

# Alzheimer's and Dementia; The Global Ecosystem

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Chair, World Dementia Council

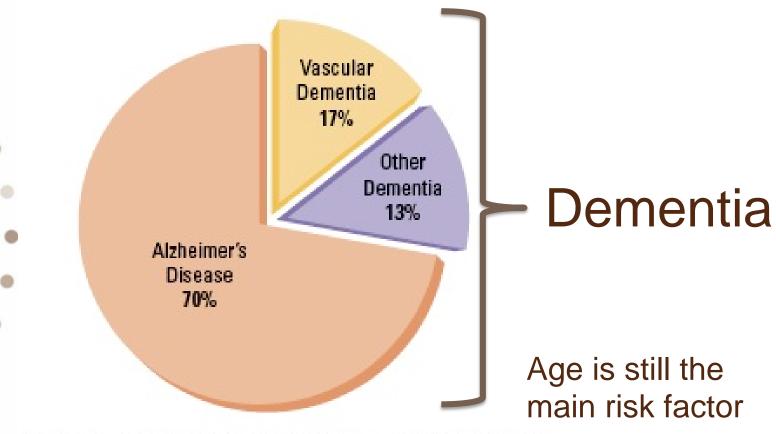
DIAD Meeting Toronto, 2016

#### Goals of this Presentation

- Ultimate goal is to discuss the current global ecosystem advocating to face the global challenge of dementia
- Some of the elements we will discuss together
  - Extent of this global challenge
  - Extent to which global policy makers are aware of the challenge
  - Examples of global actions that are currently deployed
  - Importance of the role of those living with dementia and their families/carers
  - Where to next ....



# Alzeimer's Disease Responsible for the Majority of Cases of Dementia

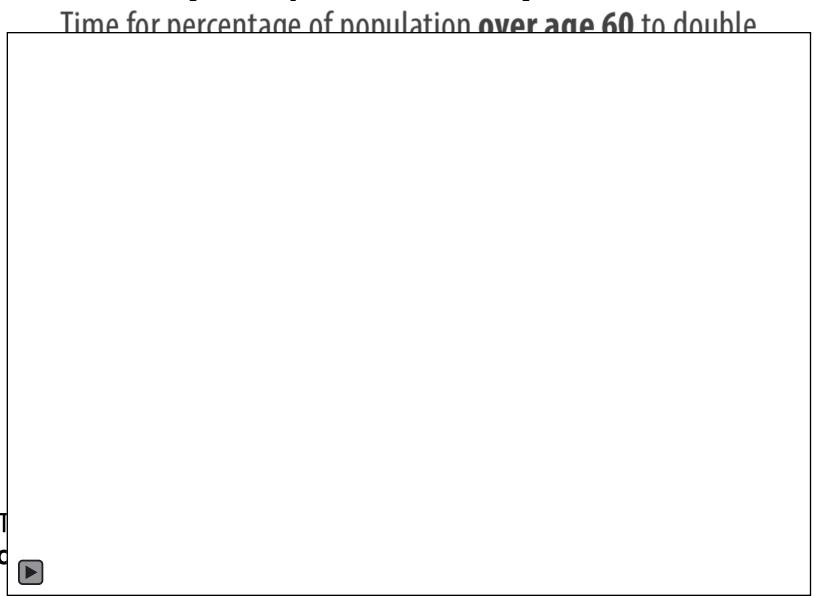


Source: Plassman, BL; Langa, KM; Fisher, GG; Heeringa, SG; Weir, DR; Ofstedal, MB, et al. "Prevalence of Dementia in the United States: The Aging Demographics, and Memory Study. *Neuroepidemiology* 2007; 29:125-132.31

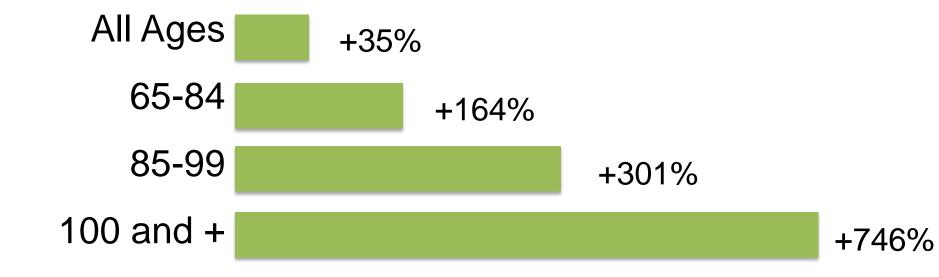


# Populations are getting older

# Population ageing is happening much more quickly than in the past



#### % of Growth of Population 2005-2040



Source: US Census Bureau Inspired by Daigo Fujirawa/Globe Staff

#### The global impact of dementia

Around the world, there will be 9.9 million new cases of dementia in 2015,

one every 3 seconds

46.8 million people worldwide are Itving with dementia in 2015.

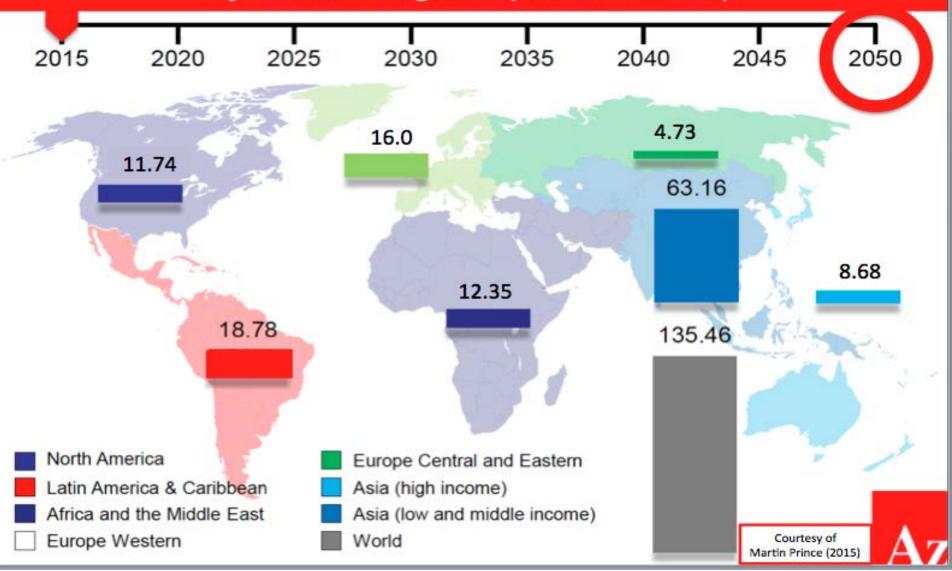
This number will almost double every 20 years.

Much of the increase will take place in low and middle income countries (LMICs): in 2015, 58% of all people with dementia live in LMICs, rising to 63% in 2030 and 68% in 2050.



The World Alzheimer Report 2015 was independently researched by King's College London and supported by Bupa.

# Numbers of people with dementia by world region (2015-2050)



#### The Global Dementia Challenge

- Dementia is one of the most crucial public health challenges (WHO and ADI)
  - Not limited to high-income countries
  - Particularly challenging for low- and middle-income countries
- There is a a global collaboration and synergy between:
  - WHO which brings together Member States and supports the Global Dementia Observatory
  - The World Dementia Council which provides a complementary role of bringing together individuals from all stakeholders groups in order to support, amplify and coordinate a global response
  - In coordination with ADI and OECD
  - Connecting with other initiatives (e.g., GBHI, GCBH)



#### The Initial World Dementia Council

- In Dec 2013, UK hosted a G8 Dementia Summit
- Goal was to bring together experts across the world to start a global conversation about solutions for dementia
- The Summit resulted in a declaration that set out an international response to dementia with the aim of identifying a cure or a disease modifying therapy by 2025





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France's President Sarkozy had put Alzheimer as a national priority in 2008 and lead a European rally around collaborative research at the origin of JPND







#### The Initial World Dementia Council

- In February 2014, the UK Prime Minister appointed Dr Dennis Gillings as the World Dementia Envoy & established the World Dementia Council (WDC)
- WDC Members are from a wide range of experts from research, academia, industry, the NGO sector, people living with dementia & governments





#### G7 to Global – The Continuity Model

- Following the WHO First Ministerial conference in March 2015 a broad consensus was reached amongst key global stakeholders & the WDC, on a global model to pursue with the challenge of dementia
- A complementarity approach:
  - Establishment of the WHO Global Dementia Observatory
  - Actions from the WDC Global Teams that are independent of governments & any one organisation or sector
  - ➤ No formal governance between these two pillars, but a collaborative approach to optimize global impact



#### The Current World Dementia Council

- Since February 2016, WDC membership has been expanded globally
  - New members drawn from a range of sectors & organisations across the wider global dementia community (24 Members)
  - Chair/Vice-Chair Yves Joanette/Raj Long





#### The Current World Dementia Council

#### Includes

People living with dementia

#### Hilary Doxford Early onset AD at 53

Volunteer at UK Alzheimer's Society
Lots of international involvement
Works as Business Manager
with some accommodation

#### Kate Swaffer

Early onset AD
Very active in the Alzheimer's Australia
Dementia Committee
Co-founder, co-Chair and Editor of
Dementia Alliance International

"Nothing about us, without us."



#### The Current World Dementia Council

- Includes
  - People living with dementia
  - Head of associations representing people living with dementia and their caregivers

Taiwan India UK Indonesia Nigeria USA



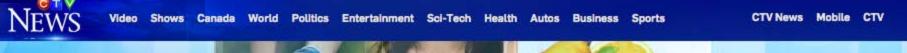


#### Specificity of Young Onset Dementias

### Alzheimer Society of Canada on Young Onset Dementias

- Be working at the time of diagnosis
- Have dependent children/parents living at home
- Have significant financial commitments (mortgage, children university fees, etc.)
- Be physically fit
- Be more aware of their symptoms
- Find it hard to accept losing skills
- Find it difficult to get information, support and services adapted to younger people with dementia





#### Health



HOME HEADLINES

**DIET AND NUTRITION** 

FITNESS

**BODY AND MIND** 

LIFESTYLE

# The younger face of dementia: Ottawa man shares wife's battle with the disease



#### CTV National News: A silent epidemic



Avis Favaro reports on the heartbreak and confusion when dementia strikes the young.

#### CTV News Channel: Early Alzheimer's diagnosis



Why aren't more people diagnosed with Alzheimer's earlier in life? Dr. Carmela Tartaglia of the Tanz Centre For Research explains.







#### Untangling Alzheimer's

Thursday, July 17, 2014 at 8 PM on CBC-TV



# Wellness in Early Onset Familial Alzheimer Disease: Experiences of the Tahltan First Nation



#### Current Priorities of the Council

- 1. Global Team 1 Raj Long, Lead
- 2. Global Team 2 Chris Llewellyn, Lead
- 3.
- Global Team 3 Philippe Amouyel, Lead
- 4.
- Global Team 4 Harry Johns, Lead
- 5. Global Team 5 Ron Petersen, Lead

#### In

- Women and dementia
- Awareness
- Stigma
- Inequalities



An Independent Report on the Global Regulatory Approach to Achieve the Development of Safe, Effective and Affordable Drugs for Dementia

Executive Summary and Recommendations

Raj Long

#### Progress – Finance Models

• In March 2015, the WDC helped to shape the UK Govt-led work to establish the *Dementia Discovery Fund* – a ground breaking public/private venture capital fund which aims to finance pre-clinical research to find new drugs to treat dementia. The initial fund level is just over \$100m & it aims to raise a further \$100m during 2016





#### Progress – Research, Open Science and Big Data



#### **Dementia Research and Care**

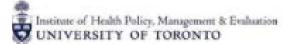
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#### **Addressing Dementia**

THE OECD RESPONSE















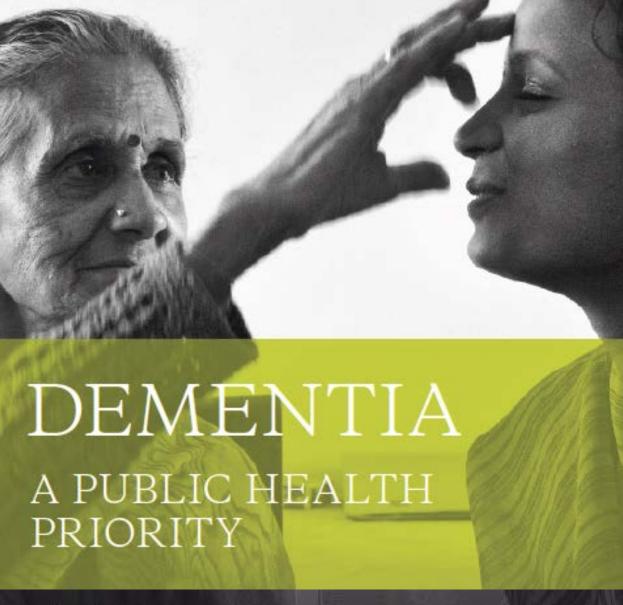


# The World Dementia Council Moving Forward

- The World Dementia Council is now ready to move forward
- The 5 Global Teams made up of Council Members and other experts will facilitate moving forward on all five priorities and cross-cutting themes
- The World Dementia Council will be working closely with WHO, OECD, ADI, Industry and all stakeholders to help promote, connect the dots and accelerate truly global approaches and solutions
- Important Action-Meeting on July 28-29 in Toronto



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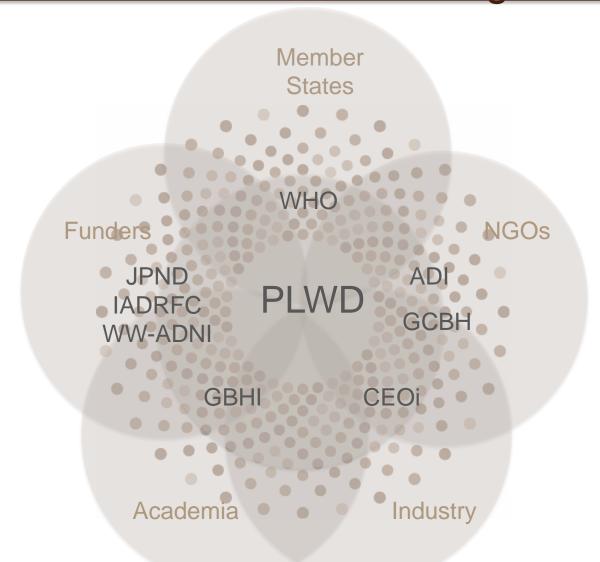








# Altogether .... Moving Forward







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info@worlddementiacouncil.com

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