Challenging the Stigma of Dementia

Jennifer Bethell, The Kite Research Institute, University Health Network
Roger Marple, Board of Directors, Alzheimer Society of Alberta
Laura Middleton, Department of Kinesiology, University of Waterloo

Acknowledgements

The Canadian Consortium on Neurodegeneration in Aging (CCNA) Stigma and Social Inclusion Group is supported by the Alzheimer Society of Canada through their commitment to the CCNA.

All opinions and statements expressed in this presentation are our own.

CCNV
Consortium canadien en neurodégénérescence associée au vieillissement

CCNA
Canadian Consortium on Neurodegeneration in Aging

Société Alzheimer Society
CANADA

Outline

In this talk, we will address the following questions:

1. What is stigma?
2. How do we know stigma is an important topic in dementia?
3. What are the health impacts of stigma for people living with dementia (and care partners)?
4. What are strategies we can use to overcome stigma and promote social inclusion?

What is stigma?

STIGMA[1]

The possession of (or the belief that one possesses) some attribute, or characteristic that conveys a social identity that is devalued in a particular social context

PUBLIC STIGMA[2]

When the general public endorses stereotypes about disease and disability and then discriminates against them.

SELF-STIGMA[2]

Public stereotypes directed inwardly, towards one's self.

LABEL AVOIDANCE[3]

Process whereby individuals decline or refuse to engage with specific types of services in order to avoid being labeled or stereotyped.

STRUCTURAL STIGMA[4]

Intentional and unintentional private and public institutional rules, regulations, and norms that discriminate against individuals with stigmatized conditions.

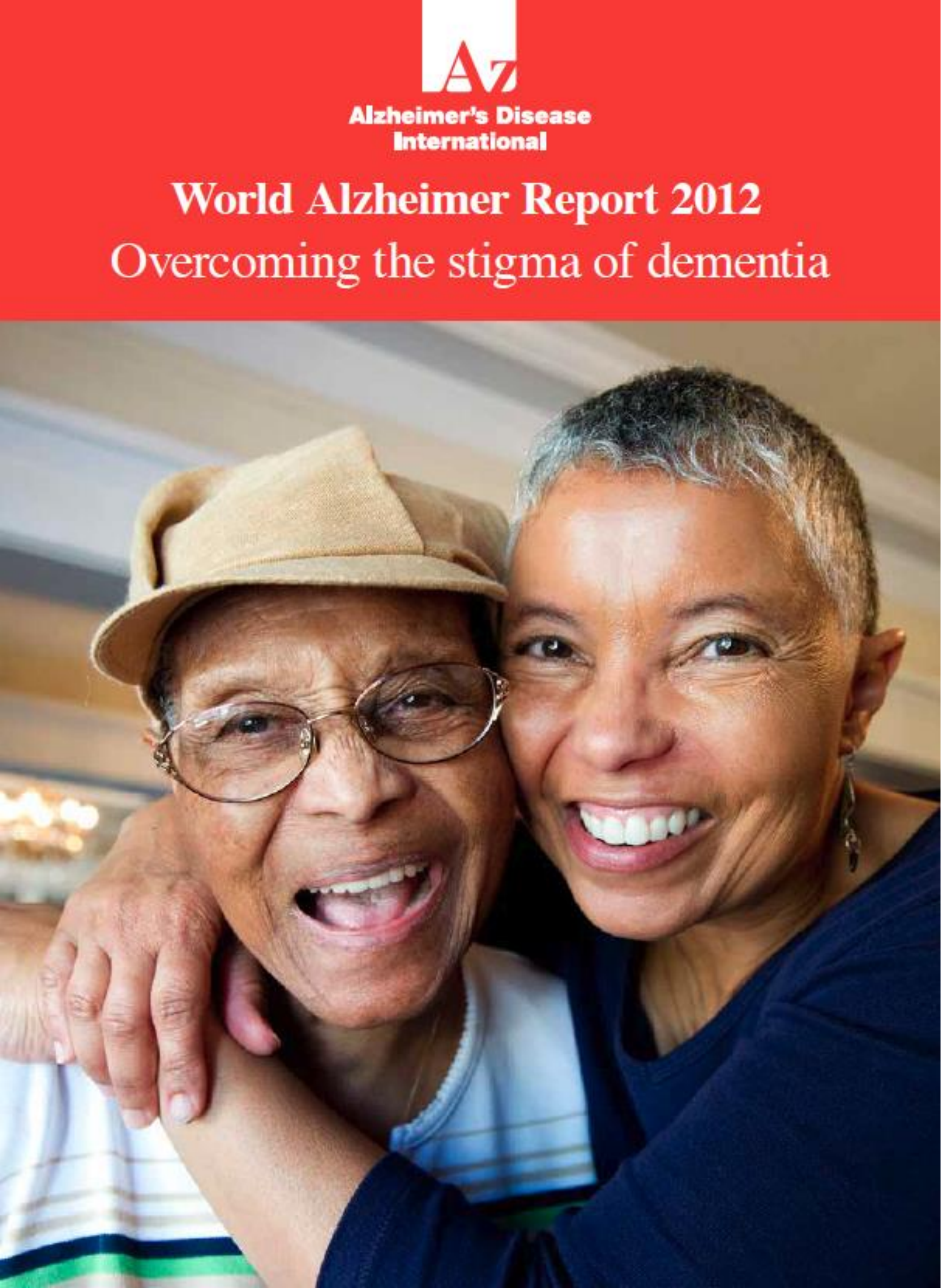
COURTESY STIGMA[5]

Sometimes called 'stigma by association', this is when the impacts of stigma are experienced by someone who associates with the person who is stigmatized.

References: 1 Crocker, Major, Steele, 1998 | 2 Jones & Corrigan, 2014 | 3 Corrigan & Watson, 2002 | 4 Corrigan et al, 2004 | 5 Goffmann, 1963
– via Canadian Consortium on Neurodegeneration in Aging (CCNA) Stigma and Social Inclusion group

How do we know stigma is an important topic in dementia?

Because people living with dementia, care partners, clinicians, researchers, policy makers and health charities & organizations - in Canada and around the world - say so!


Alzheimer's Disease International

World Alzheimer Report 2012

Overcoming the stigma of dementia

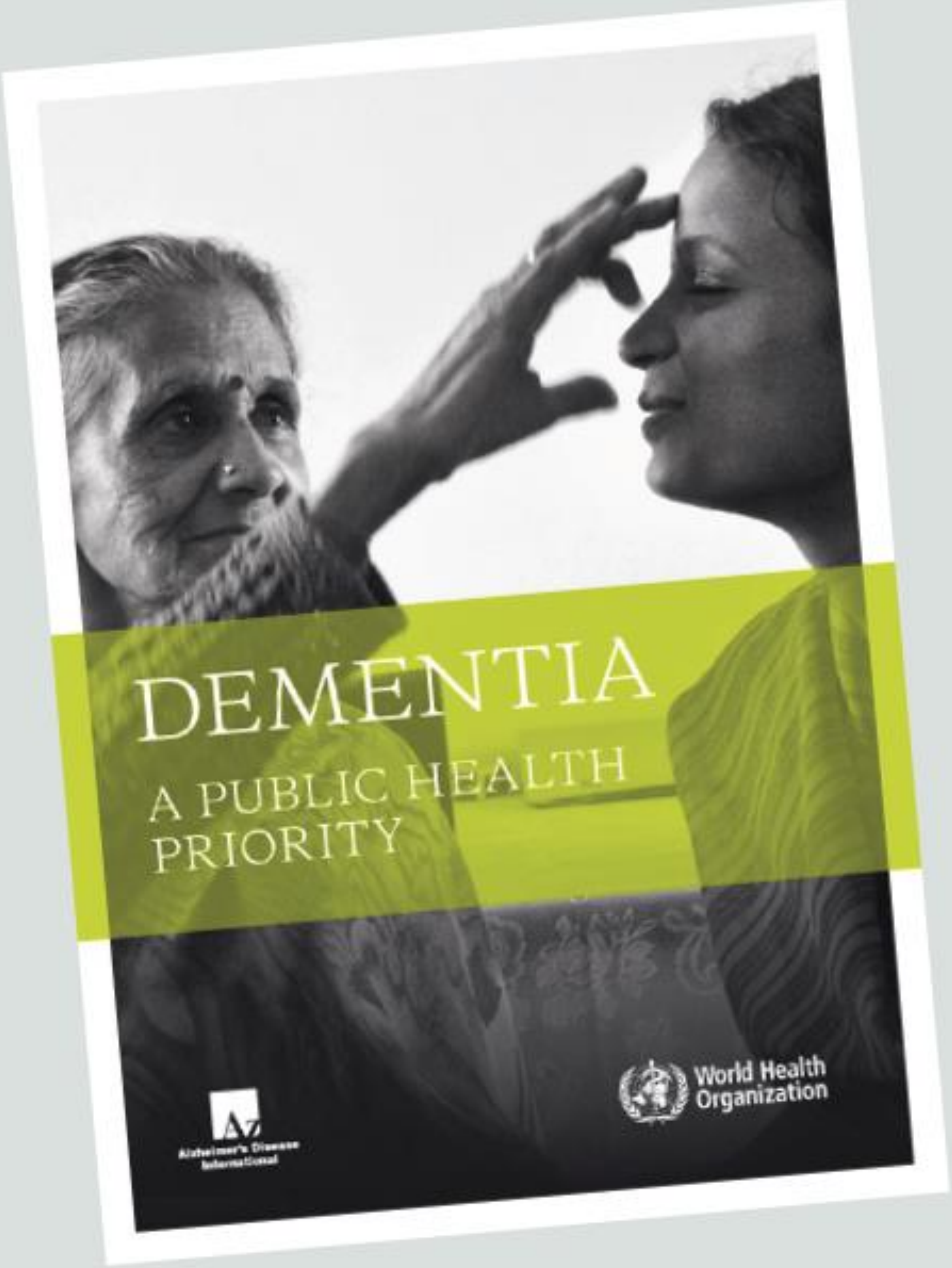
Low levels of understanding about dementia lead to various misconceptions resulting in perpetuation of stigma which is prevalent in most countries at various levels. People with dementia are often isolated, or hidden, because of stigma or the possibility of negative reactions from neighbours and relatives to behavioural and psychological symptoms. The idea that nothing can be done to help people with dementia often leads to hopelessness and frustration.

Urgent action is required to improve the understanding of dementia and so reduce stigma. It is with this aim that Alzheimer's Disease International (ADI) has produced this report on stigma to coincide with World Alzheimer's Month 2012.

Overcoming stigma will help tremendously with achieving ADI's vision of an improved quality of life for people with dementia and carers.

Dr Jacob Roy Kuriakose
Chairman
Alzheimer's Disease International

https://www.alz.co.uk/research/world-report-2012



DEMENTIA

A PUBLIC HEALTH PRIORITY

Alzheimer's Disease International

World Health Organization

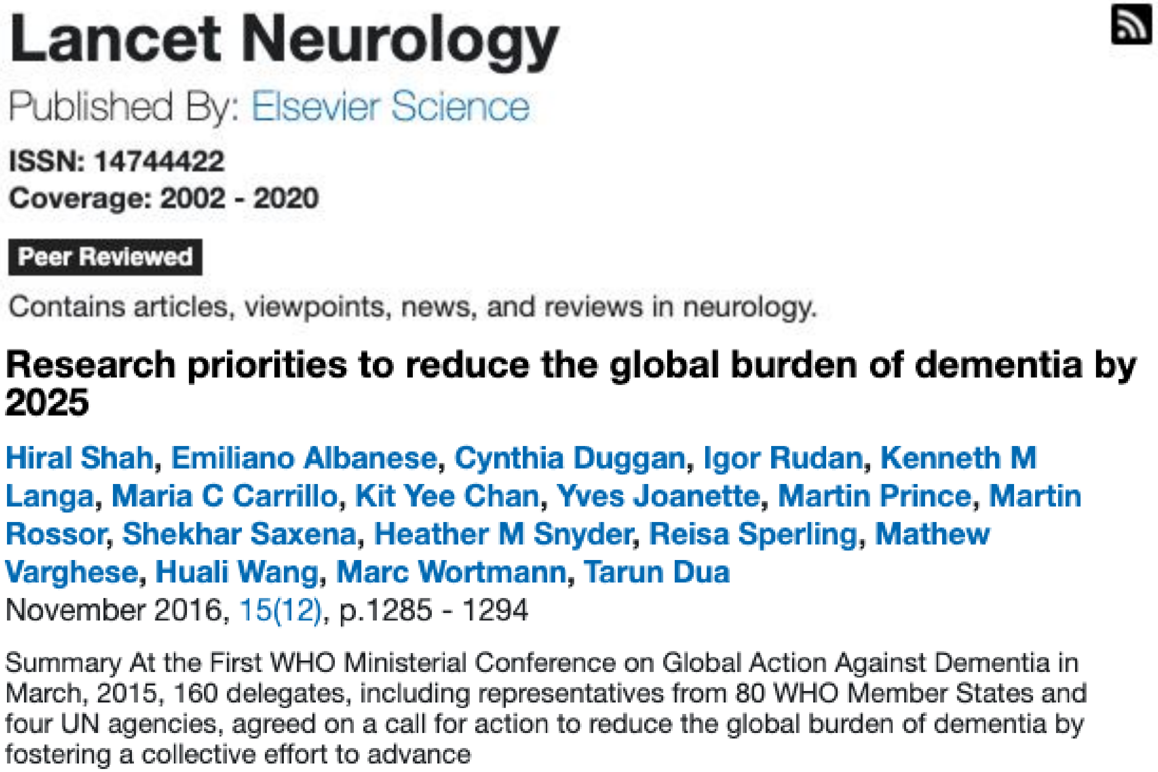
SUMMARY POINTS

- Research shows that public awareness of dementia is growing, especially in high-income countries. However, public understanding is mixed and there is a fear associated with dementia which contributes to the stigma attached to the syndrome and the delay or failure in seeking help.

- There is an urgent need for improving the awareness and understanding of dementia across all levels of society in order to improve the quality of life for people with dementia and their caregivers.

- Awareness-raising and improved understanding can reduce the stigma associated with dementia and reduce the fear of the disease. Better understanding in society generally and among those who provide the care should increase help-seeking and help-giving.

https://www.who.int/mental_health/publications/dementia_report_2012/en/



Lancet Neurology

Published By: Elsevier Science

ISSN: 14744422
Coverage: 2002 - 2020

Peer Reviewed

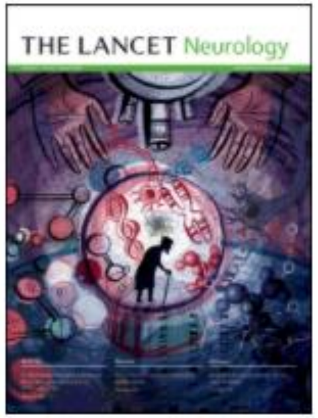
Contains articles, viewpoints, news, and reviews in neurology.

Research priorities to reduce the global burden of dementia by 2025

Hiral Shah, **Emiliano Albanese**, **Cynthia Duggan**, **Igor Rudan**, **Kenneth M Langa**, **Maria C Carrillo**, **Kit Yee Chan**, **Yves Joanette**, **Martin Prince**, **Martin Rossor**, **Shekhar Saxena**, **Heather M Snyder**, **Reisa Sperling**, **Mathew Varghese**, **Huali Wang**, **Marc Wortmann**, **Tarun Dua**

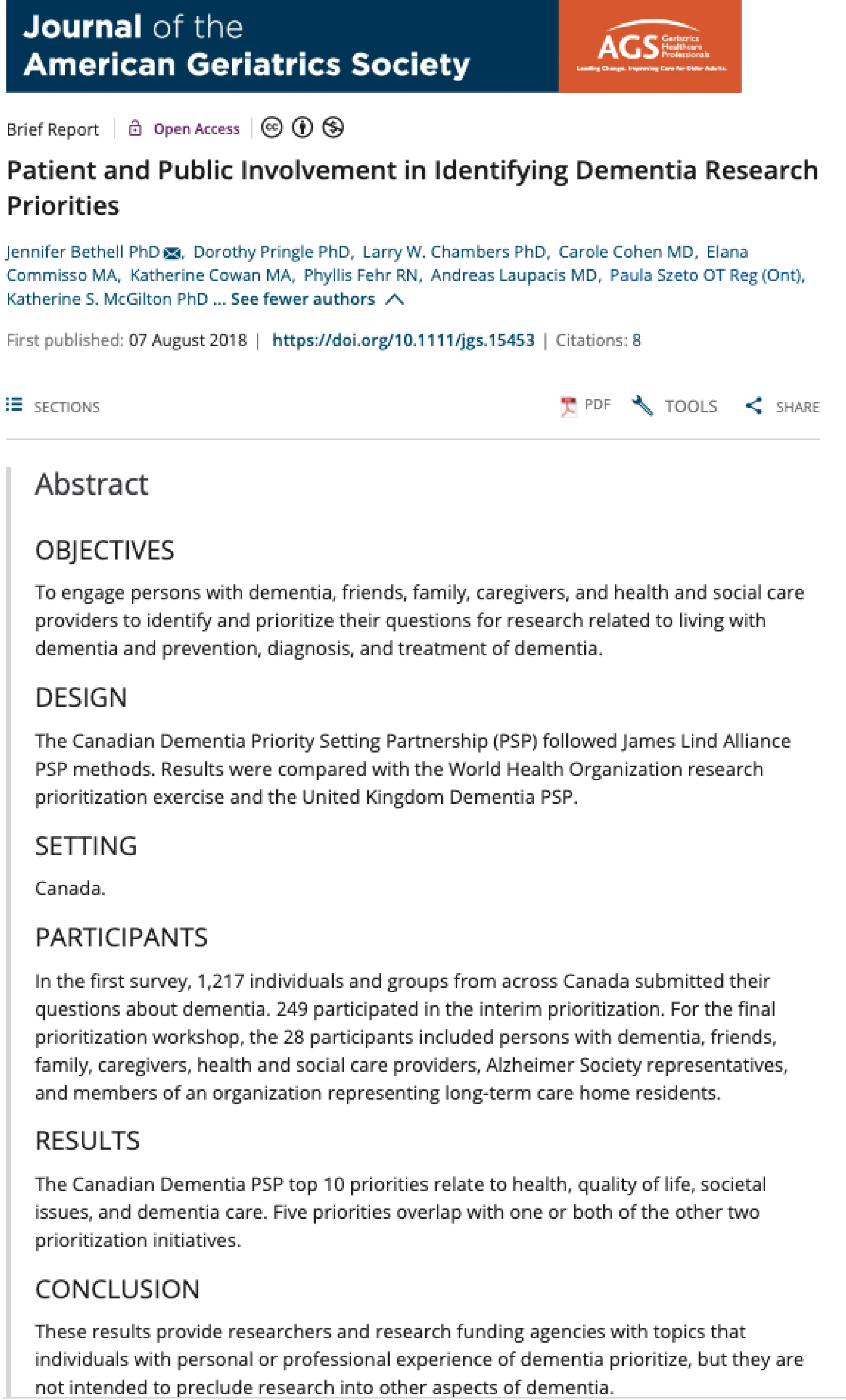
November 2016, 15(12), p.1285 - 1294

Summary At the First WHO Ministerial Conference on Global Action Against Dementia in March, 2015, 160 delegates, including representatives from 80 WHO Member States and four UN agencies, agreed on a call for action to reduce the global burden of dementia by fostering a collective effort to advance



Top thematic research avenue within “Public awareness and understanding” research domain (7 domains in all):

Determine the effectiveness and cost-effectiveness of dementia-friendly communities, and other population strategies that target stigma and discrimination, and promote inclusion and quality of life.



Journal of the American Geriatrics Society

Brief Report | Open Access

Patient and Public Involvement in Identifying Dementia Research Priorities

Jennifer Bethell PhD, Dorothy Pringle PhD, Larry W. Chambers PhD, Carole Cohen MD, Elana Commisso MA, Katherine Cowan MA, Phyllis Fehr RN, Andreas Laupacis MD, Paula Szeto OT Reg (Ont), Katherine S. McGilton PhD ... See fewer authors

First published: 07 August 2018 | https://doi.org/10.1111/jgs.15453 | Citations: 8

Abstract

OBJECTIVES

To engage persons with dementia, friends, family, caregivers, and health and social care providers to identify and prioritize their questions for research related to living with dementia and prevention, diagnosis, and treatment of dementia.

DESIGN

The Canadian Dementia Priority Setting Partnership (PSP) followed James Lind Alliance PSP methods. Results were compared with the World Health Organization research prioritization exercise and the United Kingdom Dementia PSP.

SETTING

Canada.

PARTICIPANTS

In the first survey, 1,217 individuals and groups from across Canada submitted their questions about dementia. 249 participated in the interim prioritization. For the final prioritization workshop, the 28 participants included persons with dementia, friends, family, caregivers, health and social care providers, Alzheimer Society representatives, and members of an organization representing long-term care home residents.

RESULTS

The Canadian Dementia PSP top 10 priorities relate to health, quality of life, societal issues, and dementia care. Five priorities overlap with one or both of the other two prioritization initiatives.

CONCLUSION

These results provide researchers and research funding agencies with topics that individuals with personal or professional experience of dementia prioritize, but they are not intended to preclude research into other aspects of dementia.

Top 10 Priorities for Research from the Canadian Dementia Priority Setting Partnership

1. What is the impact of stigmas associated with dementia and mental health issues on persons with dementia and their families? What are effective ways of reducing the stigma experienced by persons with dementia and their friends, family and caregivers/care partners?

I
LIVE
WITH
DEMENTIA

Let me help you understand. Dementia doesn't define me. It's just part of my life story. Alzheimer Societies across Canada are sharing stories like mine while providing programs and services to Canadians who live with dementia.

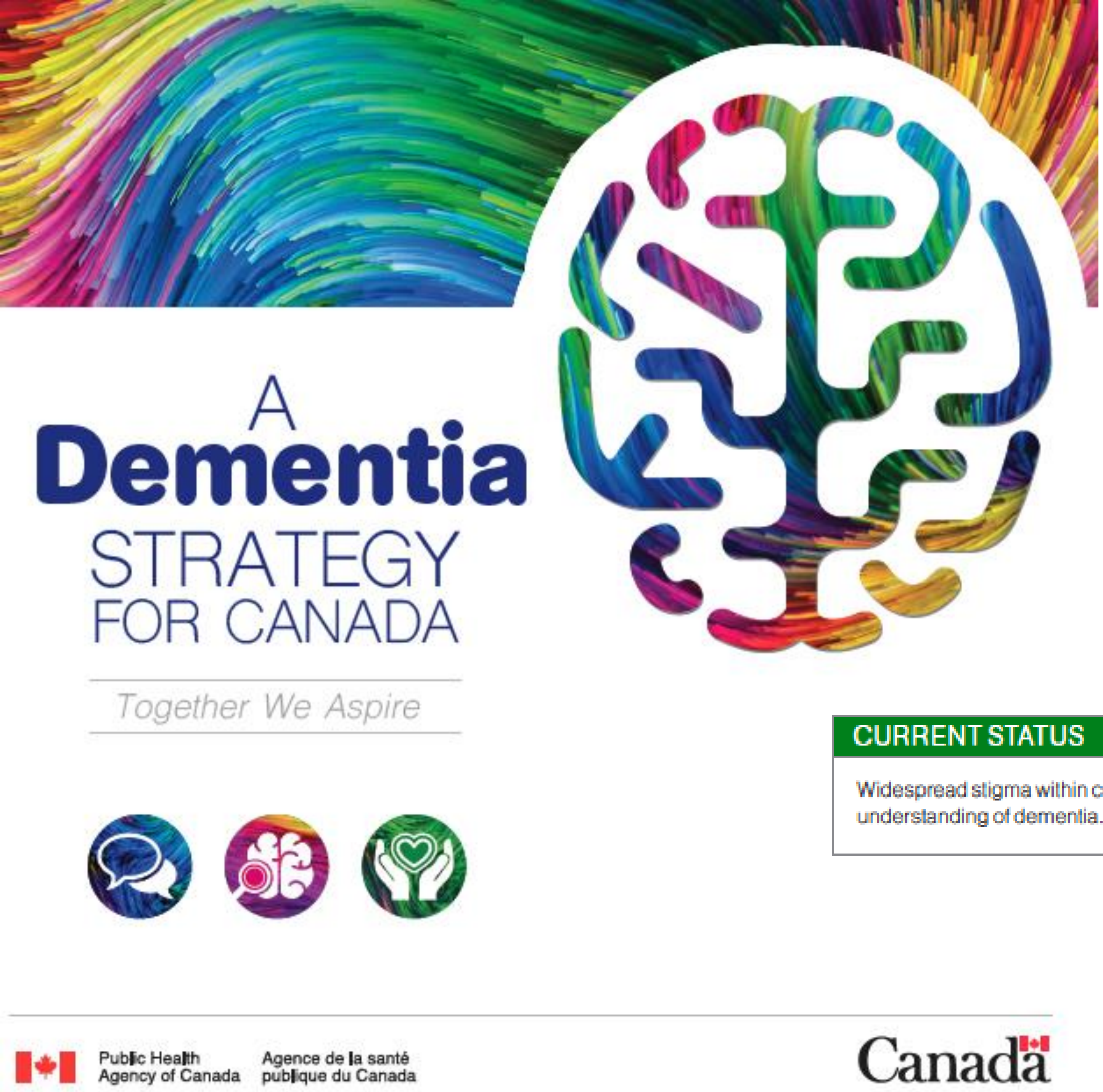
Read my story and learn how you can help at
ilivewithdementia.ca **#ilivewithdementia**

Alzheimer
Society

MY NEW YEAR'S RESOLUTION
is to end dementia stigma

Alzheimer
Society

i**live**with**dementia**.ca | #i**live**with**dementia**



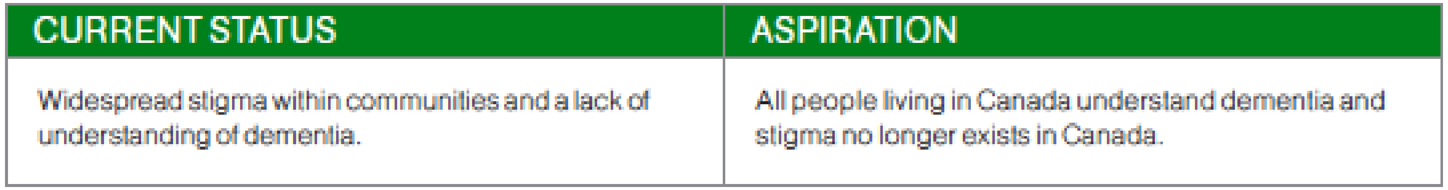
A
Dementia
STRATEGY
FOR CANADA

Together We Aspire

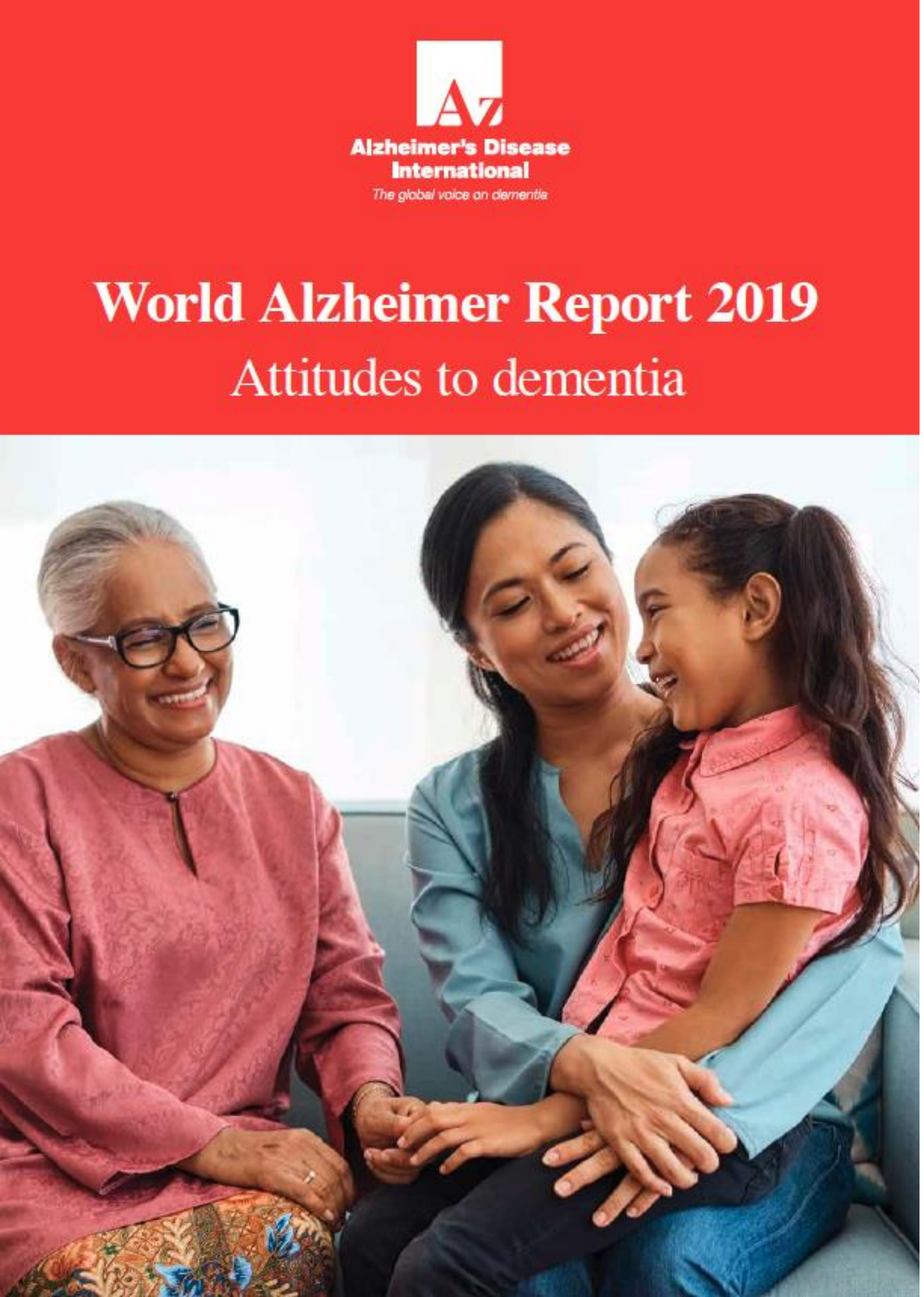
Public Health Agency of Canada
Agence de la santé publique du Canada

Canada

Area of focus 4.1: Eliminate stigma and promote measures that create supportive and safe dementia-inclusive communities



CURRENT STATUS	ASPIRATION
Widespread stigma within communities and a lack of understanding of dementia.	All people living in Canada understand dementia and stigma no longer exists in Canada.



Alzheimer's Disease International
The global voice on dementia

World Alzheimer Report 2019
Attitudes to dementia

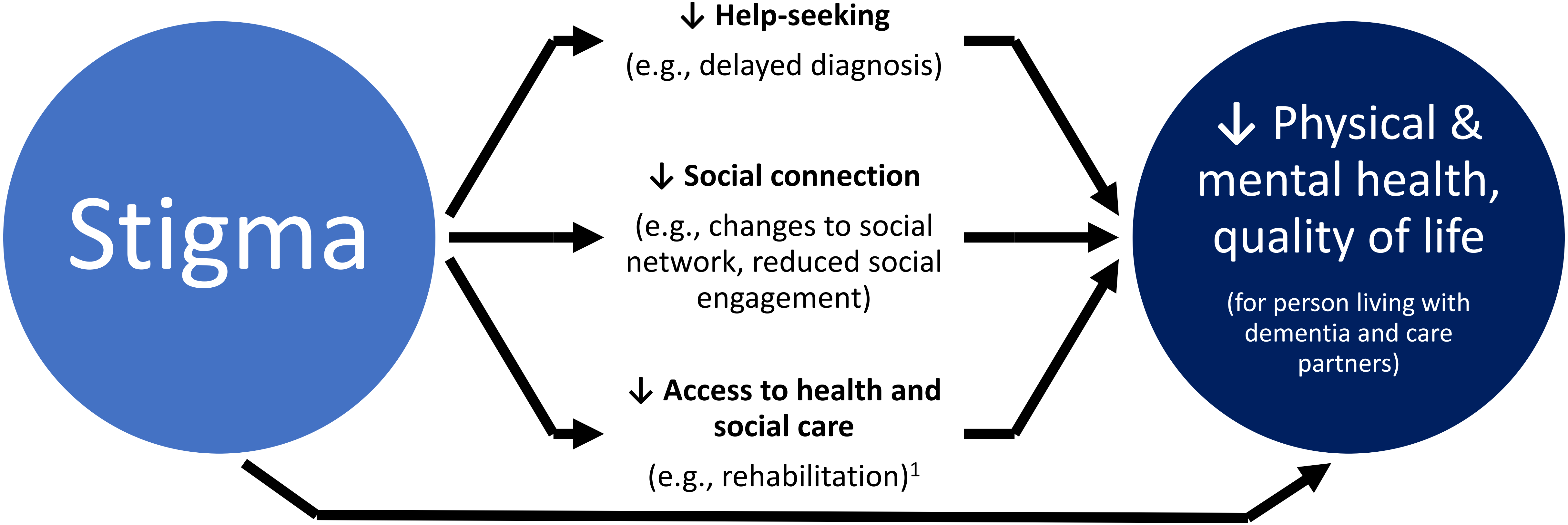
Recommendations

Stigma and knowledge issues around dementia are evidently still major barriers, not only to people seeking out more information, advice, support and a diagnosis but also in the basic understanding of Alzheimer's disease and related dementias as a medical conditions, that require treatment, support, even rehabilitation. By default, stigma thus also impacts negatively on research and research participation as we strive for a disease modifying treatment breakthrough.

Therefore, it is essential to take action, to improve awareness, to help dispel lingering myths around dementia and ultimately aim to reduce or even eradicate stigma.

https://www.alz.co.uk/research/world-report-2019

What are the health impacts of stigma for people living with dementia (and care partners)?



Stigma

↓ **Help-seeking**

(e.g., delayed diagnosis)

↓ **Social connection**

(e.g., changes to social network, reduced social engagement)

↓ **Access to health and social care**

(e.g., rehabilitation)[1]

↓ Physical & mental health, quality of life

(for person living with dementia and care partners)

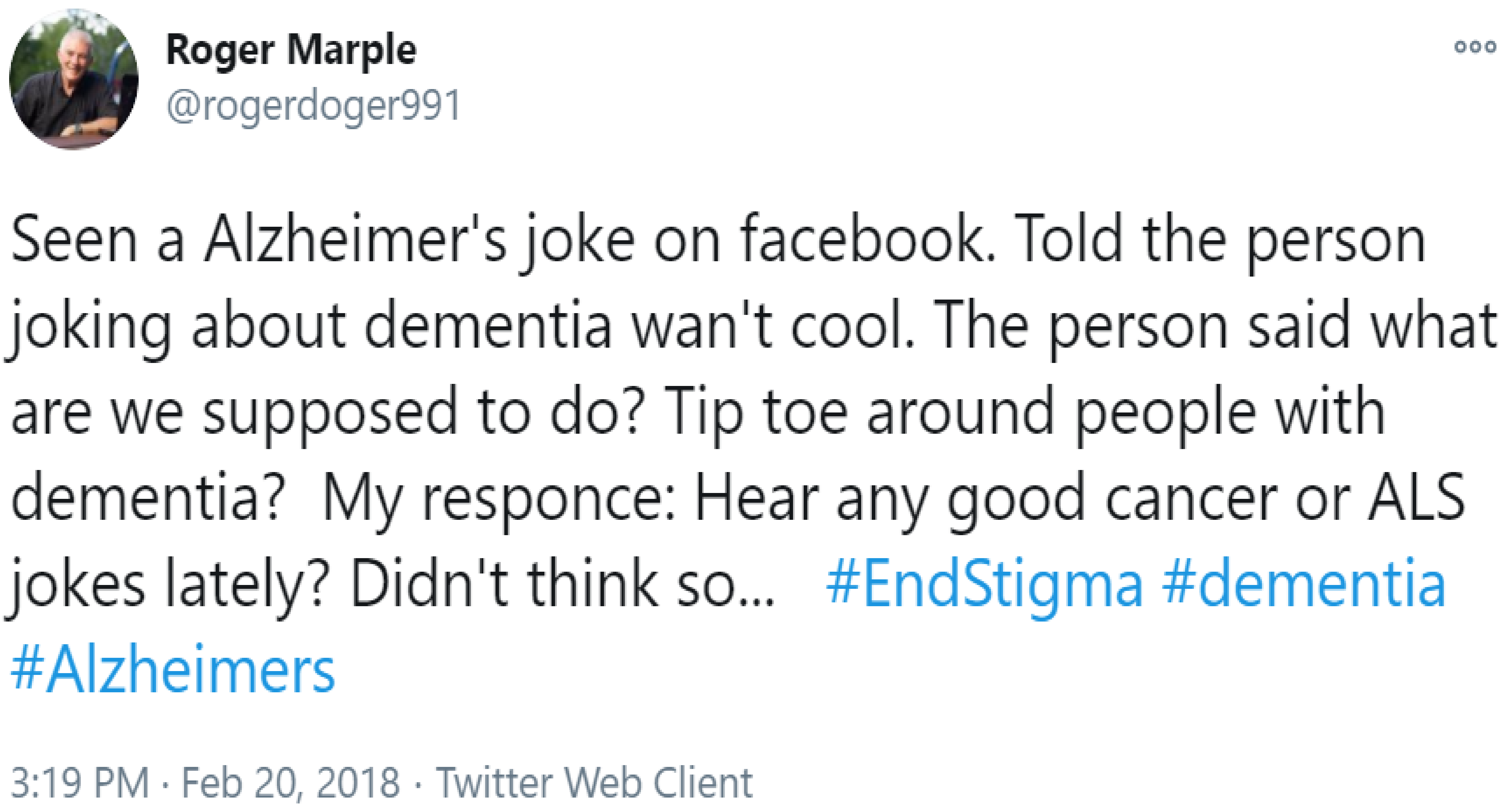
NOTE: These are only <u>some</u> of the ways stigma can impact the health of people living with dementia and their care partners.

---

[1] Middleton L, McAiney C, Wighton MB, Lisa Poole L, Marple R. Ensuring Rights to Health, Independence, and Rehabilitation among Canadians Living with Dementia. 2020 Conference Editorials. https://sciencepolicy.ca/posts/ensuring-rights-to-health-independence-and-rehabilitation-among-canadians-living-with-dementia/

Canadian Dementia Research Priorities

1. Addressing Stigma
2. Emotional Wellbeing
3. Impact of Early Treatment
4. Health System Capacity
5. Caregiver Support
6. Access to Post-dx Info
7. Care Provider Education
8. Dementia-Friendly Communities
9. Implementation of Best Care Practices
10. Non-Drug Approaches to Management



Roger Marple
@rogerdoger991

Seen a Alzheimer's joke on facebook. Told the person joking about dementia wan't cool. The person said what are we supposed to do? Tip toe around people with dementia? My responce: Hear any good cancer or ALS jokes lately? Didn't think so... #EndStigma #dementia #Alzheimers

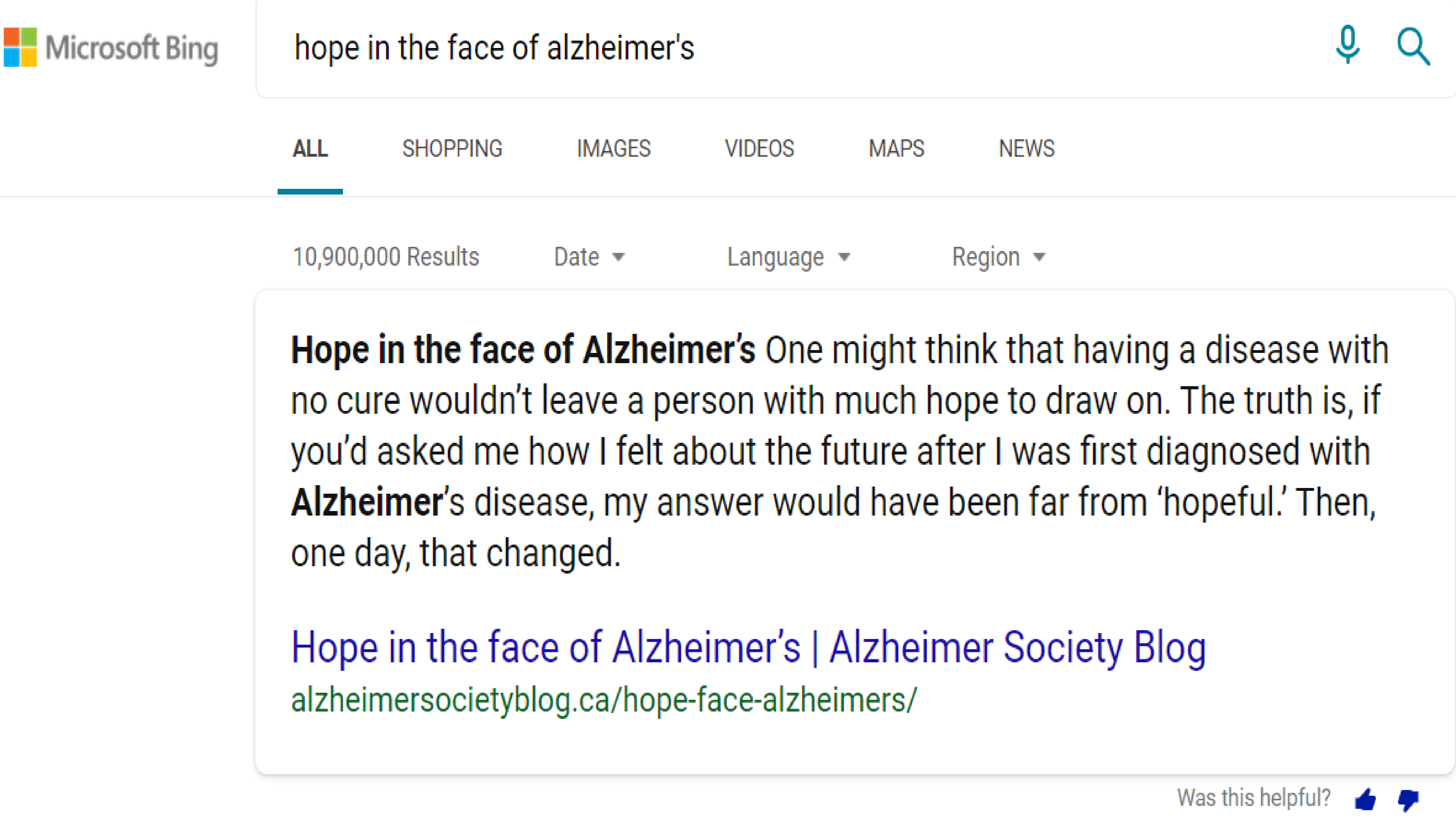
3:19 PM · Feb 20, 2018 · Twitter Web Client

Roger Marple
@rogerdoger991

I had some input towards this article along with some other amazing people, and as a person living with dementia, I sure approve this message. 😁

Laura Middleton @lauraemiddleton · Nov 12

"Rehabilitation is just a first step but an important one that can facilitate the highest possible standard of health and independence" @MaryBethWighton @llpoole @CarrieMcAiney @rogerdoger991 @CanadaDementia . sciencepolicy.ca/posts/ensuring...



hope in the face of alzheimer's

10,900,000 Results

Hope in the face of Alzheimer's One might think that having a disease with no cure wouldn't leave a person with much hope to draw on. The truth is, if you'd asked me how I felt about the future after I was first diagnosed with **Alzheimer**'s disease, my answer would have been far from 'hopeful.' Then, one day, that changed.

Hope in the face of Alzheimer's | Alzheimer Society Blog

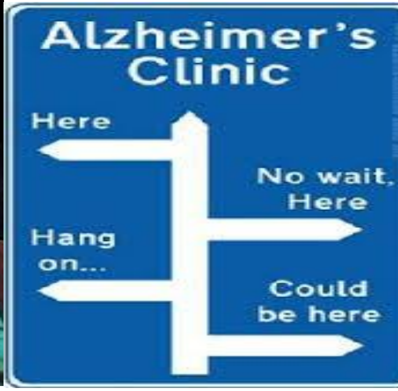
alzheimersocietyblog.ca/hope-face-alzheimers/


HI, WELCOME TO ALZHEIMER CLUB
FIRST RULE OF ALZHEIMER CLUB IS...
IS... OH, HI. WELCOME TO ALZHEIMER CLUB
Space-Cow.com


I MAY HAVE ALZHEIMER'S
BUT AT LEAST I DON'T HAVE ALZHEIMER'S
memegenerator.net


I may have alzheimer's, but at least I don't have alzheimer's.
ALZHEIMER'S
Have fun finding the Easter Eggs you hid


Whatever happened to our sexual relations?
I don't know. I don't even think we got a christmas card from them this year.


Alzheimer's Clinic
Here
No wait, Here
Hang on...
Could be here


HEY I JUST MET YOU
AND THIS IS CRAZY
I HAVE ALZHEIMER'S
HEY I JUST MET YOU

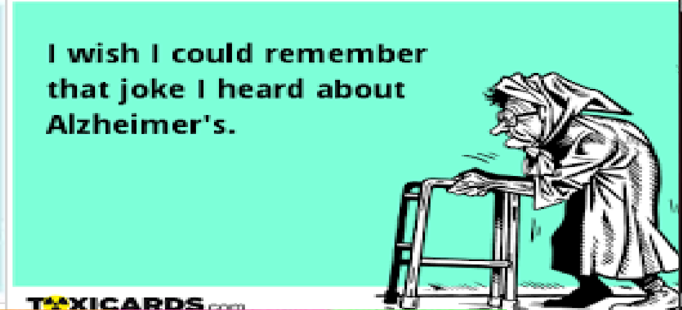

I'V FORGOTTEN... WHAT TIME IS THAT 9'O CLOCK MEETING TOMORROW !!! ... ...

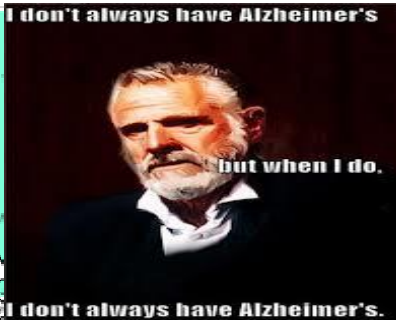

Wanna hear a joke, kid?
Why did the Alzheimer's patient forget the punchline to his joke?
Wanna hear a joke, kid?


In 2012 more money was spent on Boob jobs and Viagra than on Alzheimers research. In 40 yrs time we'll all be walking around with perky breasts, stiff willies, and will have no freakin clue why !
Shut Up I'm Still Talking
www.facebook.com/ShutUpImStillTalking

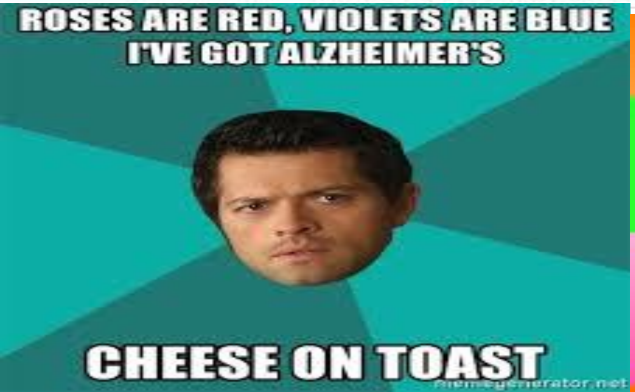

i was gonna tell you a joke anout alzheimer's
but i forgot


Alzheimer's is no joke.
I forgot what I was going to type.
your e cards
someecards.com


I wish I could remember that joke I heard about Alzheimer's.
TOXICARDS.com


I don't always have Alzheimer's
but when I do,
I don't always have Alzheimer's.


AN ALZHEIMER'S CURE WILL ALSO PREVENT SENIORS FROM ACCIDENTALLY PUTTING IN THE WRONG PAIR OF STORE-BOUGHT TEETH...
HOPENCHANGECARTOONS.COM


ROSES ARE RED, VIOLETS ARE BLUE
I'VE GOT ALZHEIMER'S
CHEESE ON TOAST
memegenerator.net


HOW MANY ALZHEIMER'S PATIENTS DOES IT TAKE TO CHANGE A LIGHTBULB?
TO GET TO THE OTHER SIDE
MyConfinedSpace.com


YO MAMA'S SO OLD
SHE WAS DIAGNOSED WITH ALZHEIMER'S AND DOESN'T REMEBER YOU


I TOLD YOU THAT I DO NOT HAVE ALZHEIMER'S I HAVE "SOME-TIMERS SOMETIMES I REMEMBER AND SOMETIMES I DON'T !!
Shut Up I'm Still Talking

End dementia stigma:
Speak up when you hear
a dementia joke.

Alzheimer
Society

Ilivewith**dementia**.ca | #**Ilive**with**dementia**

<u>All of us</u> fighting stigma of dementia together

Roger Marple
@rogerdoger991

I have always thought if we were all rowing our boats in one direction towards making #dementia stigma go away how quickly we could affect change. Challenging the Alzheimers joke telling culture in public media would be a good start. A world wide movement . That is my wish.


BKW
191
191
220
152
BKW
105
BKW
204
BKW
62
175
BKW
37
BKW
245
BKW

TEAMWORK

Coming together is a beginning.
Keeping together is progress. Working together is success.

Henry Ford

POSTERENVY.COM

The Dementia-Inclusive Choices for Exercise (DICE) Project

Over-arching Aim:

To increase the quality and number of physical activity opportunities that meet the needs of people living with dementia.

- ➢Overcome stigma
- ➢Promote inclusion

The Human Rights Rationale
UN Convention for the Rights of Persons with Disability

Several articles directly support right to participation in physical activity/exercise:

Article 25: Health
- Same range, quality, and standard of health care and programs in the person's own community

Article 26: Habilitation & Rehabilitation
- Effective measures to support maximum independence, full physical, mental, social ability and full inclusion/participation in all aspects of life

Article 30: Participation in cultural life, recreation, leisure and Sport
- Participation on an equal basis in sport, recreation, leisure

The Human Rights Rationale:
Canadian Charter of Rights for People with Dementia

1. To be free of discrimination of any kind
2. To benefit from all of Canada’s civic and legal rights
3. **To participate in developing policies that affect my life**
4. **To access support so that I can live as independently as possible and be as engaged as possible in my community**
5. To get the information and support I need to participate as fully as possible in decisions that affect me
6. To expect that **professionals involved in my care are trained in dementia** and human rights, treat me with respect and dignity, **offer me equal access** to appropriate treatment options
7. To access effective complaint and appeal procedures when my rights are not protected or respected

Canadian Dementia Research Priorities

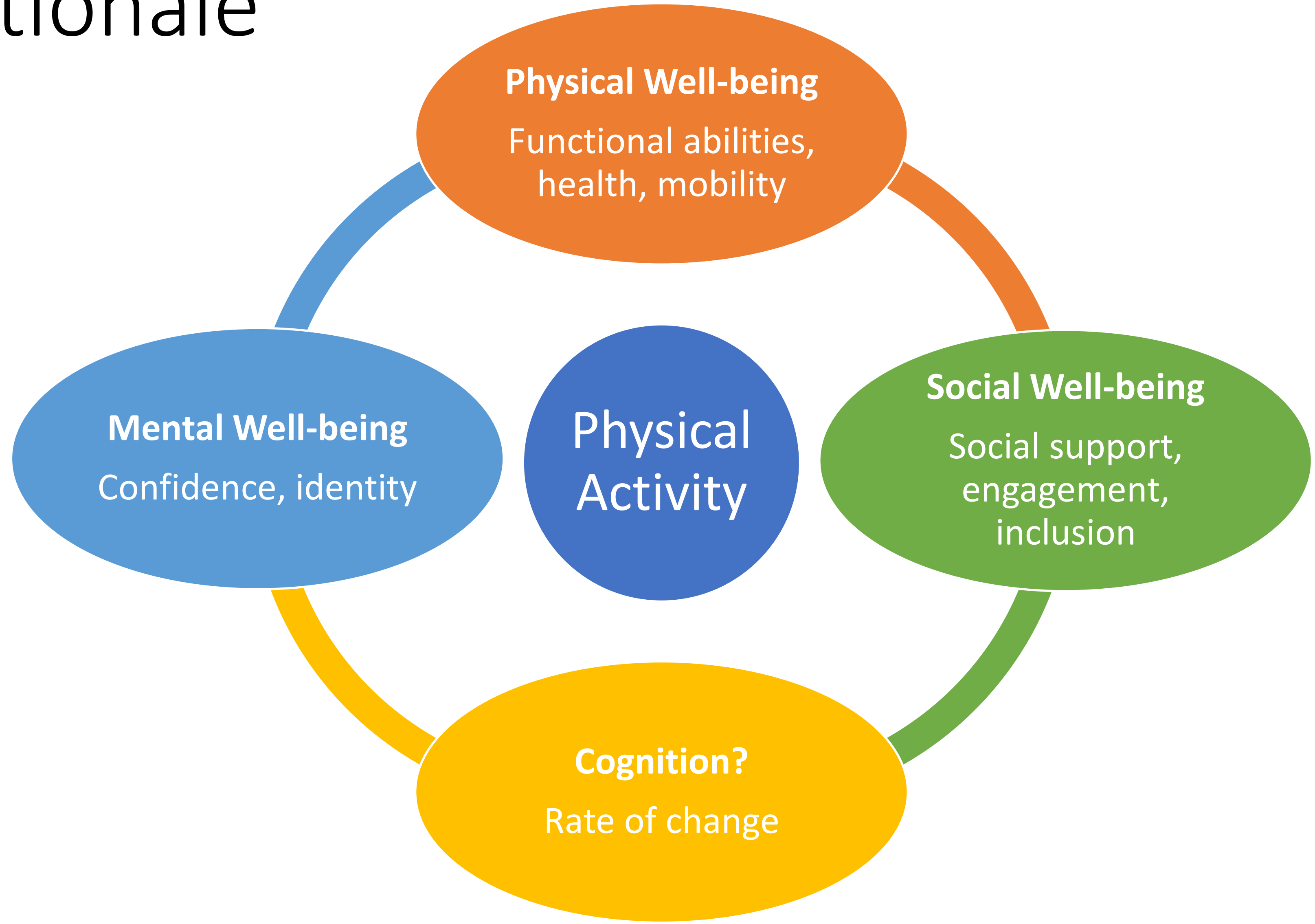
1. Addressing Stigma
2. Emotional Wellbeing
3. Impact of Early Treatment
4. Health System Capacity
5. Caregiver Support
6. Access to Post-dx Info
7. Care Provider Education
8. Dementia-Friendly Communities
9. Implementation of Best Care Practices
10. Non-Drug Approaches to Management

Reference: Bethell, J., Pringle, D., Chambers, L.W., Cohen, C., Commisso, E., Cowan, K., Fehr, P., Laupacis, A., Szeto, P. and McGilton, K.S. (2018), Patient and Public Involvement in Identifying Dementia Research Priorities. J Am Geriatr Soc, 66: 1608-1612. doi:10.1111/jgs.15453

The Clinical Rationale

Best evidence and guidelines recommend exercise to improve physical/cognitive function in dementia

People living with dementia recognize the social/mental benefits of exercise.



Physical Well-being

Functional abilities, health, mobility

Mental Well-being

Confidence, identity

Physical Activity

Social Well-being

Social support, engagement, inclusion

Cognition?

Rate of change

References: Van Alphen et al. 2016| Martin-Ginis et al. 2017 | Forbes et al. 2015

Barriers and Facilitators to Exercise among People with MCI/Dementia

CAPABILITY

Cognitive: changes to memory, attention, planning

Physical: mobility, fatigue, co-morbidities

Motivation

Lack of motivation, apathy

Encouragement, social engagement, meaningful activities

Opportunity

Social: (fear of) stigma, care partner beliefs

Physical: transportation & accessibility; lack of programs that meet needs & preferences

References: Van Alphen et al. 2016| Hobson et al. 2020| Bechard et al. 2020.

Barriers and Facilitators to Exercise among People with MCI/Dementia

CAPABILITY

Cognitive: changes to memory, attention, planning

Physical: mobility, fatigue, co-morbidities

Motivation

Lack of motivation, apathy

Encouragement, social engagement, meaningful activities

Opportunity

Social: (fear of) stigma, care partner beliefs

Physical: transportation & accessibility; lack of programs that meet needs & preferences

Public/Self stigma: Fear of or experience of people judging them

Structural stigma: lack of planning for inclusion, accessible transportation

References: Van Alphen et al. 2016| Hobson et al. 2020| Bechard et al. 2020.

Barriers and Facilitators to Exercise among People with MCI/Dementia

CAPABILITY

Physical: mobility, fatigue, co-morbidities

Mental: cognitive impairment, apathy

Some will be difficult to change. Some could be improved with access to exercise

Motivation

Apathy, lack of motivation

Encouragement, social engagement, meaningful activities

Opportunity

Physical: transportation & accessibility; lack of programs that meet needs & preferences

Social: care partner beliefs/ support, (fear of) stigma

References: Van Alphen et al. 2016| Hobson et al. 2020| Bechard et al. 2020.

Barriers and Facilitators to Exercise among People with MCI/Dementia

CAPABILITY

Physical: mobility, fatigue, co-morbidities

Mental: cognitive impairment, apathy

Some will be difficult to change. Some could be improved with access to exercise

Motivation

Apathy, lack of motivation

Encouragement, social engagement, meaningful activities

Access to exercise programs could provide encouragement, social engagement, meaningful activity

Opportunity

Physical: transportation & accessibility; lack of programs that meet needs & preferences

Social: care partner beliefs/ support, (fear of) stigma

References: Van Alphen et al. 2016| Hobson et al. 2020| Bechard et al. 2020.

Barriers and Facilitators to Exercise among People with MCI/Dementia

CAPABILITY

Physical: mobility, fatigue, co-morbidities

Mental: cognitive impairment, apathy

Some will be difficult to change. Some could be improved with access to exercise

Motivation

Apathy, lack of motivation

Encouragement, social engagement, meaningful activities

Access to exercise programs could provide encouragement, social engagement, meaningful activity

Opportunity

Physical: transportation & accessibility; lack of programs that meet needs & preferences

Social: care partner beliefs/ support, (fear of) stigma

By training exercise provider and support staff, we could:

- **improve undertraining of dementia**
- **improve inclusive practices**
- ***maybe* reduce stigma**

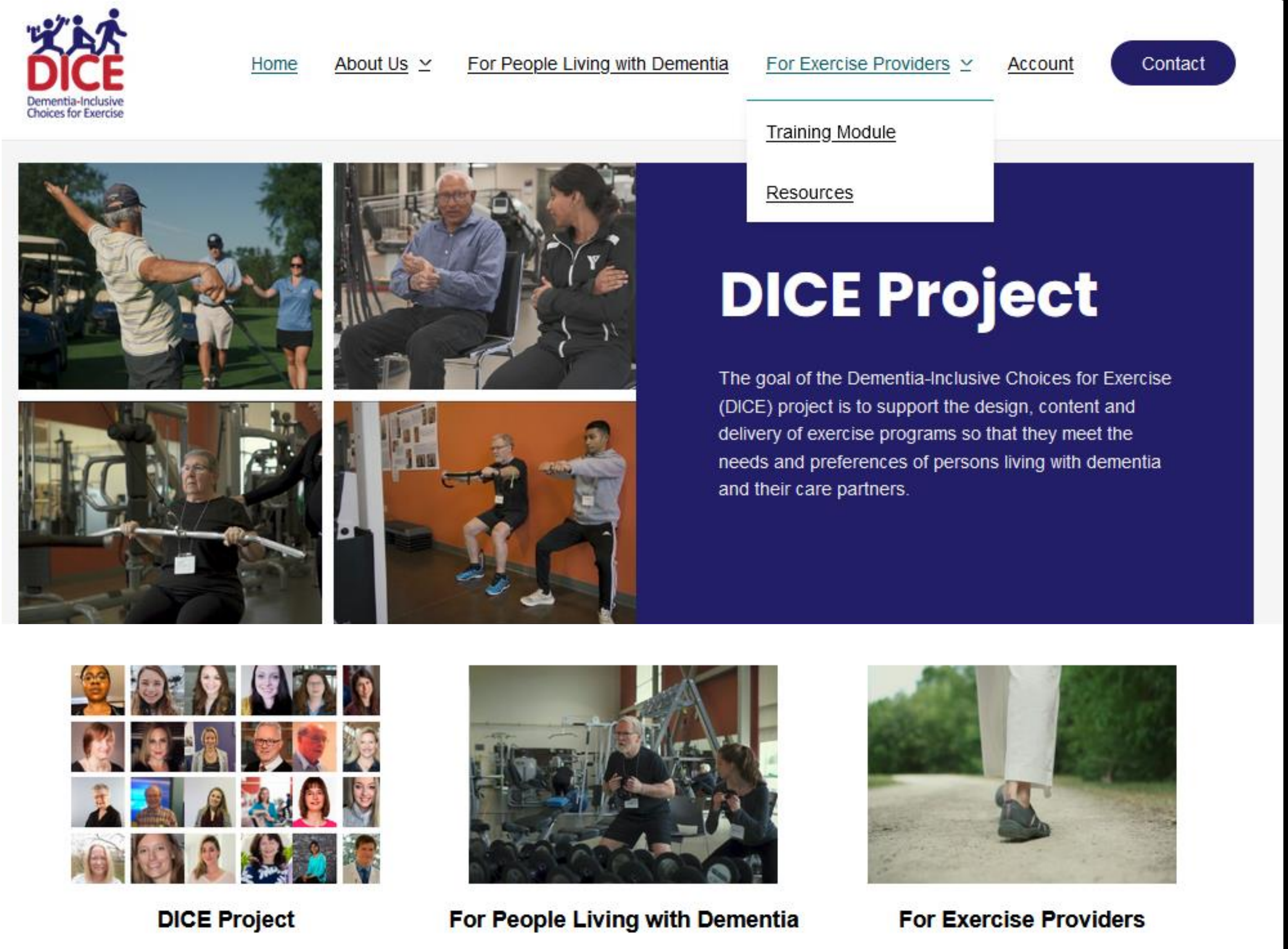
References: Van Alphen et al. 2016| Hobson et al. 2020| Bechard et al. 2020.

Supports Needed for Exercise

ENABLEMENT:

Need for exercise providers who understand
the unique and diverse needs of people living with dementia
and can support them in exercise.

What we have developed



DICE Project

The goal of the Dementia-Inclusive Choices for Exercise (DICE) project is to support the design, content and delivery of exercise programs so that they meet the needs and preferences of persons living with dementia and their care partners.

1. **Training for exercise providers:**
    - Understand dementia
    - Understand benefits of and recommendations for exercise among people living with dementia
    - Gain skills to provide exercise in a dementia-inclusive manner
2. **Destigmatizing videos**
    - Included in training
    - Regarding dementia, exercise, and delivery
3. **Resources for people living with dementia and their partners**

Final words…

For (quantitative) researchers: Few evidence-based stigma reduction approaches and no ‘gold standard’ to evaluate stigma;[1]

- ➢an important, emerging area of research![2]

For providers: it is your responsibility to understand dementia and promote inclusion of people living with dementia

For people living with dementia: you have a right to (and responsibility for) inclusion

For everyone: knock off the dementia jokes!

References: 1 Herrmann et al, 2018| 2 Kim, Werner, Richardson & Anstey, 2019

Thank you!

Jennifer Bethell

Email: jennifer.bethell@uhn.ca

Roger Marple

Twitter: @rogerdoger991

Laura Middleton

Email: laura.middleton@uwaterloo.ca