Let’s talk about dementia

#LetsTalkAboutDementia
#WorldAlzMonth  @AlzDisInt
www.worldalzmonth.org
Toolkit

World Alzheimer’s Month 2019

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Introduction

September 2019 will mark the eighth World Alzheimer's Month, an international campaign to raise dementia awareness and challenge stigma. During this time, Alzheimer associations and other stakeholders around the world organise advocacy and information events, as well as Memory Walks, media appearances, social days and fundraising days. The impact of this campaign is growing, but the stigma and misinformation that surrounds dementia remains a global problem and challenge.

World Alzheimer's Day (21st September) was launched in 1994 to mark the 10th anniversary of Alzheimer’s Disease International (ADI) and has grown significantly since then. In 2018 we know of 84 countries that undertook activity during the month and especially around World Alzheimer's Day. Our member associations, partner organisations, health care professional, scientists, researchers all get involved in helping raise awareness and we are attracting more global, regional and national media coverage to help amplify the message, including BBC World Service, Sky News, Al Jazeera and Huffington Post.

This year we need your dedication and help to continue to raise awareness through our "Let's talk about dementia" campaign. Through talking we help break down the fear and the stigma and we encourage people to seek out information, support and advice.

Alzheimer’s Disease International will once again be mobilising our networks to get everyone actively involved in the campaign. We ask that you do the same. Remember to tell us what you are doing so we can help promote your activities and events and always tell your press and media about it. Speak to journalists, ask radio stations to cover the story or do a phone-in about dementia, promote it through social media.

This toolkit provides you with so many options to help your World Alzheimer Month activity, from posters and suggested social media posts, to key messages and graphics. In addition, we have also provided a Campaign Guide which is available on the World Alzheimer’s Month website, full of inspiration and ideas.

September is such an important month for us all. Please do everything you can to get people talking about dementia.

Let’s talk about dementia!

Paola Barbarino
CEO
Alzheimer's Disease International

September is World Alzheimer's Month!
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Alzheimer’s Disease International

ADI is the international federation of 100 Alzheimer associations around the world, in official relations with the World Health Organization. ADI’s vision is prevention, care and inclusion today, and cure tomorrow.

ADI believes that the key to winning the fight against dementia lies in a unique combination of global solutions and local knowledge. As such, it works locally, by empowering Alzheimer associations to promote and offer care and support for people with dementia and their care partners, while working globally to focus attention on dementia and campaign for policy change from governments. For more information, visit www.alz.co.uk

ADI has offices in London, Jakarta and El Salvador with regional mentors in Asia, Africa and the Americas. We work with our official partners Dementia Alliance International, as well as with NCD Alliance, King’s College London’s Global Observatory on Ageing and Dementia Care, Swedish Care International, Alzheimer Europe and Alzheimer Iberoamerica. ADI is a partner of the STRiDE project (Strengthening responses to dementia in developing countries), led by the Personal Social Services Research Unit (PSSRU) at the London School of Economics (LSE).

A list of ADI members can be found on page 20.

Dementia factsheet

Dementia is a collective name for progressive degenerative brain syndromes which affect memory, thinking, behaviour and emotion. Alzheimer’s disease and vascular dementia are the most common types of dementia, responsible for up to 90% of cases of dementia. Symptoms may include:

- loss of memory
- difficulty in finding the right words or understanding what people are saying
- difficulty in performing previously routine tasks
- personality and mood changes

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Dementia knows no social, economic or geographical boundaries. Although each person will experience dementia in their own way, eventually those affected are unable to care for themselves and need help with all aspects of daily life. There is currently no cure for most types of dementia, but treatments, advice, and support are available.

Every 3 seconds, someone in the world develops dementia. The number of people living with dementia around the world is over 50 million, which is expected to almost double every 20 years, reaching 152 million by 2050. The annual global cost of dementia is over $US one trillion annually, which will double by 2030.

Dementia is now widely recognised as one of the most significant health crises of the 21st century.

An absence of dementia public policy renders governments woefully unprepared for the dementia epidemic. See below for details of a global plan on dementia adopted by the World Health Organization (WHO) in 2017. It is essential that governments around the world act now to reduce the impact of dementia, by raising awareness and promoting risk reduction, and by supporting increased diagnosis, care and research.

For more information, visit: www.alz.co.uk/about-dementia

Global action plan on dementia

In May 2017, WHO adopted the Global plan of action on the public health response to dementia 2017-2025. One year on, ADI released the report From plan to impact: Progress towards targets of the Global plan on dementia, that details the global developments made since the adoption of this plan, finding that progress has been far too slow. ADI launched an update to the report at the 72nd World Health Assembly in May 2019: From plan to impact II: The urgent need for action.

The Global plan committed all 194 member states of the WHO to seven action areas: dementia as a public health priority; dementia awareness; risk reduction; diagnosis, treatment and care; support for carers; data and research. It contains targets for each area that individual governments should meet by 2025.

Area one of the plan outlines dementia as a public health priority with a target for 75% of WHO member states to develop or implement a national plan or dedicated policies on dementia. The adoption of a plan is especially important in countries with limited existing support for, or awareness of, dementia.

However, as the ADI report identifies, the scale of challenge is huge and the response has been too slow. Only 32 plans have been developed since the 2017 Global plan was adopted, but over 21 new plans are needed each year to hit the 2025 target.

If acted upon, the global plan could:

- Continue to spread the word that dementia is not a normal part of ageing and that those affected with dementia should be empowered to live as well as possible;
- Increase coverage of diagnosis and support, risk reduction and improved awareness of dementia;
- Dramatically improve research and understanding of dementia that could lead to new treatments and ultimately a cure for the condition.
Global awareness campaigns such as World Alzheimer’s Month directly contribute towards the second action area of the Global plan, with the eventual target of having all 194 Member States having at least one functioning national public awareness campaign on dementia to foster a dementia-inclusive society by 2025.

**World Alzheimer’s Month 2019**

September 2019 will mark the eighth World Alzheimer’s Month campaign, an international campaign to raise dementia awareness and challenge stigma.

The primary objective of World Alzheimer’s Month is to reach out to as many countries as possible, showing the global impact of dementia and promoting dementia awareness and what we can do to help support those living with the disease.

**Let’s talk about dementia: End the stigma**

The theme for this year’s World Alzheimer’s Month campaign is *Let’s talk about dementia: End the stigma*. We’re encouraging people all around the world to understand the importance of recognising dementia as a disease and challenging the stigma that surrounds the condition.

This ‘back to basics’ approach concentrates on awareness-raising, with a simple, easy to understand and impactful message, which is broad and adaptable to every country.

Alzheimer associations, groups and individuals around the world are encouraged to use this theme to focus their messages and campaigns on advocacy and public awareness with a packed month of activities including information provision, Memory Walks, fundraising events and media appearances.
Key messages

- This World Alzheimer’s Month we want you to talk about dementia. We need to address the stigma that exists worldwide.

- World Alzheimer’s Month is an opportunity to tackle fear and stigma surrounding dementia everywhere.

- Lack of knowledge about dementia leads to inaccurate assumptions about its effects on the person and their family and negative stereotypes about how a person with dementia will behave.

- Stigma and negative attitudes around dementia persist in every country. This World Alzheimer’s Month, we want to talk about it.

- There are over 50 million people around the world living with dementia.

- Someone in the world develops dementia every 3 seconds.

- The number of people living with dementia is predicted to triple, rising to 152 million by 2050.

- The economic burden of dementia is US$1trillion every year, a figure that will double by 2030.

- As few as one in ten individuals receive a diagnosis for dementia in low- and middle-income countries.

- Governments have an opportunity and a responsibility to dramatically increase awareness, detection and diagnosis of dementia, by meeting targets of the World Health Organization (WHO) Global action plan on dementia.

- The World Health Organization (WHO) has recognised the burden of the epidemic by introducing the Global action plan on the public health response to dementia 2017-2025. One of the five key action areas is dementia research and innovation. Other areas such as risk reduction and diagnosis, treatment and care are also highly related to dementia research.

- September is World Alzheimer’s Month, an international campaign to raise dementia awareness and challenge stigma. Each year, Alzheimer associations from around the world unite to organise advocacy and information provision events, as well as Memory Walks and fundraising days.

*We will be providing further key messages once the analysis of our attitudes around dementia survey is completed.*
How to describe World Alzheimer’s Month

It is important that we present a positive image and consistent message about World Alzheimer’s Month across all associations, groups and organisations around the world. We therefore ask members to use the following text when describing World Alzheimer’s Month.

*September is World Alzheimer’s Month, an international campaign to raise dementia awareness and challenge stigma. Each year, Alzheimer associations from around the world unite to organise advocacy and information provision events, as well as Memory Walks and fundraising days.*

The impact of this campaign is growing, but the stigmatisation and misinformation that surrounds dementia remains a global issue. This September is our time for action, when the global dementia family unites to call for and demand change.

World Alzheimer’s Month is coordinated by Alzheimer’s Disease International (ADI), the umbrella organisation of Alzheimer associations around the world.

Join the campaign! Visit [www.worldalzmonth.org](http://www.worldalzmonth.org) to see how you can get involved. Here you can find further tips and examples of previous events in our World Alzheimer’s Month campaign guide.

World Alzheimer Report 2019

Between April and June 2019, ADI commissioned the London School of Economics and Political Science (LSE) to create the *world’s largest survey on people’s attitudes around dementia*, to form the basis for the World Alzheimer Report 2019. The response from members, partners and the general public was superb, with almost 70,000 people across 156 countries and territories completing the survey.
Translations into 32 languages by volunteers from all over the world enabled a truly global reach, which will have a direct impact on the effectiveness of follow-up policy and advocacy opportunities on both a national and international level.

The report will maintain the wide appeal of the World Alzheimer Report 2019, featuring survey results alongside expert essays and case studies and is due to be released in September 2019, during World Alzheimer’s Month. Key messages and infographics presenting the survey findings will be made available in August.

ADI will be posting updates on the World Alzheimer Report 2019 on our website.

Materials and resources

Why we need you

ADI relies on the involvement of a large network of members, health-care professionals, people living with dementia, care partners, policy makers and other stakeholders worldwide to support World Alzheimer’s Month.

Individuals, groups and organisations can help us raise awareness about dementia through their networks and communication platforms with stakeholders and local communities, and by using their local, regional, national and international outreach.

Communications

- Use our World Alzheimer’s Month posters, graphics and social media assets to show you are participating in and supporting the campaign.

- Reach out and engage with groups and organisations, including Alzheimer and dementia associations – help amplify the campaign message and raise awareness.

- Develop and publish your own series of communications about World Alzheimer’s Month, such as articles or blogs, or share our graphics on how to spot the signs of dementia, risk reduction, the cost of dementia, the forecast numbers of people with dementia and, importantly, the Let’s talk about dementia message.

- Support the campaign on social media by using our World Alzheimer’s Month Social Media Banners and hashtags #LetsTalkAboutDementia and #WorldAlzMonth.

Posters

This year we have developed a much bigger set of photo-based posters for you to use and we will be adding more options, including some new graphic posters, in the next few weeks. Please use one or all of them. Visit the website for more details: www.worldalzmonth.org.

You will also find additional graphics and a summary Bulletin below (and on the World Alzheimer’s Month website) which can be used to enhance your communications, including the prevalence figures, cost figures, the warning signs and risk-reduction graphics.
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Region of the Americas upweighted dementia awareness campaign

ADI and the Pan American Health Organization (PAHO) are working together to plan and deliver a regional dementia awareness campaign for the Region of the Americas. The campaign coincides with the end phase of the PAHO regional action plan on dementia and will run during September to complement World Alzheimer’s Month. The campaign will be adapted for five languages: English, Spanish, Portuguese, French and Dutch. The additional materials are specific to the Region of the Americas but can be accessed by all at www.paho.org/lets-talk-dementia.
Let’s Talk About Dementia

September 2019 will mark the seventh World Alzheimer’s Month™, an international campaign to raise awareness of dementia and challenge stigma. This year’s campaign promotes the important messages that:

- We can all raise awareness by learning about dementia, learning to spot the signs, and taking simple steps to lower our risk of developing the condition
- People living with dementia and their care partners have an equal right to respect and inclusion, and to diagnosis, quality care and treatment
- Governments can reduce the human and economic impact of dementia by developing responses to the World Health Organization (WHO) Global action plan on the public health response to dementia by 2025

**If you are living with dementia:**
Remember that you don’t have to be alone. It is possible to live more positively with dementia than is often the public perception, by seeking support from your family and friends, health and social workers, from the Alzheimer association in your country and by joining Dementia Alliance International (DAI).

**If you are worried about developing dementia:**
Speak to your doctor about any concerns. Alzheimer associations in many countries provide support with seeking a diagnosis and living with dementia, as well as information on risk reduction and help to find support groups.

**If you are a care partner:**
Caring for someone with dementia can be challenging. It is also important to take care of your own physical and mental health needs as this will make a big difference to the well-being of yourself and the person you are caring for. Don’t be afraid to ask for help or to join the Alzheimer association in your country to advocate for change or subscribe to DAI to receive their resources, blogs, newsletters and attend their monthly educational Webinars.

**As a society:**
The stigma that surrounds dementia remains a global problem. Alzheimer associations and self-advocacy organisations encourage awareness of the social and personal impact of dementia. Dementia is not a normal part of ageing. Understanding the experiences of those affected remains important to support inclusion, empowerment and respect. Greater awareness, including recognising the symptoms of dementia, is crucial to encourage more people to seek diagnosis and receive support.

**As a government:**
Developing a national dementia plan will help your country to deal with the growing impact of dementia. In 2017, the World Health Organization adopted a global plan that urges countries to develop their own national responses. Implementing a plan helps to increase national awareness and education about dementia and can improve access to diagnosis, treatment, care and earlier detection of dementia can also help lower the financial impact of dementia on the healthcare system.

Bulletin
Bulletins are a useful tool as they summarise the campaign and key messages. They can be used for interviews and distributed at events.
What is dementia?
Dementia is a collective name for progressive brain syndromes that cause deterioration over time of a variety of different brain functions such as memory, thinking, recognition and language, planning and personality. Alzheimer's disease accounts for 50-60% of cases of dementia. Other types of dementia include vascular dementia, dementia with Lewy bodies and fronto-temporal dementia.

Most kinds of dementia have similar symptoms including:
- Loss of memory
- Problems with thinking, planning and language
- Failure to recognise people or objects
- Personality and mood changes

By 2050, the number of people living with dementia around the world will have almost trebled to 152 million, making the disease one of the most significant health and social crises of the 21st century.

Alzheimer's Disease International
Alzheimer's Disease International (ADI) is the international federation of Alzheimer associations around the world, in official relations with the World Health Organisation. ADI is the global voice on dementia and each member is the national Alzheimer association in their country which supports people with dementia and their families. Our vision is prevention, care and inclusion today, and cure tomorrow. www.alz.co.uk

Dementia Alliance International
DAI is an international non-profit organisation whose membership is exclusively for people with a medically confirmed diagnosis of any type of a dementia. It represents, supports, and educates others living with the disease, and the wider dementia community by globally representing persons with dementia. DAI’s vision is a world where people with dementia are valued and included, and is widely accepted as the global voice of dementia. To become a member of DAI, go to www.join dai.org

World Alzheimer's Month
September is World Alzheimer's Month™, an international campaign to raise awareness and challenge dementia stigma. Each year, more and more countries are participating in World Alzheimer's Month events and awareness of dementia is growing, but there is always more to do. www.worldalzmonth.org

Finding help
Support and information is available worldwide from Alzheimer associations in 100 countries. These associations exist to provide advice for carers and people with dementia. To find your Alzheimer association visit www.alz.co.uk/associations

Dementia Alliance International (DAI) hold regular online support groups and webinars for members. To find out more visit www.infodal.org

Join the campaign
To find out more visit:
www.worldalzmonth.org
@AlzDisInt #WorldAlzMonth
#LetsTalkAboutDementia

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Here are some sample messages that you can use for Facebook and Twitter. Copy and paste them or make your own!

Stigma and negative attitudes around #dementia persist in every country. This World Alzheimer's Month, we want to talk about it. #WorldAlzMonth #LetsTalkAboutDementia

Remember to use the hashtags #WorldAlzMonth and #LetsTalkAboutDementia

Social media banners
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5 ways to help reduce your risk of dementia

Research suggests that leading a healthy lifestyle may help to reduce a person's risk of developing dementia later in life. The general rule is what’s good for the heart is good for the brain, so both should be well looked after with a balanced diet and regular physical and mental exercise.

Much of what’s needed are simple activities you can include in your day to day life. Remember, it’s never too late to make any of these changes.

Below are five ways you can help to reduce your risk of developing dementia:

1. **Look after your heart**

   Smoking, high blood pressure, high cholesterol, diabetes and obesity all damage the blood vessels and increase the risk for having a stroke or a heart attack, that could contribute to developing dementia in later life. These problems can be prevented through healthy lifestyle choices and should be treated effectively if they do occur.

2. **Be physically active**

   Physical activity and exercise are powerful preventive medicines, helping you control your blood pressure and weight, as well as reducing the risk of type II diabetes and some forms of cancer. There is also some evidence to suggest that some kinds of physical activity can reduce the risk of developing dementia. The good news is that getting active is proven to make us feel good and is a great activity to do with friends and family.

3. **Follow a healthy diet**

   Food is fuel for both brain and body. We can help both to function properly by eating a healthy, balanced diet. Some evidence suggests that a Mediterranean-type diet, rich in cereals, fruits, fish, legumes and vegetables can help to reduce the risk of dementia. While more studies are needed on the benefits of specific foods or supplements, we do know that eating lots of foods which are high in saturated fat, sugar and/or salt is associated with a higher risk of heart disease and is best avoided.

4. **Challenge your brain**

   By challenging the brain with new activities, you can help build new brain neurons and strengthen the connections between them. This may counter the harmful effects of Alzheimer’s disease and other dementia pathologies. By challenging your brain, you can learn some great new things. So how about learning a new language or taking up a new hobby?

5. **Enjoy social activities**

   Social activities may be beneficial to brain health because they stimulate our brain reserves, helping to reduce our risk of dementia and depression. Try and make time for friends and family. You can even combine your activities with physical and mental exercise through sport or other hobbies.
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**ADI Members (as of July 2019)**

Contact details can be found on the ADI website: [www.alz.co.uk/associations](http://www.alz.co.uk/associations)

- **Argentina** – Asociación de Lucha contra el Mal de Alzheimer (ALMA)
- **Armenia** – Alzheimer's Disease Armenian Association
- **Aruba** – Fundacion Alzheimer Aruba (FAA)
- **Australia** – Dementia Australia
- **Austria** – Alzheimer Austria
- **Barbados** – Barbados Alzheimer's Association
- **Belgium** – Ligue Nationale Alzheimer Liga
- **Bermuda** – Alzheimer's Family Support Group
- **Bolivia** – Asociación Alzheimer Bolivia (AAB)
- **Bonaire** – Fundashon Alzheimer Bonaire
- **Bosnia Herzegovina** – Udruženje AiR/Association AiR - Sarajevo
- **Brazil** – FEBRAZ – Federação Brasileira de Associações de Alzheimer
- **Bulgaria** – Compassion Alzheimer Bulgaria
- **Canada** – Alzheimer Society of Canada
- **Cayman Islands** – Alzheimer’s and Dementia Association of the Cayman Islands
- **Chile** – Corporacion Alzheimer Chile
- **PR China** – Alzheimer’s Disease Chinese
- **Costa Rica** – Asociación Costarricense de Alzheimer y otras Demencias Asociadas (AS-CADA)
- **Croatia** – Alzheimer Croatia
- **Cuba** – Sección Cubana de la Enfermedad de Alzheimer
- **Curaçao** – Stichting Alzheimer Curaçao
- **Cyprus** – The Cyprus Alzheimer Association
- **Czech Republic** – Česká alzheimerovská společnost
- **Denmark** – Alzheimerforeningen
- **Dominican Republic** – Asociación Dominicana de Alzheimer
- **Ecuador** – Fundación TASE (Trascender con Amor Servicio y Excelencia)
- **Egypt** – Egyptian Alzheimer Society
- **El Salvador** – Asociacion de Familiares Alzheimer de El Salvador
- **England, Wales, NI** – Alzheimer’s Society
- **Finland** – Alzheimer Society of Finland/Muistiliitto ry
- **Germany** – Deutsche Alzheimer Gesellschaft
- **Ghana** – Alzheimer's and Related Disorders Association Ghana
- **Gibraltar** – Gibraltar Alzheimer’s & Dementia Society
- **Greece** – Panhellenic Federation of Alzheimer’s Disease and Related Disorders
- **Guatemala** – Asociación ERMITA, Alzheimer de Guatemala
- **Honduras** – Asociación Hondureña de Alzheimer
- **Hong Kong SAR China** – Hong Kong Alzheimer’s Disease Association
- **Hungary** – Hungarian Alzheimer Society
- **India** – Alzheimer’s and Related Disorders Society of India (ARDSI)
- **Indonesia** – Alzheimer Indonesia
- **Iran** – Iran Alzheimer's Association
- **Ireland** – The Alzheimer Society of Ireland
- **Israel** – Alzheimer's Association of Israel
- **Italy** – Federazione Alzheimer Italia

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UAE – 4get-me-not Alzheimer’s Organization
Uruguay – Asociación Uruguaya de Alzheimer y Similares (AUDAS)
USA – Alzheimer’s Association
Venezuela – Fundación Alzheimer de Venezuela
Virgin Islands – Virgin Islands Alzheimer’s Association
Zimbabwe – Zimbabwe Alzheimer’s and Related Disorders Association

Sponsors

We couldn’t achieve all that we do during World Alzheimer’s Month without the kind and ongoing support of our sponsors:

*World Alzheimer’s Month Champion: F. Hoffmann-La Roche*

*World Alzheimer’s Month Partners: Janssen Neuroscience, Otsuka America Pharmaceutical, Eisai Co Ltd*

*World Alzheimer’s Month Sponsors: Biogen, Home Instead, IQVIA*
ADl Staff

Chief Executive Officer – Paola Barbarino
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Paola is in charge of all aspects of ADI’s work. Collaborating with the Board, Paola implements finance and campaign strategies. Paola represents ADI at international conferences and in the NCD Alliance and takes part in WHO and UN meetings.

Policy, Communications and Publications Director and Deputy CEO – Chris Lynch
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Chris is responsible for ADI's policy, communications and publications strategies alongside his position as Deputy CEO. Chris represents ADI at meetings and conferences, including at the WHO and UN.

General Manager – Michael Lefevre
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Michael is in charge of all aspects of ADI's Finance and IT systems, projects, HR and governance including financial reporting, accounts and planning.

Head of Events – Jane Cziborra
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Jane is responsible for the organisation of all conferences and events throughout the year, including the ADI International Conference, regional conferences and the Alzheimer University programmes around the world.

Research and Policy Project Lead – Wendy Weidner
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Wendy is responsible for ADI’s participation in the STRiDE (Strengthening responses to dementia in developing coun-

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tries) project and other research that ADI is involved in, including liaising with ADI's Medical and Scientific Advisory Panel.

**Head of Development – Nikki Bayliss**

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Nikki is responsible for leading ADI's fundraising, including managing relationships with key donors and partners. Nikki works closely with the rest of the team to support organisational development and achieve the objectives of ADI.

**Regional Director, Asia Pacific Regional Office – DY Suharya**

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DY works from Indonesia, as the Regional Director of the Asia Pacific regional office, to foster collaboration among members, strengthening their capabilities and reaching out to non-member countries.

**Regional Director, Americas Regional Office – Joost Martens**

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Joost works from El Salvador, as the Regional Director of the Americas including Caribbean, North, Central and South American countries. He is in charge of fostering collaboration among associations, strengthening their capabilities and developing new members in the region.

**Membership Manager and Membership Development Programme Lead – Laura Dabas**

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Laura is responsible for the support and development of ADI's existing and new members, including leading ADI's Alzheimer University programme and encouraging the development of Alzheimer’s and dementia organisations in new countries.
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Communications and Policy Officer – Annie Bliss
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Annie manages ADI's communications portfolio, as well as ADI's policy engagement, including with the World Health Organisation.

Communications and Administration Assistant – Taylor Paatalo
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Taylor assists with ADI's communications, social media and newsletter.

Events and Administration Coordinator – Katie Bingham
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Katie works on events including the ADI conference, regional conferences and other meetings. Katie is also responsible for the day-to-day administration of the ADI office.

Finance Assistant – Katarzyna Pogorzelska
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Kat works part time on finance and fundraising administration.

Finance Officer, Asia Pacific Regional Office – Irma Rachmatiah
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Irma works part time from Indonesia, assisting with the financial administration of the Asia Pacific regional office.