



A Guide to planning a successful World Alzheimer's Month Campaign

World Alzheimer's Month 2022

www.alzint.org/wam

Campaign Toolkit World Alzheimer's Month 2022

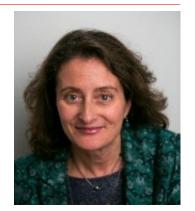
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Introduction

It's that time of the year again!!! The time when we get together and remind the world of the importance of acknowledging the existence of Alzheimer's disease and dementia and, by doing so, decrease the stigma that goes with the disease. We argue for this all year round but when our voices come together in September the overall impact is much stronger, the world media and press pays attention and we get a lot more traction. This is why World Alzheimer's Month and World Alzheimer's Day are so important.



Stigma is still one of our biggest problems in many countries, as is Governments' incapacity to accept that Alzheimer's disease and dementia are present in all countries, and that they need to take

action to make the lives of people living with dementia and their families better. Dementia is the 7th leading cause of death globally. There are over 55 million people living with dementia and the number grows every year. It possibly impacts at least 250 million people globally, probably more, given the high demands of care and the often invisible army of carers. The cost to society is over 1.3 trillion dollars and rising rapidly every year as well.

Last year 111 countries took part in World Alzheimer's Month an increase of 14% on the previous year. In 2021 we got an amazing 45 million interactions with our social media hashtags - an increase of 125% over the 20 million of 2020. With your help we aim to do even better this year. Every time our movement grows, our voices get stronger and our influence with Governments grows too. As much as our associations and civil society in general are doing an amazing job of helping both those living with dementia and their families too, it is only Governments that hold the real power to scale up diagnosis, support, treatment and care. They are the institutions we need to confront and that's when our collective voices can demand more action.

This year the key focus area of the World Alzheimer Report is post-diagnostic support, something that is often forgotten once people have been diagnosed, with terrible consequences for families who could have otherwise been prepared and connected with support groups and information that could lower the impact of a diagnosis and its aftermath. The hashtag of World Alzheimer's Month 2022 is still #KnowDementia #KnowAlzheimers and the tagline "Together we can do so much!" really encapsulates the essence of this year's World Alzheimer's Month.

When you will go out and campaign, remember that you are representing the most stigmatised and vulnerable, the most ill equipped to defend themselves and are advocating for the Cinderella of the major diseases. When you speak to the press, to your governments, to social media, you and only you are defending our cause and representing the voiceless millions who can't make their own case. So many count on us!!! I count on you!!! Please make our voices stronger. Together we can do so much!!!

Paola Barbarino

CEO Alzheimer's Disease International

Alzheimer's Disease International

ADI is the international federation of 105 dementia and Alzheimer's associations from around the world and is in official relations with the World Health Organization (WHO). 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 and dementia 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 campaigning for policy change from governments. A list of ADI members as well as the ADI team can be found on our website.

ADI advocates for the implementation of the WHO Global plan of action on the public health response to dementia 2017-2025 universally adopted by WHO member states in May 2017. 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.

Every year since the launch of the WHO Global plan on Dementia, ADI has published a progress report entitled 'From Plan to Impact' documenting the progress of Member States towards achieving the targets set out in the plan. To learn more about ADI's advocacy and research work please visit our website.

ADI also engages in awareness raising and the destigmatisation of Alzheimer's disease and dementia through various activities but most notably through its **World Alzheimer's Month** campaign.



Decade of WAM











A decade of World Alzheimer's Month: A selection of materials from the last 11 years

September 2022 will mark the eleventh **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 engage as many countries as possible, to to adopt all seven action areas of awareness raising activities and achieve a primary commitment from all countries adopting the WHO Global action plan on dementia. The month of activities shows a truly global, regional, national and local level response to promote dementia awareness and what we can do to help support those living with the disease.

Know Dementia, Know Alzheimer's

The focus for this year's World Alzheimer's Month campaign is post-diagnostic support, stimulated by recent developments and potential breakthroughs, in both dementia treatment and support. This campaign is intended to follow on from where last year's campaign finished at the point of diagnosis.

The World Alzheimer Report 2022 is also focused on post-diagnostic support and will launch on World Alzheimer's Day (21 September 2022). Through its rigorous approach we will be looking at the role of government, healthcare professionals and civil society in post-diagnostic support. We will also be highlighting gaps, and shining a light on the experiences of people who are living with dementia and their families. Throughout World Alzheimer's Month we will continue to empower more people to join our movement as 'Together, we can do so much'

This builds on the 2019 World Alzheimer's Month theme of 'Let's Talk About Dementia,' aimed at raising global awareness around dementia and challenging the stigma that continues to persist globally.

The campaign theme *Know Dementia, Know Alzheimer's* is all about the power of knowledge. Once you know more about dementia, you are armed with information, advice and support and are better able to prepare and to adapt. Knowledge is power!

You will see from the campaign materials and toolkit below, the combination of approaches, using both the *Warning Signs* and the theme *Know Dementia, Know Alzheimer's* is very effective.

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 and dementia associations, alongside all those involved in the treatment, care and support of people living with dementia, 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.

Join the campaign! Visit www.alzint.org/wam 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.

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 and are 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

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 dementia, with some limited treatments, focussing attention on the importance of care, information, advice and support.

Every 3 seconds, someone in the world develops dementia. The number of people living with dementia around the world is over 55 million, which is expected to almost triple to 138 million by 2050. The annual global cost of dementia is over US\$ 1.3 trillion annually, which will more than double to US\$ 2.8 trillion annually by 2030.

Dementia is now the 7th leading cause of death worldwide

An absence of dementia public policy renders governments woefully unprepared for the dementia epidemic. 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. It is vital that all governments create and fund national dementia plans, in line with the WHO Global action plan on the public health response to dementia.

For more information, visit: www.alzint.org/about

Key messages

Dementia & post-diagnostic support

- Dementia is not a normal part of ageing.
- 2. Post-diagnosis support can help to enable independence, and facilitate living at home and in the community for as long as possible.
- 3. In many parts of the world, post-diagnostic support is insufficient, difficult to access or not available at all.
- 4. 50% of the costs for dementia are related to informal care.
- The annual global number of informal care hours provided to people with dementia living at home was about 133 billion hours in 2021. This is the equivalent of more than 67 million full-time workers.
- 6. Women provide a substantial proportion of informal care to people with dementia, with around two thirds of primary caregivers overall being women. This figure is significantly higher in LMICs, areas which will account for 71% of the global prevalence of dementia by 2050.

- 7. In low and -middle-income countries, 90% of the care for those living with dementia occurs in the home.
- **8.** Even in the absence of a cure or disease modifying treatment, there are still medications which can help with some of the symptoms.
- 9. Non-pharmacological and psychosocial supports are vital to maximize independence.
- 10. Evidence suggests that when people with dementia and their families are well prepared and supported, feelings of shock, anger and grief are balanced by a sense of reassurance and empowerment.
- **11.** National dementia plans are the best tool governments have available to tackle dementia and should have a strong focus on post diagnosis support at their heart.
- **12.** Support for carers is integral to strong post diagnosis support.

Statistics

- 1. There are over 55 million people around the world living with dementia.
- 2. Someone in the world develops dementia every 3 seconds.
- 3. The number of people living with dementia is predicted to almost triple, rising to 139 million by 2050.
- 4. The economic burden of dementia is US \$1.3 trillion dollars every year, a figure that will more than double by 2030.
- 5. Almost 62% of healthcare professionals worldwide wrongly think that dementia is part of normal ageing.
- 6. Almost 80% of the general public are concerned about developing dementia at some point and 1 in 4 people think that there is nothing we can do to prevent dementia.
- 7. 35% of carers across the world said that they have hidden the diagnosis of dementia of a family member.
- 8. Over 50% of carers globally say their health has suffered as a result of their caring responsibilities even whilst expressing positive sentiments about their role.

COVID-19 and dementia

- 1. The COVID-19 outbreak has highlighted the lack of preparedness of health systems globally to provide routine services and support to people living with chronic conditions such as dementia.
- 2. During lockdown and restrictions, it is essential that older people, especially those living with dementia, are not socially excluded.
- 3. During the COVID-19 pandemic, it is imperative that people keep talking about dementia, seeking out information, advice and support.
- 4. Do not wait until after lockdown or restrictions end to speak to your doctor about experiencing symptoms of dementia. Speak to your doctor and contact your national Alzheimer or dementia association.
- During COVID-19, talk to your national Alzheimer' or dementia association. If available, consider using their helplines, websites, social media and online events to stay up to date with advice and information about support.

Advocacy

- 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.
- 2. 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. Awareness raising is one seven key action areas of the plan with a target of 100% of Members States delivering national campaigns by 2025.
- National dementia plans are the best tool available to governments as a robust response to dementia in their countries. Currently there are just 40 national dementia plans (32 from WHO Member States).
- 4. Robust, post diagnosis support models can enable governments and healthcare systems to better support people living with dementia and can be cost saving, delaying or reducing hospital and care admissions and enabling people and carers to stay in work, careers and education.
- 5. September is World Alzheimer's Month, an international campaign to raise dementia awareness and challenge stigma. Each year, Alzheimer and dementia associations from around the world unite to organise advocacy and information provision events, as well as Memory Walks and fundraising days.

Timeline

Late June: World Alzheimer's Month Toolkit and campaign materials available

Late June: World Alzheimer's Month Bursary Application opens (member associations)

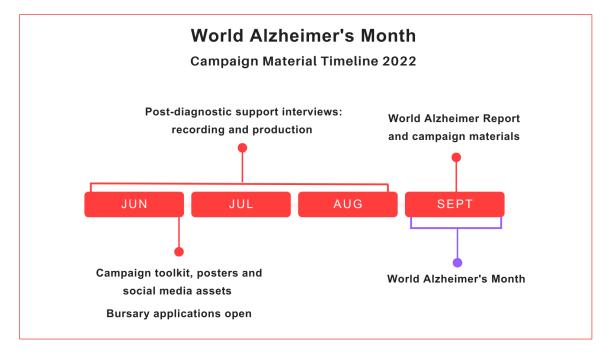
June-July: Filming of video vignettes – testimonials of the diagnosis experience globally

July: World Alzheimer's Month Bursary Application opens (member associations)

August: Media and Social Media Training delivered by Edelman & Mana Communications

September: World Alzheimer's Month

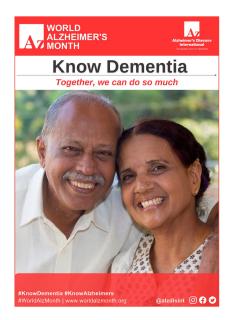
21 September: Launch of the World Alzheimer Report 2022 and World Alzheimer's Day



Campaign Materials

This year we are making available posters, social media cards, infographics, video vignettes and specific information relating to the World Alzheimer Report available. For 2022 we have introduced new posters and social media cards and refreshed those that worked best in 2021.

As an international organisation, we recognise the importance of diversity in our materials, which is why this year's selection has continued to maintain these diversity, including a new selection of materials to encompass those with disabilities in addition to dementia.

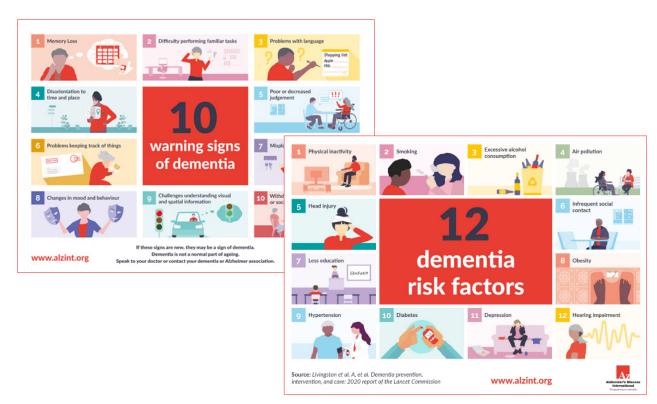






10 Warning Signs of Dementia infographic

Last year we have refreshed our '10 Warning Signs of Dementia' infographic which visually depicts 10 of the most common signs which may be related to the onset of dementia. Additionally we also have a poster which depicts the 12 modifiable risk factors for dementia.



Social Media banners

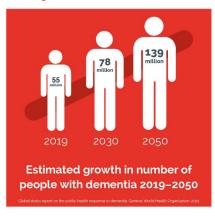
As with the posters, we refreshed the photo-based social media cards and resized them so that they comply with new social media specifications. Some examples have been included below but please visit the website for the complete set: www.worldalzmonth.org.

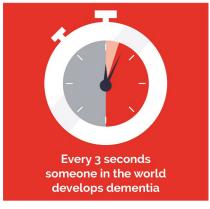


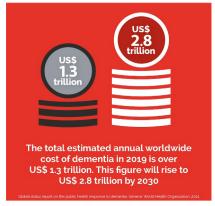




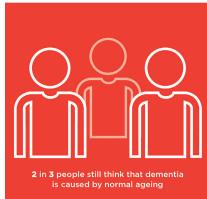
Graphics

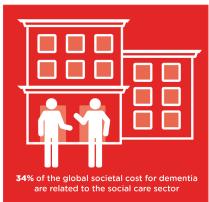


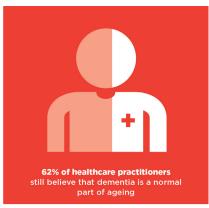


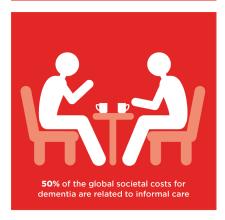


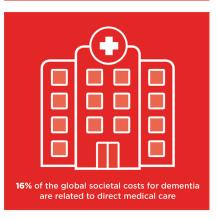












Organising an event

A successful event will allow you to deliver your message to your key target audiences while helping to build your public profile. It is important to ensure that people coming to your event are aware of why they should participate, are given plenty of notice and have a smooth and well-organised day. Some of our members have been running events for over 25 years and so have gained a lot of experience about what works and what does not. Below are some of their tips for running a successful event.

Please only organise in-person events if you feel safe to do so and if social distancing measures in your country permit public gatherings.

Before the event

Identify both your target audience and your potential partnerships. Decide who you want to influence with your campaign – it could be policy makers or the population at large. Then, identify individuals and organisations interested in planning World Alzheimer's Month activities and make partnerships with them. Some ideas include: hospitals, senior citizens groups, schools, colleges, universities, women's groups, religious groups, ageing charities, those working in non-communicable diseases and mental health groups.

Choose an activity with clearly defined and achievable objectives. Without objectives, you cannot measure whether your event has been a success or not. Examples may include, hosting an event where 50 people attend or securing the attendance of a high ranking official

Be realistic about what your association can undertake. The human and financial resources that are required should not be underestimated. It is better to run a small, successful event than a bigger, more chaotic one.

Publicise, publicise, publicise your event! Use social media, flyers, posters, announcements, TV and radio, newspaper and newsletter advertising to make sure that the widest audience possible knows about your event – and wants to come!

Delegate: be clear who is responsible for what. Give people deadlines for completing their tasks and have regular meetings to check the progress being made.

Invite people to your event. Who you invite will depend on your target audience. You could invite your top health official in government, such a Minister of Health, if you are advocating to your government. Invitations themselves serve to raise awareness and encourage people to become involved. A follow-up phone call is often an effective tool

On the day

Having an event that runs smoothly is vital, whether it takes place inperson or virtually. **Hold a meeting before the event with all those involved** to run through the timetable for the day, contact details for key staff and arrangements for the media.

Ensure your staff are well briefed about their responsibilities, what to do in the case of an emergency and what message you are trying to promote to those attending. They are ambassadors for your association.

Emphasise the global aspect of World Alzheimer's Month. Draw attention to the work being done both by your association and by ADI.

TIP

Struggling for Ideas? Look at our World Alzheimer's Month Reports for inspiration **Engaging the media** Brief your spokespeople and your photographer. Spokespeople should have a list of talking points and be well versed in your key messages. The photographer needs to be aware of what is expected of him/her.

After the event

Remember to say thank you to all the people who made your event possible and memorable! This may include sponsors, invited guests and volunteers. This will make people feel valued and encourage them to support your association in the future.

Evaluate your activities. This can be done easily by preparing a simple questionnaire collating the views of helpers and those participating. Were the defined objectives achieved? What was a success and what are your learning points? Do those who attended have a better understanding of dementia? Have their questions been answered? This process is essential to build on the achievement for future World Alzheimer's Month campaigns.



DY Suharya, ADI Regional Director for Asia Pacific, with Elphie the Elephant, the ALZI mascot, on World Alzheimer's Day in Jakarta, Indonesia

Virtual events

Below are some examples of platforms for virtual events that ADI has tried and tested. However, there are many platforms and applications that have been developed in response to the renewed necessity for virtual interactions, so please look into these as well. Be sure to check the platform is secure, using a meeting password where possible.



When choosing the right platform, it is important to check that it has the features you need for the event or meeting – for example, chat, Q&A, live polls, the ability to share screen, slides or video, breakout rooms etc. These interactive features can be very important to engage your audience and receive feedback. It is worth considering what your audience is and how important various elements of interaction are – in particular whether the platform is dementia friendly.

- Zoom Suitable for large events; a range of subscription options, including a free version which holds up to 100 participants.
- Google Hangouts Free; suitable for smaller meetings or calls, up to 25 video participants but up to 150 people can participate in the chat
- Skype Free; suitable for smaller meetings or calls, up to 50 people.
- WhatsApp Free; suitable for smaller meetings or calls.

Choose the right time and date

Once you have defined your audience and chosen your platform, the next consideration is when to schedule the event. If you are aiming for a global audience, a time which captures the most time zones could be a good option. Using an app like **Timeanddate.com** can be useful for letting your audiences know when the event is happening in their time zone. Do some research to ensure there are no other major events or public holidays happening on that day which may detract from your event. Live tweeting during the event as well as making recordings available are a useful way of reaching a larger audience with your information provision and awareness raising.

Promoting your event

This step should not be overlooked! With so many events taking place online now, it is important that you market your events effectively, so they are in people's calendars early. Make sure to provide key information on the event, such as any fees or donations, speakers, activities, duration, and the motivation behind the event. Platforms such as Eventbrite (or even a simple Excel sheet) can be useful for gathering information such as names and occupation so you know who to expect on the day.

It is important to select the most effective channels for sending out this information. Social media, email and newsletters are a good place to start, but it is important to tailor the information to each communication channel. Creating clear and eye-catching graphics is an effective way to grab attention, and you can utilise video content to explain sign-up and introduce the aims of the event – essentially to get people interested and excited for the event! It's also a great way to fundraise.

On the day

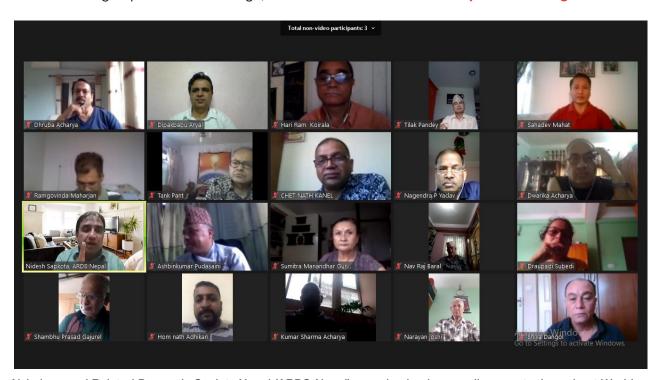
The most important thing is that your event is engaging. An engaged audience is more likely to take something away from the event, and importantly to donate. Just as you would with a live event, pose questions to your audience using the chat, Q&A or poll functions. Encourage discussion and sharing of knowledge, ideas and experiences. You can achieve this by breaking the discussion into smaller groups, and by selecting speakers who can pre-prepare their points.

Set a clear time and break up the session as much as possible. It will be difficult to maintain the audience's attention during events which run over 90 minutes, so we recommend limiting it to 60-75 minutes if possible. It is important to provide breaks and encourage people to get up and stretch if the session is predominantly seated. Also be sure to run through the general 'house-keeping' rules to note to ensure the event runs smoothly.



After the event

The most important thing to do after your event is to thank your attendees, including any other organisers, participants, speakers and any sponsors or funders. Giving a summary of the event can be useful way of leaving people with defined outcomes. Encourage sharing of the event on social media, including providing the recording and/or slides. A survey can be useful to understand what can be improved for next time, and also to provide any funders with testimonials. Make sure you have the correct permissions for saving the data of participants and ask them to sign up for future mailings, in line with **international data protection regulations**.



Alzheimer and Related Dementia Society Nepal (ARDS-Nepal) organised a dozen online events throughout World Alzheimer's Month

Call to Action: Lighting famous landmarks in purple

We encourage our members to request to have landmarks lit up to commemorate World Alzheimer's Month or World Alzheimer's Day. For example, as a consequence of the COVID-19 pandemic we have seen the lighting up of large monuments such as the Empire State Building, the pyramid of Khufu and the Shard in recognition of the contribution of healthcare workers.

If you aim to request that buildings and landmarks be lit up in purple (or whatever colour you feel is most representative of dementia in your country) as a symbolic gesture of your country's commitment to supporting people living with dementia and their carers, please be sensitive to the current pandemic and do not be surprised if you are met with more resistance than usual. You will also have to consider how many people will be able to see the monument without usual access to public transport, etc., but sharing the images on social media is a wonderful way to extend the reach of the message. Your local TV or print media may also want to cover the story.

- Landmark officials receive many requests to have landmarks 'lit up' in acknowledgement of different events and causes (especially since the global COVID-19 pandemic). Some landmarks may not facilitate this, due to being 'listed' buildings, already having an existing partnership with a particular charity or without wanting a fee. Do not be disheartened.
- A phone call is always advisable. Alternatively, check the website of the landmark; some
 more established landmarks, such as the Empire State Building, have a dedicated section
 on their website to lighting requests. If you are unable to find the correct information, e-mail
 is always the next best step.
- The best person to speak to will always vary but customer service, the operations department or the publicity department is always a good place to start and they may be able to point you in the right direction. With smaller venues, it is likely you will need to discuss with the manager. When writing your request, it is always a good idea to make your email/letter more personal by sharing your reasons for taking part in the campaign and why it is so important to you. Use your existing contacts!
- If you have organised the building to be lit up far in advance (this is advisable), make sure you get in touch again nearer the time, just to ensure it is still fine to go ahead.







Examples from World Alzheimer's Month 2021. From left Jakarta's National monument (Indonesia); Contraloría General de la República de Panamá and İzmir Clock Tower (Turkey)

Fundraising

Fundraising can be an important part of any event and has the potential to make an incredible impact on ADI and our membership organisations' ability to raise awareness and reduce stigma. We have created a bespoke **World Alzheimer's Month fundraising pack** filled with useful hints and tips to boost your fundraising. Whether you're an individual taking on a challenge of a lifetime this September, friends wanting to get together or a company promoting a team building activity – we have something to suit everyone.

We know that social distancing and travel restrictions may make fundraising more difficult, but here are a just few ways you can fundraise virtually for World Alzheimer's Month:

- Hold a virtual quiz: A quiz night can be held virtually providing a great way to catch up with
 your loved ones and boost people's spirits. Host a quiz online and ask your friends to pay to
 play.
- **Donate your commute**: With so many people working from home, we are saving huge amounts in travel costs, not to mention time! You could donate a week's travel to ADI.
- Wear it red, or purple, or orange all virtually! Rock your association's coloured shirts, t-shirts or hat for a whole week and get sponsored to do so. Update your social media and let your followers see what you're doing
- Virtual coffee morning: Partner with a business or host your own virtual coffee morning, where people donate the cost of their favorite drink to charity. It is also a great way to keep your supporters and sponsors engaged with your activities.
- **Virtual race day:** encourage your supporters to run either outside or on a treadmill at the same time. Afterwards, have a live-stream event to celebrate the accomplishments of your participants and of course congratulate the winner. Money can be raised through event registration and sign ups.
- **Birthday fundraiser**: With so many of us unable to celebrate our birthdays why not ask people to donate the money they would have spent celebrating with you to ADI and help thousands of people worldwide living with dementia.
- Virtual memory walks: Hold a sponsored memory walk. It is a fantastic family and socially distanced way of raising money to help people living with dementia and their carers.



Singapore - Alzheimer's Disease Association organised 'Walk2Remember



Alzheimer Scotland Memory Walk Big Weekend 2020 - your walk, your way!

Working with your government

Organising a successful meeting with government ministers and officials

Thoroughly research and prepare for your visit. Be clear about the purpose of your visit and what you want to achieve. Develop, rework and refine your messages in advance. Keep on top of policy developments (e.g. If there is a change in top health official in government, such a Minister of Health, are they supportive of dementia?)

- · Let the official express his or her point of view.
- Public officials, whether elected or appointed, have many parties competing for their attention. Use your time constructively and work on your presentation while you wait your turn.
- Public officials and their staff are human and expect common courtesy. They may be more helpful if you treat them with respect.

You can ask ADI to

or contact with the

Ministry of Health.

write a letter of support

to facilitate a meeting

- Get to the point quickly. Show that you know how valuable their time is.
- Keep it simple! Don't be too technical, too detailed, too complex, or too indirect. Get to the point, cover the basics and make sure the official understands your main point.
- An unwieldy group can make everyone uncomfortable, distract from your message, and
 waste valuable time getting set up. Make certain that the group has already decided on a
 spokesperson and stick with that decision.
- If possible, include a person with dementia or a care giver the voice of lived experience is powerful.
- Your reputation is everything, so try to be as prepared as possible before entering a meeting.
- Always ask for the official's support.
- Remember to call/send a note of thanks to the person you visited to remind them of your visit. You could also send them a Tweet to thank them or remind them of the discussion.
- Follow up your visit with a phone call or subsequent letters if your requests are not met.
- Public officials are busy but are more likely to take notice if you make your presence felt through frequent correspondence.
- Make use of facts, statistics, case studies, stories and involve people with dementia and their carers.



The Chief Minister of Gibraltar, Fabian Picardo, recorded a video message for World Alzheimer's Day

- Watch the 'Principles of Advocacy' online masterclass delivered by Glenn Rees, Honorary
 Vice President of Alzheimer's Disease International, in English and in Spanish (Al captioning
 is available for most other languages on YouTube but these may not be perfect).
- Watch the 'Update on the Global Dementia Action Plan' online masterclass delivered by Dr Katrin Seeher, Technical Officer, Department of Mental Health and Substance Abuse, World Health Organisation (WHO), in English.

How to get people to participate in your advocacy and public policy events

- The number of people you attract to your event in important. The size of your group at an event speaks volumes about your message and cause.
- Call your board members, support group leaders and service providers you have good relationships with. They are great sources of people who understand your message and will be more likely to help recruit others to attend your event.
- Lack of transportation and difficulty in finding care arrangements can be barriers for carers who want to attend functions. If you can provide assistance with these obstacles, do!
- A senior association person (board member, staff) needs to be visible at the event to 'shepherd' participants, troubleshoot, and assure they know the role of the group's presence.



- Identify and prepare a media spokesperson.
- Security is usually taken very seriously especially when visiting government officials. When information given to you about an event is said to be 'confidential', it is so for a reason. Keep it that way.
- Give the best information possible to all attendees.
- Call and ask participants directly to attend an event. Don't just assume an invitation or flyer will get people to come when you need them.
- Don't forget to say 'thank you' to all carers and speakers who attend an event. A simple 'thank you' goes a long way to assuring their support in the future.

Media

World Alzheimer's Month is an important time for media activity for your association. It is an excellent opportunity to get TV, radio and newspaper coverage and to let people in your country and area know that your association exists to support local people with dementia and their carers.

Suggested media to target

- National, regional and local daily and weekly newspapers
- Broadcast media including TV, radio stations and online broadcasters and influencers
- Health and life-style magazines
- Trade journals e.g. dementia journals, care journals, non-profit journals
- Medical journals e.g. journals targeting general practitioners, nurses, psychiatrists
- National, regional and local television networks
- National, regional and local radio stations

Suggested messages

Before contacting the media, you need to be clear what your key messages are and who you are trying to reach with this message.

Here are a few suggestions:

General Public

- If you are worried about your memory, speak to your doctor
- Contact your local Alzheimer or dementia association who will be able to provide you with information, support and details of any services available in your area
- Although there is no cure at present, some treatments are available, and a diagnosis provides an opportunity to discuss dementia and plan for the future to maximise your quality of life

People with dementia and carers

- Make contact with your local Alzheimer or dementia association

 we can provide information and support to help you
- If you are a carer, remember to take care of yourself



Press article featuring Dr Hamed Al Sinawi, Oman Alzheimer's Society

Government/policy makers

- The number of people with dementia is set to increase dramatically as people live longer. Develop appropriate services to support people with dementia and their families now
- Our association represents people with dementia and their families and can help advise you on what actions to take

Medical professionals

- Memory problems are not a normal part of ageing. If a patient is worried about their memory or is disorientated or confused, do not dismiss their symptoms – investigate the possible causes
- If you diagnose a person with dementia, give them and their carer the contact details of the local Alzheimer association
- Update your knowledge of diagnosing, managing and treating dementia and consider being a medical advisor to your Alzheimer association

Always plan your media strategy before you begin anything else.

- What is your goal?
- Target audience
- Time frame
- Do you need a budget?
- What will success look like?

Starting out

It seems obvious but having knowledge of your organisation, what it stands for, its goals and current strategies to achieve them is vitally important.

Ensure all potential spokespeople are equipped with easy messaging, key messages and some notable statistics that they can use. This gives a great starting point to any interview and provides a good point of reference. This does not need to be extensive, try and keep it to 5 bullet points that are always relevant.

As well as knowing your organisation and its objectives, also know your target audience, target media outlets, and your internal stakeholders. These lists will come in very handy during media outreach.

The media landscape is changing. Long gone are the days of long lunches and easy deadlines. Journalists are under constant pressure to do more with less time.

While this does make it harder to get a story covered, with some organisation and preparation you can put yourself ahead of the pack. There is a genuine appetite for dementia related news, especially with a human-interest angle. Journalists will often take an easy story option, so make it entertaining and informative, ensure you have quotes already in your media release and provide a third-party or 'case study' to emphasise your point from an outsider perspective

Will they notice my email? Will they like me? Will they eat me alive?

This is part of your journey into the media landscape. Every journalist, broadcaster and publication is different. Some have odd habits and expectations, others are easy-going, the better you understand them, the more likely they are to respond.

The biggest tip we can give is that 'the phone is your friend'. You can't treat media relations like the workplace, an email, in most cases, will not suffice.

Remember, journalists can receive hundreds of emails per day, they may not see yours, they might have been busy at the time of sending or maybe your headline didn't capture their attention enough to warrant opening it.

TIP

Journalists love local case studies

By calling the journalist, you get their attention. Now it's your time to shine!

Keep it short, sharp and simple. Check if they got the email, tell them why they should cover the story and what you can provide them.

You will often get told 'we'll see how it goes' or 'we'll get back to you' - they often won't. Keep calling until they say yes, or no. Sometimes they might yell, or slam the phone. Sometimes they might not be interested, it's ok. Don't let it discourage you, be persistent and you will get results.

Top Tips

Understanding the media is one thing, but generating media coverage is another! Here's some things you can do to give yourself a better chance of achieving coverage.

- 1 Research the publication or broadcaster and let them know you follow their work. They'll appreciate the attention.
- 2 Know your content! If you're pitching it, you better know how to sell it! Practice before you call.
- 3 Identify your spokesperson and PR/Media contact. Brief them beforehand to gain insights.
- 4 Organise having someone share their story as a case study, check their availabilities and brief them on key-messages. Lived experience is very powerful, the voices of people with dementia and carers are often emotive and persuasive. Professionals, including doctors and nurses are also very attractive to the media. Ensure all resources are prepared - photos (including headshots), video, statistics and graphs.
- 5 Are there any local events that you can link-in with? Alternatively, will your story clash with another local event?
- 6 Have you contacted key stakeholders before media? Send them an FYI, they'll appreciate it!
- 7 Have you contacted the Mayor, Minister or other people of influence? They might just be free!
- 8 Prepare a file to note down for each journalist's response. It will help for the next time you pitch.

Key Messages

Key messages are vital in media relations, whether it be in a media release, interview, quote or on the website. Key messages are talking points that you can repeat with gusto as often as possible. It promotes the organization or mission/goal in a compelling and informative way.

Another great use of key messages is that they can come in very handy during interviews. On occasion, your spokesperson may get lost, confused or hit with a hard to-answer question. Having a few ready-made key messages that they can say easily and precisely, without effort or thought, can be extremely useful.

This list should not be extensive, three to five usually works best. They should be able to be recited as easily as their own birthday. And add in key messages about your own country.

Some example key messages to include:

- Every 3 seconds someone in the world develops dementia
- Dementia costs US\$ 1.3 trillion per year and is set to more than double to 2.8 trillion by 2030
- Dementia is the 7th leading cause of death worldwide
- The annual global number of informal care hours provided to people with dementia living at home was about 133 billion hours in 2021
- Informal dementia care provided is equivalent to 67 million full time workers
- Women provide a substantial proportion of informal care to people with dementia, with around two thirds of primary caregivers overall being women. This figure is significantly higher in LMICs, areas which will account for 71% of the global prevalence of dementia by 2050
- Most people with dementia do not receive a diagnosis or post-diagnostic support
- Today, more than 55 million people worldwide are living with dementia
- As populations continue to age, the prevalence of dementia is expected to increase to 139 million people by 2050
- National dementia plans are the best tool governments have available to tackle dementia and should have a strong focus on post diagnosis support at their heart
- Support for carers is integral to strong post diagnosis support



Alzheimer's Disease International World Alzheimer's Month

Organising a media event

An effective means of getting media coverage for your event is to hold a news conference or a media event. Use the following check list to help you organise one:

- ✓ Invitation list print press, radio, television, online. Don't forget your own spokespeople or stakeholders.
- ▼ Time and date try not to compete with other events.
- ✓ Photo/Video opportunity.
- ✓ Call back the invited press to confirm their attendance.
- Media kit include media release, biographies, background, factsheet, photographs etc.
- ✓ Anticipate possible questions from the media and prepare answers.
- Focus all answers on a small number of key messages.
- ✓ On-site arrangements room/area booking, name signs on the podium/table for speakers, audio/visual equipment.
- Refreshments if desired.

Speaking to the media

Before the interview

Ask the interviewer why they want to interview you, establish how much they know about the subject and what more they want to find out. Ask the interviewer what their first question is going to be - so that you have a moment to prepare. Try to identify who else they might be interviewing on the subject and find out all you can about the publication or programme they are working for.

The better you know your interviewer, the more relaxed you'll be and the better you'll perform. At the very least you should remember that journalists generally work at great speed and under intense pressure. They have to find a colourful angle that will attract the reader or viewer. If you can help them do that and remain true to your own organisation, you've got a much better chance of being asked back.

Don't go into an interview before you've prepared some notes on the subject you will be talking about. If a journalist comes on the phone for an immediate quote promise to call back and spend at least a few minutes preparing your quote.

You might have several points to make but at the very most your audience will remember two or three. The less you say, the more they'll remember, so try to identify the issues and subjects that will appeal most to the audience.

During the interview

Remember the principle of the 3 Cs: Confidence, Clarity, Control

Confidence - Have confidence in your own knowledge. You know your subject better than the journalist.

Clarity - Use a clear, conversational style. Establish a maximum of three key messages and illustrate your points with anecdotal examples for credibility. Avoid jargon.

Control - Take charge of the interview. Preparation is the key. No such thing as a wrong question, only wrong answers. And use the ABCD technique:

- A. Acknowledge and Address the question. 'That is a good question', Yes, no, I don't know, I'm not able to answer that.
- B. Bridge. However, what I can tell you is.. let's be clear.. great question, I'll start
- C. Control and Clarity. Key messages from your interview brief
- **D.** Dangle. What's really interesting is... (Shape the story in your direction)

Writing a media release

Format and style

Use the organisation's letterhead and an agreed format, double-spacing, on one page, two at the most. 'Media Release' and date in large print at the top. Include the name and title of the person for whose attention the release is.

The style throughout must be concise, journalistic, as catchy and intriguing as possible. Imagine the reader knows nothing about your organisation. Does this story stand out? Is it clearly of interest to readers/viewers? In short, is it tempting to an editor inundated with press releases daily?

Heading/Title

A catchy, short title giving a sense of the story in very few words.

First paragraph

Absolutely vital that it be short (ideally no longer than 30 words), to the point and newsworthy. It must clearly state the 'five W's': Who, What, Where, When and Why (in any order). This paragraph should be able to stand on its own as a concise piece of information.

Second paragraph

Provide the next piece of information: either more details about the above, or new information.

Third paragraph

This paragraph should be an effective quote from someone involved who is willing to talk to the press if requested. The quote must add a new dimension and key messaging.

Additional paragraphs

This should be necessary information that is essential to the story OR additional spokespeople contact details

Name, title, telephone number and home or mobile phone should be included in clear, bold print at the bottom of the document.

Additional information

Describe your association in a few words. Give the basic statistics and background information about your association (e.g. when it was formed, number of branches).

Sending images to the media

Images are best attached as jpegs. If images are too large, use WeTransfer or the journalist's preferred method.

We have included an example press release below from last year's World Alzheimer's Month campaign. A new one for this year will be circulated before September 2021.



EMBARGOED UNTIL 00.01AM 1st SEPTEMBER 2021 (GMT)

COVID-19 could be a 'Trojan horse' causing future waves of dementia, global experts investigate

- ADI warns that COVID-19 could further add to the dementia pandemic, urges the WHO, governments and research institutions to prioritise research on link between COVID-19 and dementia
- Research suggests neurological impact of COVID-19 can accelerate dementia symptoms and related brain pathology
- Prominent global dementia experts from ADI's Medical and Scientific Advisory Panel form investigative working group to research concerning link between long-COVID and dementia
- Globally, millions could face increased or accelerated risk of dementia, as a consequence of long-COVID, knowing the warning signs of dementia now more important than ever

LONDON - 1 September 2021: At the start of World Alzheimer's Month, Alzheimer's Disease International (ADI), the global federation for over 100 Alzheimer's and dementia associations across the world, is calling on the World Health Organisation (WHO) and governments to urgently fast track research on the potential impact of COVID-19 on increasing dementia rates.

Emerging research is showing that the neurological impact of COVID-19 on the brain can increase both a person's likelihood of developing dementia, and the rate that dementia-related pathological changes develop in the brain. ADI has established a working group of leading dementia researchers to investigate this emergent field.

Recent <u>research</u> revealed at the 2021 Alzheimer's Association International Conference (AAIC) indicates that some patients who had COVID-19 may experience an acceleration of Alzheimer's Disease/Alzheimer's Disease-Related Dementias symptoms and pathology.

This research shows that serum biomarkers of neuronal injury, neuroinflammation and Alzheimer's disease correlate strongly with the presence of neurological symptoms in COVID-19 patients.

ADI CEO, Paola Barbarino, says that most governments around the world are not prepared for the oncoming wave of dementia, or the additional impact from COVID-19.

"Many dementia experts around the globe are seriously concerned by the link between dementia and the neurological symptoms of COVID-19," says Barbarino. "Even before COVID-19 and this emerging risk, forecasts estimate dementia cases to rise from 55 million to 78 million by 2030, with costs rising to US\$2.8 trillion annually. We urge the WHO, governments and research institutions across the globe to prioritise and commit more funding to research and establish resources in this space, to avoid being further overwhelmed by the oncoming pandemic of dementia."

ADI's Medical and Scientific Advisory Panel (MSAP), consisting of 75 global dementia experts, has formed a working group of scientists and medical professionals to help understand the magnitude of the problem and make recommendations on how to deal with it.

"We have a global grouping of the world's most prominent dementia researchers and experts who have established a working group to look at this emergent field of research," continues Barbarino. "Our MSAP working group will liaise with other international working groups, including one led by the

Social media

One of the most powerful ways to help us spread the message for World Alzheimer's Month is through social media. Below you will find some social media banners and example posts which you can use or adapt.



Twitter

@AlzDisInt Interact with us on Twitter and use the official World Alzheimer's Month hashtags **#KnowDementia #KnowAlzheimers #WorldAlzMonth**. Be sure to mention @ AlzDisInt so we can share your messages.



Facebook

/alzdisint Be sure to like our Facebook page and share our posts about World Alzheimer's Month. Connect with us and share your activities, updates and photos, and you could make it into our official campaign photo album.



Linkedin

linkedin.com/company/alzdisint



Instagram

instagram.com/alzdisint



Youtube

youtube.com/user/alzdisint



This #WorldAlzMonth & beyond, it's important that you & your loved ones #KnowDementia & #KnowAlzheimers warning signs

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

- September is World Alzheimer's Month! This #WorldAlzMonth, join us and @AlzDisInt in helping to raise dementia awareness around the world. #KnowDementia #KnowAlzheimers
- If you are concerned that you or a loved one is showing symptoms of #dementia, it's
 important that you talk to a doctor, even during #COVID19. This #WorldAlzMonth,
 #KnowDementia warning signs
- Dementia is not a normal part of ageing, so getting a timely diagnosis can help you take control and plan ahead. This #WorldAlzMonth, we should all #KnowDementia and #KnowAlzheimers

Remember to think about including visuals when posting your messages. **Social media messages with pictures and videos are more likely to be seen and shared by your audience.** You can use and adapt our social media banners at: **www.alzint.org/wam**.

Remember to use the hashtags

#WorldAlzMonth, #KnowDementia and #KnowAlzheimers

Social Media Tips

- Keep language clear, friendly and positive. Don't write too much in one post, summarise
 what you want to say and then link to an external site to provide more information if needed.
 Be sure to always stay on message
- Use colourful, high quality images or videos to catch attention! When we look at social media, our attention span is often much shorter, so people may not notice your posts if they don't include engaging visuals (e.g., bright graphics, animations, a video)
- Be creative with your campaigning, don't be afraid to try something new!
- Post your content on a regular basis. Be sure to spread out your posts, so that they don't overwhelm your followers
- Think of innovative ways to engage your followers by starting debates and interactive campaigns, such as utilising platform features (i.e. Twitter polls and Facebook Live). What would make you stop and read a post or Tweet, or get involved with a campaign?
- If you can, ask one or two volunteers or staff members to manage your social media accounts. This will help in making sure that posts aren't replicated and management is clear
- Ask questions of your audience! Ask them to engage, leave comments or share your message

Social media best practices

Facebook

- Used as a means to connect with users via friends, co-workers, and others who share similar interests or who have common backgrounds
- People will 'Like' your page which then means your posts will appear in their News Feed (homepage). They can then comment or 'Like' posts and most importantly, share them with their Facebook friends
- You can also connect to similar or supporting organisations and global networks like ADI so you can see their updates in your own News Feed
- Emotion-driven content, including video, performs particularly well on Facebook.
 (A good example of 'emotion-driven content' is the popular Instagram account 'Humans of New York')
- Be sure to like our Facebook page and share our posts about World Alzheimer's Month.
 Connect with us and share your activities, updates and photos on our wall and you could make it into our official campaign photo album

WhatsApp

- Free messaging app that lets users text, chat, and share media, including voice messages and video, with individuals or groups
- Great for organising and for keeping in contact with groups or supporters.
- The ability to share both audio, pictures and video allows group participants to share their own media which can be used for social media posts or other communications.

Twitter

Allows us to share news with one another quickly without having to directly 'connect' or 'friend' one another, as is required on Facebook

- By using the official World Alzheimer's Month hashtag #WorldAlzMonth you can join a conversation or debate and extend the reach of your tweet
- Engage with us on Twitter (@AlzDisInt) by tagging us and liking and retweeting our tweets. Be sure to follow us so we can see your updates and retweet your messages

TIP

Use a website such as www.bitly.com to shorten the URL, especially for social media sites such as Twitter which have a character limit.

Key hashtags to include within social media posts:

- #WorldAlzMonth
- #KnowDementia
- #KnowAlzheimers
- #WAM2022

World Alzheimer's Month Suggested Social Calendar

It is important to plan your social media engagements to allow you to both successfully advertise and showcase events, but also to ensure a consistent delivery of material to your followers. Planning in advance is also helpful if there are several members working within your team.

To help you plan your dates and messages for World Alzheimer's Month, we have put together a **free calendar for World Alzheimer's Month**, which you can download for Microsoft Excel, Numbers (Apple), and Sheets (Google). This document includes a calendar example to help you organise specific dates in September, as well as a layout (with sample messaging) to organise your social media messages (pictured below).

The date and timing of posts should always be an important consideration. Each social media platform has different days and times that work best for other people seeing your content.

TIP

There are different tools you can use online to organise and schedule your social media posts in advance. However, be aware that most of these services cost money and will charge you after a trial period. (You can directly schedule your posts on Facebook and Twitter free of charge)



Alzheimer's Disease International World Alzheimer's Month

Measuring Success

Measuring content and overall campaign performance is can often be neglected or forgotten about. However, measuring your digital campaign can be helpful for knowing if you were able to reach new audiences, garner interest or reactions from your campaign and more.

The focus of your measurement will depend on who the evaluation is for e.g., funders, the board of your association, or participants. Evaluation should not only help you measure how successful your event was, it should also help you get the most out of World Alzheimer's Month and make sure all your activities run smoothly and effectively.

Good, effective planning for a World Alzheimer's Month activity is a necessity for your event to be a success and good, effective planning means building in evaluation as you go. Identify who your target audience is and what you hope to achieve with them through your World Alzheimer's Month event, and you will be able to measure how effective you were in your aims and objectives.

You should evaluate all aspects of your World Alzheimer's Month work to give a meaningful report. For each aspect, you should identify some aims and how you are going to measure whether or not you achieved those aims. The following are some steps you might consider adopting:

1. The Planning

- Make a timetable of your event
- After the event, review whether the timetable was realistic. Did you have to make any alterations?
- What were the views of those involved on how your plan went?

2. The People Involved

- List all the people and organisations you contacted to take part in your event
- After the event, list all the people and organisations that actually came
- What functions did they fulfil?
- Get their opinions of the event. What did they like, what did they not like? What worked well, what did not work well?

3. The Event

- Record details of venues, facilities and materials used
- How much material did you distribute at the event?
- Take photos of the event
- Do an observation study of the target groups response
- Record the media coverage it generated e.g. words spoken, number of features written, number of words written

4. Your Audience

- State who your target group was
- Use surveys to find out how many people you reached, if they knew it was World Alzheimer's Month, if they took part, what action they took
- Keep a note of how many people you spoke to yourself, how many leaflets were handed out?

5. The Media

- When assessing the results of your media coverage, don't just measure number of articles or interviews on TV. Develop a scoring system to assess quality based on the number of key messages communicated.
- Was the media coverage positive or negative?

Some ways of getting answers for your evaluation process may include:

- On the spot questionnaires. They need to be short and easy to complete. Ask only for information that you will use.
- Informal feedback encourage participants to express opinions in visitors' books, graffiti walls, video boxes.
- Research keep track of how much material you distributed and how many people attended your event, visited your website that day and called your helpline.

Remember that World Alzheimer's Month is a moment of time for raising awareness but should be backed up all year round. The people who participated in your event have an interest in your association. Try to keep in contact with them – you might want to cultivate them into potential volunteers or donors!

Here are some ways of keeping in touch:

- Collect contact details on the day and follow up with a circular letter, email thanking them
 for their participation and giving them some feedback about the event. Tell them about the
 highlights, what you achieved and what you may be planning for next year.
- Remember to send out any information you promised promptly.
- Invite people who participated in your event to do so again the following year.



Wear Purple Campaign with the Virgin Islands Alzheimer's 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 Champions: Roche



World Alzheimer's Month Partners: Biogen, Novo Nordisk and Otsuka America Pharmaceutica







World Alzheimer's Month Sponsors: **Acadia, Eisai, Eli Lilly, GE Healthcare, Home Instead, MSD, Prothena, Summerset** and **Tunstall**

















