

The demanding situation of informal caregivers who care for people with dementia

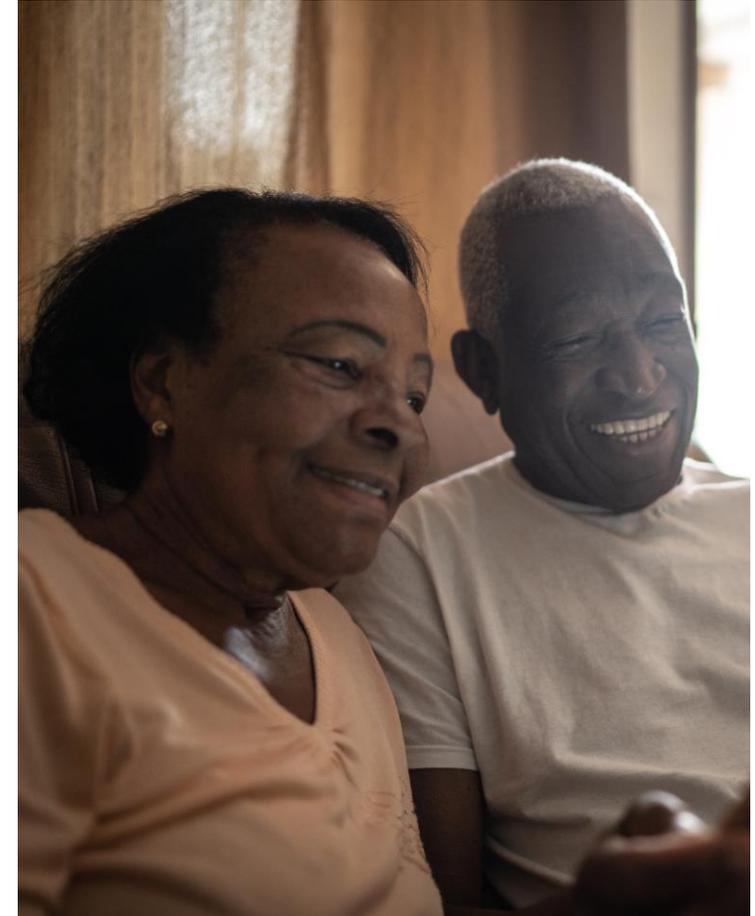
Lewis Arthurton
Communications and Policy Manager
Alzheimer's Disease International



About ADI



- **Established in 1984**
- **Umbrella organisation of Alzheimer and dementia associations around the world - 105 full members associations and federations, only one per country. Over 20 in development**
- **We represent our members at the WHO, the UN, OECD and other global and regional bodies**
- **Promoter of World Alzheimer's Month**
- **Publisher of the World Alzheimer Report and others**



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



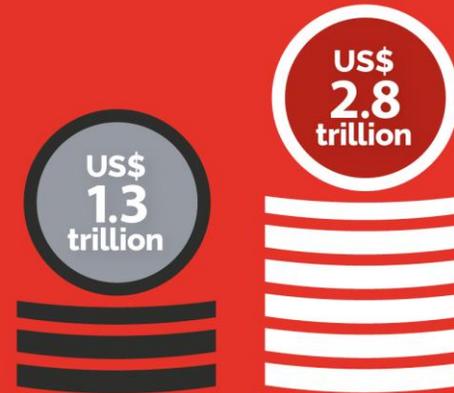
ADI's strategy



The global impact of dementia

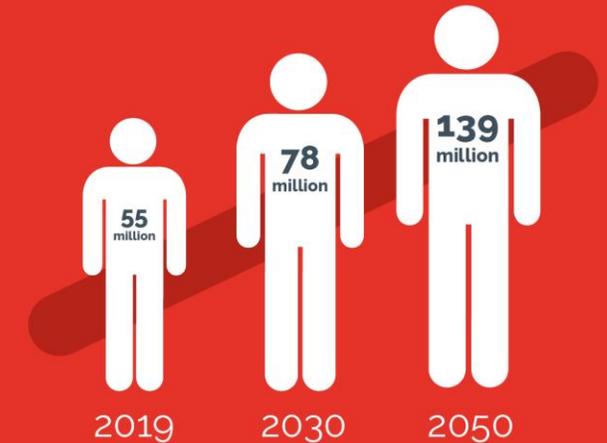


Every 3 seconds
someone in the world
develops dementia



The total estimated annual worldwide
cost of dementia is over US\$ 1.3 trillion.
This figure is forecast to rise to
US\$ 2.8 trillion by 2030*

*WHO Global status report 2021



Estimated growth in number of
people with dementia 2019–2050*

*WHO Global status report 2021

Spotlight on the region



Austria

2019	2050	Percentage Increase
146,000	309,629	111%

Montenegro

2019	2050	Percentage Increase
8,247	14,870	80%

Serbia

2019	2050	Percentage Increase
129,117	178,262	38%



Why support for carers is so important



Alzheimer's Disease International
The global voice on dementia



Global estimates of informal care

Alzheimer's Disease International and Karolinska Institutet

- The annual global number of informal care hours provided to people with dementia living at home was about **133 billion hours** in 2021
- equivalent of more than **67 million full-time workers**
- Globally the cost of informal care for those living with dementia stands at **650 billion US dollars.**
- Carers often feel isolated and are at risk from physical and mental health issues

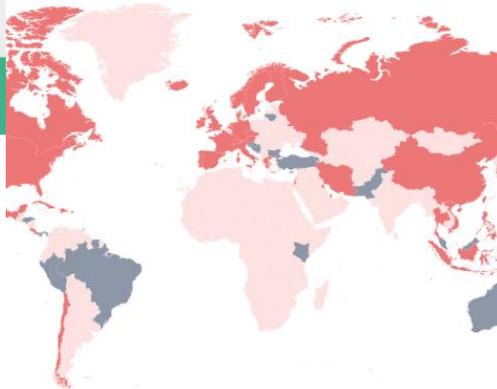
WHO's Global action plan on dementia



Towards a dementia plan:
a WHO guide

From Plan to Impact V

WHO Global action plan:
The time to act is now



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



Why National Dementia Plans?



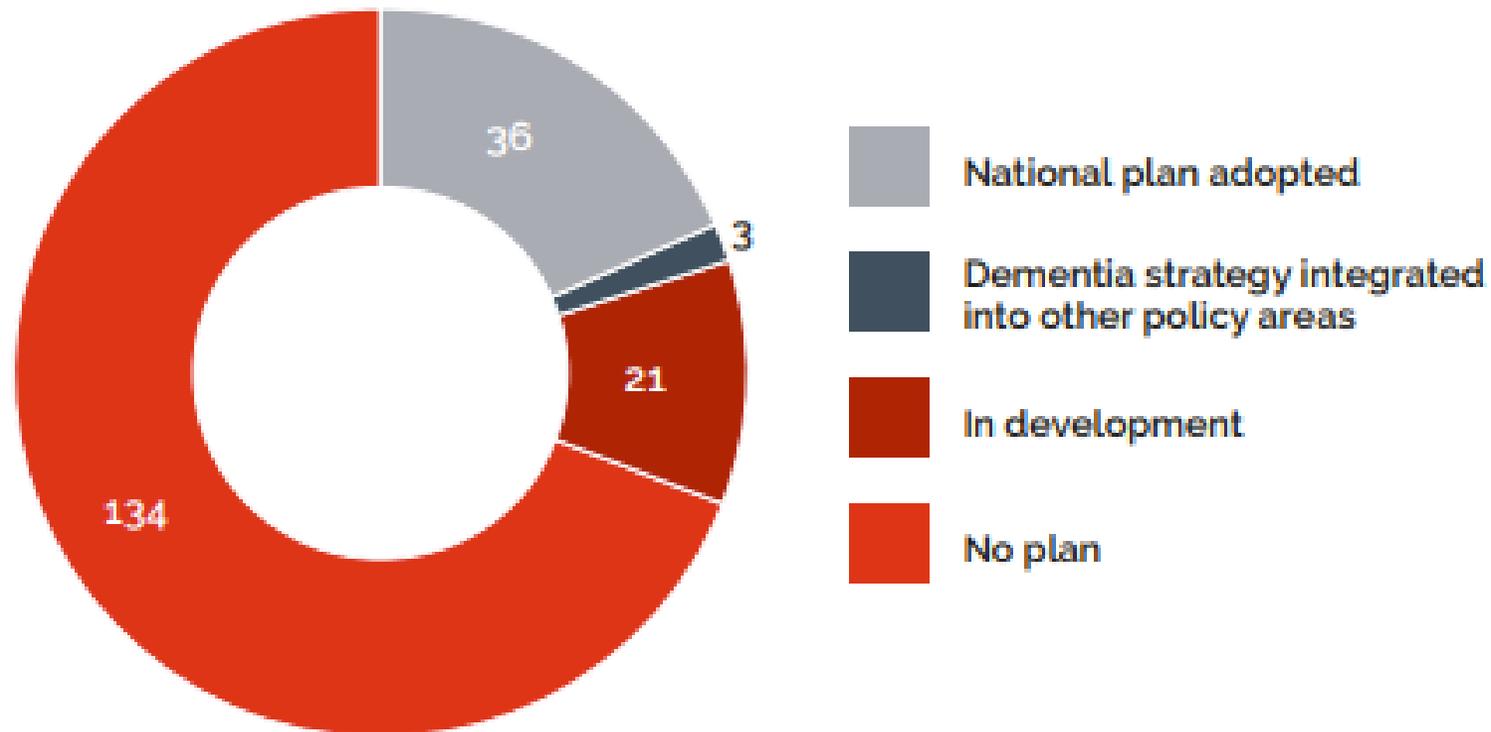
- The best strategic planning tool
- Puts a focus on diagnosis, post-diagnostic support and care pathways for people living with dementia and **their carers**
- Focus on public health campaigns, increased awareness, combating stigma
- Focus on healthcare professional training
- **Support for carers**
- Promotion of risk reduction messages
- Measuring and tracking prevalence & incidence
- Preparedness for a drug breakthrough



National dementia plans - Summary



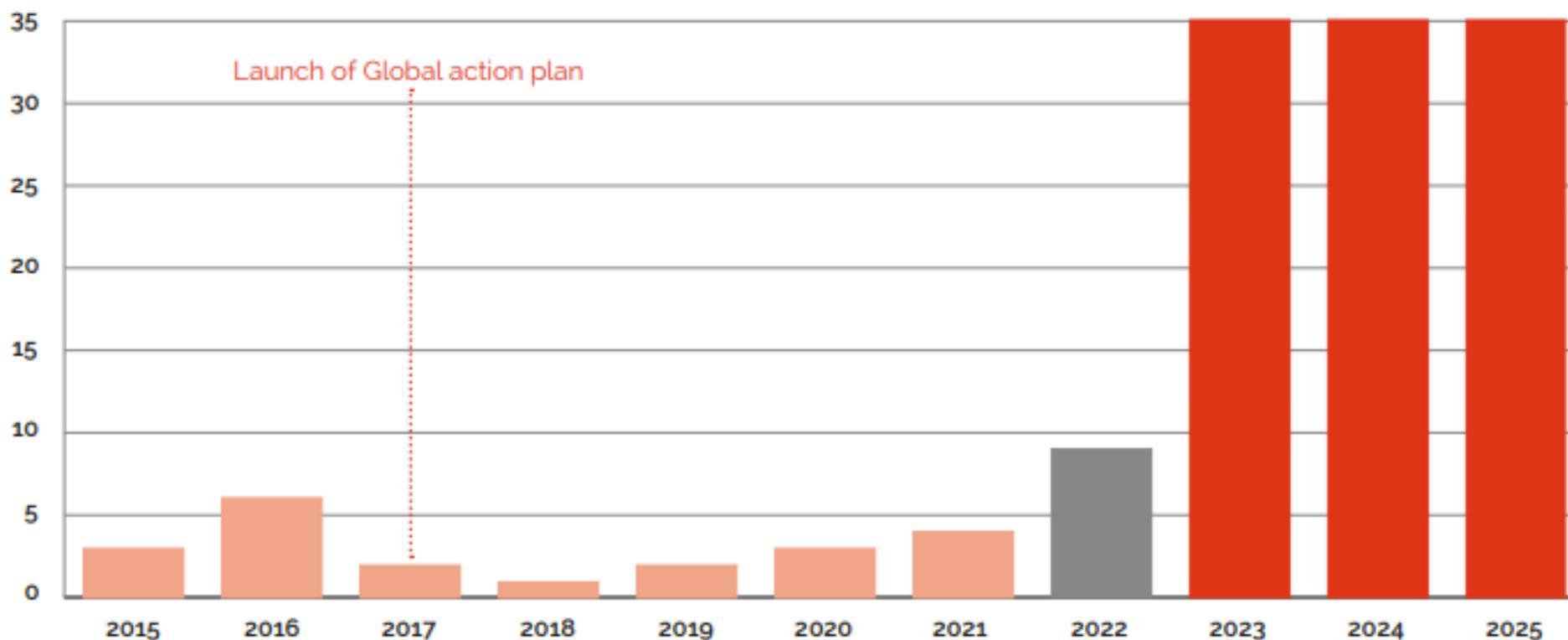
WHO member states implementation of national plans



National dementia plans - Summary



Number of dementia plans adopted annually since 2015 (all states) and number of plans needed every year to meet WHO 2025 target of 75% of member states.



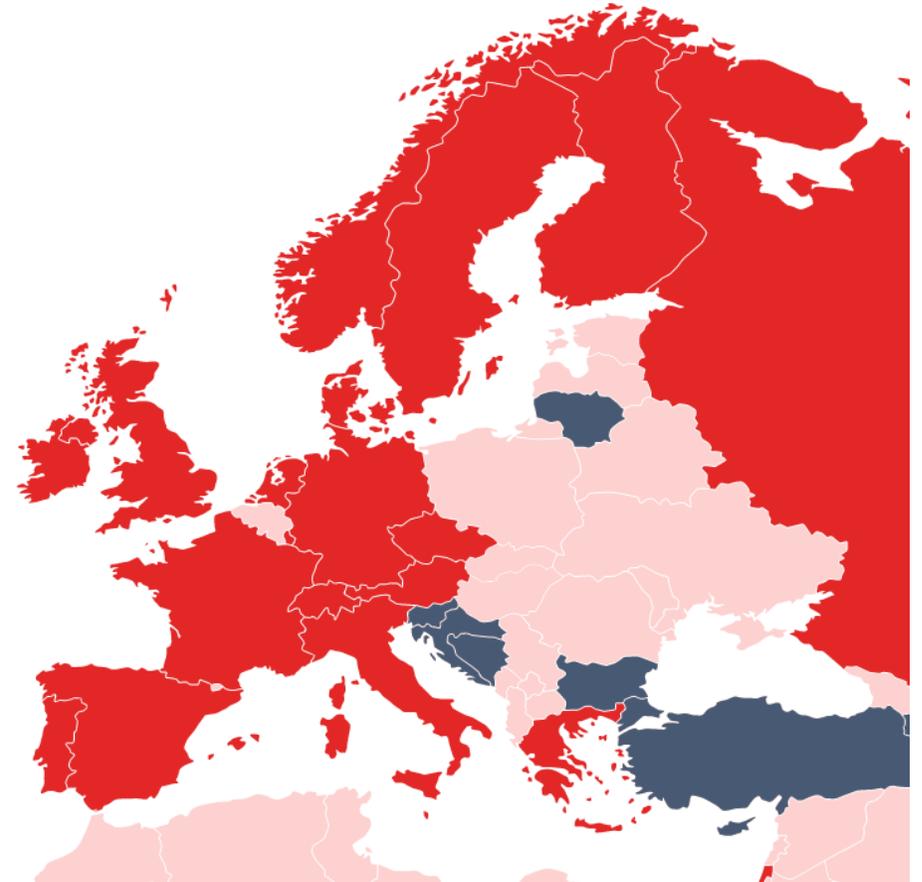
35 new plans needed every year from 2023 to cover 75% of member states by 2025. This calculation is based on information available in April 2022 and an assumption of no additional plans launching this calendar year.

Spotlight on the region



- Austria has a fully funded and adopted national dementia plan
- No known national dementia plans under development in either Serbia or Montenegro.

**All 194 WHO Member States
unanimously adopted the global
action plan on the public health
response to dementia in 2017**



The role of associations in providing support

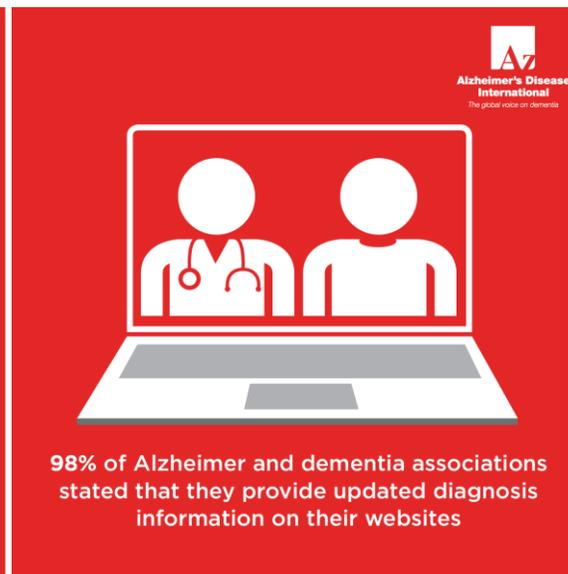
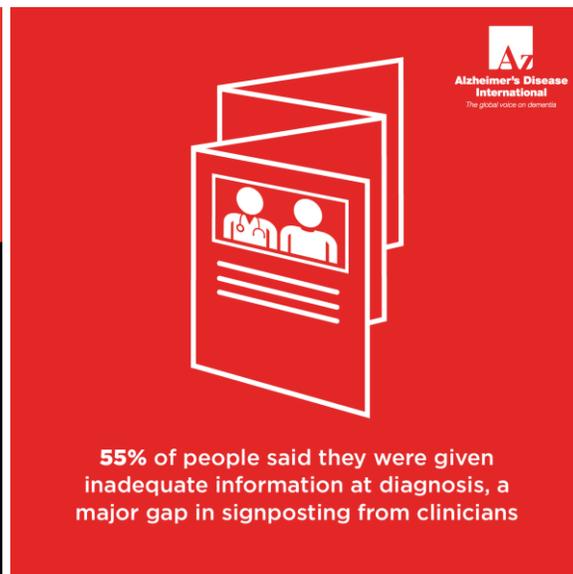
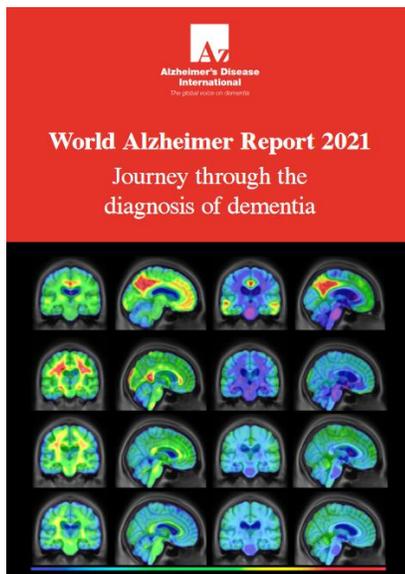


- ADI is the federation of 105 Alzheimer and dementia associations from around the world.
- Associations provide much needed advice and support to those living with dementia and cares.



FUTURA
NVO

No ADI member in Serbia



The role of associations in providing support

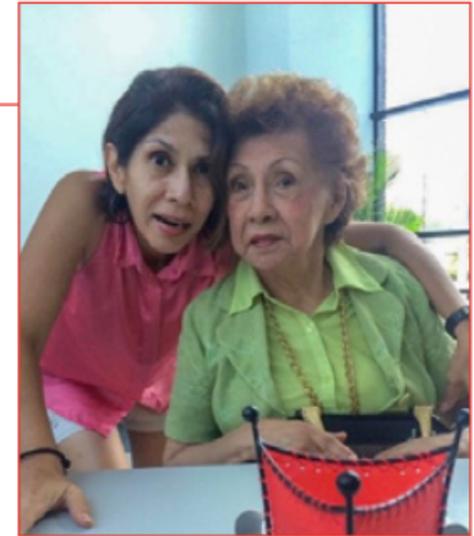


Perla Echeverria Cuidador, Venezuela

I am the daughter of a patient diagnosed with Alzheimer's disease since November 2012. For nine years, my family has been learning every day to live with this condition. At first, it was very hard because we refused to accept it. We did not know what to do or how to deal with it.

It is very, very important to seek help. Here in Puerto Ordaz, there is an Alzheimer's Foundation and they helped me a lot. I attended the talks and the doctors provided all the information. Also, people caring for relatives with dementia shared their experiences – this is very important so that you don't feel alone in the world. With help, we acquire a certain boldness to deal with such a situation. Otherwise, without alternatives and help, we wear ourselves out: we fight, we cry, we feel frustrated, and we blame the patient.

Now, we have a new lifestyle at home, and we know how to cope and experience the Alzheimer's stages little by little. In my mother's case, the progression of the disease has been very slow. She is on medication, she is being cared for, and we are aware of any changes or situations that are out of the ordinary. We let the doctor know so that she can make the necessary adjustments. My mother is doing very well, and her condition is stable. Her doctor is taking good care of her.



Translated from Spanish

Contribution of associations in care

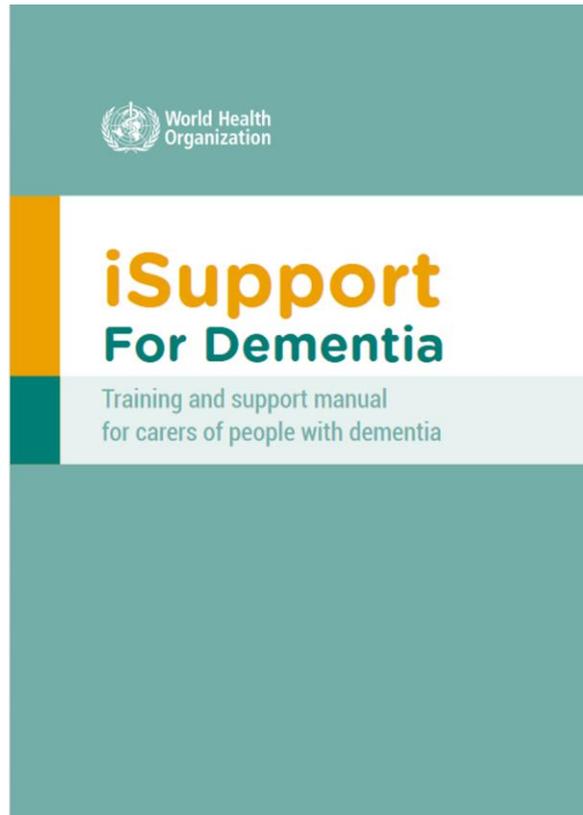


Training for doctors, nurses, and other medical staff is embedded in the medical school in Costa Rica



Rehabilitation, training and physiotherapy in Guatemala and India

WHO iSupport for dementia carers



- iSupport is primarily a self-help tool for caregivers of people with dementia, including family members, relatives and friends.
- The manual comprises five modules and accompanying exercises, namely: (i) introduction to dementia; (ii) be a helper; (iii) take care of me; (iv) provide daily care; and (v) coping with behavioral changes.
- iSupport can be adapted to national or local contexts and needs.

Caring for someone living with dementia in a crisis



- In recent years much of ADI's work has involved providing support for carers and those living with dementia (as well as our associations) during humanitarian crisis and conflict.

Are you living with dementia?

Practice these tips during COVID-19



Try to

- ✓ Continue with your daily routine as best you can
- ✓ Call loved ones via phone or video calls
- ✓ Play games that exercise the brain
- ✓ Write down reminders, e.g for groceries or to wash your hands
- ✓ Do gentle physical exercise
- ✓ Connect with your local Alzheimer's association for further advice & resources



Як допомогти людині з деменцією в надзвичайній ситуації?

Поради для родичів, доглядальників, волонтерів громадських організацій, членів громад та людей з деменцією



Forgotten in a Crisis

Addressing Dementia in Humanitarian Response





**Alzheimer's Disease
International**

The global voice on dementia

THANK YOU.

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Visit our website: www.alzint.org

