First WHO Ministerial Conference on Global Action Against Dementia
Geneva, Switzerland
March 16-17 2015

EMERGING LEADERS IN DEMENTIA COMMUNIQUÉ

Introduction

We, the 120 selected Young Leaders in Dementia, met in Ottawa, Tokyo, Washington D.C, and London to discuss innovative ideas to address dementia. The UK Science and Innovation Network organized this event which coincided with the Global Action Against Dementia Legacy Events, in order to raise awareness of the UK G7 Dementia Summit and its Legacy.

We are leaders from multiple sectors (e.g. universities, healthcare, research, start-ups, social innovation, engineering, economics, communication, law, and application design). We discussed creative and innovative ideas covering a diverse range of topics, ranging from technological advances in dementia research and dementia awareness campaigns to economic burden and incentives in dementia care and urban design to address the six priorities put forward by the World Dementia Council (WDC).

Our goals were:
1) to develop innovative ideas from the younger generations' points of view to support the WDC's ongoing work;
2) to develop and lead a sustainable global network for all generations working to address the challenges presented by this neurodegenerative disease;
3) to emphasize the concept of dementia as a global disorder that spans the generations which can immediately benefit from evolving technologies and non-traditional partners.

The following communiqué summarizes ideas that emerged from the four events in Canada, Japan, USA, and Europe.

Working Together Across Sectors, Regions, and Generations

At each event, communication between and across sectors was among the most discussed themes. Both the importance of a common medium to share information as well as a common language was emphasized in our discussions.

1. Connecting the Public:

We discussed moving the topic of dementia awareness beyond the traditional academic publications and conferences into the realm of public relations. In order to involve entire communities (from academics to front-line health care workers), we need everyone to have a general understanding and awareness of dementia. Awareness campaigns such as "Dementia Friends" can be tried in different regions and nations. We also support programs such as the *Center for Public Engagement with Science and Technology* of the American Association for the Advancement of Sciences which provides scientists and clinicians with better training in communicating with the leaders in other sectors and the society at large.

2. Connecting the Sectors:

In order to realize the goal of synergizing disparate fields, it will be critical to have a core group of *Research Liaisons*- experts in their own fields able to translate domain-specific information to other disciplines. These Research Liaisons will identify and coordinate regional, national, and international networks; promote knowledge exchange between disciplines; develop innovative gatherings for leaders in health care, data analytics, engineering, computer science, public policy, economics, decision science and investors; and expand the current research focus on drug treatment to encompass all aspects of dementia care and cure. To further capitalize on existing platforms- scientific conferences, governmental forums (G7) and technology and innovation gatherings- and stimulate collaboration across sectors, these Research Liaisons will develop specific dementia proposals that can be delivered within these venues.

3. Connecting the Generations:
We discussed the need for continuing engagement of younger generations in actions against dementia. Education programs during primary and secondary education can develop dementia awareness and address dementia prevention across the lifespan. Within families of persons with dementia, cross-generational training for family and informal caregivers should be developed to bridge the gap between generations. Finally, we urge governments and NGOs to increase the appeal and training for working with persons with dementia such as establishing national scholarship funds for those pursuing education or training in dementia care or cure.

4. Connecting the Regions:
Like other global challenges, context (region, culture, gender, etc) is often a forgotten element in understanding dementia care and cure. We encourage leaders in dementia to examine the biological, cultural, educational, and social backdrop of persons with dementia and their caregivers as well as how these factors influence decision-making in prevention, care, and cure. At the same time, we call for a core set of outcome measures applicable to diverse settings to allow for translation of findings across borders.

5. Connecting the Sciences:
It is essential to identify and fund innovative ideas and projects to tackle the challenges above. While collaboration is often encouraged between sectors, there is no clear mechanism to foster in-depth cooperation. We discussed new funding models for dementia research, including introducing a collaborative prerequisite to government and NGO research grants; multi-national grants to improve collaboration across borders; inclusion of nations not traditionally involved in dementia research; and a *Dementia Grand Challenge* sponsored by the WDC or the G7 to jumpstart radical breakthroughs in the prevention, cure, and care of dementia.

Dementia Friendly Communities

All groups called for establishing and promoting practices which enhance the quality of life for those with dementia and their caregivers.

1. Awareness:
Awareness is the first step towards removing the stigma of ageism and cognitive impairment. Achieving mutual understanding between persons with dementia, their caregivers, and the public will reduce the fear and stigma surrounding dementia. We discussed the need for immediate

action to understand and remedy society's reluctance to systematically address day-to-day dementia and caregiving challenges through public relations campaigns and policy changes.

2. The dementia narrative:
There is an increased desire for information from persons with dementia and their caregivers. It is imperative that those impacted by dementia are afforded the opportunities to participate in research design, policy development and practice changes. Perspectives of the persons with dementia and their caregivers need to be integrated into our dementia education and awareness campaigns. Furthermore, the research community must include qualitative perspectives to empower the dementia narrative.

3. Supporting our skilled workers:
Dementia specific education, such as *Person Centered Care*, for front-line health care providers increases the quality of care delivered and the safety of those working with persons with dementia. Continuing on-the-job training for frontline workers and resources for community healthcare providers will delay the time to chronic care facilities use, relieve the burden of family caregivers, increase the quality of life for persons with dementia, and prevent burnout by the dementia workforce.

4. Women at the epicenter of the disease:
Addressing the disproportionate burden of dementia on women is critical for targeting novel solutions for the prevention of dementia and long-term support of caregivers in creating dementia-friendly products and communities.

5. Branding campaign and one-stop shop:
We propose the use of an international dementia-friendly symbol (e.g., the Purple Angel) to clearly identify dementia-friendly products and service. This can lead to the creation of one-stop shops that identify, treat and care for those affected by dementia and their caregivers. Additional multidisciplinary expertise can be further integrated into such one-stop shops in the future, as well as dementia and caregiving education and support.

6. Mobile technologies:
We recognize the power of mobile technologies in developed and developing countries, and see the opportunity to use these to improve access to care and support for persons with dementia and caregivers in resource-rich and resource-limited areas. Feedback from mobile technology also provides a new platform for research in understanding dementia and caregiving in the different community settings and resource availability.

Developing Care Standards

If dementia is to be addressed as a global problem then efforts must be made to develop and promote standards of care within and between nations. Key steps must be taken to ensure that care standards reflect the dyad of dementia (patient & caregiver) and are adaptable according to various cultural, economic and gender specific contexts.

1. Care standards across the disease spectrum:
These include: implementing dementia specific curriculum in training programs (health, law, services); supporting comparative research across nations to identify best practices for chronic care; improving end of life care standards and practices: early and correct diagnosis and accurate and timely communication to improve overall wellbeing of those living with dementia. Developing a global *toolbox* for the different facets of dementia research that takes into account the limited resources of underserved nations should be an immediate goal of the WDC and its affiliates.

2. Evaluating outcomes:
There is a need to establish measurable indexes to effectively evaluate outcomes that help prevent, care for and cure those with dementia based on subjective measures and accurate information (e.g. use of indicators, standards of care).

Conclusion

We, the Emerging Leaders in Dementia conclude this communiqué with the recognition that younger generations are pivotal in both dementia action progress and innovation. In order for us to accomplish the goal of finding a cure for dementia by 2025, collaboration among key sectors is imperative as is engaging and involving all generations. We applaud the World Health Organization and the World Dementia Council for making room for younger generations to be involved in dementia action progression and innovation.

- Title: **YOUNG LEADERS IN DEMENTIA COMMUNIQUÉ**
- Authors: Young Leaders in Dementia (Canada, Japan, USA, Europe)
- Document Purpose: Policy
- Publication date: 10 March 2015
- Target audience: World Dementia Council; World Health Organization
- Contact details: youngleads.dementia@gmail.com