

WEBINAR



Let's talk about
**Dementia in Latin America
and the Caribbean**

SEPTEMBER 25 - 2020 | 10:00 AM (EST)

@BIDgente

Presented by:



Paola Barbarino

CEO

Alzheimer's Disease International

Moderator: María Laura Oliveri

Before we start...



40 minutes

+



15 minutes



Questions
via chat



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WEBINAR



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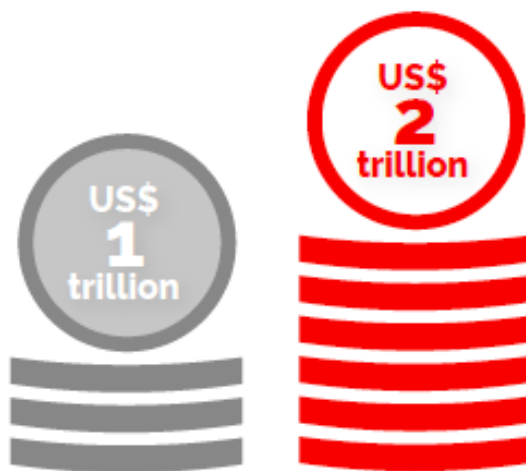


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International**

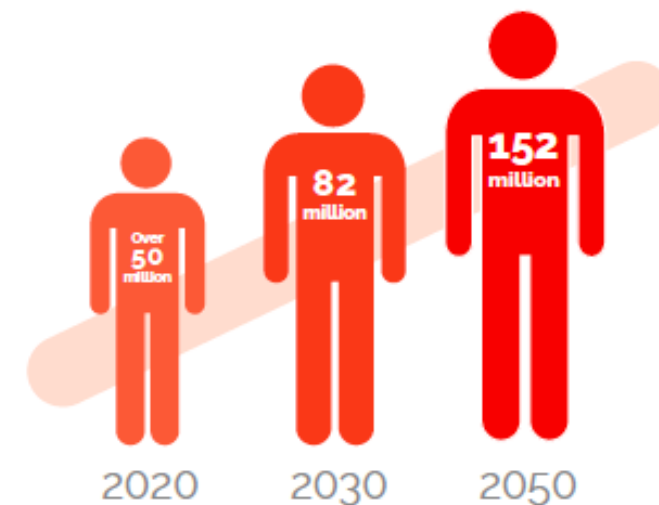
The global voice on dementia



Around the world, there will be one new case of dementia every 3 seconds



The total estimated annual worldwide cost of dementia in 2020 is over US\$1 trillion. This figure will rise to US\$ 2 trillion by 2030



Estimated growth in number of people with dementia 2020–2050

Dementia in Latin America and the Caribbean



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The Americas
11.4 million people
with dementia

Latin America
6 million

North America
5 million

The Caribbean
480,000

Source: World Alzheimer Report 2015

Can include problems with memory loss, thinking speed, language, understanding and judgement

Dementia

An umbrella term for a collection of symptoms that are caused by disorders affecting the brain. There are over 100 types of dementia.

Commonly accompanied by deterioration in emotional control, social behaviour or motivation

- **Alzheimer's disease** Most common, accounting for approximately 50-75% of all dementias
- **Vascular dementia** Second most common dementia, accounting for approximately 15-25% cases
- **Mixed dementia** At least 1 in every 10 people is diagnosed with a mixed dementia – most common is a combination of Alzheimer's disease and vascular dementia
- **Frontotemporal dementia** Second most commonly diagnosed dementia in people under the age of 65.
- **Lewy body dementia** A complex condition affecting 10-15% of those with dementia.
- **HIV-associated dementia** A consequence of HIV infection, typically seen in advanced stages of the disease.

Source: Kate Swaffer, 2020

Dementia and mental health

- **Positioning of dementia within mental health**
 - WHO Brain Health Unit
- **Leave no one behind**
 - MH and neurological conditions should be treated as any 'visible' health condition would

THE LINKS:

- **Mental health of people with dementia and carers**
- **Similarities in symptoms and experiences**
 - Lack access to services and support, face stigma and are denied their human rights
 - Need to focus on risk factors and psychosocial determinants

But dementia presents unique problems



Dementia and NCDs



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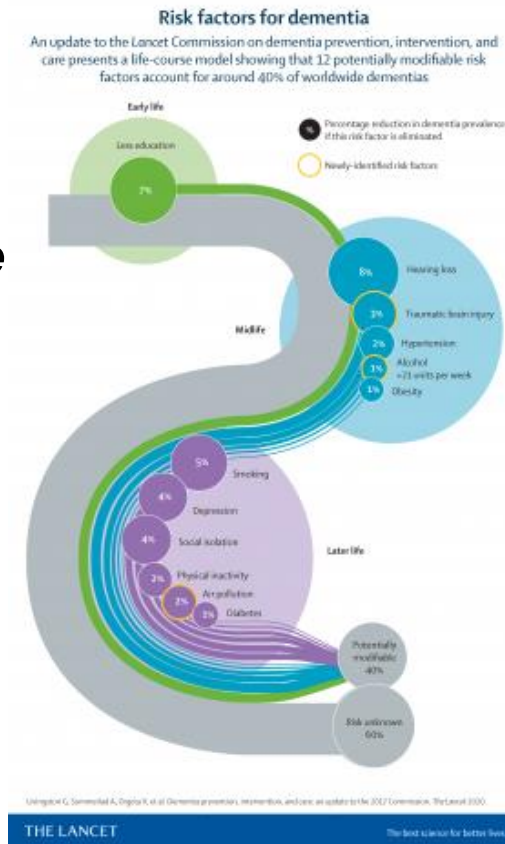
- Dementia risk profile very similar to other major NCDs, with common occurrence of comorbidities, but often grouped separately

- Expanding evidence base:

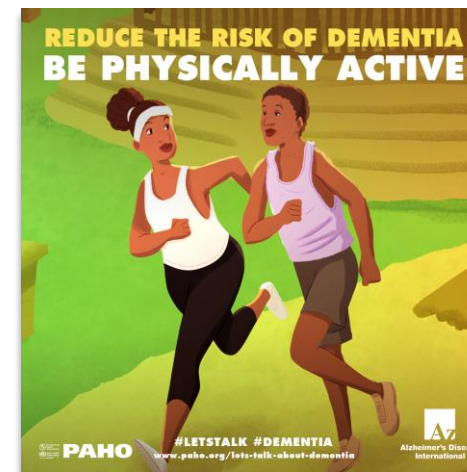
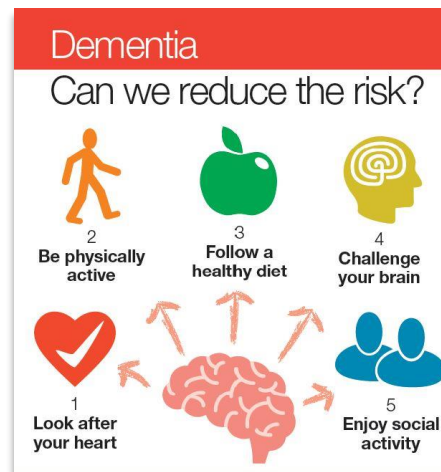
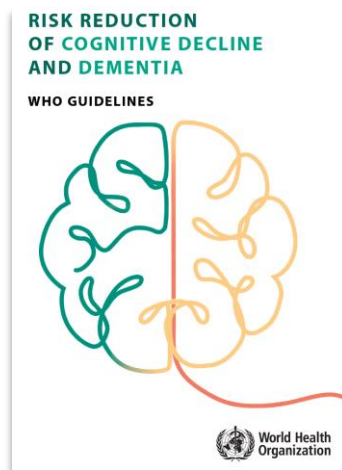
- **WHO Guidelines;**

- **2020 Lancet paper:**

Dementia prevention, intervention, and care

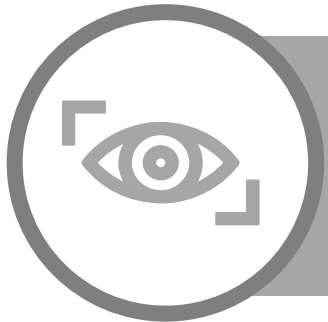


“Including dementia”



About Alzheimer's Disease International (ADI)

- **Established in 1984**
- **The umbrella organisation of Alzheimer associations around the world**
- **102 member associations & federations**
- **18 associations on the Membership Development Programme (MDP)**
- **Official Relations with WHO**



Our vision is prevention, care and inclusion today, and cure tomorrow



WHO's Global action plan on dementia



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Towards a dementia plan: a WHO guide



Action areas

Dementia as a public health priority



Dementia awareness and friendliness



Dementia risk reduction



Dementia diagnosis, treatment, care and support



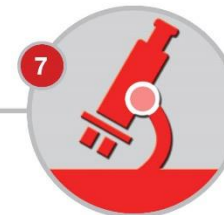
Support for dementia carers



Information systems for dementia



Dementia research and innovation

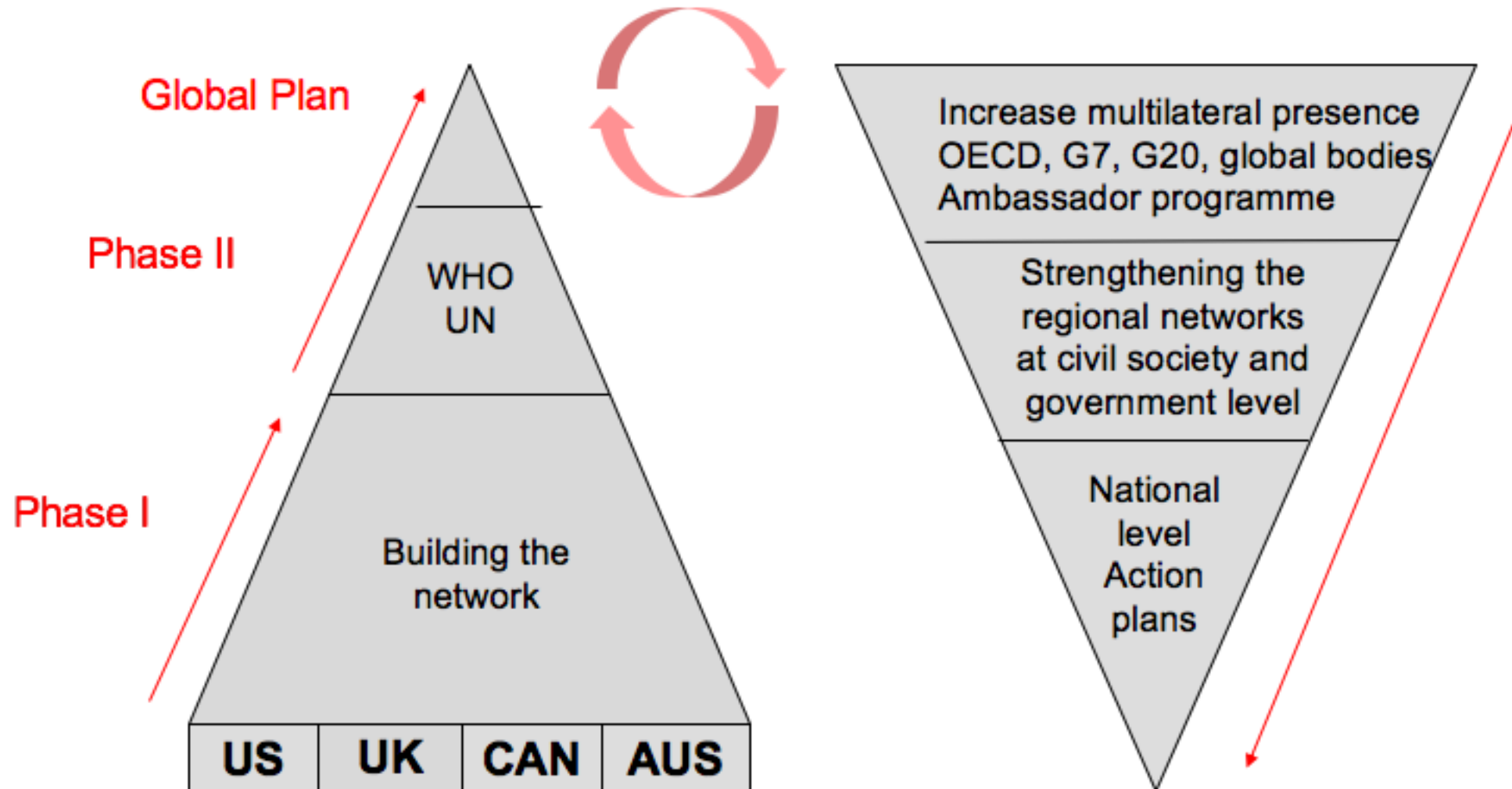


ADI's Strategy



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ADI's Objectives

- Raise **global awareness** about dementia
- **Build and strengthen Alzheimer associations** throughout the world
- **Support associations** so they are better able to meet the needs of people with dementia and their carers
- **Advocate for people** with dementia and their carers on a global level
- **Stimulate research**, especially in lower and middle-income countries

WHO's Global action plan on dementia

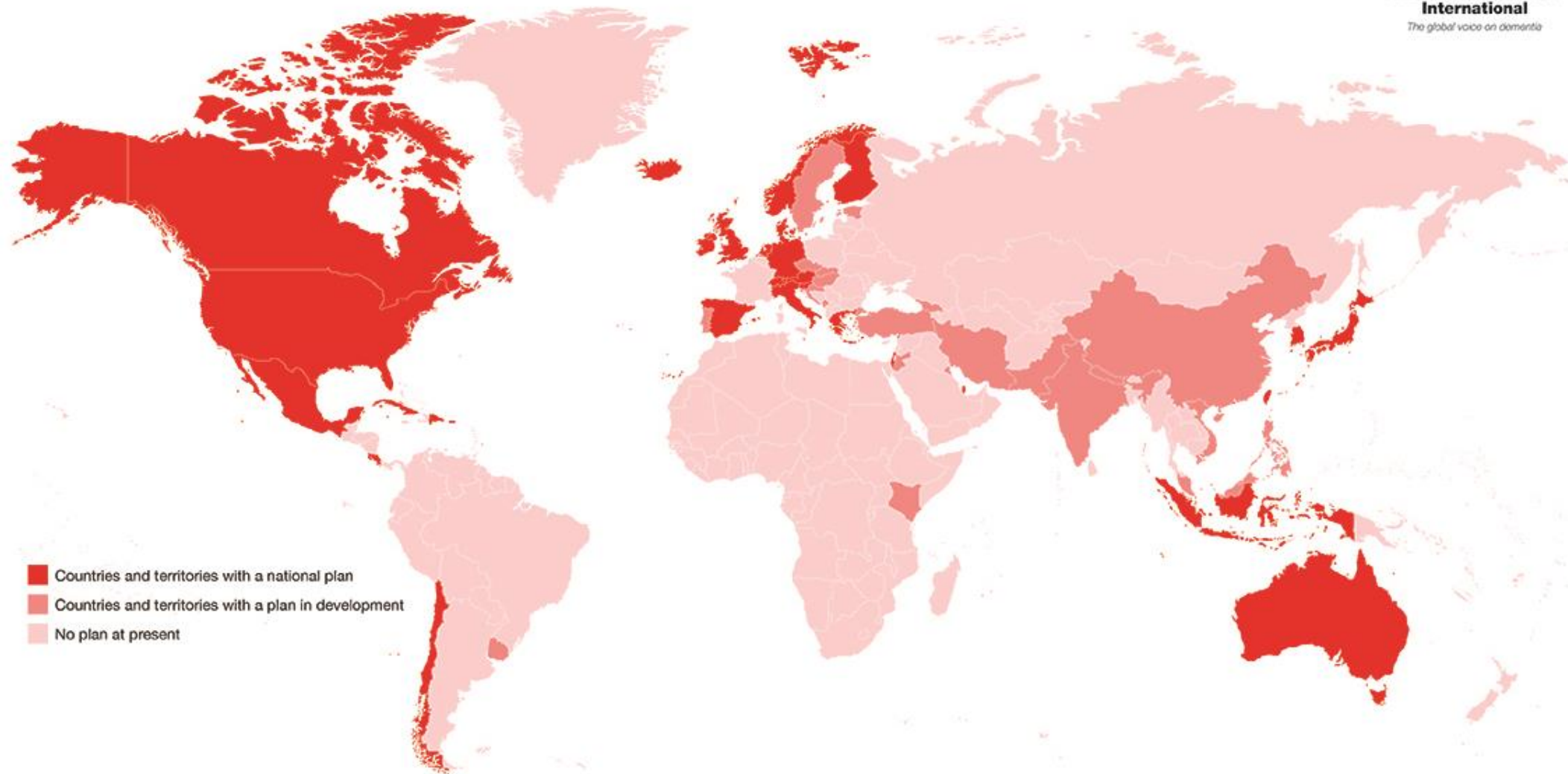


Real concern that the progress made under the Global plan will be reversed by COVID-19 on the national and international level, especially as there has not been an adequate focus on non-communicable diseases.

Countries with plans on dementia or in development in 2020



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- Countries and territories with a national plan
- Countries and territories with a plan in development
- No plan at present

Countries with national dementia plans					
Australia	Cuba	Iceland	Luxembourg	Puerto Rico	Switzerland
Austria	Denmark	Indonesia	Macau SAR	Qatar	TADA Chinese Taipei
Bonaire	Dominican Rep.	Ireland	Malta	Republic of Korea	UK
Canada	Finland	Israel	Mexico	Singapore	USA
Chile	Germany	Italy	Netherlands	Slovenia	
Costa Rica	Greece	Japan	Norway	Spain	

Countries with national dementia plans in development				
Barbados	Czech Republic	Jordan	Pakistan	Uruguay
Brunel	Estonia	Kenya	Philippines	Vietnam
China	Georgia	Kuwait	Portugal	
Croatia	Hungary	Malaysia	Slovak Rep	
Curacao	India	Montenegro	Sweden	
Cyprus	Iran	Nepal	Turkey	


*Source:
ADI (2020)
From plan to impact III*

World Alzheimer's Month




- World Alzheimer's Month held around the world since 2012
- World Alzheimer's Day, 21 September
- Global importance of World Alzheimer's Month following adoption of Global Plan on Dementia in May 2017
- 2019: Activities held in over 90 countries this year and growing
- 2020: Primarily virtual campaign given COVID-19 restrictions

World Alzheimer's Month 2020: Let's talk about dementia




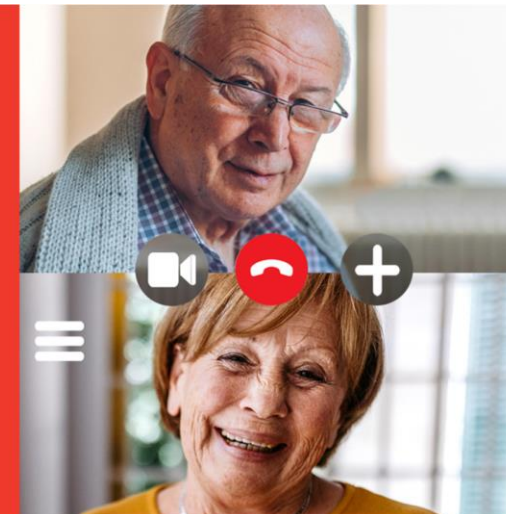
**World
Alzheimer's
Month**

#Parlonsdeladémence
#WorldAlzMonth
www.worldalzmonth.org




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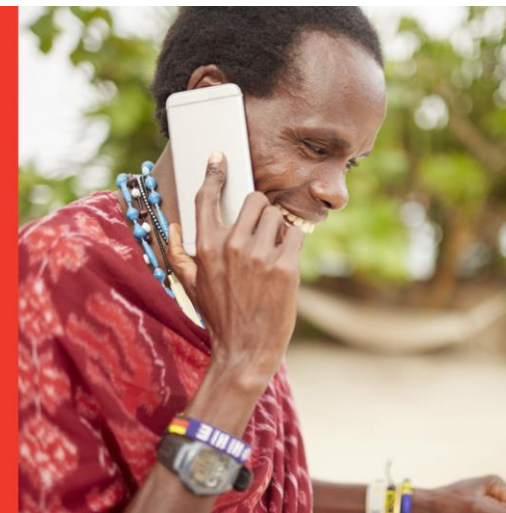
**World
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#Hablemosdedemencia
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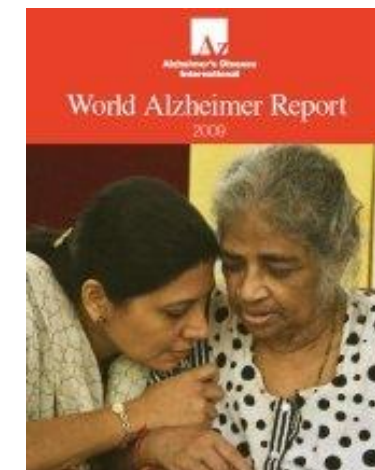
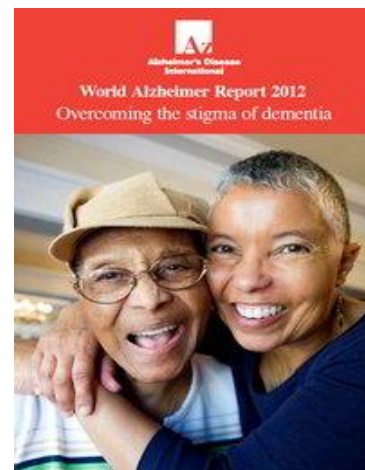
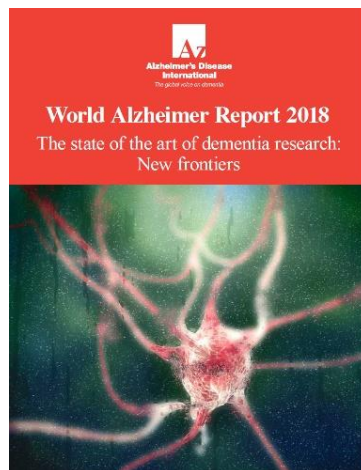
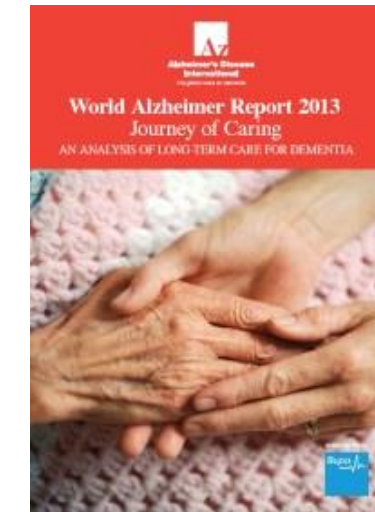
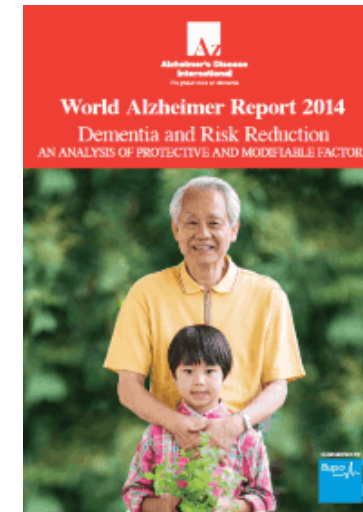
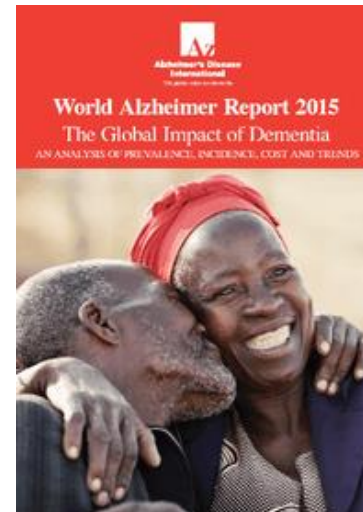
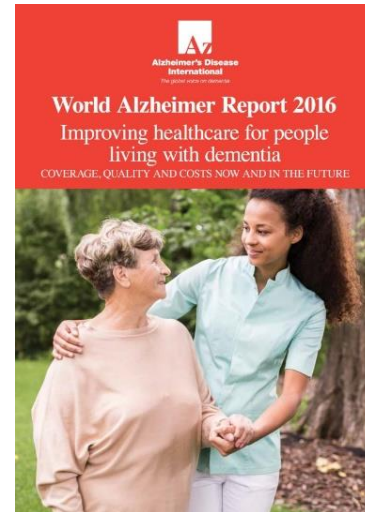
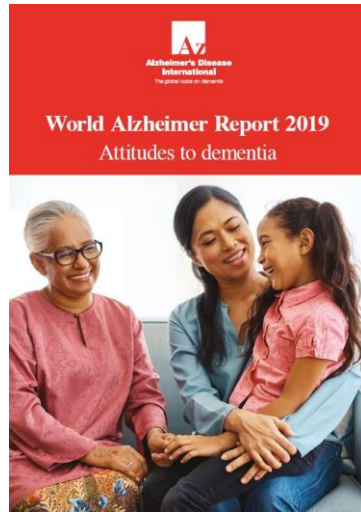


World Alzheimer Reports



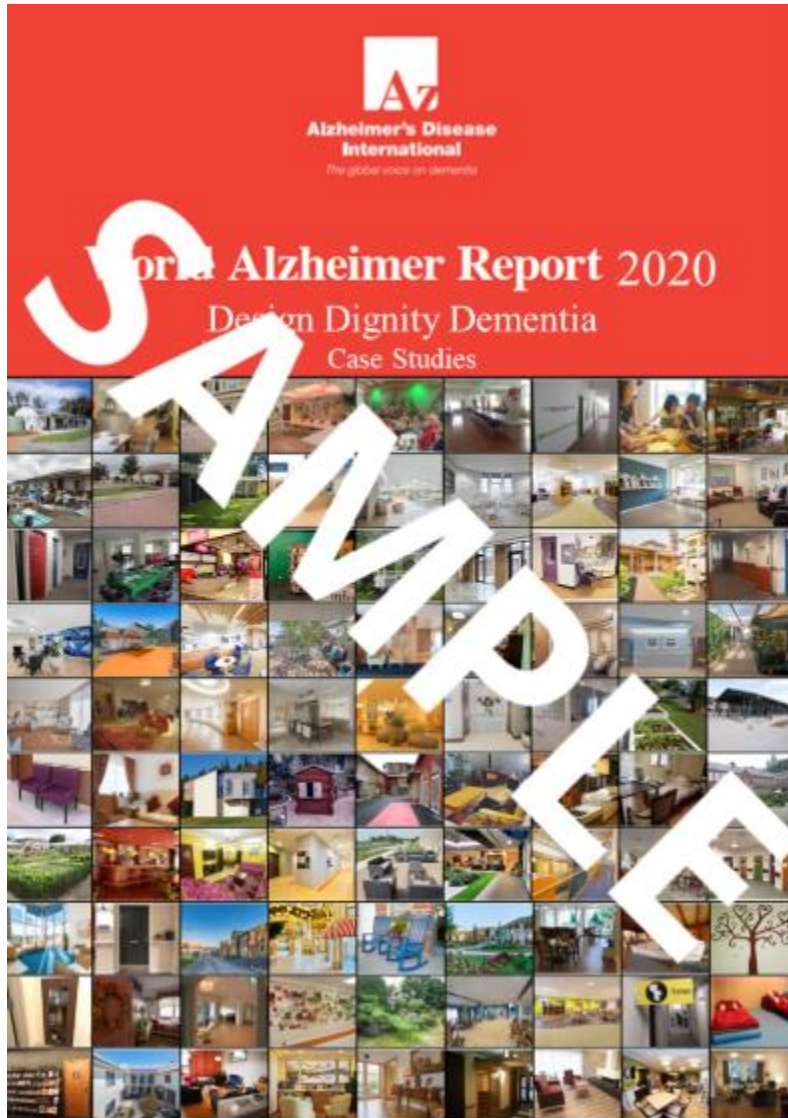
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www.alz.co.uk/publications

World Alzheimer Report 2020



Dementia related design and the built environment

- In partnership with Wollongong University, Australia
- Cross cultural approach
- Focus: progress to date, best practice and innovation across multiple environments including in home/domestic settings, day and residential care, hospitals and public buildings and spaces

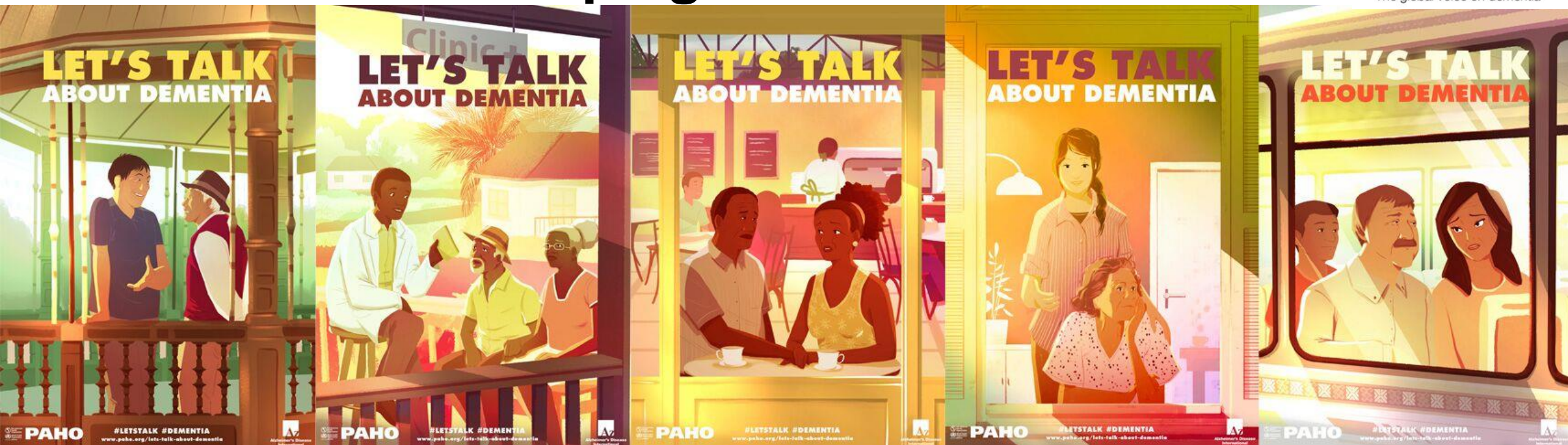
www.alz.co.uk/worldreport

ADI-PAHO regional awareness raising campaign



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1. Encouraging improved awareness and attitudes towards people with dementia – with a focus on healthcare practitioners
2. Stimulating people to start talking about dementia – that first difficult conversation
3. Encouraging people to seek out more information, advice, support and even a diagnosis

ADI-PAHO regional awareness raising campaign

- Dementia affects everyone differently but there are some common warning signs
- This interactive quiz provides information and encourages people to seek out further information, advice and support if they have concerns
- The importance of timely diagnosis



TU PUNTUACIÓN

5/10

Si usted tiene cualquiera de estos síntomas o está preocupado por un amigo o pariente, le recomendamos que vaya al médico para conversar sobre sus inquietudes y que busque más información en internet.

VER TODAS LAS ADVERTENCIAS

EMPEZAR TEST

**HABLEMOS SOBRE
DEMENCIA**



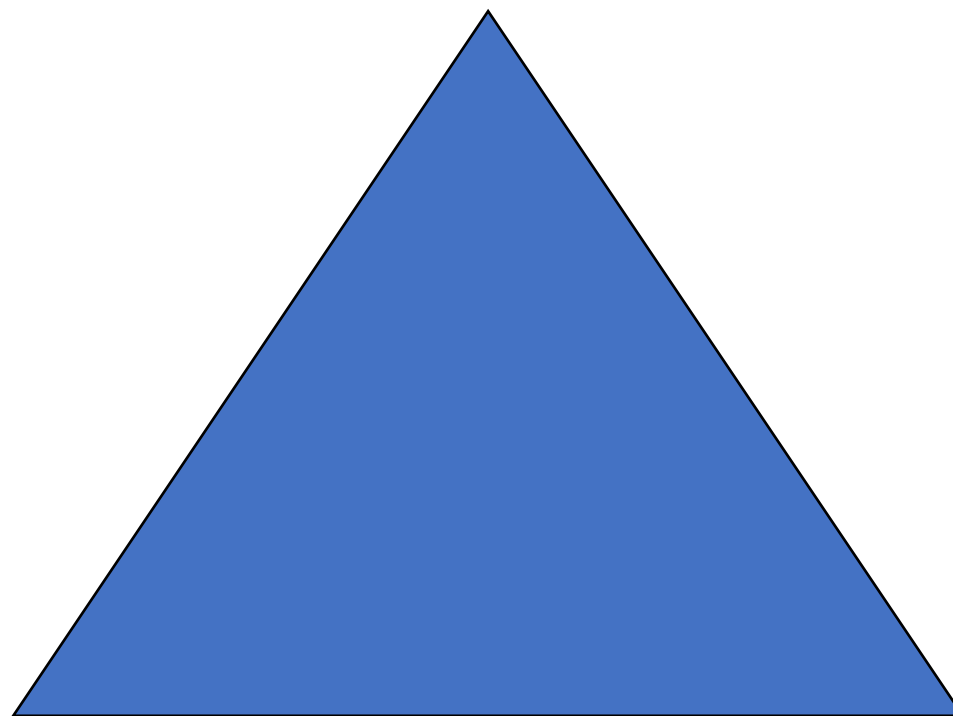
ADI-PAHO regional awareness raising campaign

- Risk factors for dementia
- Be physically active, enjoy social activity, challenge your brain, follow a healthy diet, look after your heart
- Shared with many other non-communicable diseases



Additional outcome of campaign

**Alzheimer association /
federation**



Ministry of Health

PAHO country office

**July 2020:
Dominican Republic
launched a plan**



COVID-19 and dementia

- **Mental health issues** - Isolation, anxiety, stress, depression
- Older people disproportionately affected, including **discrimination**
- Complications of other **NCDs** and exacerbated/new NCDs
- **Scarcity of resources and triage decision making**
- **Delayed diagnosis, transition**
- **Post diagnostic support challenges** – face to face
- **Interruption of clinical trials and research**



Our rapid response to COVID-19 was enabled through

- Working with our Asian members when lockdown started in Europe
- **Coordinating with our contact in China, Prof. Wang, to write about caring during COVID-19**
- Reading about COVID-19 and realising that our natural constituency and the 'at risk' age range overlapped
- **Understanding very quickly that there was a problem with triage and I wrote about it on LinkedIn to raise awareness**
- Gathering resources from all over the world very quickly
- **Organising member webinars to support each other in early March - learnt a lot**
- Realising that there was huge interest in what we were doing, we started working with the press and opened our webinars to the public

As our resources began to gain traction

- **We launched an emergency appeal in April and started raising much needed funds**
- **We side-lined our business plan and much of the work we already had in progress in favour of focusing on COVID-19**
- **We made some strategic decisions about alliances and partnerships**
- **We exploited our agility and nimbleness to its maximum extent**
- **As we had some staffing changes we ensured that health and mental wellbeing of the whole team was prioritised above all**

Our motivation: future focus

We were concerned that:

1. Our constituency's rights were trampled

2. That there was not enough information on practical issues

3. That governments would deprioritise dementia after all returned to normality

ADI's response to COVID-19



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General resources

Resources for carers and people with dementia

Additional support for Alzheimer's & dementia organisations

Resources from Alzheimer and dementia associations

Mental health and well-being

Videos

Blogs



Older persons

Information and support for refugees, BAME, indigenous & other marginalised groups

Resources in English, Spanish, Portuguese, Arabic, Greek

The screenshot shows the Alzheimer's Disease International website with a red header. The main navigation bar includes 'Home', 'Global Information', 'Global Solutions', 'Global Knowledge', 'News', 'Contact', and 'Donate'. A prominent banner reads 'Read ADI's most recent guidance on COVID-19'. Below this, there are two informational sections. The first, titled '¿Estás cuidando a una persona con demencia? Practica estos consejos durante COVID-19', is split into two columns: 'Intenta de:' (Try to) and 'Evita:' (Avoid). The 'Intenta de:' column lists: 'Mantenerse en contacto regular con tus seres queridos por teléfono o por videollamada', 'Colocar recordatorios en casa para lavarse las manos', 'Hacer ejercicio regularmente, pero escucha a tu cuerpo - no te excedas', 'Mantener una rutina diaria', and 'Limitar mirar o leer las noticias hasta una o dos veces al día'. The 'Evita:' column lists: 'Tácticas aterradoras para que la gente se lava las manos o practica el distanciamiento social', 'Noticias o ruido mediático innecesarios', 'La siesta no programada o el sueño prolongado, que pueden causar problemas de sueño', and 'Enojarse si la persona está confundida o molesto por la situación'. The second section, titled 'Are you living with dementia? Practice these tips during COVID-19', lists: 'Continue with your daily routine as best you can', 'Call loved ones via phone or video calls', 'Write down reminders, e.g for groceries or to wash your hands', 'Do gentle physical exercise', and 'Connect with your local Alzheimer's association for further advice & resources'. The website footer includes the ADI logo and the tagline 'The global voice on dementia'.


ADI's response to COVID-19



Dementia Care during the COVID-19 Outbreak

Huali Wang, MD/PhD
Executive Vice President, Alzheimer's Disease Chinese (ADC)
Peking University Institute of Mental Health
National Clinical Research Center for Mental Disorders

- ADC presentation (English): **Almost 10k views**



Agenda

- Concept of continuum of dementia care
- Impact of COVID-19 outbreak on persons with dementia (PWD) and their carers
- Mental health and psychosocial support (MHPSS) for PWD and carers

- Publication of a Lancet article 'Dementia care during COVID-19' by Huali Wang, Paola Barbarino, Serge Gauthier et al.

ADI's response to COVID-19: Realising the overlap and raising awareness



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"We are living through unprecedented times, but one thing is clear: ADI's natural constituency, people affected by dementia and their families, are amongst the hardest hit. We have a global network and it has been natural for our members to collaborate through this crisis, show solidarity and work together. But we have also learnt that there are hard truths that we all need to face. This is the spirit in which we have reengineered ADI to be at the forefront in providing, guidance, evidence-based information and cohesion through these difficult times. Our aim is to help you understand the impact on our community as events unfold and take better and more informed decisions. Stay safe." - Paola Barbarino, Chief Executive of Alzheimer's Disease International (ADI)

COVID-19 and dementia: Difficult decisions about hospital admission and triage

COVID-19 is a new viral infection that presents an unprecedented problem for everyone, including people with dementia and their families and carers¹ worldwide. Although the scale and impact of COVID-19 varies from country to country, at an individual level, people affected by dementia and their families and carers are having to cope with rapidly changing information and guidance at a time when they have been asked to isolate from their regular support systems in the wider community.



Age, dementia and the allocation of health resources during and beyond COVID-19

Dr Linda Barclay, Department of Philosophy, Monash University and Glenn Rees, Chair of Alzheimer's Disease International

The extraordinary circumstances of the COVID-19 pandemic bring into sharp focus a fact of life that most of us ignore: that health care resources are always limited. This is very true for people with dementia and more generally for people with disabilities. They are limited by political and economic decisions concerning expenditure on medical research, drug subsidies, health care funding and so on. These long-term issues will not be resolved in mid crisis, but they are relevant to the way the crisis is handled. It is an opportunity to draw attention to longstanding issues and not give up in despair.

This article explores issues in health resource allocation, measurement of quality of life, the options open to decision makers and the importance of transparency in decision-making. There is no simple answer to complex decision making but the clear requirement is for transparent decision making in judgements that impact on people's lives. The need goes beyond guidelines that are understood and acceptable to doctors and consumers and relevant in times of crisis at the bedside to broader issues of health policy, structural and legal issues.

COVID-19 and dementia webinars



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The top section of the webinar interface. On the left is a title slide with a world map on a wood-grain background. The text reads: "ADI webinar Wednesday 22 April" and "Supporting people with dementia during COVID-19: experiences and advice from around the world". On the right is a "Question and answer" slide with a graphic of four overlapping speech bubbles containing question marks. The text "AlzDisInt Diwebinar" and "Theme 1" is visible at the bottom of this slide.



Major concerns for people living with dementia & carers



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1.

Excess dementia mortality in long-term care facilities, in hospitals, and at home, but data is sorely lacking

2.

Diagnosis rates for dementia have decreased during the outbreak – impact on cognitive decline

3.

Palliative and end of life care must be supported, including at home

4.

Triage guidelines must not be used in discriminatory way

5.

Psychosocial support for both people with dementia and carers

COVID-19 and dementia: future gazing

- Unavailability of support and social services?
- Political de-prioritisation of dementia?
- Impact of COVID-19 on diagnosis of dementia
- Disruption of clinical trials?
- Development of vaccinations?



ADI and IADB collaboration

- Over the two decades the number of people with dementia will increase by 52% in North America and 52% in the southern Latin American cone.
- The number of people aged 65 and over in the Americas has nearly doubled since 1995, from 62 million to 116 million in 2019
- We don't have members yet in Antigua and Barbuda, Bahamas, Belize, Colombia, Dominica, Grenada, Haiti, Panama, Paraguay, Saint Lucia, Saint Vincent and the Grenadines

ADI and IADB collaboration

- **Supporting people who are part of the silver economy to live at home and in the community for longer:**
- What kind of public-private sector collaborations could we encourage?
- What sort of policy responses could facilitate this?



THANK YOU.

Follow ADI on Twitter and Instagram @AlzDisInt | Like us on Facebook /alzheimersdiseaseinternational

Visit our website: www.alz.co.uk

Follow my global advocacy work on Linked In, Twitter and Instagram @paola.barbarino





Questions and Answers

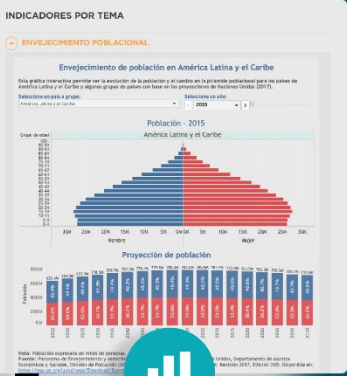
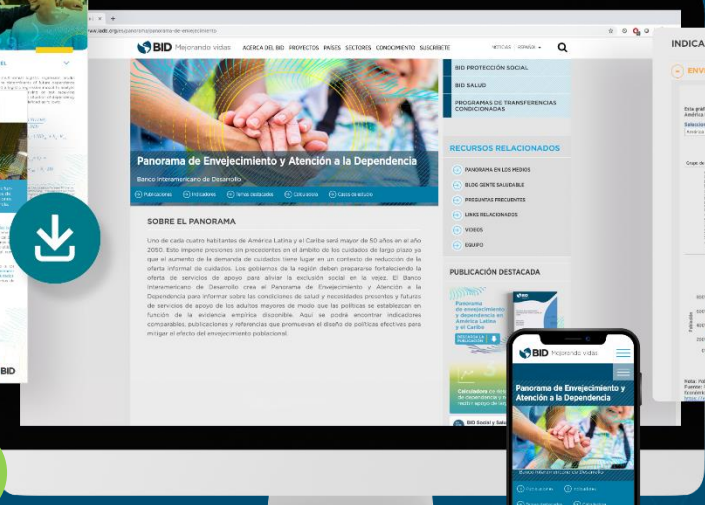
Panorama of Aging and Long-term Care



Publications

COVID-19 and aging

Thank You



Case Studies

Calculator

Indicators

<https://www.iadb.org/panorama-of-aging>

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