Part 1．Keynote Speech

International trends and prospects for participation by people with dementia in promoting dementia policy

Kate Swaffer

(Interpreter) Mariko Terada

Kate Swaffer

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Profile

- Lives in Australia, 65 years old.
- She has a diverse career, including working as a nurse in a dementia ward and as an owner-chef.
- In 2008, she was diagnosed with young-onset dementia at the age of 49.
- After the diagnosis, she began advocacy activities by people with dementia.
- In 2014, she co-founded Dementia Alliance International (DAI), an organization run exclusively by people diagnosed with dementia, and is active as its chairperson.
- For 16 years since being diagnosed with young-onset dementia, she has been striving to live positively with dementia, rather than just waiting to die from it.
- She has been actively campaigning for dementia to be supported as a "disability" and for the rehabilitation of more than 57 million people living with dementia around the world.
- She has made multiple statements and speeches at the United Nations and the World Health Organization (WHO), and was the first person with dementia to be invited as a speaker by the WHO, where she advocated for the rights of people with dementia.
- Her work to help other people living with dementia to live more positively with dementia is being incorporated into advocacy and policies in countries including Australia, New Zealand, the United Kingdom, Japan, Singapore, Taiwan, Indonesia, Canada, Europe, and the United States.
- Ambassador for the National Australia Day Council (a non-profit social enterprise of the Australian Government, the national coordinating body and council for the Australian of the Year Awards and Australia Day).
- She also serves as an ambassador for Step Up For Dementia Research in Australia.
- Currently, she is a researcher, consultant, and writer. She is currently PhD Candidate at the University of South Australia.

Published works

What the hell happened to my brain?:
Living Beyond Dementia

Translated by Mariko Terada,
Creates Kamogawa Publishing, 2017

Awards

2018, Global Leader, 100 Women of Influence in Australia
2017, SA Australian Of The Year

Kate Swaffer

National Gallery of Australia AOTY Exhibition

Kate Swaffer

PhD Candidate, University of South Australia
MSc, BPsych, BA, Grad Dip Grief Counseling, Retired. Nurse
Researcher, Campaigner, Speaker, Author, Educator
Co-founder, Dementia Alliance International
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@DementiaAllianc

International trends and prospects for participation by people with dementia in promoting dementia policy

Dementia

- An estimated 57 million people with dementia globally (Lancet: 2019)
- In 2015, Japan had the highest prevalence of dementia (23.3 per 1,000 people) in the world (OECD)
- More than 42 million people with dementia, but without a formal diagnosis (ADI: 2021)
- Dementia is a major cause of disability and dependence globally (WHO: 2022)
- Over 1 billion people live with some form of disability (WHO: 2022), yet people with dementia continue to be excluded from proactive disability advocacy and support
- 7th leading cause of death globally (WHO: 2022); the leading cause of death in women in the UK and Australia, and 2nd cause of death overall in Australia (DA: 2022); predicted to soon be the leading cause of death of men and women in Australia.
- People with dementia are frequently denied their basic rights and freedoms (WHO: 2022)

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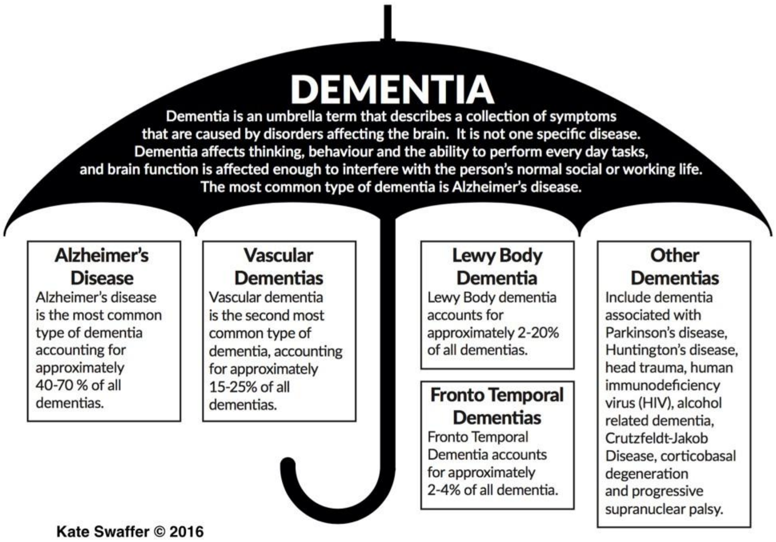

DEMENTIA

Dementia is an umbrella term that describes a collection of symptoms that are caused by disorders affecting the brain. It is not one specific disease. Dementia affects thinking, behaviour and the ability to perform every day tasks, and brain function is affected enough to interfere with the person's normal social or working life. The most common type of dementia is Alzheimer's disease.

Alzheimer's Disease
Alzheimer's disease is the most common type of dementia accounting for approximately 40-70 % of all dementias.

Vascular Dementias
Vascular dementia is the second most common type of dementia, accounting for approximately 15-25% of all dementias.

Lewy Body Dementia
Lewy Body dementia accounts for approximately 2-20% of all dementias.

Fronto Temporal Dementias
Fronto Temporal Dementia accounts for approximately 2-4% of all dementia.

Other Dementias
Include dementia associated with Parkinson's disease, Huntington's disease, head trauma, human immunodeficiency virus (HIV), alcohol related dementia, Crutzfeldt-Jakob Disease, corticobasal degeneration and progressive supranuclear palsy.

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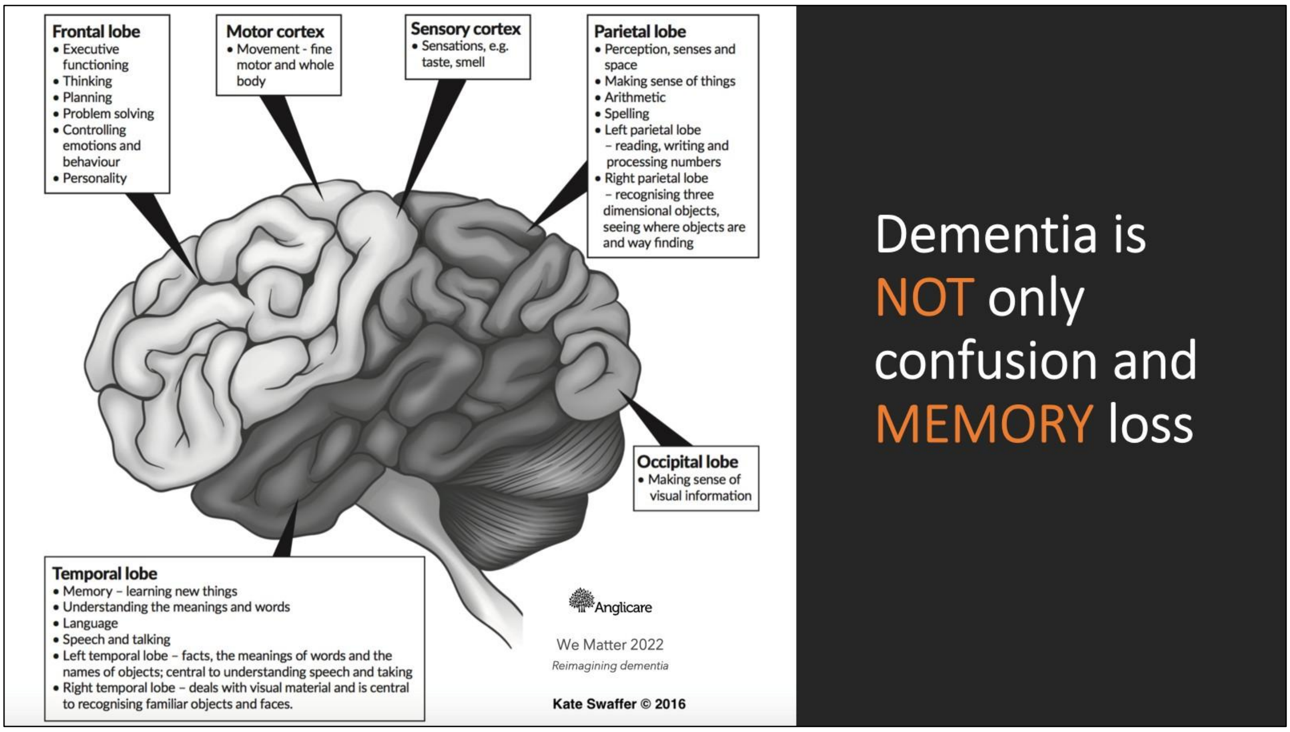

Frontal lobe
- Executive functioning
- Thinking
- Planning
- Problem solving
- Controlling emotions and behaviour
- Personality

Motor cortex
- Movement - fine motor and whole body

Sensory cortex
- Sensations, e.g. taste, smell

Parietal lobe
- Perception, senses and space
- Making sense of things
- Arithmetic
- Spelling
- Left parietal lobe
  - reading, writing and processing numbers
- Right parietal lobe
  - recognising three dimensional objects, seeing where objects are and way finding

Occipital lobe
- Making sense of visual information

Temporal lobe
- Memory – learning new things
- Understanding the meanings and words
- Language
- Speech and talking
- Left temporal lobe – facts, the meanings of words and the names of objects; central to understanding speech and taking
- Right temporal lobe – deals with visual material and is central to recognising familiar objects and faces.

Anglicare

We Matter 2022

Reimagining dementia

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Dementia is NOT only confusion and MEMORY loss

I've learned that people will forget what you said, people will forget what you did, but people will never forget how you made them feel.

(Maya Angelou)

de**ME**ntia from the

INSIDE OUT

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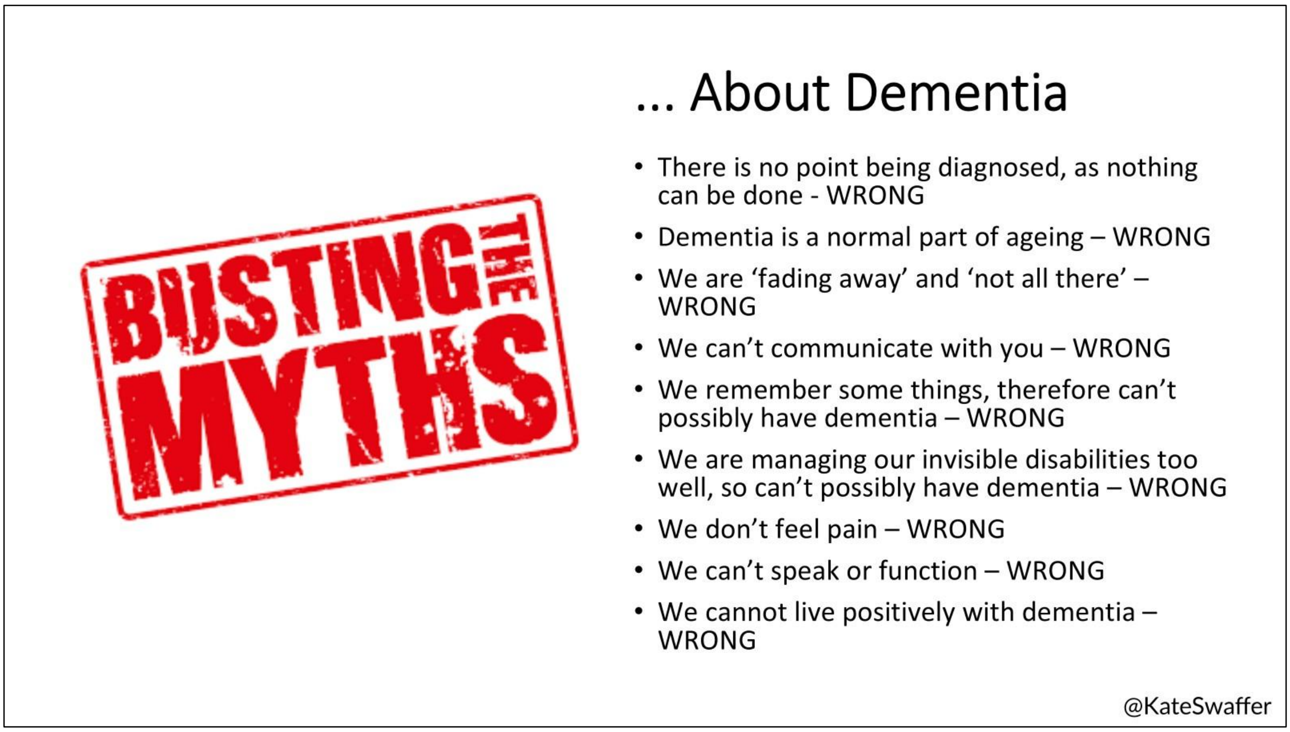

… About Dementia

- There is no point being diagnosed, as nothing can be done - WRONG
- Dementia is a normal part of ageing – WRONG
- We are ‘fading away’ and ‘not all there’ – WRONG
- We can’t communicate with you – WRONG
- We remember some things, therefore can’t possibly have dementia – WRONG
- We are managing our invisible disabilities too well, so can’t possibly have dementia – WRONG
- We don’t feel pain – WRONG
- We can’t speak or function – WRONG
- We cannot live positively with dementia – WRONG

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Prescribed Disengagement©

ONCE
YOU
CHOOSE
HOPE,
ANYTHING
IS
POSSIBLE

Therapeutic nihilism, in part due to myths, and the lack of disease modifying or curative drugs .

- What is Prescribed Disengagement©?
- What is the impact on people with dementia?
- What is the impact on care partners and family members?

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‘nobodiness’

In the last 16+ years, and only since being diagnosed with young onset dementia, have I experienced first-hand the **‘sense of nobodiness’**.

I now better understand the harmful stigmas and discriminations faced by other marginalised groups, such as First Nations Australians, Negro Americans and the LGBTIQ+ community.

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I’m still here...

*There is a systemic and gross underestimation of the **capacity** of all people diagnosed with de**ME**ntia, even in the later stages of the disease.*

(Kate Swaffer, 2016)

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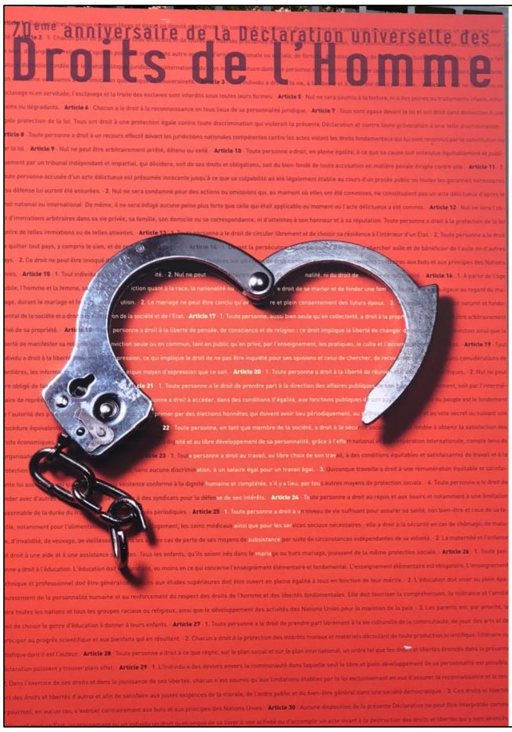

Violations my Rights

Rights breach 1: Denial of Universal Health Coverage - Article 25: Health; Article 26: Habilitation and rehabilitation

Rights breach 2: Denial of equal inclusion and social participation - Article 19: Living independently and being included in the community; Article 29: Participation in political and public life: Article 30: Participation in cultural life, recreation, leisure and sport

Rights breach 3: Denial of employment and reasonable accommodations - CRPD Article 5: Equality and non-discrimination; Article 17: Work and employment; Article 29: Participation in political and public life and Article 30 Participation in cultural life, recreation, leisure and sport

Rights breach 4: Denial of rehabilitation - Article 26: Habilitation and rehabilitation

Rights breach 6: Denial of disability* support to live independently - Article 19 – Living independently and being included in the community

*** Not being told at the time of, or very soon after diagnosis the symptoms of dementia are disabilities is a violation of my rights**

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Let us not forget…

Honouring and remembering the Pioneers

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2000: DASNI was Founded

DASN
International
Dementia Advocacy and Support Network
A worldwide organization by and for those diagnosed with dementia,
working together to improve our quality of life

The Dementia Advocacy and Support Network International (DASNI) was opened on the Yahoo website on 8 November 2000 by Lorraine Smith , for people with early-stage dementia and their care partners. She registered it as a non-profit organisation in Montana. Its first annual meeting was held on 6 October 2000, during the Heartland Memory Walk in Kansas.

The second annual meeting was held in Montana in June 2001, and 12 of the then 82 members attended in person, while others kept in touch by email and in chat. DASN International was formed and a new website www.DASNInternational.org was developed, although this is no longer active, and sadly has not been archived.

DASNI members borrowed the motto, **'Nothing about us without us'** from the disability community, and this is one most other dementia advocates have adopted.

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DASNI Founding Members

Twelve people with dementia aspired to make a difference.

1. Christine Bryden, Australia (DAI member), diagnosed 1995
2. Peter Ashley, England, UK (dec 2015, DAI member), diagnosed 2000
3. Jeannie Lee, USA (DAI member, and past board member)
4. Morris Friedell, USA
5. Phil Hardt, USA
6. Candy Harrison, USA
7. Carole Mulliken, USA (DAI member, and past DAI board member)
8. Jan Phillips, USA
9. Lorraine Smith, USA (dec, 2022)
10. Alan Gibb, New Zealand
11. Brian McNaughton, New Zealand
12. Mary XXX, USA

* Images not available for all DASNI Founding members

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This led to the emergence of multiple Dementia Working/Advisory Groups

The Scottish Dementia Working Group

the scottish dementia working group

run by people with dementia

The SDWG was inspired by pioneer self advocate in 2021, James McKillop (diagnosed in 1995), and founded in 2022, with the support of Social Researcher Heather Williamson.

Funded by Alzheimer's Scotland and the Scottish government.

James and Heather both questioned why there was a voice for carers and professionals, but not for people with dementia. It was also James who suggested Alzheimer's Europe set up a Working Group.

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Why do advocates have to keep repeating each other?

October 15, 2003: The 2001 ADI conference in Christchurch, New Zealand, was an extraordinary event because of the input of people with dementia. This was the first-time people with dementia attended the international conference as full participants.

12 people with dementia came, some from as far away as Canada, United States and Australia. The contribution of these twelve turned the conference into an amazingly challenging and inspirational event – for conference delegates and the wider public.

Here were people with dementia showing in such an irrefutable way that not only does life continue after diagnosis but that people with dementia have much to offer within the Alzheimer's organisation.

People with dementia participated throughout the conference, from the delivery of a standing-ovation opening address to oral presentations, running workshops and media interviews. The DASNI stand was a drawcard in the exhibitors' hall.

(DASNI and ADI history - by Verna Schofield: 2018)

- Fiji
- Brunei
- China
- Hong Kong
- India
- Indonesia
- Iran
- Japan
- Philippines
- Qatar
- Singapore
- South Korea
- Sri Lanka
- New Zealand
- United Arab Emirates
- Uganda
- Canada
- Haiti
- Jamaica
- Mexico
- Puerto Rico
- United States
- Ethiopia
- Belgium
- Croatia
- Cyprus
- Taiwan
- Estonia
- Finland
- France
- Georgia
- Ireland
- Italy
- Netherlands
- Poland
- Serbia
- Spain
- Sweden
- Switzerland
- Australia
- Denmark
- Vatican City
- Ghana
- Mali
- Mauritius
- South Africa
- United Kingdom
  - England
  - Wales
  - Ireland
  - Scotland

Prescribed Disengagement© and Advocacy

Due to prescribed disengagement, our pre diagnosis life, our dreams and our hope are stripped away at the time of, or soon after diagnosis.

Advocacy brings it back as it provides meaningful, purposeful engagement.

However, the banner to new advocates is not passed often enough for multiple reasons including not wanting to give up living with renewed purpose.

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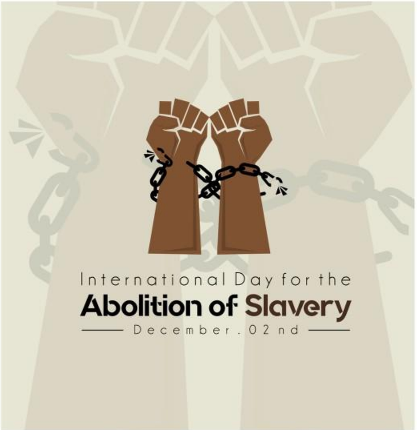
Involving advocates will mean equitable inclusion... Rare!

- The experience of these groups of people with dementia, sometimes with care partners, is that the contact with others with dementia gives them greater self confidence in speaking out in public and in raising awareness, and gives people hope and purposeful engagement.
- As we endeavour to increase the number of people to become advocates globally, as the voices of people are important, but they must pass the baton to empower new advocates, leadership and speaking roles
  - This is critical due to changing capacity and dementia being a terminal disease.
- It is also crucial we work collaboratively and against more silos as these potentially weaken all advocacy.
  - There is only one pot of money, so if we are all vying for it, it becomes a competition, instead of active advocacy

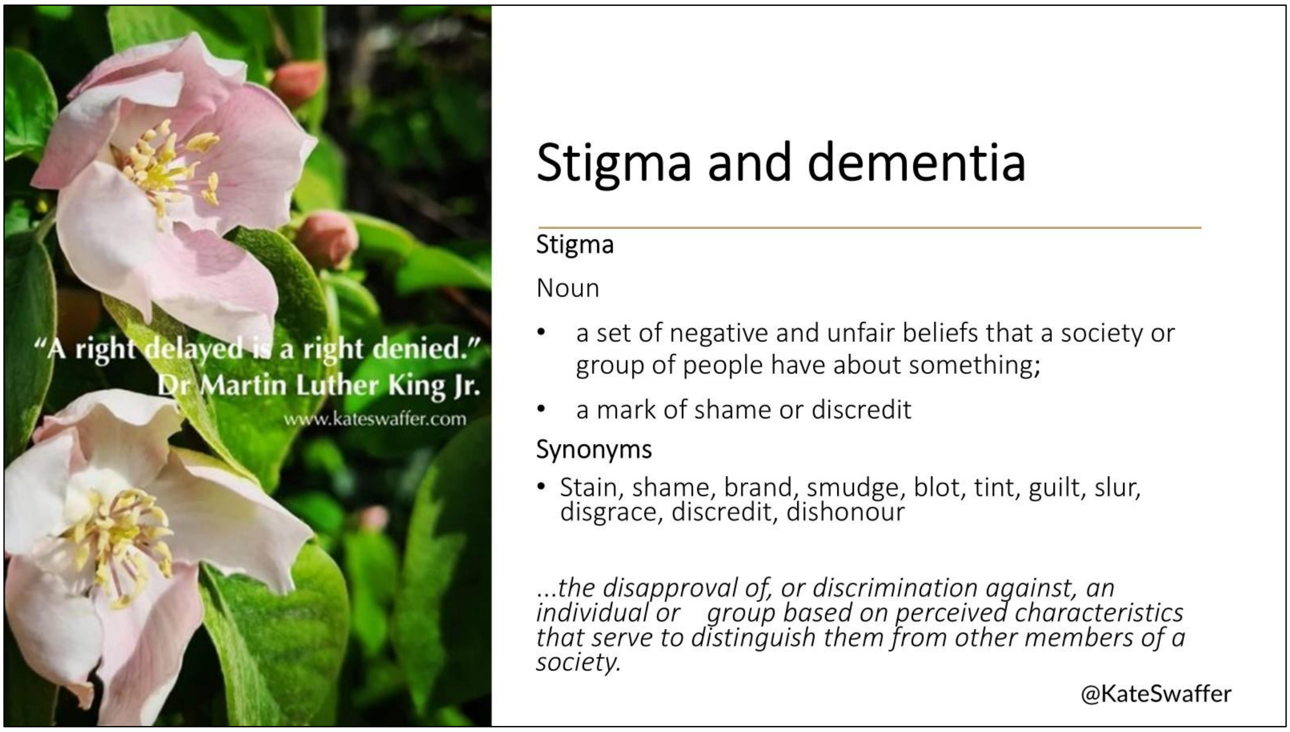
The increased involvement of unpaid advocates causes harm and stigma...

- Economic stigma, and other stigmas abound, and whilst advocates continue to work for free, it is little different to slave labour, except people are 'happy' just to be included;
- This is important because, for example, all other disabled groups of people are campaigning for fair and equal wages or fees, for their work;
- People with disabilities due to dementia are not yet well represented in other disability advocacy, nor are they remunerated fairly, if at all in most countries.



Despite 40 years of advocacy & research... Stigma and Discrimination remains pervasive.

We need change, NOW!



"A right delayed is a right denied."
Dr Martin Luther King Jr.
www.kateswaffer.com

Stigma and dementia

Stigma

Noun

- a set of negative and unfair beliefs that a society or group of people have about something;
- a mark of shame or discredit

Synonyms

- Stain, shame, brand, smudge, blot, tint, guilt, slur, disgrace, discredit, dishonour

...the disapproval of, or discrimination against, an individual or group based on perceived characteristics that serve to distinguish them from other members of a society.

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The evidence confirms things have not changed.

The 2024 ADI World Alzheimers Report and Research confirms:

- A timely, accurate diagnosis is still difficult to get
- There are few, if any post diagnostic supports or services
- Stigma and negative attitudes towards people with dementia are worse than 5 years ago (ADI:2024)
- We do not receive disability assessment or referrals to disability support, including rehabilitation, as we would if we had a stroke or TBI; nor advised the symptoms of dementia are acquired disabilities
- Enabling environmental design is not common
- People who need assisted living arrangements are institutionalised, segregated, and many experience multiple forms of abuse, neglect and human rights violations

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Reimagining Dementia

By reimagining – and reframing - dementia as a disability, we reinforce the rights for people with dementia as described in the UN Convention on the Rights of Persons with Disabilities (CRPD).

This approach also gives us the most hope of people accessing rehabilitation, beyond the basic continence management, swallowing (near death), and basic Activities of Daily Living (ADL’s).

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Dementia as a disability

Dementia is one of the major causes of disability* and dependency among older people worldwide.

World Health Orgnaisation, Dementia, https://www.who.int/news-room/fact-sheets/detail/dementia

* The WHO has defined dementia as a major cause of disability for over a decade

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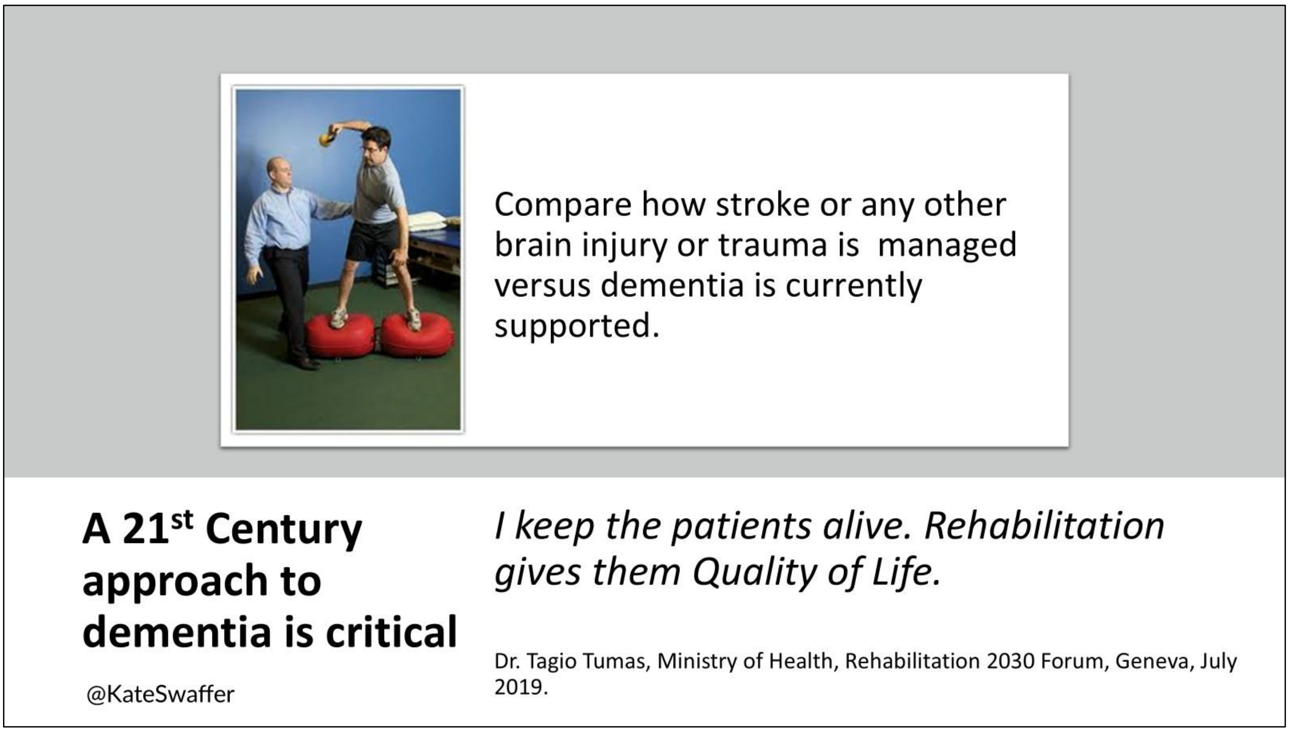

Compare how stroke or any other brain injury or trauma is managed versus dementia is currently supported.

A 21st Century approach to dementia is critical

I keep the patients alive. Rehabilitation gives them Quality of Life.

Dr. Tagio Tumas, Ministry of Health, Rehabilitation 2030 Forum, Geneva, July 2019.

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Strategies to Reablement & Living Well: The Olympics of My Life

- Respect for persons agency
- Focus on what we can still do, not what we can't do
- Manage the symptoms as acquired disabilities
- Grief & Loss counselling
- Rehabilitation, e.g.,
  - Speech therapy
  - Occupational therapy
  - Exercise 6 days/week
  - Exercise physiology
  - Physiotherapy
  - Neuro physiotherapy
  - Dietician
- Enabling built environments
- Equal inclusion
- Other non pharmaceutical interventions, e.g., Mindfulness, Psychology, humour, intimacy, relationships, volunteering, journaling, etc.
- Communication access (SCOPE Australia)
- Provide disability assessment
- Set up strategies to support independence, e.g., Webster packs, Laminated reminders

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Positive outcomes of Rehabilitation, Reablement and Reimagining Dementia

- Improved QoL & well being
- Reduces the human and economic cost of dementia for people with dementia, their care partners and governments
- Increases independence, for longer
- Decreased 'burden' to families, the community and governments

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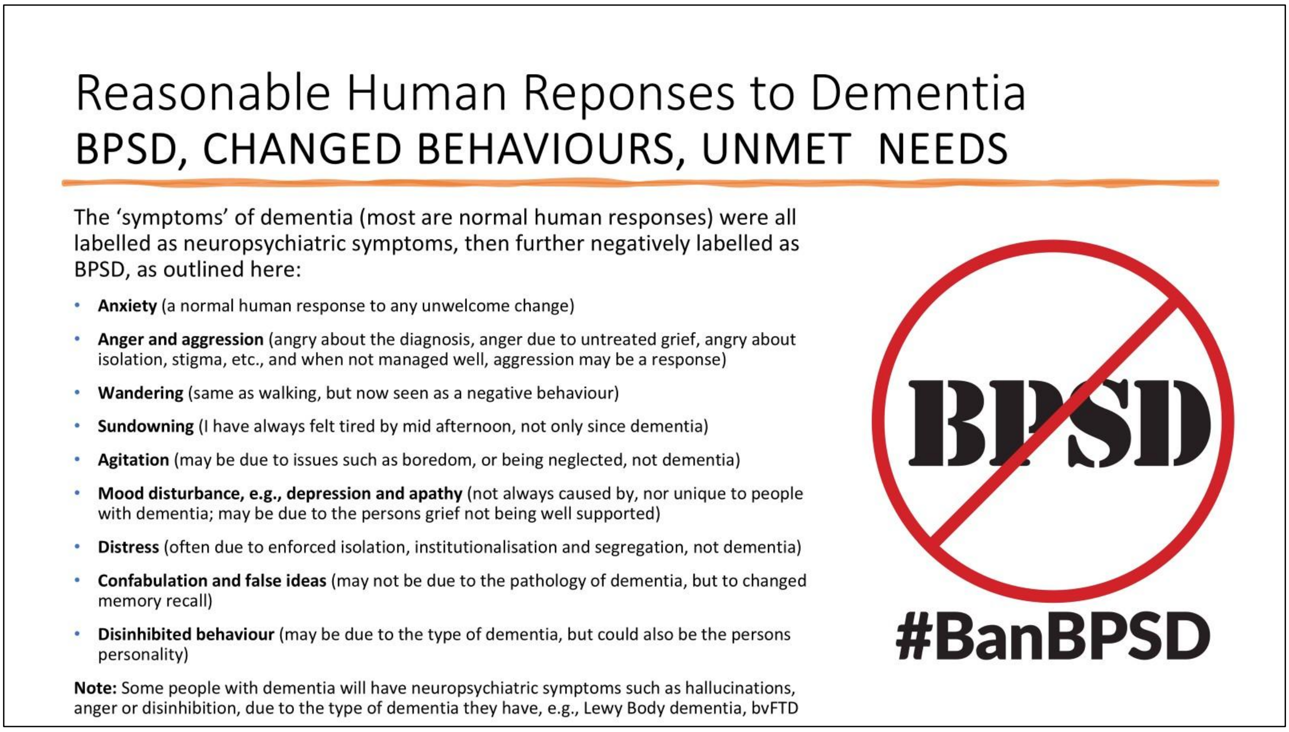
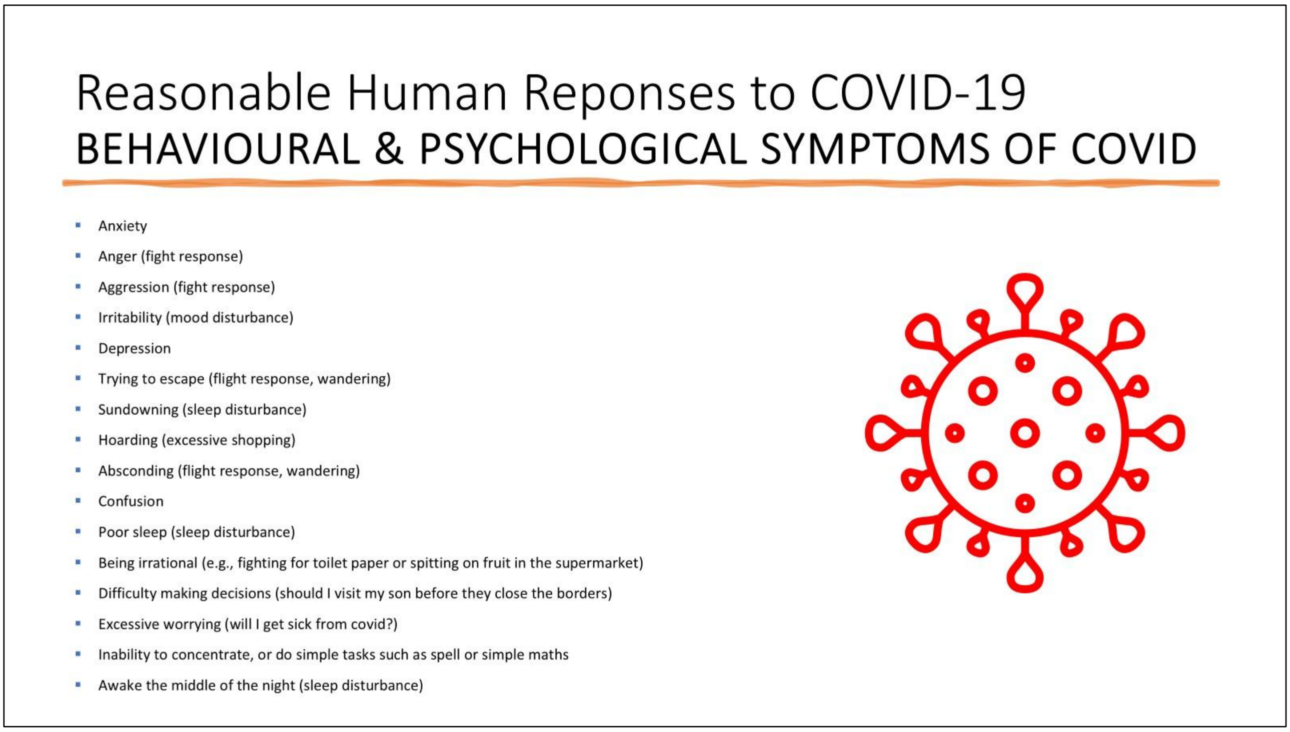


Reasonable Human Reponses to Dementia
BPSD, CHANGED BEHAVIOURS, UNMET NEEDS

The ‘symptoms’ of dementia (most are normal human responses) were all labelled as neuropsychiatric symptoms, then further negatively labelled as BPSD, as outlined here:

- **Anxiety** (a normal human response to any unwelcome change)
- **Anger and aggression** (angry about the diagnosis, anger due to untreated grief, angry about isolation, stigma, etc., and when not managed well, aggression may be a response)
- **Wandering** (same as walking, but now seen as a negative behaviour)
- **Sundowning** (I have always felt tired by mid afternoon, not only since dementia)
- **Agitation** (may be due to issues such as boredom, or being neglected, not dementia)
- **Mood disturbance, e.g., depression and apathy** (not always caused by, nor unique to people with dementia; may be due to the persons grief not being well supported)
- **Distress** (often due to enforced isolation, institutionalisation and segregation, not dementia)
- **Confabulation and false ideas** (may not be due to the pathology of dementia, but to changed memory recall)
- **Disinhibited behaviour** (may be due to the type of dementia, but could also be the persons personality)

Note: Some people with dementia will have neuropsychiatric symptoms such as hallucinations, anger or disinhibition, due to the type of dementia they have, e.g., Lewy Body dementia, bvFTD



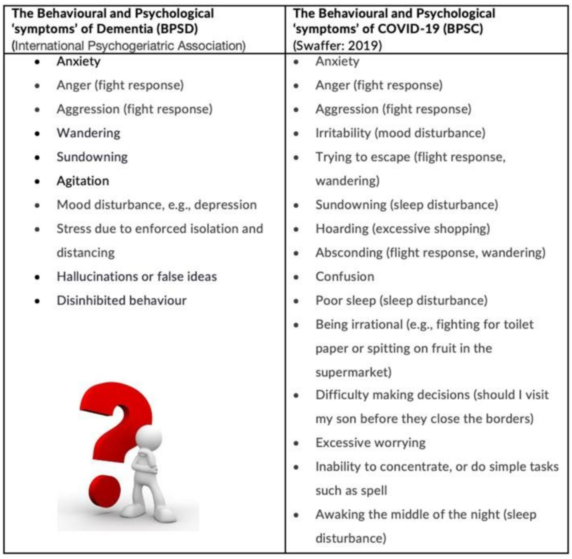
Reasonable Human Reponses to COVID-19
BEHAVIOURAL & PSYCHOLOGICAL SYMPTOMS OF COVID

- Anxiety
- Anger (fight response)
- Aggression (fight response)
- Irritability (mood disturbance)
- Depression
- Trying to escape (flight response, wandering)
- Sundowning (sleep disturbance)
- Hoarding (excessive shopping)
- Absconding (flight response, wandering)
- Confusion
- Poor sleep (sleep disturbance)
- Being irrational (e.g., fighting for toilet paper or spitting on fruit in the supermarket)
- Difficulty making decisions (should I visit my son before they close the borders)
- Excessive worrying (will I get sick from covid?)
- Inability to concentrate, or do simple tasks such as spell or simple maths
- Awake the middle of the night (sleep disturbance)

BPSD vs BPSC

LESSONS FROM COVID

- COVID-19 has caused more ‘challenging behaviours’ than dementia...
- But society prefers to see them as reasonable human responses



The Behavioural and Psychological ‘symptoms’ of Dementia (BPSD) (International Psychogeriatric Association)	The Behavioural and Psychological ‘symptoms’ of COVID-19 (BPSC) (Swaffer: 2019)
• Anxiety • Anger (fight response) • Aggression (fight response) • Wandering • Sundowning • Agitation • Mood disturbance, e.g., depression • Stress due to enforced isolation and distancing • Hallucinations or false ideas • Disinhibited behaviour	• Anxiety • Anger (fight response) • Aggression (fight response) • Irritability (mood disturbance) • Trying to escape (flight response, wandering) • Sundowning (sleep disturbance) • Hoarding (excessive shopping) • Absconding (flight response, wandering) • Confusion • Poor sleep (sleep disturbance) • Being irrational (e.g., fighting for toilet paper or spitting on fruit in the supermarket) • Difficulty making decisions (should I visit my son before they close the borders) • Excessive worrying • Inability to concentrate, or do simple tasks such as spell • Awaking the middle of the night (sleep disturbance)

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Dementia Friendly Initiatives

Friendly, or UNFRIENDLY?

If we believe a human rights approach is the way forward, we must also consider this:

Q: Is it ok to continue with initiatives such as Dementia Friendly Communities and Dementia Villages that continue to segregate, and where people with dementia are labeled by their disease and disability and not equally included, and not paid to work in these initiatives?

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Dementia Villages
Dementia Friendly

These terms label people by their disability and dementia diagnosis.

These initiatives segregate people with dementia.

Instead, we need Inclusive Communities for everyone.

Labels are for clothing.
Labels are for food.
Labels are for things.

Labels are not for people.

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Labelling by Disease or Disability

IT'S NOT OK FOR OTHERS BUT POPULAR FOR DEMENTIA...

Imagine replacing the signs with:

- Leprosy
- Cancer
- Schizophrenia
- Bipolar
- AIDS
- LGBTIQA
- Indigenous communities
- Diabetes
- Heart Disease
- Multiple Sclerosis
- Autism
- ADHD

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Cultural differences

The differences do not necessarily make stigma easier or harder for any group; they merely highlight differing reasons for stigma.

- Developed countries, such as the UK and Australia
- Low- and-Middle-Income countries
- Black and Asian Minority Ethnic (BAME) communities
- Religious beliefs
- Witchcraft
- Gender
- LGBTIQA+
- Generational differences

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Stigma may have also contributed to health care professionals, organisations and researchers ignoring dementia is a cause of disability in post diagnostic pathways, and a denial of disability support in the workplace.

Supporting dementia as a condition causing multiple acquired disabilities is critical.

Not to is a violation of the persons' disability rights

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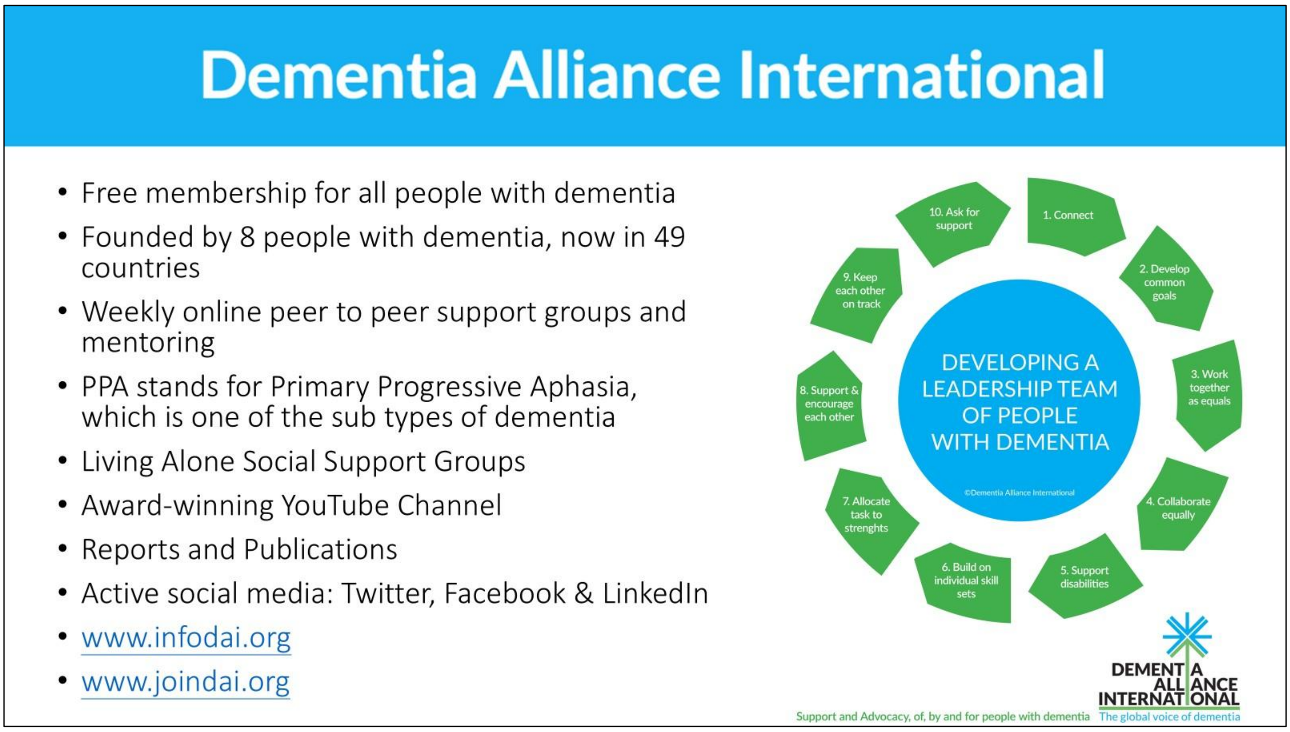
Opportunities to stop stigma

- Reasonable accommodations for people to remain at work (if that is their wish)
- Stop the paternalistic 'welfare' approach to 'care'
- Equitable inclusion is not 1 or 2 people on a board or a few people with dementia on an advisory group (unpaid)
- **Employ us! Stop the slave labour!**
  - If we weren't prescribed disengagement at diagnosis, many of us would have remained employed
  - Especially important in ALL dementia friendly initiatives
  - Dementia advocacy proves with support, we can still work, but now, it is unpaid work, which equates to slave labour

Stigma contributes to the belief detention and segregation of people with dementia in 'care' is acceptable

- Residential Aged Care Facilities
- Secure Dementia Units
- Dementia Villages
- Accommodation that is not be locked, but does not provide the individual with support to self-determination, agency and independence
- Congregate style assisted living settings cause further human rights violations through detention AND segregation based on a health condition AND disability



Dementia Alliance International

- Free membership for all people with dementia
- Founded by 8 people with dementia, now in 49 countries
- Weekly online peer to peer support groups and mentoring
- PPA stands for Primary Progressive Aphasia, which is one of the sub types of dementia
- Living Alone Social Support Groups
- Award-winning YouTube Channel
- Reports and Publications
- Active social media: Twitter, Facebook & LinkedIn
- www.infodai.org
- www.joindai.org

DEVELOPING A LEADERSHIP TEAM OF PEOPLE WITH DEMENTIA

1. Connect
2. Develop common goals
3. Work together as equals
4. Collaborate equally
5. Support disabilities
6. Build on individual skill sets
7. Allocate task to strenghts
8. Support & encourage each other
9. Keep each other on track
10. Ask for support

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DEMENTIA ALLIANCE INTERNATIONAL

Support and Advocacy, of, by and for people with dementia The global voice of dementia

DEMENTIA ALLIANCE INTERNATIONAL

The global voice of dementia

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SEE THE PERSON NOT THE DEMENTIA

info@infodai.org
www.dementiaallianceinternational.org
www.joindai.org
@DementiaAllianc

Only by working together, will we create change...

Thank you

Q & A

"I've lived every day like it was my last. And now that it's here, honestly, it's kind of anticlimactic."

the Research Study on Building an International Network for the Participation of People Living with Dementia to Promote an Inclusive Society funded by Ministry of Health, Labour and Welfare's subsidy for elderly health promotion project, etc. in FY2024.

Connecting the baton for people with dementia at home and abroad

The 'Relay of Hope' International Forum 2025

〜Promoting an inclusive society by valuing the voice, power and connection of people with dementia〜

14 February 2025.

Tokyo Center for Dementia Care Research and Practice