

Press Release

World Dementia Council Goes Global

Rising dementia figures in low- to middle-income countries demands urgent global assault

The World Dementia Council (WDC) re-formed at yesterday's meeting in London, becoming truly globally representative in recognition of the urgent need to tackle the biggest disease burden facing the world today. The number of people with dementia worldwide is estimated to be 47.5 million. This is predicted to rise to 75.6 million by 2030, and almost triple by 2050 to 135.5 million, largely due to the increase in low- and middle-income countries, where 63% of disease burden falls - yet they have the least capacity to cope. Every year, there are 7.7 million new cases: one every four seconds¹.

Originally formed by the World Dementia Envoy Dr Dennis Gillings post G8 summit (2013) and previously supported by the UK government, the WDC has now become fully independent. It has expanded to bring together the broadest range of influential global leaders from all sectors, with expertise in and experience of dementia, enabling them to challenge and support Governments, industry, NGOs, public sector, academia, the research community and people with dementia worldwide, bringing them together in a concerted effort to address the global dementia crisis.

This follows a broad consensus across all dementia stakeholders and communities that a global collaborative approach is essential. The WHO First Ministerial Conference on Dementia (Geneva, March 2015) marked a significant milestone in the global fight against dementia, culminating in a Call For Action adopted by participants highlighting the importance of maintaining momentum and promoting global efforts to tackle dementia.

At this first meeting of the re-formed Council, Dr Gillings handed over the post as Chair of WDC to Dr. Yves Joanette, Scientific Director at the Canadian Institutes of Health Research (CIHR) Institute of Aging, and Vice-Chair, Raj Long, Senior Advisor at the Bill & Melinda Gates Foundation.

The WDC will apply a truly global approach to the following five priorities: finance, drug development, the ground-breaking sharing of big scientific data (all covering cure progress), improvements in care and risk reduction. There will be an elevated focus on stigma and awareness-raising; investment in technology, both to advance care and reduce long-term care costs; and a drive to find an international solution to ensure swift access of any new medicines when they become available.

From 2015 to 2050, people living with dementia will almost double in Europe, somewhat more than double in N. America, triple in Asia and quadruple in Latin America and Africa². To ensure global influence, WDC members have increased from 19 to 24, including new members from Nigeria, Argentina, Indonesia and Taiwan, and welcomed 10 new Associate Members.

The worldwide cost of dementia care is soaring: the World Alzheimer Report 2010 predicted an 85% increase in costs by 2030, and the costs are expected to rise more quickly in low- to middle-income countries, in part due to social changes reducing the availability of families to provide care. The current cost is estimated as US\$818 billion by Alzheimer's Disease International – if dementia were a country, it would be the 18th largest economy, more than the market value of Apple (US \$742 billion).

The WDC's initial objective has been to overcome barriers to innovation and unlock investment around the world, in order to achieve the G8 summit's aims to find a cure or disease-modifying medicine by 2025 while also improving care for people with dementia. So far, it has made huge progress, setting up the Dementia Discovery Fund – the first such to bring together private, public and philanthropic investment, raising US\$100 million; achieving an unprecedented collaboration of 11 international medicine regulators from 10 agencies, leading to Raj Long's *Finding a path to a cure*' report advising on how to speed up the dementia drug pathway; and the adoption of national dementia plans by 22 countries.

Care of people with dementia varies hugely across the world, and many experience stigma and social isolation – 40% say that they have been avoided or treated differently³. Dementia is sometimes perceived as a normal sign of ageing, mental illness or even by certain cultures as having supernatural elements. People can also be victims of abuse, for example being beaten for being 'stubborn', restrained regularly, both physically and by use of antipsychotic drugs, and cast out from their communities⁴.

WDC Chair, Dr. Yves Joanette, said: "The world has to face up to the staggering personal and economic impact of the biggest disease challenge that we face today. I'm delighted to welcome the new international members of our re-formed Council. Together, we have to mount a truly global assault to change the lives for people with dementia and their caregivers, including the most neglected and isolated. We will do so by amplifying the voices of people with dementia, organisations and communities to reach all corners of the world. I look forward to working closely with my colleagues to challenge and support all Governments in addressing this issue."

WHO Director-General, Dr Margaret Chan, said: "There is a tidal wave of dementia coming our way worldwide. We need to see greater investments in research to develop a cure, but also to improve the quality of life of people living with dementia and the support given to their caregivers."

The English Secretary of State for Health, Jeremy Hunt, said: "I thank the World Dementia Council and Envoy for the remarkable progress they have made so far, setting us well on the way to achieve the aims we first established at the G8 Summit as part of the UK Presidency in 2013. While we are seeing progress in drug development and greater understanding of this disease, there can be no cause for complacency and I look to the World Dementia Council to use their expertise and global reach to drive governments, industry and regulators to further action."

Hilary Doxford, WDC member and person living with dementia, commented: "The Council's amazing work has given me hope, because no single organisation, sector or country can fight this on their own. Last month, Nigeria became the most recent country to launch the Alzheimer's Society's Dementia Friends initiative. By supporting the roll-out of such programmes internationally we can increase awareness, tackle stigma, and improve lives - and ultimately defeat this devastating condition."

"I've been inspired to support the UK's 'Join Dementia Research', celebrating its anniversary this week, which speeds up research by getting people with and without dementia to sign up now to take part in future studies. And with the Council's support, we can promote vital projects like this across other countries."

Case Study

Rosemary's life was turned upside-down when her husband Tony was diagnosed with early-onset Alzheimer's in 2006 at just 63. Rosemary says: "When the diagnosis came, he was in

denial. Nowadays, he can't communicate with us anymore and we're not sure if he recognises us. It's sad to think our grandchildren have never known their real granddad. It's opened my eyes to the urgent need for new treatments to stop this disease in its tracks."

ENDS

Notes to Editor

References

1. WHO, <http://www.who.int/mediacentre/factsheets/fs362/en/>
2. WHO, http://www.who.int/mental_health/neurology/dementia/dementia_thematicbrief_epidemiology.pdf?ua=1
3. World Alzheimer Report 2012, <https://www.alz.co.uk/research/WorldAlzheimerReport2012.pdf>
4. WHO http://www.who.int/mental_health/neurology/dementia/dementia_thematicbrief_human_rights.pdf?ua=1

World Dementia Council

The World Dementia Council is a group of independent individuals from a wide range of constituencies – people with dementia, pharma industry, regulatory, charities, research organisations, care providers and finance/economics, with a broad range of skills, and from different parts of the world who together will seek to lead and coordinate global efforts to tackle dementia, ensure a collaborative approach to addressing the challenges posed by dementia and galvanise action all over the world, including through others, in the areas of awareness, prevention, diagnosis, stigma, disease-modification, cause and care. Visit <https://worlddementiacouncil.wordpress.com/> for further information.

The Council members (as ratified Thursday 25 February)

Prof. Dr. Ricardo F. Allegri, Prof. Philippe Amouyel, Hilary Doxford, Kiki Edwards, Dr. Dennis Gillings, Peggy Hamburg, Paul Hogan, Jeremy Hughes CBE, Dr. Franz Humer, Dr. Yves Joannette (Chair), Harry Johns, Dr. Kiyoshi Kurokawa, Chris Llewellyn, Raj Long (Vice-Chair), Prof. Ronald C. Petersen M.D. Ph.D., Prof. Pierluigi Nicotera, Meera Pattabiraman, Larry Renfro, Dr. Paul Stoffels, DY Suharya, Kate Swaffer, Li-Yu Tang, George Vradenburg.

Dementia Friends

The concept of dementia friends was first adopted by Japan. Alzheimer's Society's Dementia Friends programme followed, and is the UK's biggest ever initiative to change the way people think, act and talk about dementia, tackling the stigma resulting in social exclusion.. This pioneering initiative is now spreading worldwide, with similar initiatives being rolled out in Canada, Mauritius, South Korea, Scotland, Israel, Nigeria, Germany, Gibraltar and Denmark. Visit www.dementiafriends.org.uk/ for further information.

Join Dementia Research

'Join dementia research' promises to accelerate the pace of dementia research by allowing people with and without dementia to register their interest in studies, helping researchers find the right participants at the right time. It is a collaboration between the National Institute for Health Research, Alzheimer's Research UK, Alzheimer's Society, Alzheimer Scotland

and UCL Partners, and has been developed as part of the Prime Minister's Challenge on Dementia. It is funded by the Department of Health and NHS England through the SBRI Healthcare Programme. Visit www.joindementiaresearch.nihr.ac.uk for more information.