



Alzheimer's Disease
International

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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.

Sharing knowledge in London



Alzheimer association representatives from Ghana, Namibia, Nicaragua, Nigeria and the Philippines joined ADI staff in London at ADI's annual Alzheimer University programme for emerging associations in August. See the back page for the full story.

Launch of World Alzheimer's Month 2013

World Alzheimer's Month 2013 got underway at the beginning of September with a variety of lively and educational events taking place worldwide.

The Lanka Alzheimer Foundation in Sri Lanka led the way with six weeks of events and activities beginning in mid-August. Doctors volunteered their time to carry out memory screening on a no-charge basis and, following the event, the Foundation will now organise memory screening sessions each month.

On 4 September, Asosiasi Alzheimer Indonesia hosted a talk show in Central Jakarta, featuring presentations from association representatives alongside ADI Policy Adviser Mike Splaine and Dr Maramis from the WHO who both spoke via internet video call. The event took place at @america, a place designed by the US Embassy and USAid for gatherings. The show, which marked the first public event to highlight the ten warning signs of dementia in Indonesia, was attended by around 25 journalists and 75 members of the public.

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Alzheimer's Disease International

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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 31 October 2013.

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Editorial

Marc Wortmann, Executive Director



This month has been very busy for everyone in the Alzheimer and dementia movement. World Alzheimer's Month has become a major part of the year with lots of activities and the number is still increasing, with the launch of reports, media events, public lectures, Memory Walks, film and book releases and other activities to raise awareness. I've done more interviews for radio, TV and newspapers than in any other year and I know it has been the same for a number of colleagues. The key feature of World Alzheimer's Month this year was the *World Alzheimer Report 2013* on long-term care.

The coming months are going to be very important from a public policy perspective. ADI will be involved in several initiatives in different WHO regions, especially in Central and South America. On top of this we will be involved in the G8 meeting in December here in London. These are all opportunities to improve health systems and get better services in place for those who are hit by Alzheimer's and dementia. We also hope that more countries will launch a national plan or strategy and we were very pleased to learn that a plan was launched for Chinese Taipei at the end of August.

So keep in touch and follow the news! You can keep track through this newsletter, the website www.alz.co.uk, the conference websites www.adi2014.org for the next ADI conference and www.adidubai2013.org for the conference in the Middle East in December, as well as Facebook and Twitter (see left for social media details).

I wish you a very successful fourth quarter of 2013 and hope to see you soon at one of our events!

Events

10 – 12 October 2013
23rd Alzheimer Europe Conference
Valletta, Malta
Web: www.alzheimer-europe.org/EN/Conferences

16 – 19 October 2013
VII Congreso Iberoamericano de Alzheimer
XI Reunion de Asociaciones de Alzheimer de Iberoamerica
Montevideo, Uruguay
Web: <http://aibuguay2013.com>

17 – 20 October 2013
8th International Congress on Vascular Dementia (ICVD 2013)
Athens, Greece
Web: www.kenes.com/vascular

25 – 27 October 2013
6th International Conference on Alzheimer's Disease and Related Disorders in the Middle East
Istanbul, Turkey
Web: alzheimermiddleeastconference.org

14 – 16 November 2013
6th Clinical Trials Conference on Alzheimer's Disease
San Diego, USA
Web: www.ctad.fr

17 – 20 November 2013
IAHSA 10th International Conference
Shanghai, China
Web: www.iahsa.net/China_2013.aspx

8 – 9 December 2013
2nd Middle East and North Africa Conference of Alzheimer's Disease International
Dubai
Web: www.adidubai2013.org

11 – 14 December 2013
16th Asia Pacific Regional Conference of Alzheimer's Disease International
Hong Kong SAR and Macau SAR
Web: www.aprc2013-hongkong-macau.com

1 – 4 May 2014
29th International Conference of Alzheimer's Disease International
San Juan, Puerto Rico
Web: www.adi2014.org

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

■ News

Launch of World Alzheimer's Month 2013

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Alzheimer Scotland launched a new 4 seconds appeal, highlighting the fact that every 4 seconds there is a new case of dementia somewhere in the world. The two-week appeal aimed to raise funds for Alzheimer Scotland to continue to provide information, advice and practical support to people with dementia, their carers, partners and families across Scotland.

The launch of the *World Alzheimer Report 2013* also took place this month. The focus of this year's report is on long-term care and we hope that it will assist in influencing improvements in care policy worldwide.

A full report on both the launch of the *World Alzheimer Report 2013* and World Alzheimer's Month will be featured in the next issue of *Global Perspective*.



Asosiasi Alzheimer Indonesia representatives at the @america event in Central Jakarta

Twinning Programme updates

Indonesia and the Netherlands

In June, Asosiasi Alzheimer Indonesia (AAZI) hosted their first caregiver training session, developed in partnership with Alzheimer Nederland staff. The session was attended by 30 caregivers and an entry survey was carried out to find out their hopes from the course and their concerns.

A meeting took place following the programme with Alzheimer Nederland's Executive Director Gea Broekema. During this meeting it was decided that an Executive Director was required for AAZI and DY Suharya has been appointed to this role. Efforts are now underway for AAZI to become a more professional organisation with the ongoing support of Alzheimer Nederland and ADI.

New twins

A new Twinning Programme partnership between Deutsche Alzheimer Gesellschaft and Turkish Alzheimer Association has been formed. The relationship is still in the early stages, but ADI looks forward to working with both associations and updates will appear in future issues of *Global Perspective*.

Landmark meeting in Caribbean

In August, ADI hosted the first meeting of its members within the English-speaking Caribbean region. The meeting took place in Sint Maarten and combined elements of ADI's Alzheimer University programme with a scoping session to gain more knowledge of the challenges faced across the set of Caribbean islands.

During the successful event, ADI learnt that people with dementia in the Caribbean face the growing issue of migration, with a large number of younger people and potential family carers moving away from their family to another of the islands in the region. Another concern is the lack of services and facilities available for the small populations of the islands with the limited demand for services and lack of funding for building facilities.

Speakers at the meeting included the Prime Minister of Sint Maarten and Daisy Acosta, who shared the latest interventions developed by the 10/66 Dementia Research Group.

The feedback and information gained during the meeting will be included in a document currently being developed by ADI, in partnership with associations in the Pan American region, which aims to make dementia a priority for the Pan American Health Organization.

ADI would like to thank the Sint Maarten Alzheimer Foundation for hosting the meeting and Bupa for supporting it.

Member profile

Tunisian Alzheimer Association, Tunisia

The challenge of Tunisian Alzheimer Association, formed in March 2006, is to understand more about those caregivers who are particularly vulnerable.

Our intervention consists of providing information, raising awareness about dementia, sustaining care support and offering details of the symptoms of dementia.

We need to integrate dementia care with general health care by adding a dementia care component to the existing services, mainly to the medical and nursing courses.

We aim to establish home care programmes with families through active support from network trained professionals. Caregivers should receive training that takes into consideration the

specific needs of dementia care while adhering to the general principles of palliative care.

We should not neglect the development of specialised dementia care services in Tunisia. The Alzheimer Center created in Al-Razi hospital and memory consultation are examples of such services newly introduced in Tunisia. These centres focus on geriatric psychiatry and dementia care.

Attention needs to be directed towards the development of age-appropriate long-term care policy. There has to be mechanisms for ensuring the social and juridical protection of older people. We must convince the decision makers and governments about the urgent need to face the public health challenges posed by dementia.



A wool cushion created by someone living with Alzheimer's disease

The first priority is to identify and support home based care of people with dementia. The second priority is to develop specialised dementia care services in general hospitals. We need more clinicians involved in dementia care. We also need more centres with a special interest in dementia care. The third priority is to encourage good quality research.

All these priorities need a collaborative interaction between the Alzheimer's family, associations and government.

Alzheimer's: a true problem in Tunisia

Leila Alouane PhD, President of Tunisian Alzheimer Association, and Dr Ilhem Karoui, Geriatrician, member of Tunisian Alzheimer Association

Tunisia is a small country in North Africa which is facing a rapid demographic transition associated with social and medical impacts. This unprecedented pace of demographic ageing presents an enormous public health challenge. Ageing people make up more than 10% of the Tunisian population, with 3.4% of them diagnosed with dementia.

In our country, older people are accorded great respect, both within their families and society. But, the traditional strong social support systems seem to be under strain due to the rapid social restructuring and economic changes sweeping the region. It is estimated that there are

about 35,000 people with dementia in Tunisia. This number is likely to increase by 200% in the next three decades.

Moreover, the rapid spread of obesity, the rising prevalence of type 2 diabetes and hypertension among old people in Tunisia affect the relative incidence rates and lead to a higher than expected prevalence in the near future.

The low-skilled caregivers' strain, along with all that contributes to the behavioural disturbances and stress, is as high as in developed countries despite home care and extended family networks. Dependency imposes additional economic strain on families, as Alzheimer's disease is not covered by social services. People with dementia are nursed at home by their families due to the lack of institutional care in Tunisia. This is a

fair social situation as there are more people in the house to share such a responsibility. However, Tunisian women are taking up employment outside their homes to supplement the family income, but also keep the exclusive responsibility of the family care which is a heavy burden. In addition life-assisting facilities which provide long-term care are few and expensive in Tunisia. This puts enormous pressure on the families and caregivers. The latter themselves should be viewed from a public health perspective; the healthier the caregiver remains, the better the care recipient's quality of life will be.

The negative effect of inadequate care falls on partners or children, as intensive caring can also have adverse effects on the psychological health of the caregivers. They are likely more at risk of developing mental health problems, particularly depression, than other adults of the same age.

Members' forum

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

ARGENTINA

New play about dementia

A new play about dementia, *Nunca Lejos de Ella* (Never Far From Her), premiered in Buenos Aires, Argentina at the end of May. The director of the play, which is based on the book *The bear came over the mountain* by Alice Munro, contacted Asociación Lucha contra el Mal de Alzheimer (ALMA) during the rehearsals to gain information and experiences to feed back to the actors to help them portray the characters.

Ana Baldoni, Director of ALMA, attended the opening night and was invited to say a few words as an introduction before the start of the play. The programme, given to all of those in the audience, offers contact details for ALMA as well as some general information about dementia.

To find out more about ALMA visit www.alma-alzheimer.org.ar



The new play directs audiences to ALMA for support

CANADA

New Safely Home partnership

The Alzheimer Society of Canada announced in July that they have partnered with the Canadian MedicAlert Foundation to launch the MedicAlert® Safely Home® programme.

The *Safely Home* programme ensures that people with dementia who have gone missing arrive back home safely with the help of an emergency 24 hour hotline. Members of the programme receive a MedicAlert ID bracelet with their membership number and the emergency hotline number engraved onto it. If a person with dementia goes missing or is found, the bracelet enables the person to be easily identified and returned back home.

A similar partnership with MedicAlert exists in the USA and another scheme in New South Wales, Australia has seen the development of an identity bracelet and collaboration with the local police.

To find out more about the Canadian collaboration visit www.alzheimer.ca/en/Living-with-dementia/Day-to-day-living/Safety/Safely-Home

COSTA RICA

ASCADA propose national plan

A proposed national plan for Alzheimer's disease and other dementias, developed by Asociación Costarricense de Alzheimer y Otras Demencias Asociadas (ASCADA) was



Raymond Jessurun (left), representing ADI, and Dr Norbel Roman (right), President of ASCADA, deliver the proposed national plan to Costa Rica's Vice Minister of Health

delivered to the Ministry of Health in Costa Rica in July.

The plan was received by Dr Sissy Castillo Ramirez, Vice Minister of Health, and it is hoped that this is the first step towards the development of a government plan in the country.

For more information about ASCADA visit ascadacr.wordpress.com

DENMARK

New campaign to reduce stigma

In July, Denmark's Board of Health launched a new campaign to raise awareness of dementia and reduce stigma, *Demens er noget, vi taler om* (Dementia is something that we talk about).

The Board of Health worked with Alzheimerforeningen, ADI's member association in Denmark, on the campaign. Conversation rooms were available around the country in 10 Danish cities from July to August. These rooms enabled people to talk about dementia, find out the early symptoms and discuss any worries they may have for themselves or a loved one. Members of the public could also

CONTINUED OVER THE PAGE

order a conversation-starter pack to use at home. The pack contained coffee, cake and some advice on how to start a conversation about dementia.

The launch of the campaign follows research findings from the country's Health Protection Agency that suggests that nearly a quarter of people do not want to talk about dementia and many fear it.

For more about the campaign visit www.talomdemens.dk

SINGAPORE

Corporate donations success

Alzheimer's Disease Association (ADA) Singapore raised S\$111,000 in August at a Pitch To Win event in front of an audience of corporate representatives.

ADA had only three minutes to pitch their plans to develop a new ADA Family of Wisdom programme, inspired by a similar activity run by TADA Chinese Taipei. The programme, which ADA expects will help up to 100 families, will provide a

centre offering respite care services to carers of people with dementia.

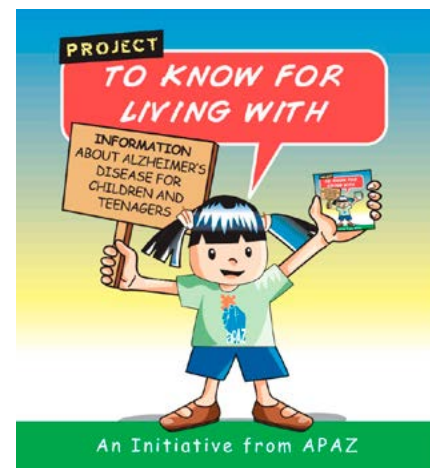
In preparation for the event, ADA was offered coaching sessions on how to prepare a successful pitch to corporates. ADA received donations from 10 of the 20 donors in attendance. They hope to begin running their new programme by the end of the year.

For more information about ADA visit www.alz.org.sg

TRINIDAD & TOBAGO, BRAZIL AND CANADA

Partnership for booklet launch

In the June issue of *Global Perspective* we presented the entries for the first ADI-MetLife Foundation Awards, including a project run by APAZ in Brazil which saw the successful introduction of a booklet about dementia for children and teenagers. Following this success, the Alzheimer's Association of Trinidad & Tobago worked closely with APAZ and the Alzheimer Society of Canada to



The original booklet developed by APAZ in Brazil

launch the booklet at an international meeting in Barbados earlier this year.

The official launch in Trinidad & Tobago took place in May at the Holistic Primary School where children were given copies of the booklets along with work sheets from the Alzheimer Society of Canada.

News of the launch reached the media in Trinidad & Tobago and it is expected that more copies will be required in the future as the association works with further schools to distribute it.

SCOTLAND

Dementia Dogs introduced

In July, Alzheimer Scotland announced that the first two dementia dogs had been introduced to families of those with early stage dementia. The dogs, Kasper and Oscar, have been specially trained to provide assistance to people with dementia and their carers by helping with various tasks, such as retrieving medicine when an alarm goes off, waking a person up and ensuring that the person with dementia and carer stay active.

The Dementia Dogs project was originally developed by students at the Glasgow School of Arts and went on to be implemented by a partnership between Alzheimer



Frank and Maureen Benham with Oscar, their assistance dog

Scotland, Dogs for the Disabled and Guide Dogs Scotland.

To find out more about the project visit www.dementiadog.org

Dementia newsflash

■ Argentina

Asociación Lucha contra el Mal de Alzheimer (ALMA) hosted their first Alzheimer Café in August with the support of Alzheimer Nederland. The event was a great success and a second Café will take place in September.

■ Australia

Following on from their ongoing work with culturally diverse groups, Alzheimer's Australia WA has recently started working with a group in China that has contacts in both Vietnam and Cambodia. This partnership will enable them to work more closely with Vietnamese and Cambodian communities in Australia.

■ Ireland

The Alzheimer Society of Ireland has received recognition in the Crystal Clear Health Literacy Awards. The Society received the award for Best Project in the Community or in a Social Setting for their booklet *I have dementia... I have rights. Know your rights.*

■ Russia

Russia's first dementia self-help group was launched in June. The group meet once a month and have set up a page on social media site Facebook. A member of the group, Daria Dmitrieva, is developing a project to create a photography exhibition featuring pictures of older people from around the world to show the positive aspects of ageing.

■ Research update

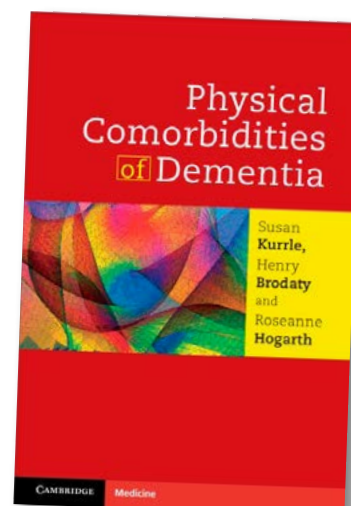
Physical Comorbidities of Dementia

The publication Physical Comorbidities of Dementia, written by Susan Kurrle, Roseanne Hogarth and Henry Brodaty, was published by Cambridge University Press in 2012.

Comorbidity refers to having more than one illness or condition at the same time, although the conditions are independent of each other. There is a lack of knowledge about physical conditions that occur more frequently in dementia, even though these conditions cause significant morbidity and management challenges. This book summarises evidence for their prevalence (how often they occur), aetiology (causes) and management.

- 70-80% of people with dementia will fall at least once a year, which is twice the rate in the non-dementia population and fractures occur three times more commonly. No interventions have been shown to prevent falls in people with dementia.
- People with dementia have a five-fold higher rate of delirium which is often unrecognised.
- 10-20% of people with dementia will have a seizure, six times the rate in the non-dementia population.
- Weight loss may occur up to 20 years before the onset of dementia and people with dementia lose up to 10% of their body weight during the course of their dementia.
- Reported rates of urinary incontinence are about 33% in the community and 50% (up to 80%) in residential care; its aetiology and management are complex.
- Sleep apnoea and Lewy body dementia are two possible causes of the 25-50% rate of sleep disturbance reported in dementia.
- Symptoms of visual dysfunction can occur before cognitive symptoms and include blurred and distorted vision, difficulty recognising familiar objects and faces, difficulty reading or writing and visual hallucinations.
- Oral disease can be miserable and distressing for affected persons yet it can be preventable and treatable.
- Plaque accumulation, caries, dry mouth, gum disease and less use of dentures can all lead to pain and decrease oral intake.
- Frailty – weight loss, decreased muscle strength and slow walking speed – happens before cognitive changes and may share underlying mechanisms such as increased proinflammatory cytokines, mitochondrial malfunction and oxidative stress.

It is important to note that these are treatable and in many cases reversible conditions. Attention to physical comorbidity can improve the quality of lives of people with dementia. The book provides clear explanations of each comorbidity and recommends ways to treat them.



Physical Comorbidities of Dementia is available now online from Cambridge University Press www.cambridge.org

■ Living with dementia

Live life to the fullest, even with dementia

Michael Ellenbogen, USA

My name is Michael Ellenbogen and I live in the USA. I am a writer. I am a husband. I am a father. I was a high level manager. In 2008, I was diagnosed with Alzheimer's disease after struggling to get a diagnosis since my first symptoms at age 39.

Over the past few years I have visited many websites that talk about Alzheimer's/dementia. The one thing that they all have in common is that not one of them encourages those of us who have the disease to continue to live and enjoy our lives. While I realize AD is a progressive and devastating disease, we are still here and we are still alive, so treat us that way. Do not write us off.

I have always been savvy when it comes to finances and have always been a saver. One day I was speaking to a friend of mine who has AD, and I was telling her how I did not want to spend a lot of the money I had saved, because I wanted to leave it for my wife for that rainy day. My friend told me: 'This is the rainy day. What are you waiting for?' She was right,

and that's exactly how I started to think.

Just because we are living with AD, does not mean we should curl up and think our lives are over before they actually are. There is so much more we can still do to enjoy life – make wonderful memories with your loved ones before the days turn ugly.

One thing I had always wanted was to own a convertible, so we purchased one. I wanted to drive it down to the Keys in Florida. I have a friend out in California who also has AD. She has an RV and had planned to travel around the country before she declined and was incapable of driving anymore. One day she mentioned that she was going to the Keys and I decided to meet up with her. I also wanted to go deep-sea fishing to catch a big game fish. Don't get me wrong I am not a person who goes fishing, but it was something I have always wanted to do. I had looked into it and it was very pricey, but it has always been on my bucket list. I think we all have a list if we stop and think about it.

I had no real plans; I just wanted to go out and drive my convertible, to feel the fresh air and admire the beautiful scenery and enjoy nice weather. I had a great time. I had a permanent smile on my face. I decided to stay with my friend in the RV for a week and visit various campgrounds along the way. That was a whole new experience, and some of the places we stayed at had fabulous views.

It was great to be out on our own, not having to rely on caregivers all the time. We had some difficulties, but we were able to manage on our own. It cost me a few extra dollars along the way because when I purchased something I could not remember the price in order to be able to compare, and sometimes I took the wrong road and had to take the turnpike, but these were minor issues. This road trip made me feel so much better about myself. It was good for my mind; I came back stronger because of what I had achieved.

This disease has a way of making you feel like you are no longer capable of doing things on your



Michael with his wife, preparing for their ride on a blimp in August

own. You lose your self-esteem and your self-confidence. After this trip I felt great.

I did have the opportunity to go fishing. It was such a beautiful day with perfect conditions.

The fish were not really biting to begin with but it didn't matter; I was just happy to be on a boat again. Then I caught a fish that was about 10-12 inches long. Then I caught a barracuda that was at least 18 inches long, and then one over two feet long. Not too long after that I got

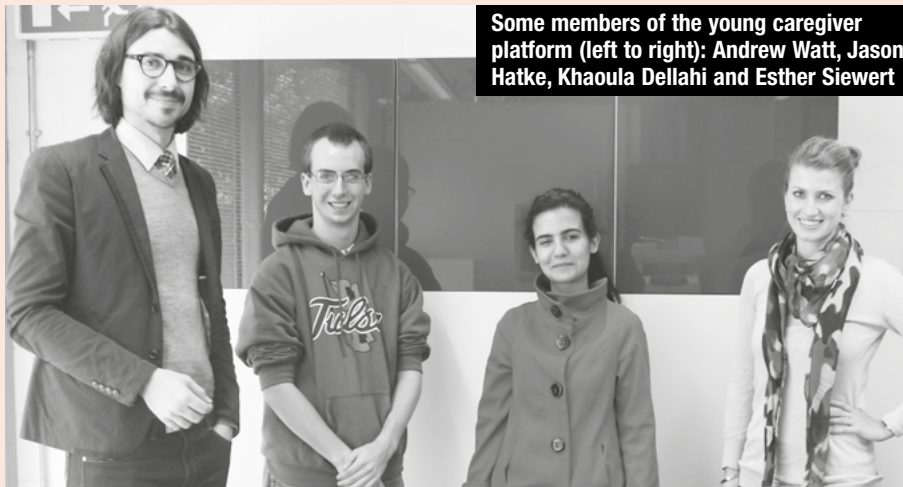
the big one, a king mackerel that was 42 inches long! You should have seen the smile on my face. It is memories like this that we need to be making.

My friend in the RV has decided that she will not just use her mother's china and silverware on special occasions. Instead she took them with her in the RV. It gives her pleasure to use them every day. How many of you have a wonderful expensive hand bag or nice watch, which

you only use on a special occasion?

Life is short; take pleasure in using those treasured items now. Start to create your own bucket list. Don't just write it; DO IT! There are many wonderful memories that you can still make. Make them now before it's too late. Stop focusing on the negatives. Make these last few years be the best of your life. You must do this now, before your mind no longer works.

■ Carer's story



Some members of the young caregiver platform (left to right): Andrew Watt, Jason Hatke, Khaoula Dellahi and Esther Siewert

would be the most humble thing that we can do for them, for us.

Andrew Watt, Australia

What were you like when you were 18? Were you bookish, into sports, a bit of a wild one or some amalgam of the three and then some? If you were anything like me, you were just coming to terms with who you were as a person and trying to figure out who you wanted to become as you tried to navigate the rocky path towards autonomy. And of course your parents didn't understand what it was you were going through, but your friends and other people your age could, they were your support network back then.

When I was 18, my father was diagnosed with Alzheimer's disease, he was 52. My friends didn't understand what the diagnosis would mean and there was no one my own age who I could talk to about what was happening and what was still to come. I was alone.

The simple truth is that when we think of Alzheimer's disease we naturally tend to picture someone in the later stages of their life, in the twilight years of their 70s or 80s. However, a growing number of Alzheimer's diagnoses are being made in people who are in their 40s, 50s and 60s, bringing with them untold challenges for their young families. Just as we support the individuals who carry a diagnosis of dementia, it is also important that support is available for the younger people affected by the diagnosis of a parent or a loved one. It is for this reason that I'm proud to be working alongside ADI in the development of an online support network for young people affected by dementia, a network that will give young people the opportunity to seek support and share their experiences with other young people around the world.

ADI's new Young Caregiver Platform

In June, ADI hosted a meeting in London to mark the beginning of a new platform for young carers of people with dementia. In this issue's *Carer's story*, members of the platform share their personal experiences and explain why the creation of the platform is so important.

Esther Siewert, Netherlands

Every disease has its own difficulties. Not only for the people with the disease, but also for their loved ones. Seeing someone you love struggling is heart-breaking. This is also the case for young carers. When you are young, you have enough trouble discovering how to live yourself! Taking care of a mother or father with dementia is a hard job to manage. Young carers grow up so much faster. The problem is that sometimes they have no one to talk to. Besides caring, sharing is so important! That is why we created this new platform for young carers. Speaking with other young carers will lift some weight off of their shoulders because then they know: 'I am not alone'.

Khaoula Dellahi, Morocco

My story with Alzheimer's started with receiving wrong information about the disease. I was asked to make a report about Alzheimer's disease, and thought that the

disease only affects the memory. I met the president of AMAMA (the Moroccan Association of Alzheimer's and related diseases) who was a 27 year old young man. After talking for 30 minutes about his experience as a caregiver, I realised that it wasn't only about forgetting, but the beginning of a new life for the whole family. Later I met other caregivers in an 'Alzheimer's Café'. I saw in their eyes how pleased they were to share their stories. Yet, the younger ones were a little bit shy, or found it difficult to talk in the presence of their parents.

Although the family members share a common life with a relative with dementia, the occupations differ from one person to another. As young people dealing with dementia we want to understand why it happened to us, why our life is different, and why travelling in the summer can be too difficult.

I've met young caregivers who had to abandon work, school, or change their orientation only to be close to their beloved. Creating a platform where they can express themselves

■ How associations help

Receiving more than you give

Elizabeth, Canada

Elizabeth was shocked when her beloved husband Alan developed Alzheimer's disease at 65 years of age: 'Alan was an Anglican priest. He was outgoing and charismatic and just loved being out in the community trying to find some way he could help.'

As Elizabeth prepared to take on the new role of caregiver, she turned to her local Alzheimer Society for help. A dedicated Society counsellor, Joy, helped her access valuable community services and offered strategies to manage Alan's changing physical and emotional needs.

'Assuming the role of caregiver meant that I was able to take care of Alan in our home where he was most comfortable. I was so grateful for Joy's regular visits during those years – she would often just listen. She also advised me of the help available to us through the Community Care Access Centre. And when she saw me getting overtired, she was very sensitive in suggesting a couple of overnight stays for Alan at the Lodge.'

Despite being 'on call' 24/7 during that time, I am so thankful we were together.'

Even after Alan was moved to the Lodge in the last eight weeks of his life, Elizabeth and her children continued to provide care: 'Alan would sometimes become agitated especially when it was bath time. I would go down and help him through the shower and dress him.'



Elizabeth with her daughter on Thanksgiving in 2010

'My son and daughter visited their Dad every night they possibly could. And they made sure he had some of his favourite music to listen to which seemed to calm him. Once the summer holidays began that year, my granddaughter came to visit too.'

Alan died at 70 years of age. To honour his memory, Elizabeth began volunteering at the Lodge, helping feed patients and assisting in religious services. 'Alan's ministry, which had included the Lodge, and the exceptional care he ended up receiving there, were an inspiration to me. I often know people who have just arrived and I can talk with the family, as I know how they are feeling.'

'I would certainly encourage people to volunteer. I seem to receive far more than I give.'

Elizabeth speaks of her Alzheimer Society counsellor Joy as someone to whom she could express feelings about what was happening: 'It was such a blessing to be able to talk to Joy openly about things that were difficult. She was always so patient and kind.'

To find out more about the Alzheimer Society of Canada visit www.alzheimer.ca

News

Alzheimer University: Sharing knowledge in London

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Attending sessions on providing information, delivered by Jos van der Poel from Alzheimer Nederland, and working with volunteers, run by Andrew Oldham from Alzheimer's Society in the UK, participants gained a strong understanding of the basics of running an Alzheimer association. Hannah Clack, Senior Press Officer from Alzheimer's Society, offered guidance on working with the media and prepared participants by coordinating practice interviews.

ADI Chairman Jacob Roy attended part of the programme as Caroline Staffell from the International Alliance of Patients' Organizations spoke about the benefits of collaborations and partnerships.

Phil and Pat Murray joined participants on the final day and offered advice on setting up support groups and involving people with dementia. Overseen by Rosie Leavett, Project Manager for Alzheimer Scotland's *Seize the Day*, Phil and Pat spoke of their experiences as participants and coordinators of support groups since Phil's diagnosis of vascular dementia three years ago.

Following the event, former Director of Policy at Alzheimer Scotland, Jan Killeen, joined the participants from Ghana as they travelled home. Jan will now begin working with the association who have already held meetings to discuss their action plans based on what they learnt from the Alzheimer University programme.



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



Dementia: Working Together for a Global Solution

Join us in Puerto Rico!

Registration is now open for the 29th International Conference of Alzheimer's Disease International. The event will take place from 1 to 4 May 2014 in San Juan, Puerto Rico, and those who register before 7 February 2014 will benefit from the early bird registration rate.

Abstract submission for the conference is open until 31 October 2013. If you have some new research you would like to share with the conference's international delegation or a personal story to tell then visit the conference website to find out how you can play a part in this exciting event.

For information, to register or submit your abstract visit www.adi2014.org

Working together at AAIC®

The Alzheimer's Association welcomed a delegation of almost 5,000 to their international conference, AAIC, in Boston, USA in July. The latest research findings were presented at the event, on topics including risk factors, diagnosis and therapies.

The high attendance enabled ADI staff to build upon existing partnerships with the signing of the new agreement with Alzheimer Europe. A meeting also took place with representatives from ADI member associations in Canada, USA and UK to discuss a side event at the forthcoming G8 dementia summit later in the year.

Serge Gauthier was also welcomed to his first meeting as Chairman of ADI's



ADI staff and Chairman with Dr Mary Mittelman and delegates from ASCADA in Costa Rica

Medical and Scientific Advisory Panel and news of ADI's work was spread widely within the exhibition area, with the support of some enthusiastic volunteers.

To find out more about AAIC and news from this year's conference visit www.alz.org/aaic

In the next issue of *Global Perspective*

- A full report on World Alzheimer's Month 2013
- News from regional conferences