Living well: the community challenge

Moderator: Paola Barbarino
CEO, ADI

#DefeatingDementia
Introducing the concept of dementia friendliness in global dementia policy

Paola Barbarino
Chief Executive, ADI
INFOGRAPHIC
The global impact of dementia

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

50 million people worldwide are living with dementia in 2018. This number will more than triple to 152 million by 2050.

The total estimated worldwide cost of dementia in 2018 is US$1 trillion. This figure will rise to US$2 trillion by 2030.

About Alzheimer’s Disease International (ADI)

Our vision is prevention, care and inclusion today, and cure tomorrow.
WHO Global action plan on dementia

Action areas

1. Dementia as a public health priority
2. Dementia awareness and friendliness
3. Dementia risk reduction
4. Dementia diagnosis, treatment, care and support
5. Support for dementia carers
6. Information systems for dementia
7. Dementia research and innovation
National Dementia Plans

Countries with plans on dementia or in development in 2019

Countries with national dementia plans
- Australia
- Austria
- Canada
- China
- Costa Rica
- Chile
- Czech Republic
- Denmark
- Finland
- France
- Germany
- Greece
- Ireland
- Italy
- Japan
- Korea
- Mexico
- Netherlands
- Norway
- Portugal
- Republic of Korea
- Saudi Arabia
- Singapore
- Slovenia
- Spain
- Sweden
- Switzerland
- Taiwan
- United Kingdom
- United States

Countries with national dementia plans in development
- Argentina
- Colombia
- Denmark
- Estonia
- Greece
- Hungary
- India
- Ireland
- Italy
- Japan
- Korea
- Kuwait
- Latvia
- Lithuania
- Malaysia
- Moldova
- Montenegro
- Namibia
- Netherlands
- New Zealand
- Norway
- Pakistan
- Peru
- Portugal
- Romania
- Russia
- Saudi Arabia
- Singapore
- Slovenia
- Switzerland
- Taiwan
- United Kingdom
- United States
- Uruguay
- Vietnam
Action area 2: Dementia awareness and friendliness

People with dementia must be involved as equal partners – non negotiable

- **Well being.** Supporting the person to achieve the best quality of life reasonably possible
- **Autonomy/Independence**
- **Reduced stigma and social isolation**
- **Equality.** People with dementia and their carers are respected and included in society, with their rights and capabilities recognized - CRPD
World Alzheimer Report 2019

- World’s largest survey on attitudes to dementia – almost 70,000 respondents
- Commissioned London School of Economics & Political Science (LSE)
- Essays and case studies bring the survey to life

www.alz.co.uk/worldreport2019
World Alzheimer Report 2019: revealing the gap in dementia friendliness and awareness

1 in 4 people think there is nothing we can do to prevent dementia

35% of carers globally have hidden the diagnosis of a person with dementia

62% of healthcare practitioners still believe that dementia is part of normal ageing

2 in 3 people still think that dementia is caused by normal ageing
Almost 70,000 respondents from 155 countries

2 in 3 people think that dementia is caused by normal ageing.
1 in 4 people think that there is nothing we can do to prevent dementia.
95% of the general public think they could develop dementia at some point in their lifetime.

Just under 40% of the general public think that there are adequate community services in place for people living with dementia and carers.
54% of respondents think lifestyle factors play a part in developing dementia.
91% of respondents say that people should not hide the fact they have dementia.

Men are more likely to hold stigmatising views about dementia than women. Although they were more likely to let a relative with dementia move in with them.

Attitudes of healthcare practitioners to dementia

62% of healthcare practitioners still believe that dementia is part of normal ageing.

Around 40% of the public think healthcare practitioners ignore people with dementia.

“My neurologist ignored my presence when my diagnoses was discussed with my husband.”

“They sometimes talk to my wife about things like I’m not even there, but I’m sitting right there.”

“Many healthcare practitioners often do not believe I have dementia - which is abusive and offensive. But, also, they then talk over me, about me, and never to me…”

Experiences of carers

Over 30% of carers expressed positive sentiments about their role.

Over 50% of dementia carers said their health suffered as a result of their caring responsibilities.

95% of carers globally have hidden the diagnosis of a person with dementia.

Over 60% of dementia carers said their social life suffered as a result of their caring responsibilities.

Between 25% in high income and 57% in low and lower middle income countries reported being treated unfairly in dating or intimate relationships.

People with dementia said:

“To be honest, NO ONE wants to deal with a 56-year-old guy with Alzheimer’s.”

“I call it the friendship disease. I have lost a fair amount of people in my life that at one time considered friends.”

“…my wife and I divorced due to my Alzheimer’s…her decision.”

“I don’t date at all now. As soon as I mention I have dementia, they presume the worst.”

“My best boyfriend wanted to hide me away and I spoke openly about my dementia. Hence why that relationship didn’t work…”

Dementia: not a laughing matter?

43% of respondents living with dementia in South-East Asia said their dementia symptoms were joked about by others.

67% of respondents living with dementia in Africa said their dementia symptoms were joked about by others.

Carers of people with dementia said:

“So-called Alzheimer’s humour does much more than annoy and hurt those who work hard to make life better for the 50 million plus people in the world living with dementia. It trivialises the disease.”

People with dementia said:

“If it is 100% offensive, and excruciating to joke about my symptoms (unless it is me joking about it).”

“When others who also have a dementia diagnosis joke this is just an expression that we are able to maintain a sense of humour and is a great stress reliever.”

“Laughter is good for the soul and if you can laugh about your circumstances it can reduce anxiety. So we laugh from time to time when something incongruent comes out of my mouth.”

www.siz.co.uk/worldreport2019
Some conclusions

- Need to encourage development of dementia friendly societies in order to:
  - Improve the lived experience with dementia
  - To seek the inclusion of dementia in the CPRD
- People with dementia must be equal partners
- Requires funding and support from all levels of government, as well as business and the community
Hope In The Age Of Dementia.
NEW SCIENCE. NEW KNOWLEDGE. NEW SOLUTIONS.

19-21 March 2020
adi2020.org
Alzheimer’s Disease International
The global voice on dementia

Thank you!

Follow ADI on Twitter
@AlzDisInt

Like us on Facebook
/alzheimersdiseaseinternational

Visit our website
www.alz.co.uk
Living well: the community challenge

Dr Tarun Dua
World Health Organization

#DefeatingDementia
Towards a dementia-inclusive society: a WHO toolkit for dementia-friendly initiatives (DFIs)

Tarun Dua
Department of Mental Health and Substance Use, World Health Organization
Global action plan on the public health response to dementia

The Seventieth World Health Assembly, having considered the draft global action plan on the public health response to dementia 2017–2025, decided:

(1) to endorse the global action plan on the public health response to dementia 2017–2025;

(2) to urge Member States to develop, as soon as practicable, ambitious national responses to the overall implementation of the global action plan on the public health response to dementia 2017–2025;

(3) to request the Director-General to submit a report on progress made in implementing this decision to the Seventy-third, Seventy-sixth and Seventy-ninth World Health Assemblies.

(Tenth plenary meeting, 31 May 2017)
WHO tools to support countries

- Dementia as a public health priority
  - Policy guide

- Dementia awareness & friendliness
  - Dementia-friendly toolkit

- Dementia risk reduction
  - Dementia risk reduction guidelines

- Dementia treatment, care & support
  - mhGAP toolkit for health & community workers

- Support for dementia carers
  - iSupport

- Information systems for dementia
  - GDO e-tool and platform

- Dementia research & innovation
  - BRAINS for dementia

Global Dementia Observatory (GDO)
Rationale for developing a DFI toolkit

- Ongoing lack of awareness and understanding of dementia globally
- Misconception, false beliefs and stigma in many countries
- Discrimination and human rights violations against people with dementia
GDO data on dementia inclusiveness
(based on 51 countries)

- 40% of GDO countries ran national awareness raising campaigns.
- 67% of GDO countries have at least one DFI.
- 70% of countries provide dementia training to population groups outside the health and social care sector.

Top 3
- volunteers (65%)
- police and first responders (39%)
- school children (37%)
## Development of the DFI toolkit

<table>
<thead>
<tr>
<th>Step</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Global landscaping</td>
<td>Review of relevant WHO documents and DFI literature</td>
</tr>
<tr>
<td>2. Framework</td>
<td>Conceptual cross-mapping of emerging themes and building of framework</td>
</tr>
<tr>
<td>3. Stakeholder consultation</td>
<td>Expert consultation and feedback round</td>
</tr>
<tr>
<td>4. Toolkit</td>
<td>Based on framework and existing toolkits</td>
</tr>
<tr>
<td>5. M&amp;E indicators</td>
<td>Based on framework and steps outlined in the toolkit</td>
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<td></td>
<td>Aligning with other work</td>
</tr>
<tr>
<td>6. Pilot testing</td>
<td>In selected countries from WHO regions</td>
</tr>
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</table>
20 in-depth interviews
- With civil society and policy makers
- Across all 6 WHO regions and all country income levels

6 focus groups
- With people living with dementia
- Including one in Japan and one in Australia
- Conducted by Dementia Alliance International (DAI)

Online survey
- 129 respondents from 46 countries
Towards a dementia-inclusive society: a WHO toolkit for dementia-friendly initiatives (DFIs)

A look inside the toolkit

- The toolkit supports individuals working in communities to create dementia-inclusive societies.
- It includes practical guidance, tools and exercises that can be used as facilitation tools by non-expert programme implementers in group settings.

Part I
- Dementia and human rights
- How to use this toolkit
- The DFI framework

Part II
- Module A: Developing a new DFI
- Module B: Integrating dementia into an existing initiative
- Module C: Monitoring and evaluation (M&E)
- Module D: Scaling up a DFI
The framework

- Draws on a Theory of Change model.
- Provides a structured process that guides users to undertake their own initiatives.
- Step-by-step template for carrying out, integrating, evaluating and scaling initiatives adaptable to local contexts, cultural norms, community practices and population needs.
Framework components

Vision
Make society inclusive of people living with dementia, their carers and families so that they are free to make their own choices and are protected from discrimination.

Key principles
- Participation
- Collaboration
- Leadership
- Sustainability

Primary focus
- Social environment
- Physical environment
- Holistic

Activities
All activities and actions that promote lasting change to the social and/or physical environment to help build dementia-inclusive societies.

Target groups
The individuals or groups of individuals, targeted by the DFI and its activities.
The implementation section of the toolkit

Module A: starting a new DFI
Module B: integrating dementia into an existing initiative
Module C: monitoring & evaluating a DFI
Module D: scaling up a DFI
Module A provides practical guidance and tools to **start a new DFI**.

It includes **guided steps and exercises** that help users:

- **identify stakeholders**, partners and a coordination team;
- Define **key issues and a vision** for the initiative;
- Set **goals and outcomes**, and identify primary focus areas;
- Develop activities and a **risk- and resource-management** plan.
Module B provides practical guidance and tools to integrate dementia into an existing initiative (e.g. age-friendly community).

It includes **guided steps and exercises** that help users:

- **Identify stakeholders**, partners and a coordination team;
- Gather information to map **relevant, existing initiatives** and identify key issues;
- Set a joint **vision, goals and outcomes**, and determine primary focus areas;
- Develop activities for integration and a **risk- and resource-management** plan.
Module C provides practical guidance and tools to **monitor and evaluate a DFI**.

It includes a series of **steps and exercises** that help users:

- Determine what **type of evaluation** best suits their initiative;
- Develop a **logic model**;
- Formulate **evaluation questions and indicators**.
Module D provides practical guidance and tools to scale up a DFI.

It includes tips, checklists and exercises that help users:

- Identify a DFI for scale-up;
- Determine the appropriate type of scale-up mechanism;
- Develop a vision, goals and outcomes, and determine primary focus areas for scale-up;
- Plan and implement activities for integration and a risk- and resource-management plan.
WHO also acknowledges the financial support from Canada, the European Commission, Germany, Japan, the Netherlands, Switzerland and the United Kingdom.

Thank You
Living well: the community challenge

Professor Martin Knapp
London School of Economics, UK

#DefeatingDementia
Global challenges

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London School of Economics & Political Science

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1. Scary numbers? Projected global growth in dementia prevalence to 2050

Numbers of people living with dementia (millions)

Age-specific incidence may be slowing, but only in better-educated population subgroups

Total prevalence will still grow
2. Unaffordable costs? Projected costs of dementia care in England

- Total cost increase by 249%
- Unpaid care cost by 213%
- Social care cost by 303%
- Health care cost by 194%

£ billion at 2015 prices
No disease-modifying treatments yet
99.6% failure rate of medication trials for Alzheimer’s disease, 2002-2012 (Cummings et al. Alz Res & Therapy 2014)

Why?
- Inherent inaccessibility & complexity of the brain
- Symptoms may emerge 10+ years after disease starts
- Not enough research / researchers?
- Insufficient protection for IP?

3. No cure?

Factoring in difficulties & costs of diagnostic tests, when will a ‘cure’ be affordable globally?
4. Slow, partial prevention?

Known risk factors:
- Genes (*at birth*)
- Education (*early life* +)
- Hearing loss, hypertension, obesity (*mid-life*)
- Smoking, depression, physical inactivity, social isolation, diabetes (*late-life*)

Overall population-attributable risk = 35%

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5. Substantial inequalities?

Many risk-factors have strong (socio)economic links:
- low education
- poor health behaviours
- unaffordability of good diet & exercise
- social isolation
- depression

And inequalities in access to care & support (see next)

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6. Inadequate care?

- Yes, there are evidence-based symptomatic treatments, care & support arrangements, but...

- ... few people living with dementia have access to them.

- And there are proven support services for family caregivers...

- ... but again, not widely available.

- Are there enough family & other unpaid caregivers - today and in the future?

- Wide inequalities in access to good care & support

- Treatment & care complicated by comorbid conditions
• Health & care systems unprepared for rapid population ageing
• Lack of awareness re dementia – seen as ‘normal ageing’
• Stigma (WAR2019)
• Heavy burdens on families (mainly women)
• ‘Competition’ from other health problems with noisier ‘champions’
STRiDE: Strengthening responses to dementia in developing countries

- Building capacity in generating/using research evidence to support policies to improve dementia care, treatment & support...
- ... particularly to help develop, finance, plan, implement & evaluate national dementia plans.  
  [UKRI-funded, 2018-21]

LSE in partnership with Univ Cape Town, ADI, DAI and others
Living well: the community challenge

Keisuke Naito
Vice President, Eisai

#DefeatingDementia
Session: Living well: the community challenge

Eisai Initiatives for Dementia Total Inclusive Ecosystem

Eisai Co., Ltd.

18 October, 2019
Chief Digital Officer,
Head of Dementia Total Inclusive Ecosystem

Keisuke Naito
Years of Steps living with Dementia
Japan Government and Eisai

AD drug was approved in Japan
Long-term care insurance system started

1998
2000
2001
...
2004
2005
2006
2007
2008
...
2012
2013
2014
2015
2016
2017
2018
2019

“Orange Plan”
“New Orange Plan”

Outline for Promoting the Dementia Plan “Coexistence” and “Prevention”

- Started “Japan Academy of Alzheimer’s disease”
- Launched e-65.net (Information website)
- Initiated support for co-developing community
- Added support map to e-65.net
- “Dementia Solution department” was established
- Renamed to “hhc solution department”
- “DTIE” was established
- Started partnership with Cogstate
Series of Tools we have developing
Including partnership

<table>
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<th>Awareness</th>
<th>Early recognition</th>
<th>Supporting people taking medication and their family</th>
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<tr>
<td><strong>Dementia DVD and text book for students</strong></td>
<td><strong>Cogstate Brief Battery</strong></td>
<td><strong>Medication administration support device</strong></td>
</tr>
<tr>
<td>Educational materials for correct understanding about Dementia</td>
<td>Self cognitive check tool using digital device (PC, iPad) which takes only 15 minutes.</td>
<td>&quot;e-Okusuri-san&quot;</td>
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<tr>
<td>Obtained feedback such as “I could understand the anxiety of my grand father”, “I have to be generous, not be angry”</td>
<td></td>
<td>Helping patients to reduce unused medicines due to forgetting to take, or to prevent from overdosing by ensuring prescribed dosage of medicine administered at the scheduled time</td>
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**Outing support tool**

“Me-MAMORIO”

IoT device to share location of people with dementia and elderly people who go out. Activated community watching over people with dementia and elderly people

*1 : Sold as glossary goods. Not for diagnosis  *2: Acclaimed for presenting new value to the stakeholders, "IT business award" was granted"
Initiative for Coexistence and Prevention in local government in communities

Partnered with 150 organizations such as municipal governments | Awareness | Co-developing Community

Health Check

- Questionnaire
- Cognitive function check
- Frail check etc

✓ Evidence making to maintain and improve cognitive function
✓ Reflection to next-year planning

Cognitive function is declined

Cognitive function is NOT declined

Diagnosis in medical institution
Medical Association
Professional hospitals

Diagnosis such as dementia and depression

Prevention Program
- Exercise program
- Life review
- Oral care
- Cooking class etc.

Advice to receive measures provided by the local community

Six months later

Common scale of community and medical institution, and periodic outcome measurement are required

*1: as of March 2019
Appropriate tools to be required

Investigated more than 160 cognitive check