Alzheimer's Disease International
The global voice on dementia

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Global Perspective

A newsletter for Alzheimer's Disease International: The International Federation of Alzheimer's Disease and Related Disorders Societies, Inc.

Nutrition report reveals major problems

On 11 February, ADI released a new report on nutrition and dementia, which revealed that a worrying number of people with dementia experience undernutrition. Estimates from the research reviewed found that 20-45% of people with dementia living in the community lose a significant amount of weight over one year.

The research for *Nutrition and dementia: a review of available research* was funded by Compass Group and carried out by the Global Observatory for Ageing and Dementia Care, led by Martin Prince. As well as undernutrition, the report also reviews existing research on dietary factors and dementia risk, and provides actions that could improve the nutrition of people with dementia.

The report seeks to highlight an area that, so far, has seen very little research and attention. Contained in the report are a number of recommendations for improvements in care standards, training and research.

To read the full report visit www.alz.co.uk/nutrition

Responding to the G8 summit

Hailed as a landmark event in the global dementia field, the G8 dementia summit, hosted in London on 11 December by the UK government, created a buzz in the ADI office and across the world. The following day talk was already shifting towards how to keep the momentum going and ensure promises of an increase in dementia research made by those governments and funders at the summit were kept. ADI members across the world played their part in immediately calling for action to start. Alzheimer's Society in the UK used the G8 summit as a platform to announce that they will spend £100 million (US$160 million) on dementia research over the next ten years. The Alzheimer Society of Canada sent out a clear message through the media on the need for a national dementia strategy in order to gain the government's commitment and keep up with many of the other G8 countries. Perminder Sachdev and Henry Brodaty, supported by Alzheimer's Australia, are leading a campaign calling on the Australian Prime Minister to follow the lead of the G8 and place dementia on the agenda of the G20 (Group of Twenty) at their next economic forum.

CONTINUED PAGE 3

> **ADI's Marc Wortmann**: At the moment 62% of all people with dementia live in lower and middle income countries, not in the highly developed countries. I think we here have a responsibility to those countries as well. I wonder if you, as a leader of government, can help us in bringing this to the development agenda as well.

> **UK Prime Minister David Cameron**: When we look at what the world has done on the big killer diseases globally and also what the world has done in terms of vaccination programmes you can see that the global effort (NGOs, governments, G8s) has made a real difference. So I don't see any reason why we shouldn't do the same thing with dementia. So, yes they should be part of the development agenda.

Alzheimer's Disease International

The global voice on dementia

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Send us your comments

If you have any comments about or items for the newsletter please contact the Secretariat. Articles for the next issue of *Global Perspective* to arrive by 30 April 2014.

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Editorial

Marc Wortmann, Executive Director

There is a growing awareness of the global impact of dementia in all continents of the world. Strong and persistent campaigning by many Alzheimer associations, Alzheimer Europe and ADI has put dementia high up on the global political agenda of high level bodies like the World Health Organization, European Union, G8 and OECD. The G8 meeting in December 2013 in London has created momentum to drive changes in public and private health systems around the world and in general awareness. I could clearly feel that happening when talking to policy makers over the last three months.

This is great! But it is also a fact that this new reality generates more work and challenges. We always said there is no time to lose: with a new case of dementia somewhere in the world every four seconds this is the biggest health challenge of the 21st century. Now we are entering a stage in which people will be looking to us, as the Alzheimer movement, to present solutions. So we need to develop priorities and strategies to share with governments. ADI can help by providing reports and documents, such as the comparison study of seven national plans that we released recently, which is available at www.alz.co.uk/plans-review. We will also have opportunities to discuss these issues at our annual conference in Puerto Rico, 1-4 May 2014. It will be on the agenda for the ADI Council meeting and several sessions and workshops. I hope to see many of you there!

Events

1 – 4 March
22nd European Congress of Psychiatry
Munich, Germany
Web: www.epa-congress.org

26 – 29 March
13th International Geneva/Springfield Symposium on Advances in Alzheimer Therapy
Geneva, Switzerland
Web: www.siumed.edu/cme/alzheimer

1 – 4 May
29th Annual International Conference of Alzheimer's Disease International
San Juan, Puerto Rico
Web: www.adi2014.org

8 – 11 May
The 8th World Congress on Controversies in Neurology
Berlin, Germany
Web: www.comtecmed.com/cony/2014

10 – 13 June
IFA 12th Global Conference on Ageing
Hyderabad, India
Web: http://ifa2014.in/

12 – 17 July
Alzheimer's Association International Conference (AAIC) 2014
Copenhagen, Denmark
Web: www.alz.org/aaic

20-22 October 2014
24th Alzheimer Europe Conference
Glasgow, Scotland
Web: www.alzheimer-europe.org/Conferences/2014-Glasgow

23 – 25 October
The 9th International Conference on Frontotemporal Dementias
Vancouver, Canada
Web: www.ftdvancouver2014.com

7 – 9 November
17th Asia Pacific Regional Conference of Alzheimer's Disease International
New Delhi, India
Web: www.aprc2014-india.com

VISIT WWW.ALZ.CO.UK/EVENTS FOR MORE CONFERENCES AND ANNOUNCEMENTS

RESPONDING TO THE G8 SUMMIT – CONTINUED FROM FRONT PAGE

Following the summit, the strong focus on research during the event was noted by some as not addressing the key concerns of the many people with dementia and carers who are currently living with dementia and for whom a cure by 2025 would be of no benefit.

Martin Prince, coordinator of the 10/66 Dementia Research Group and the Global Observatory for Ageing and Dementia Care, raised concern in a letter to a national UK newspaper over the current lack of investment in care, cost barriers to accessing a cure should one be found, and the need to create a more help-seeking culture to address low diagnosis rates.

At the head of the global dementia movement, ADI recognises the vital role it now plays in pushing for the cross-sector collaborations discussed and commitments made by G8 countries to be realised while continuing the call for improvements in care provision and services worldwide. ADI hopes to develop a strong working relationship with the UK government's new World Dementia Envoy, Dr Dennis Gillings.

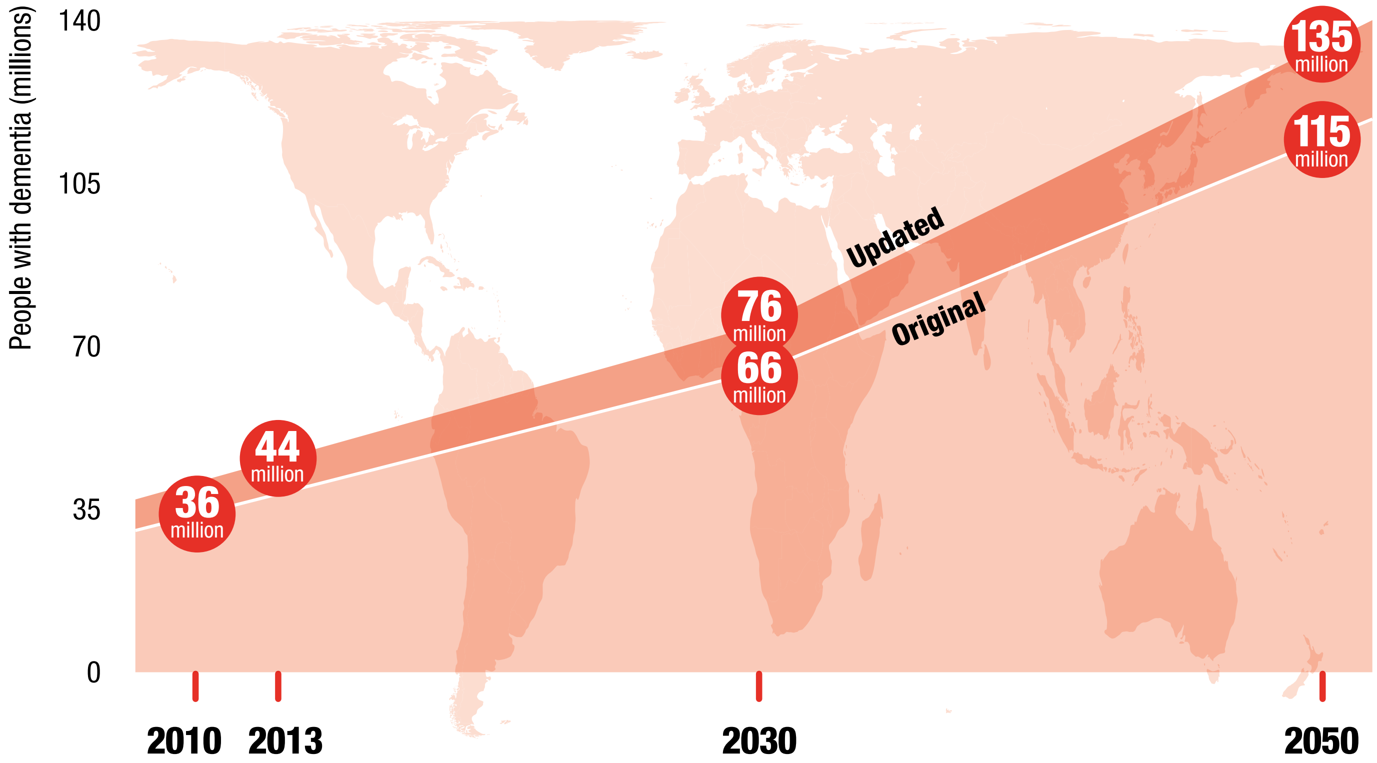
On the evening of the Summit, Alzheimer associations from most of the G8 countries met with ADI and Alzheimer Europe and agreed to create a Civil Society Global Taskforce to follow up on the Summit in three areas:

- How research efforts from Alzheimer associations can contribute to the global agenda
- Raising awareness and eradicating stigma to create a more dementia friendly society
- How health and care systems can be improved to better respond to the needs of people with dementia and their families

Three groups have been formed to work on these areas with wider coverage than only the G8 countries. This work will be led by a steering committee made up of CEOs from ADI, Alzheimer Europe, the Alzheimer's Association (USA), Alzheimer's Society (England, Wales and Northern Ireland) and the Alzheimer Society of Canada. A report on progress made will be presented at the ADI conference in May.

The rising impact of dementia

An ADI policy brief, *The Global Impact of Dementia 2013-2050*, prepared for government leaders ahead of the G8 summit in December reveals a 17% increase in the number of people with dementia worldwide compared to the original estimates made for the World Alzheimer Report 2009. It is now estimated that 44 million people are living with dementia with the figure predicted to reach 76 million in 2030 and 135 million by 2050. The brief also highlights that, by 2050, 71% of people with dementia will be living in low and middle income countries. To read the full policy brief visit www.alz.co.uk/G8policybrief



Member profile

Asociación de Alzheimer y Desórdenes Relacionados, Inc.

Asociación de Alzheimer y Desórdenes Relacionados de Puerto Rico

Asociación de Alzheimer y Desórdenes Relacionados de Puerto Rico will co-host the 29th Annual International Conference of ADI in May this year.

We are a non-profit making organisation incorporated in October 1983. The organisation is operated by a Board of Directors elected by the membership. The board consists of professionals, people living with dementia and their relatives, and members of the community that offer their services without remuneration. We have been a member of ADI since 1992.

For the past 30 years the Puerto Rico Alzheimer's Association has served the community with services and educational programmes intended to improve the quality of life of people with Alzheimer's disease and their carers, as well as people with other types of dementia.

The mission statement of the Association is centred on three areas: education, communication and service. We increase public awareness and concern of dementia and its impact on individuals, families, community and society. Efforts are constantly directed towards working in collaboration with doctors, social workers, researchers, policy makers, care facility administrators, caregivers and other health professionals. By working together we reach the families and friends of people with dementia and the general population to develop common knowledge and dissemination of scientific research, through traditional and innovative strategies that assure us the best reach.

Our vision is to contribute to the creation of a world free of dementia, and to improve the quality of life for people with dementia, families and caregivers.

Among our goals are:

1 To educate our community on dementia, by disseminating scientific research findings as well as promoting, developing and disseminating educational programmes and training guidelines on Alzheimer's disease and the best social and medical care for people with dementia.

2 To promote legislation that enhances innovative models and projects, research and educational programmes that foster a better knowledge of the dementia.

3 To promote the establishment of services to give support to the families of people with dementia.

A Memory Walk hosted by Asociación de Alzheimer y Desórdenes Relacionados de Puerto Rico

The Association offers the following services:

- One on one consultations to individuals with respect to the disease
- Educational workshops and training sessions on the disease, its causes, effects and care
- Presence in the media through mass media campaigns, ads, and interviews
- A cycle of conferences including conferences for special groups such as other health organisations
- Development of educational materials
- Referrals to specialised services
- Participation in health fairs
- Organisation and development of support groups around the island
- Direct services to people with dementia though a "Respiro" programme
- The publication of four newsletters through the year, bringing people with dementia, families, caregivers, health professionals and the general public new and updated information about the condition and the services that we offer.

To find out more about the association visit www.alzheimerpr.org
For more about the forthcoming ADI conference visit www.adi2014.org

Members' forum

ADI members: do you have news to share with the global dementia community? Please contact us

Dementia newsflash

Bangladesh

The Alzheimer Society of Bangladesh marked the launch of its website in January. The website, which can be found at www.alzheimerbd.com, is a great step forward for the Society in their awareness raising and support for people with dementia and their carers in Bangladesh.

Ireland

The Alzheimer Society of Ireland recently hosted the first meeting of their Dementia Carers Campaign Network. The Network aims to represent, raise awareness of and campaign on the needs of those who care for a person with dementia.

New Zealand

Alzheimers New Zealand have recently welcomed a government announcement in their Budget 2013 that NZ$3.2 million over three years will be allocated to raising awareness of dementia and clinical education and training.

USA

In January, the Alzheimer's Association were also pleased to learn of an increase in government funding for dementia, with a US$122 million increase in dementia research, education, outreach and carer support.

Regional meetings

ASIA PACIFIC

Participants at the Alzheimer University programme

The 16th Asia Pacific Regional Conference of ADI took place in Hong Kong SAR with two additional days in Macau SAR in December 2013. The meeting of ADI members from across the region enabled a formal introduction of Regional Director Francis Wong, who presented the first draft of the Asia Pacific regional work plan.

The conference was opened by a representative from the government in Hong Kong, which set in motion the successful event. Elements of local and Chinese culture were integrated into the conference with Tai Chi in the breaks and a Six Arts programme taking place in the foyer, including a display of artwork by people with dementia. A number of volunteers from older groups were brought in to keep the conference running smoothly, while the launch of a new Alzheimer's Education Institute also took place at the event.

From Hong Kong, delegates made their way to the final two days of the conference in Macau. ADI hosted an Alzheimer University programme, which included a number of public health officials from Macau. On the final day, ADI Chairman Jacob Roy joined delegates and members of the public from Macau in a Memory Walk.

MIDDLE EAST & NORTH AFRICA

Dubai was the host country for the 2nd Middle East and North Africa Regional Conference of ADI in early December 2013. ADI members shared news of their most recent work during the ADI business meeting, which highlighted the growing awareness and interest in dementia across the region.

During the conference opening ceremony a representative from the Dubai health authority expressed their support and this was followed by speeches from three carers on their experiences in the first conference session. Other conference sessions included an overview of dementia prevalence in the region as well as presentations from ADI Chairman Jacob Roy and ADI Policy Adviser Mike Splaine.

One of the carers who shared her story

Bupa's Graham Stokes shared knowledge on non-pharmacological interventions for managing challenging behaviours and, with the support of Prof Stokes, an Arabic translation of the Bupa and ADI charter on the rights of people with dementia was launched at the conference.

SINGAPORE

New day care home environment

Alzheimer's Disease Association in Singapore will shortly launch its new day care centre service in Tiong Bahru, which will enable people with dementia and their carers to be trained by the centre's staff in a realistic home environment. The mock-up apartment in the centre features a living room, pantry and a number of other facilities to support both carers and people with dementia to maintain an active and happy home life.

This focus on independent living and quality of life is also being supported by the country's Institute of Mental Health who will soon open special wards specifically for people with dementia.

INDONESIA

Promising ministerial visit

In December, ADI Executive Director Marc Wortmann joined representations from Alzheimer Indonesia on a visit to the country's Minister of Health, Nafsiah Mboi. The meeting was attended by six Alzheimer Indonesia representatives and eight government officials as well as the Minister.

A key topic of conversation was the development of a national dementia strategy for the country, which the Minister of Health was keen to progress. Having experience of dementia within her own family, the Minister hopes to see funding for implementation allocated to the strategy for 2015 and would like the strategy to be strong enough that it could continue to be implemented regardless of who the Minister of Health was. Marc reported positively on the meeting, commenting 'I don't very often see ministers that are so hands on.'

SRI LANKA

Workshops for carers

The Lanka Alzheimer's Foundation has recently hosted two workshops aimed at carers on the topics of cognitive stimulation therapy and palliative care. The first of these events, which took place in January, offered an overview of dementia therapies and the principles behind cognitive stimulation therapy and its application. The course was run by experts trained at University College London. The second workshop focussed on quality of life and best practice in end of life care. This session was led by a Palliative Nurse Consultant and Dementia Specialist Nurse, both trained in the UK.

TADA CHINESE TAIPEI

Dementia Friendly Store

In partnership with Rotary International, TADA Chinese Taipei have launched a new programme, *Dementia Friendly Store*, which sees businesses sign up to support their customers who have dementia and work with their family members. The initiative encourages people with dementia to continue to do the things they enjoy and remain a part of their community.

Examples of how this works include shop staff arranging payments in advance from carers so the person with dementia does not need to handle money when they go to the shop. These shop staff are also happy to exchange items chosen by the person with dementia if they are not needed. Café owners will also contact carers to reassure them that the person with dementia is fine when the person with dementia stops at the café or is found wandering.

AUSTRALIA

Young voices on dementia

In December 2013, Alzheimer's Australia NSW launched a new animated series, *My Grandmum, My Papu, My Grandpa and Me*, which features three children sharing their experiences of having a grandparent with dementia.

To watch the films visit Alzheimer's Australia's YouTube channel at www.youtube.com/AlzheimersAustralia

CANADA

Promoting early diagnosis

In January, the Alzheimer Society of Canada launched their annual Alzheimer Awareness Month campaign. This year the focus was on promoting early diagnosis, prompted by studies showing that up to half of people with dementia in the country wait too long before seeking a diagnosis. The visual promotion of the campaign centred on knit bombing, a form of street art, as a sign that a diagnosis prevents a person's life from unravelling.

To find out more about their campaign visit www.earlydiagnosis.ca

Living with dementia

‘I may have dementia, but it doesn’t define me’

Phil Murray, Scotland

Phil is diagnosed with behavioural fronto-temporal dementia and lives with his wife, Pat, in Aberdeen. This is an excerpt from an interview given following their attendance at the Alzheimer University in August 2013.

How did it feel to be told you had dementia?

Because Pat and I, especially Pat, had picked up so many strange behaviours, things that I didn’t normally do, over years before I was diagnosed officially, we had years of real worry and 'what the heck is wrong with me'. I’d been diagnosed with bipolar and depression and all this stuff and it wasn’t fitting. When I finally got the scan it came out that, at that time, it was vascular dementia. It might sound strange, but it was almost a relief. It was a relief because we knew what the problem was. I’ve always been like that throughout my life that it's unknowns I find difficult. So when I got the diagnosis it was a relief because we gritted our teeth and said ‘Let’s deal with it’.

What helped you at the beginning?

We were very fortunate, when I was diagnosed, to have an extremely wise Alzheimer Scotland Dementia Adviser. This woman was such a source of incredible caring, warmth, knowledge and strength. In retrospect all the books we got and all the stuff we read was dry and abstract, but the human contact we got was irreplaceable.

What helps you now?

Pat and Phil at the Alzheimer University in London

Strangely enough it’s still back down to human contact. I go to as many dementia groups as I can mentally manage. If I go anywhere in the morning I’m shattered in the afternoon. My brain can’t take in normal social interaction for anything over three hours. Pat is wonderful at managing and scheduling things and if there’s a big thing on in a day she won’t have anything on the next day. But what really helps me now is meetings like the Alzheimer Scotland Football Memories dementia group I go to which is with mostly men talking about football. I belong to the Positive Dementia Group in Aberdeen, which has been going for a few years. That is a marvellous group of people with different kinds of dementia. It’s good being there with other people who know where I am and I can be open with them because they know where I’m coming from. That is really very important. You’re not alone; they can relate; they can understand; they’re patient and also – because we’ve still got some of the brain cells working away – we give presentations to students. I feel that’s very important because the amount of ignorance out there about dementia is appalling still. I would imagine the average person would think of a person with dementia as someone way down the line when they don’t know who anybody is. When we’re there, students come up after the presentation and say ‘You’re the first person with dementia we’ve actually met and you’ve really changed our views entirely’. That’s what we’re trying to do.

I can put on an almost normal persona and people - I think they mean it with good intentions - say ‘You wouldn’t know Phil had dementia’ and the implication is Pat is exaggerating; ‘Why is she so tired when she’s dealing with someone who is quite normal?’ They don’t know the other side of me. Before I had these drugs I was very hyper. I could lose my temper for nothing; burst into tears. The things that people don’t see. So, when they say it they might imply that you’ve only got a bit of dementia or something. Again, it’s the misunderstanding of the condition. I always quote my friend Ronnie from the Positive Dementia Group who says ‘I may have dementia, but it doesn’t define me’.

Tell us a bit more about the Alzheimer Scotland Art Gallery Group you attend

It’s a group that meets roughly once a month. We meet at the Aberdeen art gallery where there’s a member of staff who works with us. What we do is we go out and she always asks us what we’re interested in with paintings. If we like any particular painting or theme and she’ll show us paintings related to what we like and she’ll tell us about the painter, the style and everyone shares their opinions. It’s very successful because the people who go along are all interested in art, but every single one of us has said ‘I would never have looked at that painting before’. The group is not about dementia, it’s something that gets us way from dementia and into what we think of the paintings. It’s a social outlet as well.

The next issue of *Global Perspective* will feature an interview with Phil’s wife, Pat, on her experience as a carer

Carer's story

Better dementia awareness will make a difference

Swapna Kishore, India

For well over a decade I was the primary caregiver for my mother, who had dementia.

My mother was very intelligent and fiercely independent. When she started experiencing problems, she hid her confusion and forgetfulness. Finally she became alarmed enough to approach her doctor, but he did not consider her problem serious at that stage. It was only after some years that we received her diagnosis.

Visible behaviour changes included repeating questions, getting disoriented and misplacing things. Sometimes she asked for help, only to accuse me later of "interfering". Once a voracious reader, she stopped reading. The situation kept worsening. She could no longer make tea or use the TV remote. She often contradicted herself within minutes. She falsely accused the maid of theft. She would not eat the lunch I'd cooked for her and tell neighbours I was too busy to give her food. One day I was lifting dumbbells and she said I planned to kill her with them.

To adjust to my caregiving role, I tried to understand the difficulties she was facing because of dementia. It took some experimentation and several mistakes before I figured out better ways to talk to her and help her and cope with her agitation and disorientation. I also learnt to stop feeling bad about her complaints. This adjustment was a lonely process because though doctors had warned me she'll get worse, they gave no pointers on caregiving.

One major problem was that people around us did not understand her situation. They dismissed her diagnosis claiming I was making excuses because "she looks perfectly normal". They believed her complaints (such as her saying I was starving her) and lectured me about duty and love. If she made mistakes while talking to them, they corrected her or laughed at her or exhorted her to try harder. They kept talking about elder abuse by children, which made her suspicious about me. Once a neighbour egged her to assert herself by going out alone; advice that precipitated a wandering incident.

My mother often felt ashamed after meeting outsiders. I remember her sobbing after someone said, "You claim you are a postgraduate, and you can't read this simple article?" Keen to seem normal, she rejected anything others could mock at. For example, when I suggested playing board games, she said others considered such games childish.

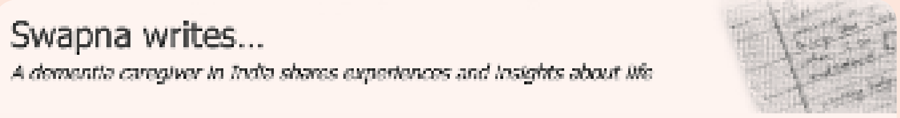
Over time, as she became more disjointed, visitors became uncomfortable and stopped coming. Though she felt abandoned, she no longer felt she had to hide her problems. She began accepting my help and agreed to do simple jigsaws and play board games. She enjoyed it when I acted out Panchatantra stories for her. Sometimes she told me jumbled anecdotes from her childhood. She smiled often and appeared peaceful. My best memories of her dementia days are of those relaxed times spent together.

In the initial caregiving years I had struggled to find my pace. I reduced professional work and social life to ensure I remained available, and was often overwhelmed and exhausted. Watching her deteriorate and suffer was emotionally difficult. I felt isolated.

I began blogging about caregiving to handle my loneliness, and was surprised when other caregivers read my blog and contacted me. As I gathered more information on dementia and care, I realised that most available information is difficult to apply in India, so I created websites and videos for dementia caregivers in India (in English and Hindi).

Persons with dementia are an integral part of society and live surrounded by others for years as their condition worsens. I believe that their quality of life will improve a lot if communities become dementia aware and dementia friendly. Symptoms will be noticed earlier, and diagnosis will be possible earlier. Families will know what to expect and plan for, and can access caregiver tools and available services and support systems. Outsiders will appreciate the genuine difficulties caused by dementia and know how to be considerate in interactions. They would not mock or stigmatise.

When I remember my mother, this is what hurts most - her crying because people said hurtful and disrespectful things. And this is what has prompted me to contribute my own bit by sharing information about dementia and care.



Swapna writes...

A dementia caregiver in India shares experiences and insights about life

India-based Swapna Kishore shares her caregiving experiences at swapnawrites.wordpress.com. She also maintains English and Hindi websites and videos for caregivers in India.

How associations help – Twinning special

In the second part of this *How associations help* special, we look further at how the ADI Twinning Programme has helped national Alzheimer associations to grow and extend their reach

Hussain Jafri, Pakistan

In 2005, ADI initiated a Twinning Programme, in which a developing association is paired with a more developed one to strengthen both organisations by tackling shared issues together. The Twinning Programme offers great potential for sharing knowledge and skills between Alzheimer associations. As part of the programme, Alzheimer's Pakistan and Alzheimer's Australia WA (Western Australia) were twinned by ADI to work together to establish and strengthen services in Pakistan for people with dementia and their families.

Since the initiation of this programme, Alzheimer Australia WA has provided technical expertise to establish a day care centre. Alzheimer Australia WA staff visited Pakistan and helped in designing the day care centre services according to the local environment. They not only helped Alzheimer's Pakistan in getting the right furniture, accessories and equipment for the day centre but also trained the staff to initiate the service. Further visits from Alzheimer Australia WA staff helped in updating the day care centre services and provided the opportunity to facilitate the continuous training for Alzheimer's Pakistan's staff and family carers on effective care for people with dementia.

A mobile office was also provided to Alzheimer's Pakistan through the Twinning Programme. A team of experts from Australia came to Pakistan to set up the office in the vicinity of the day care centre. Frank Schaper, the former CEO of Alzheimer's Australia WA, has been instrumental in initiating and nurturing this Twinning Programme and has acted as a driving force in the development of services and advocacy programmes by Alzheimer Pakistan. The Twinning Programme has served as a shortcut for Pakistan as we learned from the experiences of Australian team and did not have to repeat mistakes.

Norma Inniss, Trinidad and Tobago

The Alzheimer's Association of Trinidad and Tobago and the Alzheimer Society of Canada were one of the first twins of the programme from 2006 to 2009.

During the period the Association benefited tremendously from the support and guidance of Debbie Benczkowski, the Alzheimer Society of Canada's Chief Operations Officer. Benefits to the Association include:

- A regular supply of information brochures, books on different aspects of the disease and Forget Me Not brooches and pins continue to be received. These have been distributed at our outreach/ education programmes and seminars.
- Email addresses have been shared and contact is made regularly, particularly when advice is sought on special situations.
- Members have been sponsored to attend activities in Canada, for example, MAREP, a one day meeting during the ADI Conference in 2011.
- On my annual visits to Canada I met with Debbie Benczkowski and updated her on the activities of the Association and discussed the way forward.

A strong bond of friendship was made and it still exists today.

Debbie Benczkowski, Canada

Trinidad and Tobago is much more than Canada's warm, sunny cousin who lives near the equator! Canada, a country often thought about as cold, snowy and located well into the northern hemisphere, has been joined together in spirit with Trinidad and Tobago – enjoying warm camaraderie, considerable good will, and a desire to collaborate for over a decade. But, thanks to the generosity of ADI, these two countries were formally joined together and recognised as "twins", since 2006.

Since our birth as twins, Canada and Trinidad and Tobago have enjoyed a mutually supportive relationship, welcoming members of Trinidad and Tobago's association to Canada on numerous occasions to attend National Conferences, sharing information and educational materials to support the Alzheimer's

Representatives from Canada and Trinidad & Tobago at the ADI conference in 2009

Association of Trinidad and Tobago's activities, and helping upgrade technology resources by providing a laptop computer, fax machine and LCD projector.

During two visits to Trinidad and Tobago, I worked with the Association's Board and Executive Members to evaluate and assess the good work that was already underway, and formulate an action plan based on the key priorities and actions identified by the Board, and important to their future success.

The key objectives included:

- To have an accurate source and supply of information and resources on dementia to disseminate to those affected.
- To develop the volunteer resources to support the work of the Association and to meet programme needs.
- To raise more funds to support and sustain the Association's work.

Almost five years after the Twinning relationship officially ended, awareness of the Association's work in Trinidad and Tobago continues to build – and this awareness has also extended to people living in other Caribbean islands as well as their relatives in Canada. In Canada, the Alzheimer Society has forged new relationships and awareness with the Caribbean community in Toronto, mainly through media interviews with members of the West Indian Press.

All in all, Canada and Trinidad and Tobago's Twinning relationship has been highly fruitful, and has continued, even though formal financial support from ADI is long completed. The personal relationships that have been forged, will support continued commitments on both sides.

Research update

Alzheimer's disease: a preventable global healthcare crisis

Prospective ADI strategies with reference to the G8 Dementia Summit

Zaven S Khachaturian, PhD

The objective of this piece is to identify three critical issues as follow-up strategies to the deliberations at the G8 Dementia Summit in December 2013. The action plan for a prospective multinational initiative on 'prevention' proposed here is for consideration by ADI and member countries; the plan calls for three specific aims:

- Promotion of an international benchmark to reduce the impact of dementia by 50% within ten years.
- To facilitate greater global collaborative research though innovations in infrastructure development, resource allocation and knowledge sharing.
- To create an international resource centre to continually monitor, evaluate and prioritise the most important opportunities to advance dementia research.

At the inception of ADI, nearly thirty years ago, dementia was an obscure brain disorder, with little knowledge about the origins or underlying biology. The diagnosis was difficult; laden with great uncertainties. There were no viable interventions and the prospects for treatment were extremely dim. Awareness about the impact and the general state of the knowledge of the disease was rudimentary; only a handful of scientists worldwide had an interest in studying this disease.

In the relatively short span of three decades the field of dementia research has made remarkable progress in all aspects of the disease; except in the area of reducing the burdens of care. Now there is more knowledge about the underlying biology and the role of genetic factors. The disease can be diagnosed with greater accuracy in earlier stages and most importantly there are several interventions with the prospects of additional more effective treatments being discovered.

Now the emerging challenges for therapy development are no longer limited to interventions for reducing the symptoms of the disease but rather stem from the forward looking vision of discovering-validating disease modifying agents to alter the underlying biology and thus modify the progression of the disease. The hope is eventually to prevent the disease.

In contrast to the early history of dementia, today the prospect of delaying the onset of disabling symptoms and eventually preventing the disease is technically feasible and within the grasp of scientific community. However, the success of this strategic goal is provisional; the attainment of this vision will depend on whether the field can surmount some obstacles. As a follow-up to the historically significant G8 Dementia Summit the critical questions that policy makers in all countries with national plans must address are:

- What are the scientific, administrative, resources/infrastructure, regulatory and financial challenges that face the global research and development enterprise? What initiatives will facilitate and accelerate the development of treatments to delay the onset of the disabling consequences of the disease or total 'prevention'?

- What role ADI and/or the respective associations in member countries could/should play in a prospective multi-national initiative on 'prevention'; beyond what is being already planned or implemented as part of their respective national plans?

One possible leadership role is for ADI and member countries to promote and facilitate the formulation of well harmonised public policies, in all ADI countries, that dramatically expand international research and development resources along two aims. The first aim will be to leverage capabilities for the discovery, validation and development of new approaches that promote early and accurate prediction of people for the development of disease. The second aim will be the rapid testing of a wide range of interventions that ameliorate, delay, or ultimately prevent the onset of disease.

In order to achieve these two aims, global collaborative research requires a comprehensive international database of experimental and observational data. Like the international space station, this shared research resource will provide important new opportunities for validating new technologies and interventions of asymptomatic individuals at future risk for development of disease. The International Database for Aging & Dementia [IDAD] will support a global effort to produce longitudinal, population-based and genetically diverse data. The well-characterised cohorts will capture data from several different domains. This resource is essential for multi-national research to: 1. support prospective validation studies, 2. develop new computational algorithms/models, 3. obtain large quantities of data measurements from multiple domains, 4. establish probability risk profiles for memory disorders/dementia in asymptomatic populations and, 5. elucidate etiology and the natural history of diseases from a lifespan perspective.

ADI should constitute an international resource centre to continually monitor, evaluate and prioritise the most important opportunities to advance dementia research. Also, ADI is in a unique position to establish the governance for an international resource centre that will provide credible advice to health policy planners and enable better international harmonisation of activities. Presently no country, company or entity has the capability to attain the strategic goal of delaying or preventing chronic brain disorders. Current resources, established cohorts and ongoing longitudinal research are fragmented and inadequate. The reasons vary from relatively small sample sizes and lack of guarantee for long-term support/funding required to underwrite the longevity of cohorts.

The creation of an international resource centre is an essential first step towards identifying new opportunities and ranking priorities as the research landscape will certainly change with the accumulation of new knowledge. The strategic goal of reducing the prevalence of dementia and other chronic brain disorders is an achievable healthcare objective. A modest delay of five-years in the onset of brain disability will cut the cost of care and numbers of people affected by half. This is a worthy cause for ADI.

Zaven is a founding trustee of The Campaign to Prevent Alzheimer's Disease by 2020 (PAD2020). For more information visit www.pad2020.org. He can be contacted by email at zaven@pad2020.org

News

Help support people with dementia

A new collaboration between people with dementia from countries across the world has come together to support the inclusion of people with dementia at the ADI International Conference in Puerto Rico in May.

Dementia Alliance International is raising funds for people with dementia to attend the conference and share their experiences with the international dementia community. For many years now people with dementia have been some of the most memorable speakers at the conference and have established new and long-standing friendships with others in a similar situation. However, there is still very little funding available to bring people with dementia to the conference, meaning many who would like to experience the conference are not able to.

If you are able to donate any amount to support this really important endeavour then please visit Dementia Alliance International's Crowdrise page at www.crowdrise.com/dementiaalliance2014

News

PUERTO RICO 2014
INTERNATIONAL CONFERENCE
Alzheimer's Disease International

29th International Conference of Alzheimer's Disease international
1 – 4 May 2014
San Juan, Puerto Rico

We invite you to create connections, share experiences, gather knowledge and make a difference to the lives of those affected by dementia.

www.adi2014.org

Emerging association in Yemen

Diane Mansour, left, at the conference in Yemen in December

ADI's Special Envoy for the Middle East, Diane Mansour, attended a conference hosted by the Alqaderi Foundation for Alzheimer and Development in December 2013. The conference aimed to raise awareness and provided the foundation with an opportunity to launch their plan of action for 2014.

In attendance at the conference were representatives from the Yemeni government and one minister who spoke during the event promising to support the work of the foundation. Diane was also given the opportunity to share information about the burden of dementia and the role Alzheimer associations play.

Following the event, Diane praised the work of the foundation's leader, 'Mrs Kadri is playing a great role trying to provide support to people with dementia and their families, in addition to raising awareness in the Yemeni community.'

The Foundation plans to introduce support group meetings and regular meetings of carers this year. ADI looks forward to hearing more of their progress in the future.

In the next issue of *Global Perspective*

- **A report on the ADI 2014 conference in Puerto Rico**
- **The winner of the ADI Award 2014**
- **A look ahead to World Alzheimer's Month 2014**