Latest Science in Dementia

110 years of diagnostic criteria for Alzheimer’s disease – Philip Scheltens

Dr Philip Scheltens is Professor of Cognitive Neurology and Director of the Alzheimer Centre at the VU University Medical Centre in Amsterdam and Honorary Professor of Neurology at University College London.

Dr Scheltens provided an overview of the developments in diagnosis of Alzheimers Disease over the 110 year since Alois Alzheimer first described the condition in 1907 including:

- clinical diagnosis became possible in 1984 with release of the diagnostic criteria for Alzheimers disease which provided a list a symptoms and exclusions
- The next significant development was in 1992 when biomarkers and scanning became available. That decade also saw the term Mild Cognitive Impairment start to be used and a beginning focus on the risks relating to dementia
- In early 2000 work started on CSF studies and on Amyloid PET imaging, noting that this area still needs more work given amyloid builds up naturally in aging
- 2007 saw a significant change in thinking that diagnosis can occur much earlier based on clinical impairment and markers, and the concept of a pre-dementia stage started to emerge

2011 – 2014 saw further development and expansion of the diagnostic criteria.

He thinks things are at a tipping point now for research because if can diagnosis early with confidence its is possible to target trials and treatment options.

Takeaways for Alzheimers NZ and its Members

- Although there is not yet a cure/treatment much has happened over the past 110 years
- Dementia field follows the oncology pathway: earlier detection and personalised/precision medicine.

Where are we in the care science – Henry Brodaty

Professor Henry Brodaty is Co-Director of the Centre for Healthy Brain Ageing and Mental health and Director of the Dementia Collaborative Research Centre at the University of NSW. He is also a psychogeriatrician and head of the Memory Disorders Clinic at the Prince of Wales Hospital in Sydney. Henry is also former Chair of Alzheimers Australia and Alzheimers Disease International.

Henry provided a useful overview on what the science tells us about care and support of people living with dementia.

Diagnosis:

- Most activity has been in this space but even so at least 50% of people still do not have a diagnosis and there is still a gap of 2 to 3 years from 1st symptoms to diagnosis, family caregivers continue to report difficulties obtaining a diagnosis and stress associated with the process, and barriers continue to exist for GPS relating to attitudes and knowledge
- Efforts to address these issues internationally include incentives (UK), registers (Sweden), and online education and tools (GPCOG)
- For the future need a shift to a different model – re-enablement not disengagement - and a simple diagnostic tool eg a blood test.

Community Care:

- Services are currently variable in quality, availability and flexibility and there is little evidence on how to improve effectiveness and outcomes
- There is emerging evidence that a key worker/navigator improves outcomes, delays entry to residential care and reduces the burden on carers, but this doesn't translate to data demonstrating improved quality of life or reduced hospitalisations and may be more expensive.

There is little evidence about the impact of consumer directed care and mixed results in relation to respite care where it can increase stress

- For the future we need comprehensive models with increased flexibility and case management, and a clearer idea of costs and benefits

Acute care:

- 50% of admissions are people over 65 and a third have some form of cognitive impairment, people with dementia are more likely to have complications including falls and less likely to get rehabilitation (1 in 4) and pain relief in a timely way!
- Staff are poorly prepared to take a history from people with dementia and there is poor follow-up
- For the future, we need to create dementia-friendly acute environments and consider a cognitive screening on admission for all people over 65

Residential Care

- Residential care is often expensive, can be poorly designed with poor staffing and can increase isolation
- We don't know what levers to use to lift quality and what models support that shift
- For the future, we need new models of care, economics of scale, real person-centred care, to involve families, creativity, and to be more integrated with home and community care

BPSD

- Remains common and we still see a reliance on antipsychotics
- Non-pharma options, including real person-centred care and humour therapy is where the best results are

Palliative Care

- Remains a challenge and out of reach for most people with dementia.

Family Caregivers

- Are the mainstay of care and support for people with dementia and have high rates of depression, poor health and social isolation
- Needs good quality and comprehensive education programmes and tailored activity programmes

The challenge overall is how to translate knowledge to practice and how to bring in the multidisciplinary team

Takeaways for Alzheimers NZ and its Members

- There is much we know about what the issues are and what works in the care and support space
- Applying that knowledge remains a challenge – we need to share knowledge of what works and what does not and base our own services and standards on the evidence
- Real person-centred care remains the major challenge for us all
- Opportunity for us to be advocates for change and innovation, establish partnerships and act.

The Joint Programme for Neurodegenerative Diseases, building alliances and collaboration – Philippe Amouyel

Philippe Amouyel is Professor of Public Health at the Lille University Hospital. He is also CEO of the Foundation Plan Alzheimer and he chairs the EU Joint Programme of Neurodegenerative disease (JPND).

Given the size and scale of the dementia challenge in 2008 the EU identified neurodegeneration as one of four major challenges alongside energy, climate change, and food and health.

JPND was established as a way to encourage, facilitate and promote collaboration in the research space. There are now 30 countries in the programme with two partner countries – Canada and Australia.

Takeaways for Alzheimers NZ and its Members

- Responding to the challenge of dementia is a global matter that relies on collaboration.

Plenary Session 4 – Dementia and Disaster

The recent Earthquake in Japan and Personal Experiences – Suichi Awata

Professor Suichi Awata is team leader of the Research Team for Promoting Independence of the Elderly, Tokyo Metropolitan Institute of Gerontology. He is also director of the Medial Centre for Dementia, the Japanese Psychogeriatric Society and the Japan Society for Dementia Research.

Professor Awata noted that older people are most vulnerable to disasters and in 2011 65% of the victims of the earthquake were over 65:

Many were separated from family in the tsunami and couldn't be identified, they were often dehydrated and symptoms of dementia worsened, they spent longer in evacuation centres – creating issues for other people staying there and it as harder to place them after the disaster

There are particular issues for people living alone, and for staff

There is a need for strong interdisciplinary teams going out into the community and invest time in funding out what is happening, and local nursing homes can be better used as an emergency shelters for people with dementia. Community based integration centres also have a role.

Takeaways for Alzheimers NZ and Members

- Need to prepare for disaster now, with a particular focus on planning for sheltering and reintegrating people living with dementia
- Collaborate with home based support providers, NASC and DHB in preparedness planning.
- Highlights the importance of maintaining up-to-date client data, communication plans and planning for worst case scenario.

Impact of Chinese Earthquake on People with Dementia – Ma Hong

Professor Ma Hong is the Deputy Director, National Centre for China – D+CDC. She specialises in crisis intervention and public mental health and described the arrangements for emergency response in China.

Takeaways for the Alzheimers NZ and Members

- Local Bodies need to be educated and supported to ensure disaster response plans recognise the specific needs of people with dementia.

Disaster Preparedness – Hussain Jafri

Hussain Jafri is founder and Secretary General of Alzheimers Pakistan. He is a former board member of ADI, a Board member of International Alliance of Patients Organisations and Vice-Chair of Advisory Group of WHO's Patients Safety Programme.

Hussain described the disaster preparedness initiative,

Takeaways for Alzheimers NZ and Members

- The importance of personal and local networks
- Ensuring that people with dementia are supported in their community for disaster preparedness
- Ensure that Government and local emergency plans recognise the special needs for People with dementia.

Plenary Session 5 – Dementia Friendly Communities

This session include 9 nine short presentations on dementia-friendly communities from around the world:

- **Nigeria** – chipping away at the stigma traditionally attached to dementia in Nigeria through the UK's Dementia Friends Programme
- **Iran** – a programme for elementary schools that has touched 4,500 children
- **Argentina** – a café that provides social engagement and resources, services and support to people living with dementia
- **India** – a state-wide campaign focused around a play
- **Canada** – the Dementia Friendly Community Initiative, a mechanism for engaging with people living dementia
- **United Kingdom** – two people living with dementia talking about what dementia friendly means to them
- **Singapore** – the Dementia Friendly Singapore project
- **Japan** – initiatives from Kyoto and Kumamoto

Takeaways for Alzheimers NZ and Members

- Small, local initiatives make a difference
- Keep people living with dementia at the centre of everything we do
- Dementia Friendly is truly a global movement and it is good that NZ is on board
- By Dementia being visible in communities awareness is raised and stigma may reduce
- Develop easy to navigate physical environments in parks, town centres etc.

Plenary Session 6 – Early Onset Dementia

Early onset dementia: The Japanese approach – Heii Arai

Professor Heii Arai works at Juntendo University.

Professor Arai described the characteristics of people with young onset dementia including fairly rapid cognitive decline, and faced with family, financial and work challenges.

He described how the new Orange Plan (Japan's National Dementia Plan) supports people with young onset dementia with intensive comprehensive support, specialist clinicians and tailored programmes.

To achieve a balanced life is the goal, where people accept their diagnosis and strive for happiness.

Takeaways for Alzheimers NZ and Members

- A National Plan prioritises the important issues and keeps the focus where it needs to be
- Age appropriate services for people with young onset dementia is critical.

Young onset dementia: Diverse disorders, Diverse care- Adrienne Withall

Dr Adrienne Withall is a Senior Researcher Fellow within the School of Public Health and Community Medicine at UNSW, Australia. She is Chief Investigator of the INSPIRED Study of young onset dementia.

Dr Withall described the characteristics of young onset dementia including the presentations, the often-delayed diagnosis, family burden, the financial issues, the impact on the children, the grief experienced and the impact of differing interests and tastes.

She described the importance of communications and the language issues including that young onset groups often don't respond to the use of the word dementia.

Community supports of benefit include case management, financial planning, psychological therapy/grief counselling, antidepressants, support groups, day programmes, respite and genetic counselling.

Barriers include perceptions about a lack of need for support, eligibility criteria that exclude, services dominated by frail older people, support only available in working hours. Young onset clients can also be challenging and confronting.

And she urged people to remember that everyone is an individual – “Just because we are the same age doesn't mean we will be friend”

Takeaways for Alzheimers NZ and Members

- Keep people with dementia at the centre of everything we do – and deliver person centred services that recognise and respond to the individuals
- One size does not fit all
- Services must recognise the family, financial and social impact for early onset folk

- Services must also consider supporting and mentoring siblings and/or children (often teenagers) to understand dementia, the changes that may occur and the strategies to care for their family member.

Parallel Sessions 1

Environment and Design

6 presentations that focused on the physical environment for people with dementia:

- **Renovation of existing school buildings** surplus to use in Taiwan that have been remodelled to include a day care centre for people with dementia on the same campus. Young and old on the same site, promoting lifelong learning interaction and a better understanding between the two cohorts.
- **Home adaptation advice** - this research investigated the experiences of people with dementia and their carers in making home adaptations. They found physical needs are addressed over the cognitive needs and that adapting a home early after a diagnosis could be more beneficial.
- **Comparing Scottish and Japanese towns for being Dementia Friendly**, the outcome of this research was that Scottish city planning is more dementia friendly than Japan's. The need for an internationally recognised Dementia Friendly logo was highlighted.
- **Using existing buildings for a day service in Taiwan** (connected to the first presentation) - Taiwan has the lowest birth rate in the world and many schools are closing therefore lots of surplus buildings that are now being readapted for older people whose numbers are increasing.
- **A small idea in environmental improvement** – in order to promote ageing in place, this presenter from Japan suggested we need to address the conflict between traditional culture and modern practices, modern design can be confusing and difficult e.g. sensor taps v. old style that are familiar
- **Best Practice Guidelines for people with dementia with sight loss, developed** by an architect from the UK, promoting good natural light, use of colour and minimal clutter as important factors.

Takeaways for Alzheimers NZ and Members

- Integrating services and sites for older people with children is mutually beneficial
- Good design is integral to creating a dementia friendly environment
- To enable people to stay at home for as long as possible we need to promote making adaptations early after the diagnosis and consider what the person with dementia is most familiar with.

Dementia Friendly Communities 1

6 presentations that discussed how to achieve a Dementia Friendly City. Speakers from Romania, Italy, Japan, United Kingdom and Sweden shared their findings and experiences.

Examples of initiatives included a National Policy (Romania), public forums asking what people were not able to do in their community, what they wanted to do, what activities they enjoyed before, and what needs to change so they can still do these things (Italy), and a Dementia Café run by People with dementia in a local café (Japan).

The presentations emphasised the importance of local surveys of community, health professionals, architects and economists in partnership with people with dementia, and of testing the knowledge of the community. They also looked at the obstacles for people with dementia being included in community were stigma, physical environments such as seating in parks, the need for support, and transport.

One learning for people with dementia was to find a favourite place that you may head to and to let family know where it is

Takeaways for Alzheimers NZ and Members

- Initiatives must start with people living with dementia and focus on their needs and aspirations
- Inclusion and control are essential
- Local responses work best.

Parallel Sessions 2

Non-Pharmacological Interventions

This session included 5 presentations about non-pharmacological interventions, all but one focused on Cognitive Stimulation Therapy (CST)

- ***Comparing effects of CST and Reminiscence therapy on cognitive function*** and quality of life for people with 3 different types of behavioural problems. The researchers concluded CST had positive short-term effects and potentially longer-term benefits.
- ***Meta-analysis of CST efficacy and current guidelines*** – suggested the amount of brain reserve might affect the outcome of CST and they observed cognitive benefits despite the progression in brain damage.
- ***Reducing Anti-psychotic medications in long term care*** – Prof Brodaty from Australia presented the HALT project that is a successful non-pharmacological intervention that has been implemented for some years now.
- ***CST for Chinese people with dementia*** – researchers from Hong Kong highlighted key cultural differences in applying group CST, noting there is no evidence base of efficacy in non-western cultures.
- ***Effect of carer involvement in CST*** – UK meta-analysis and review concluded carer involvement in CST has beneficial effect on carer well-being and reducing depression. However no significant differences in levels of anxiety and carer burden.

Takeaways for Alzheimers NZ and Members

- CST is firmly established as a validated therapy with proven cognitive benefits

- Has application in residential care as a tool to minimise BPSDs as well as application in community settings.

Awareness and Stigma

6 challenging presentations on awareness and stigma from Australia, Taiwan, Canada, USA, Singapore.

Person Centred Care

This session introduced 6 different approaches to person-centred care:

- **Media therapy** – was an initiative from Japan where familiar images were used as a way to bring family and the person with dementia together in a way that as meaningful to both
- **The centre method** – was another initiative from Japan that used a fairly complex assessment and planning process to collect and use meaningful and detailed information about clients
- **Night time care** – was a research study from Hong Kong that explored sleep patterns for a group of people with dementia. The study identified 3 main reasons for poor sleep – an unfamiliar environment, noise and disturbance from the home’s routine, and issues arising from staffing changes. The study developed a night time care programme that provided activity and social engagement for clients who were mostly awake at night.
- **How person-centred are we?** – was a study from Singapore that used care mapping to assess a home in areas such as the environment, communications and language, activities and social engagement and care plans. The home was reassessed 12 months later and was showing improved interaction and engagement with residents.
- **Quality indicators in Asia-Pacific Countries** – looked at the feasibility of using European quality indicators in Asia-Pacific countries and concluded cultural issues need more thought before these indicators could be used with confidence.
- **Engaging with people with dementia** – recognising that many residents with advanced dementia spend most of the day alone this UK initiative looked at how to engage with people with advanced dementia and limited or no communication through music, touch, dolls and senses. Success relies on residents being in the right mood, staff with the right education and recognising the importance of this, the leadership in the home aligned.

Takeaways for Alzheimers NZ and Members

- Person-centred care and support has strong cultural underpinnings
- Measuring is not easy, but we must try to define and measure quality of life and person-centred care nonetheless
- Organisations – staff, education, systems, leadership can help or hinder

Parallel Sessions 3

Human Rights and Ethical Issues

- **Social and healthcare professionals supporting later life planning** - the importance of advanced directives being developed for people with dementia early in the diagnosis whilst

they can still self-decide. Self-actualisation makes later decisions easier for family and health professionals

- **Engaging people with dementia in research(NZ)** - Kay Shannon shared findings from the care facility in Rotorua based on the Dutch model which gives people with dementia greater freedom, autonomy and decision making in a safe village like environment. The findings showed that following a transition period people with dementia influenced their own environment and made decisions
- **The lived experience of risk for a person with a recent diagnosis of dementia** - key messages from the Risk discussion were:
 - What really is the risk versus the right to decide
 - We need to overcome paternalistic approaches and “allow” people with dementia to function independently as far is safe and practical
 - Give people with dementia the right to take risks and make informed choices
 - Support people with dementia to have the resilience to cope and manage their everyday life
- **Palliative Care is a human right for people with dementia** - “Many people die in pain especially those with dementia”, palliative care is a human right with access to timely appropriate treatment, pain management and comfort. Palliative care practitioners must understand dementia and interpret what the person with dementia wants if no advanced directive in place. Palliative care for a person with dementia needs to recognise the support needed by families and any assessment must include their input to develop the individual care plan.
- **Report on adult Guardianship in Japan** - seemed similar to currently practised in NZ with strong emphasis on respecting the intentions of the person with dementia regarding their ongoing support and care, living situations and end stage care.

Technology and Dementia

The 6 presentations in this session explored the use technology in dementia care.

- **Web-based intervention** - this study looked at the usability of a digital platform (Caregivers Pro - <http://caregiversprommd-project.eu/>) for people with MCI and their carers that provided a social network, meds reminder, information and cognitive games. Research revealed improvements needed to increase usability.
- **E-Health enabled pop-up Memory Clinic** – nurse led clinics in rural Australia using electronic media to access tools and provide services in remote areas such as telehealth monitoring.
- **Assistive Technology** - Jacob Roy stressed technology will never replace human care and it does have limitations however WHO is implementing a global commitment to improve access to AT via Global Cooperation on Assistive Technology (GATE).
- **An Integrated Internet of Things based solution** - the of this project was to prevent crisis/entry to hospital by using technology to send alerts to a monitoring team who then do a home visit and intervene to prevent escalation of condition.

- **Acto - dementia** – Accessible touchscreens apps used to promote health and independence, outcomes of using this technology included a reduction in boredom, minimises reliance on carers and that people with dementia found touchscreens accessible and easy to use.
<https://www.actodementia.com>
- **Immersive technology driving consumer centred care** - Maree McCabe from Alzheimers Australia outlined a variety of initiatives in use across Australia using gaming technology : the Virtual Dementia Experience that stimulates what it is like to have dementia, Educational Dementia Immersive Experience EDIE; Dementia-Friendly Home app: Virtual Forest Project (aim is to have fun).

Takeaways for Alzheimers NZ and Members

- Technology is here to stay, go online, see what is available and encourage people with dementia and health professionals to access it and use it.
- Dementia- Friendly apps are available for fun and they result in cognitive improvements, also can assist with decreasing social isolation and loneliness.

Dementia Friendly Communities 2

This session covered 6 approaches to dementia-friendly communities:

Overcoming the earthquake – told the story of post-quake recovery in Japan. 6 years on over 80,000 people with dementia are still living away from the area having essentially lost the community and connection they had. There is a need to focus on dedicated support for people in this situation.

Online peer support groups – this presentation was from one of the founders of Dementia Alliance International (DAI). He described the value of the online support groups offered by DAI held using Zoom in different time zones. The groups provide understanding and emotional support, personal experience, a confidential environment, confidence knowing they are not alone, and are empowering.

Dementia in schools – told of a project in Japan to raise awareness of dementia in junior school students through the use of picture books. This is an interactive session that included reading of the material followed by group work and resulted in raised awareness and empathy. The highlight of this session was a junior school student in the audience who responded during question time and described how important and useful he thought the project was.

Dementia Friends – described the UK Dementia Friends programme which has as its focus that people with dementia have a voice and are listened to. The programme provides face to face or video based training (40mins) followed by a commitment to raise awareness and address stigma. There is also a partners programme and a focus on ‘service’ agencies such as search and rescue and fire. The impact of the programme is being tracked through a survey. Now have 2 million Friends and one challenge has been how to keep the friends motivated and engaged – now they keep data on each Friends and have a programme of newsletter and social media engagement with them.

Dementia Partners – is a similar programme from Korea which includes individuals and organisations that now has 360,000 Partners. This programme has a 15-min training module. There is also a Partners Plus programme that includes campaigns and PR activities. And there is a component that helps with home visits for people who live alone.

Telephone Counselling – told the story of a care partners who wanted to give back in recognition of the support he had had and volunteered as a telephone counsellor for Alzheimers Japan.

Takeaways for the Alzheimers NZ federation

- Raising awareness and understanding is key to building a dementia-friendly NZ
- Success rests on the personal commitment and activity
- We can't do it alone, engaging other organisations in the cause is essential

Parallel Sessions 4

Care Coordination and Collaboration

This session included 5 presentations about integration of services and coordination of care

Improving Journeys - this presentation from the Northern Sydney Dementia Collaborative described the partnership approach between DHB, primary health, NGO, and Alzheimers Australia. The ideal client journey was mapped, key issues identified, a dementia pathway developed and implemented. Significant parallels with NZ. Of note was a discharge service from Hospital paid for by the PHO for 7-10 days only to reduce readmission to hospital.

Adjusting Self Care in Diabetic clients – this presentation described how a diabetic clinic and a memory clinic worked together at a hospital in Sweden to manage their shared clients with obvious benefits to the client.

A new Care System in Japan - this concept of this multi-functional model of care centred on interventions to enable people to stay at home for as long as possible. Services included a daycare, short term stay, home visits and a care manager.

8 Pillars Model – this presentation was about the post diagnostic support model in Scotland using a link worker. The aim is to keep people with mid to severe dementia at home and to support the carer. This is a government backed initiative and the presentation focused on an evaluation of the model. Clients noted they valued the single point of contact with the link worker. Other key components included communication, data sharing, and education. More detailed evaluation available soon on line.

Initial phase Intensive support team – this presentation from Japan explored the roles and issues that are required for a support team. Information sharing and collaboration emerged as important elements that led to the success of the team's performance.

Takeaways for Alzheimers NZ and Members

- To maintain people with dementia at home requires partnership and collaboration across social, health and community organisations. The Scottish 8 Pillars model is a good example of how this can be implemented.
- To decrease falls and hospital admissions and to support early discharge a key worker (navigator) is effective

- Interventions to keep people at home longer must include support for the carers and flexible services.

Community engagement and collaboration

Presentations from 6 countries Japan, Iran, Finland, Canada, Australia and USA.

- **Japan** - The importance of recognising that people with dementia can attend and succeed at university perhaps supported by other students/community
- **Iran** - In Iran chapters were encouraged to develop to recruit and train pensioner volunteers and increase community awareness of dementia. They developed screening and education tools with information on social changes, risk, communication, care principles when supporting a person with dementia. 40 hours training to meet the minimum requirement.
- **Finland** talked about the various emotions a person with dementia experiences with dementia diagnosis and the importance of the PWD being enabled to self-actualise, manage emotions, take risks and be loved.
- In **Canada** they have funded programmes with person centred models, gender diversity but they do rely heavily on volunteers and family. They provide culturally appropriate day programmes and target NGOs to develop dementia focussed programmes in the community
- In **Australia** they talked about tailored diagnostic interventions to reduce the risk of isolation and to support safe ageing with dementia in the community
- Some countries have developed cafes where people with dementia meet in their local area, run and support their own café on set days with support and oversight of café proprietors. People with dementia developed the menus.

Involving people with dementia in research

This workshop was based on the premise that involving people with dementia in research is a priority – it is what many people with dementia want to do, it is a human right to be able to make that decision, and it is essential if a cure/treatment is to be found. This is a very normal way to operate in the cancer world.

Henry Brodaty presented a review he had done on use of registries, noting these can be used for a variety of purposes – assessing the history of a disease, monitoring the effects of a treatment/model of care, for clinical or health research, for regulatory purposes. His review identified four broad categories – research, epidemiology, quality of care, and recruitment for research. His recommendations will be released shortly and are likely to include that registries are established in all countries, and that these are standardised internationally. He notes that the return on investment in Sweden (the world leader) is very positive at 10:1.

Piers Kotting introduced the Join Dementia Research programme which is a UK based online service to match people wanting to participate in research with research.

Takeaways for the Alzheimers NZ federation

- People with dementia want to participate in research and have a right to do so
- Registries offer significant benefit but need clear rules and management

Parallel Sessions 5

Carer Support and Training

Presentations from 6 countries Australia, Sweden, Slovenia, Ghana, Israel and UK.

- There was an interesting presentation on the challenges facing people with dementia when the majority of the paid support in the community or at home respite is provided by people from other countries who have different boundaries, understanding, food etc. This presentation highlighted the importance of understanding dementia and specifically the person and their familiar activity, culture, personal boundaries and food.
- There was significant highlight on the importance of carers/families understanding the stigma and loss of self-worth, the need to be able to self-express and make decisions, and the value of training programmes through support groups.
- Some countries, mainly Japan, provide education on dementia and caring for parent or grandparent in high schools
- The importance of developing specific resource and support for younger people (teenagers) caring for people with dementia
- The importance of health professionals and others recognising the stressors for carers such as loss of income due to full time caring role, isolation from friends and community, the stigma associated with dementia, physical needs related to tiredness, depression etc, the inability to provide for themselves. The importance of good information and advocacy for carers was also highlighted.

Rehabilitation and Enablement

Thinking outside the box – a person with dementia from Australia (John Quinn who also attended our Conference in November 2016) talking about the need for a paradigm shift in the way we think about and view people with dementia.

Dementia enablement guide – is an Australian initiative. The guide in a form of clinical pathway for multidisciplinary teams.

The electronic bidet – An Australian rest home tested use of an electronic bidet seat with residents with advanced dementia. They saw a reduction in hygiene issues and improvement in privacy and toileting and the bidets remained in use after the study had finished.

Takeaways for the Alzheimers NZ federation

- Be prepared to try new and different approaches – we need to challenge ourselves to think outside the box/accepted practise all the time

Engaging people with dementia

This session highlighted the variety of ways of engaging with people with dementia.

- **The Rosemary** - Diary is a simple and economic tool, the presenter referred to it as a pair of glasses that helps to maintain, organise and consolidate memory for every daily activity. If the initiative continues to be successful a mobile app of the diary will soon be available.

- **Enabling social inclusion for Older Men** – this presenter from the UK outlined an approach using gaming technology to enable social inclusion. He highlighted the importance of recognising and responding to unique aspects of masculinity in older men remembering they are not a homogenous or androgynous population. Guidelines have been developed and the presenter is very happy to share his work, Dr Ben Hicks bhicks@bournemouth.ac.uk
- **Dogs4Dementia, Paws for thought** - this presentation showed through a series of photos and videos the Australian initiative where Assistance Dogs support people with dementia. The programme was developed in partnership with Hammond Care and demonstrated the value of dogs in providing companionship. Through special training an assistance dog is taught to respond to cues in ways that promote confidence and independence in a person living with dementia. It is a very expensive programme to operate.
- **Changes in Japan, view from outside** - Christine Bryden has dementia and has a long association with Japan, visiting many times. She is held in very high regard and chronicled her visits to Japan and observations about how dementia is accepted in Japanese society.
- **Supporting Dementia Families in Scotland** – this presentation detailed how linked interactive screens were used in the remote Highlands to support people with dementia enabling to bridge the gap between service providers and service users. Using the screens at a well-being hub inspired activity and conversation. Screens were used for hobbies, karaoke, discovery, and reminiscence.

Takeaways for Alzheimers NZ and Members

- In New Zealand, we can adopt and adapt for our own purposes innovative use of technology and programmes that are tried and tested.
- Scotland and Australia are good places to turn to for inspiration

ADI Briefing

This briefing was for Alzheimers organisations and focused on preparation for World Alzheimers Month and the human rights agenda.

Symposia

Path to 2015: A global conversation on Healthcare System Readiness – Eli Lilly

This session looked at current developments in drug development, meeting the needs of the super aging and what is happening in the UK and US. Key points were:

- The challenge of dementia is such that without a break through in treatment or cure, the healthcare systems will breakdown
- Alzheimers organisations have a central role
- In the UK they are moving to health checks in middle age
- Its still possible to achieve the target of a disease modifying treatment by 2025
- Recruitment to clinical trials is critical and remains a challenge
- Addressing risk factor could reduce prevalence by 10 to 30%

Global Dementia Policy – ADI

This session provided an overview on where we are with the latest dementia policy:

- The Global Action Plan – which is on track to be adopted at the World Health Assembly in late May. The WHO is also establishing a Global Observatory to monitor and report on Member state’s implementation of the plan.
- The World Dementia Council – which continues to focus on connecting governments with researchers and pharma companies to progress the target of a disease modifying treatment by 2025
- The Dementia Readiness Index – which looks at the readiness and capability to innovate in the dementia space within the G7 countries.