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.

Organized by ：Tokyo Center for Dementia Care Research and Practice

joint holding ： Japan Dementia Working Group

We are experts in the experience of
living with dementia.

Kate Swaffer

Connecting the baton for people with dementia at home and abroad

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Program

◆ 13:00 Opening Remarks

Greetings from the organizer :Mr. Takeshi Erikawa, the chairman of the Social Welfare Corporation Yukufuukai.

speech by guest of honor: Mr.Osamu Yoshida , the Deputy Director-General of the Health and Welfare Bureau for the Elderly of the Ministry of Health, Labour and Welfare.

◆ 13:15 Part 1． Keynote Speech p.3

Kate Swaffer. (Interpreter) Mariko Terada.

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

14:15～14:30 Break (Video showing activities of a person with dementia in Japan)

◆ 14:30 Part 2． Talk session with Kate and Japanese people with dementia p.49

To expand participation of people with dementia

～ Including expectations for an international network among people with dementia

- ○Ms.Kate Swaffer.（ Australia .DAI Co-founder ）
- ○Mr.Tomofumi Tanno (Sendai City, Representative of Orange Door)
- ○Ms.Kazuko Fujita(Tottori City, Representative Director, Japan Dementia Working Group)
- ○Ms.Shinobu Yamanaka(Nankoku City, Representative Director, Second Story)

～ Messages from people with dementia in Asia ～ See page 36 onwards.

＜Relay messages from floor participants> p.62

- ○Ms.Haruko Sunohara (Ueda City, Ambassador of Hope appointed by the Ministry of Health, Labour and Welfare)
- ○Mr.Mamoru Roue (Bungo Ono City, Oita Prefecture Peer Supporter)
- ○Mr.Hitoshi Fukuda(Saseb0 City, Director, Japan Dementia Working Group)
- ○Ms.Miki Taira(Ishioka City, Director, NPO Dementia Association Walking Together, Ibaraki)
- ○Mr.Toru Katagiri(Eniwa City, engaged in advocacy and awareness-raising activities)
- ○Mr.Shigeyuki Kanbara (Yokote City, Ambassador of Hope appointed by Akita Prefecture)
- ○Mr.Akio Kakishita (Shinagawa Ward, Ambassador of Hope appointed by the Ministry of Health, Labour and Welfare)

◆ 15:45 Summary and acknowledgements

Dr.Syuichi Awata, General Manager ,Tokyo Center for Dementia Care Research and Practice

◆ 16:00 Closing

★Please Refer the Basic Law and other important documents (page 49 onwards).

Purpose of this forum

Living authentically with hope, and thriving together in the community, even after being diagnosed with dementia

- In Japan, this is no longer merely an ideal; it is gradually becoming a reality through the cumulative efforts and long-term trials and errors of many people over the years.*
- The Basic Act on Dementia to Promote an Inclusive Society, which places basic human rights at the forefront of its principles, was enacted in June 2023 and came into effect in January 2024. Furthermore, in December 2024, the Basic Plan for the Promotion of Policies on Dementia was approved by the Cabinet. The purpose of the act and the plan is to eliminate existing challenges and disparities, and to ensure that people with dementia can live with dignity and hope, regardless of where they reside.
- We are now at a critical turning point in the process of substantially building a vibrant inclusive society where we coexist while mutually respecting one another's personality and individuality, and supporting one another.
- What is essential for the realization of an inclusive society is amplifying the voices of those living with dementia and ensuring their participation in society. At this forum, Kate Swaffer, a global leader in the field, and people living with dementia in Japan will discuss their personal challenges as well as expectations for society as they live with hope and dignity.
- The 'Relay of Hope' is about passing on the hope and wisdom for living with dementia from one person experiencing it to another, and from those experiencing it to all people living in the same era. Let's work together to steadily expand this Relay of Hope across all positions and professions, person by person, to create and nurture an inclusive society. We hope that this forum will serve as a catalyst for each and every one of you to move forward in a better direction in your daily lives, activities, work, and endeavors.

February 2025
Tokyo Center for Dementia Care Research and Practice,
Yokufukai (Social Welfare Corporation)

This forum will be held as part of 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.

* *Information Collection on the Activities of Supporting Network Promoters for Dementia in Local Communities: Toward an Inclusive Local Communities* published by Tokyo Center for Dementia Care Research and Practice (Health and Welfare Promotion Projects for the Elderly funded by Ministry of Health, Labour and Welfare's subsidy for elderly health promotion project, etc. in FY2022.)

DC net Supporting network promoters for dementia in local communities

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

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

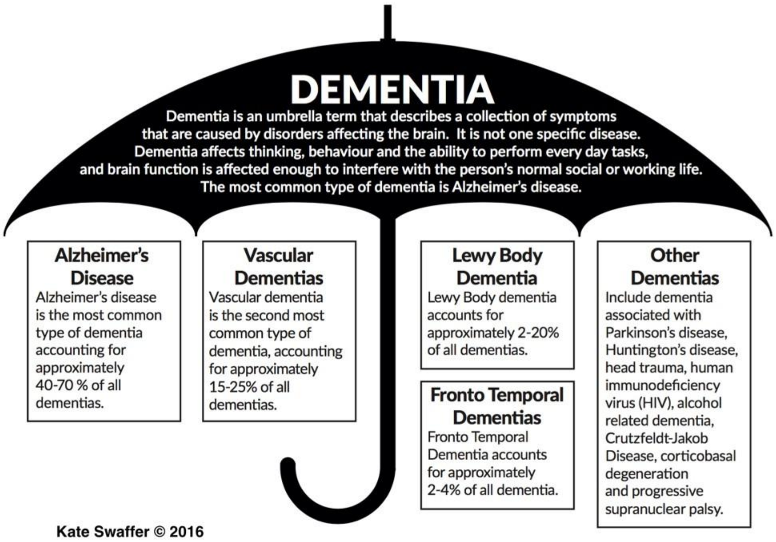
PhD Candidate, University of South Australia
MSc, BPsych, BA, Grad Dip Grief Counseling, Retired. Nurse
Researcher, Campaigner, Speaker, Author, Educator
Co-founder, Dementia Alliance International
@KateSwaffer
@DementiaAllianc

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)

@KateSwaffer



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.

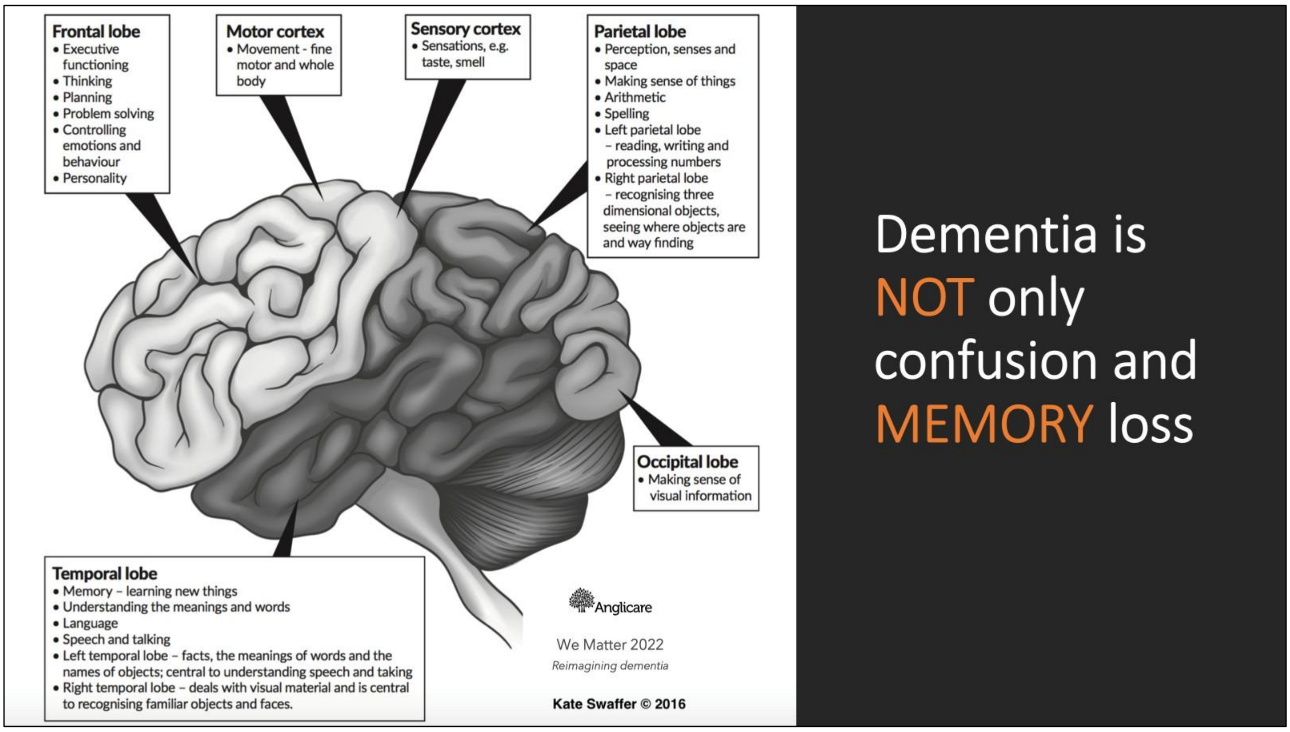
Vascular Dementias
Vascular dementia is the second most common type of dementia, accounting for approximately 15-25% of all dementias.

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.

Kate Swaffer © 2016



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

Kate Swaffer © 2016

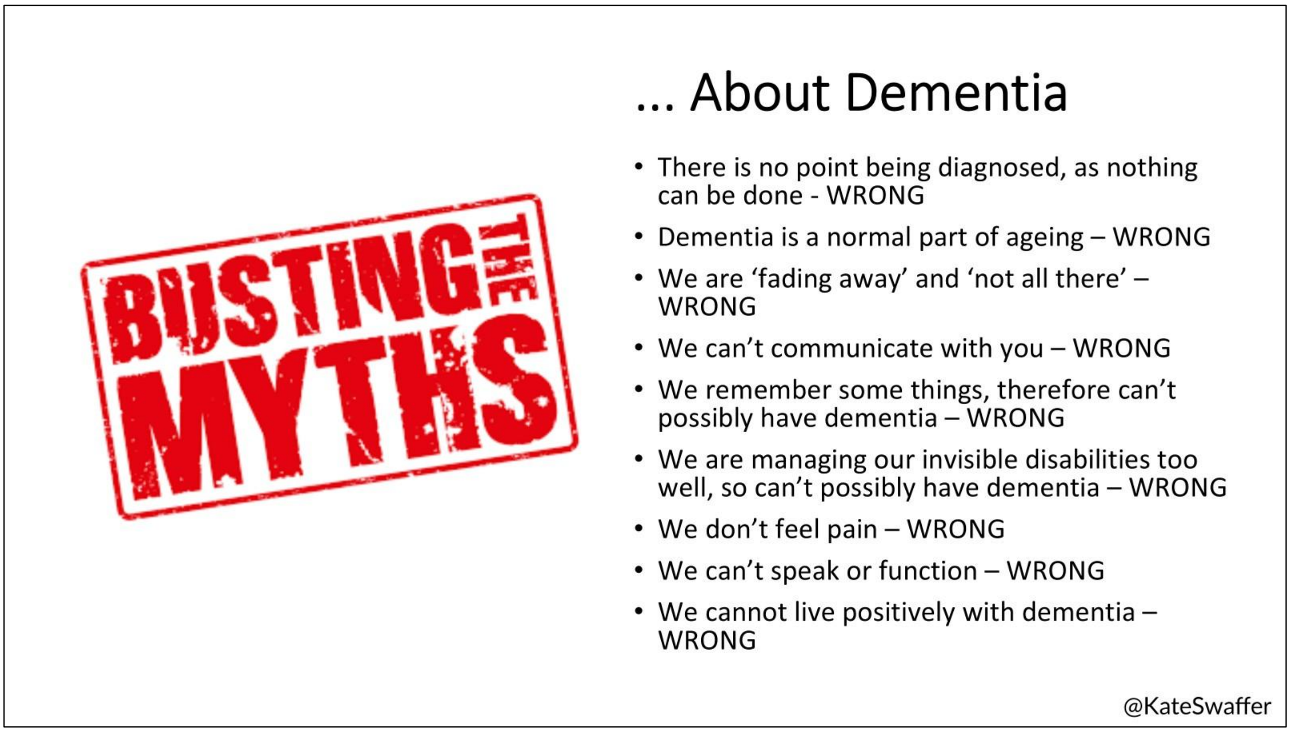
Dementia is NOT only confusion and MEMORY loss

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

@KateSwaffer



… 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

@KateSwaffer

Prescribed Disengagement©

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?

ONCE
YOU
CHOOSE
HOPE,
ANYTHING
IS
POSSIBLE

@KateSwaffer

‘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.

@KateSwaffer

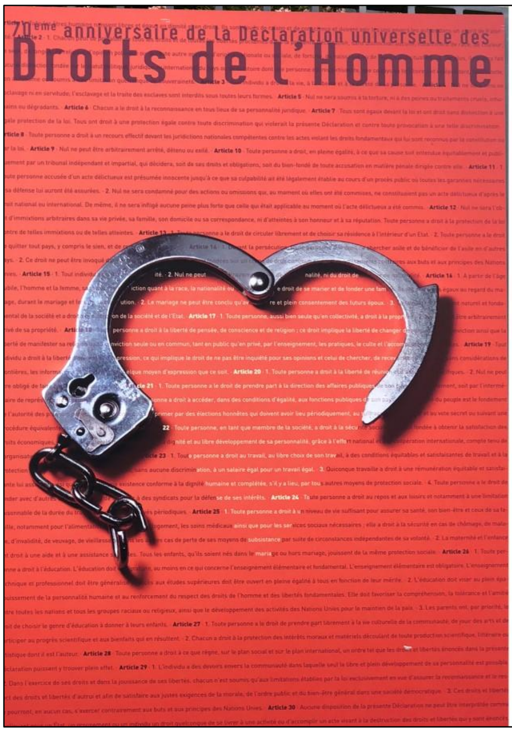
I'm still here…

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)


6+3=9 but so does 5+4.
The way you do things isn't always the only way to do them.
respect
other people's way of thinking.

@KateSwaffer



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**

@KateSwaffer

Let us not forget…

Honouring and remembering the Pioneers

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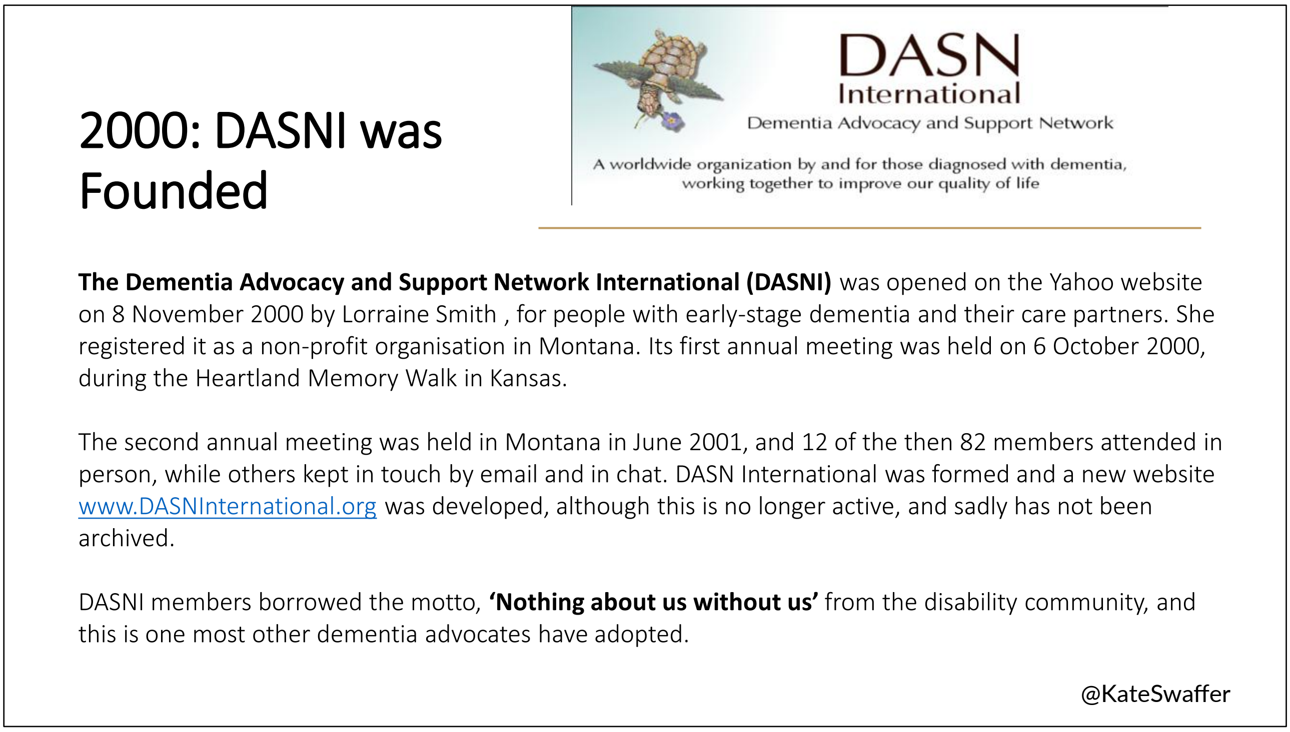

2000: DASNI was Founded

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.

@KateSwaffer

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

@KateSwaffer

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.

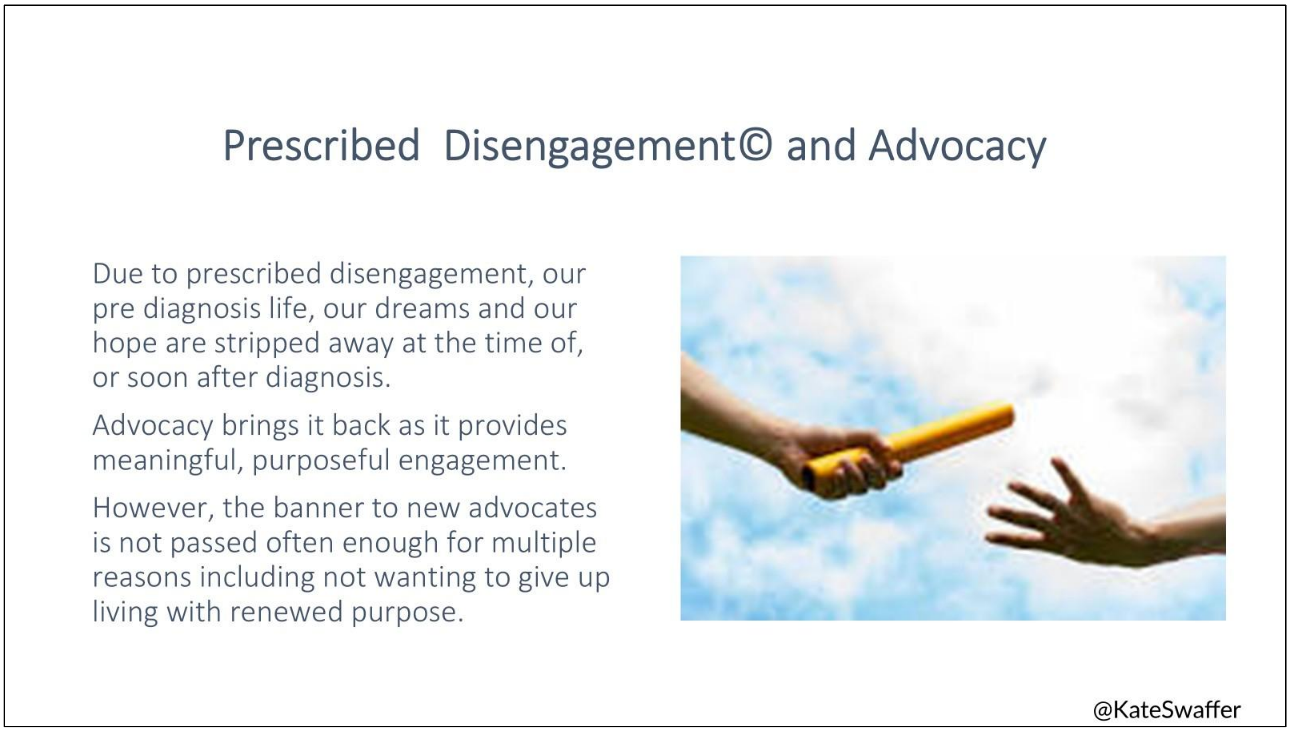
12 people with dementia came, some from as far away as Canada, United States and Australia. The contribution of these twelve turned the conference into an amazingly challenging and inspirational event – for conference delegates and the wider public.

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.

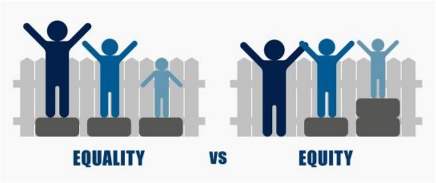
Advocacy brings it back as it provides meaningful, purposeful engagement.

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

@KateSwaffer

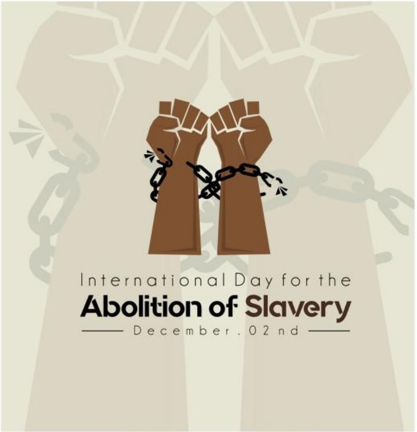
Involving advocates will mean equitable inclusion... Rare!

- 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



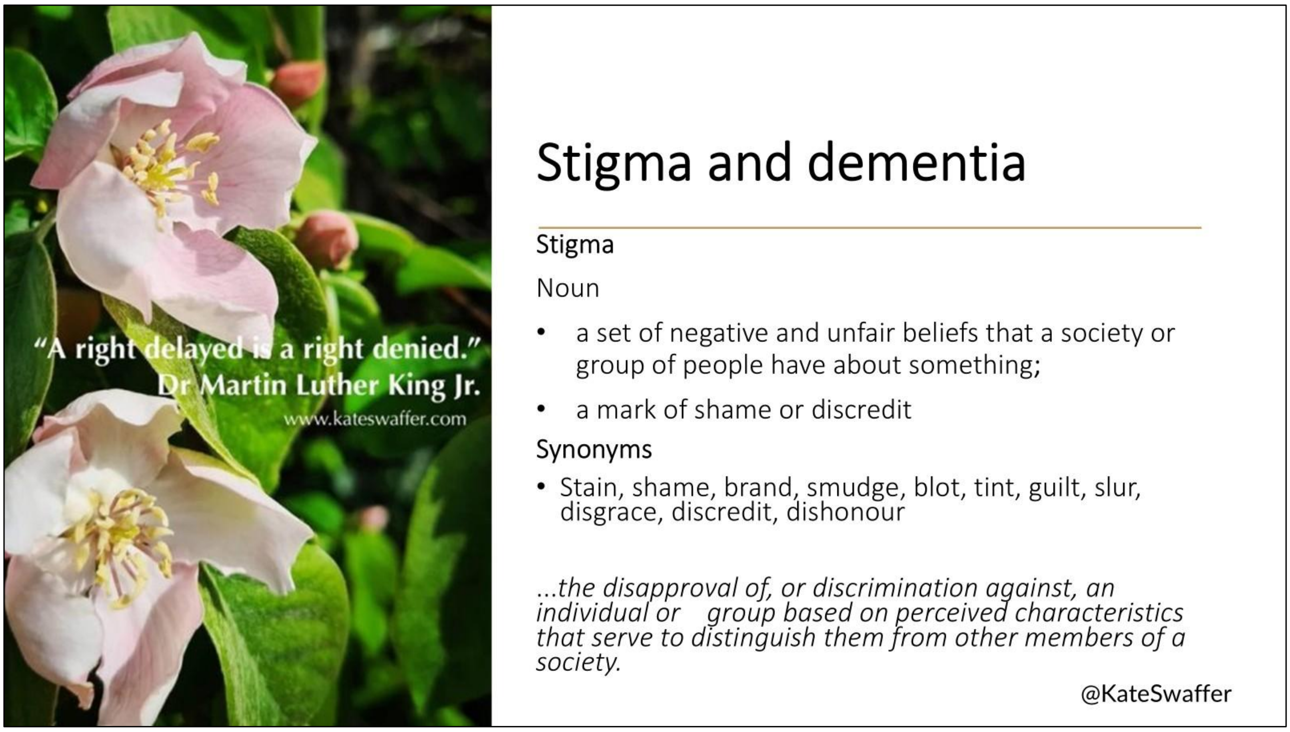
The increased involvement of unpaid advocates causes harm and stigma...

- 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.

@KateSwaffer

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

@KateSwaffer

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).

@KateSwaffer

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

@KateSwaffer

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.

@KateSwaffer

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

@KateSwaffer

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

@KateSwaffer

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)

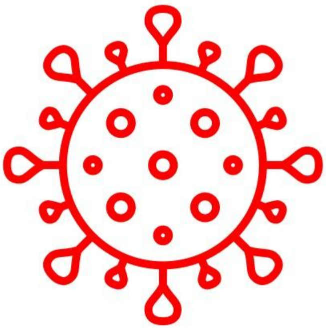
Note: Some people with dementia will have neuropsychiatric symptoms such as hallucinations, anger or disinhibition, due to the type of dementia they have, e.g., Lewy Body dementia, bvFTD

#BanBPSD

Reasonable Human Reponses to COVID-19

BEHAVIOURAL & PSYCHOLOGICAL SYMPTOMS OF COVID

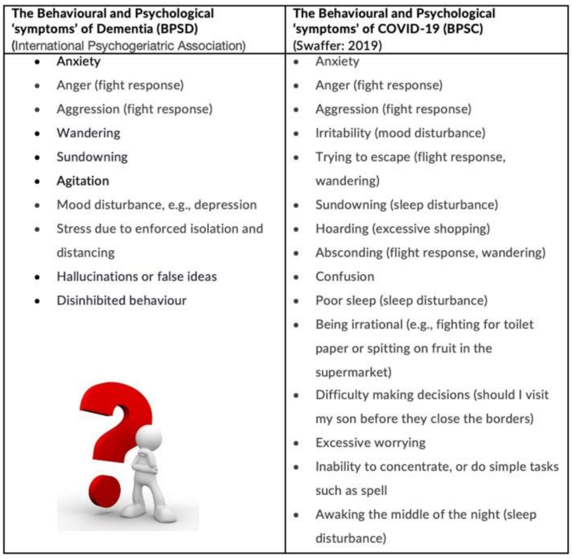
- Anxiety
- Anger (fight response)
- Aggression (fight response)
- Irritability (mood disturbance)
- Depression
- Trying to escape (flight response, wandering)
- Sundowning (sleep disturbance)
- Hoarding (excessive shopping)
- Absconding (flight response, wandering)
- Confusion
- Poor sleep (sleep disturbance)
- 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)

@KateSwaffer

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?

@KateSwaffer

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.

@KateSwaffer

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

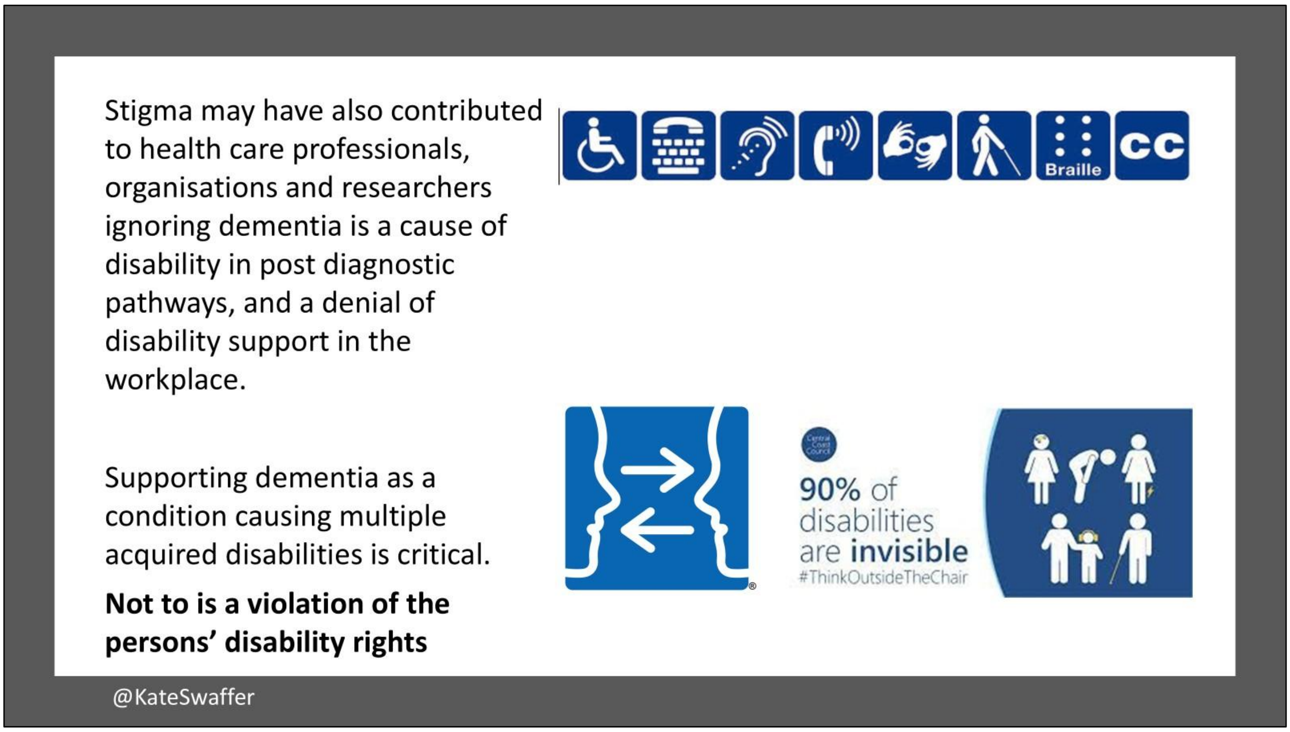
@KateSwaffer

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

@KateSwaffer



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

@KateSwaffer

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

@KateSwaffer

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

@KateSwaffer

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

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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."

Messages from people with dementia in Asia

◇ **From people with dementia in Korea**

◇ **From people with dementia in Taiwan**

Messages from people living with dementia in South Korea

■ Lee Ki-beom (Male, 63 years old, residing in South Korea)

Hello, my name is Lee Ki-beom. I'm 63 years old this year and live in Incheon Metropolitan City. After working as a public servant for about 40 years in this city, I retired.

Currently, I sometimes feel that my memory is becoming vague, and I sense that something is not quite right. After undergoing tests at the hospital, I was diagnosed with significant loss of brain cells.

At first, I was shocked, but apart from my memory being a little worse, there are hardly any major problems with my social life, so I decided not to worry about it too much. Everyone gets older and gradually declines, so I've decided to take life easy. When I think about it that way, nothing really feels inconvenient. Besides, as we get older, it's natural for people around us to help, so let's take it as normal and live life with ease. That's the mindset I'm living with now.

And, well... I don't need to take any medication right now. At the hospital, well... they say there's no treatment available, but I think forgetting can be a way to cope, so I've decided to live life with a carefree attitude.

I have many friends in similar situations, so I want to live life laughing together with them while we understand each other. Even if we cry, this disease isn't curable, right? So, let's all live our lives with laughter. Take it easy.

Translated by Associate Professor Kim Wonkyung, Department of Social Work, Faculty of Sociology & Social Work, Meiji Gakuin University

■Kang Jooyeon (Female, 64 years old)

Hello, my name is Kang Jooyeon. I'm 64 years old and live in South Korea.

I worked as an English teacher for 30 years, and two years ago I was diagnosed with Alzheimer's disease. Now I am participating in this forum as an Ambassador of Hope for Overcoming Dementia. People around me ask how I'm going to live with dementia, but I believe I can manage well, and I've been doing my best to live life to the fullest.

So, I want many people who watch this video to live with courage.

Now, let's shout these out together!

I can do it. You can do it. We can do it.

Thank you very much.

Translated by Associate Professor Kim Wonkyung, Department of Social Work, Faculty of Sociology & Social Work, Meiji Gakuin University

Reference videos

❶ Person living with dementia （Nam Cheol Yong, who lives alone) who uses the Gangdong Dementia Care Center in Seoul and volunteer guardians who are involved in supporting him (Broadcast by the South Korean cable TV station ‘D-Live’)

https://www.youtube.com/watch?v=teh2M-kasqY

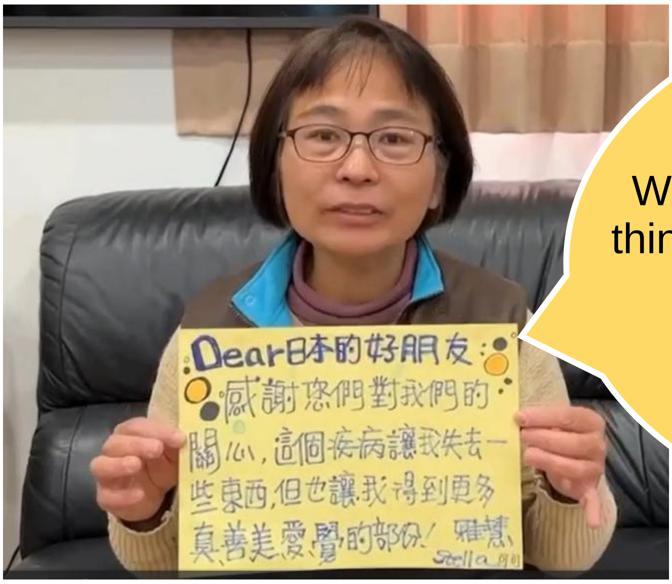
❷ Scene from the awareness-raising activities (Dementia Overcoming Day) by the Incheon Metropolitan Dementia Center and the ceremonial first pitch by a person living with dementia

https://www.youtube.com/watch?v=Rn6rwH3rzYY

Note: Both ❶ and ❷ are videos in Korean. Please use YouTube’s subtitle translation feature or other translation tools.

Messages from people with dementia in Taiwan

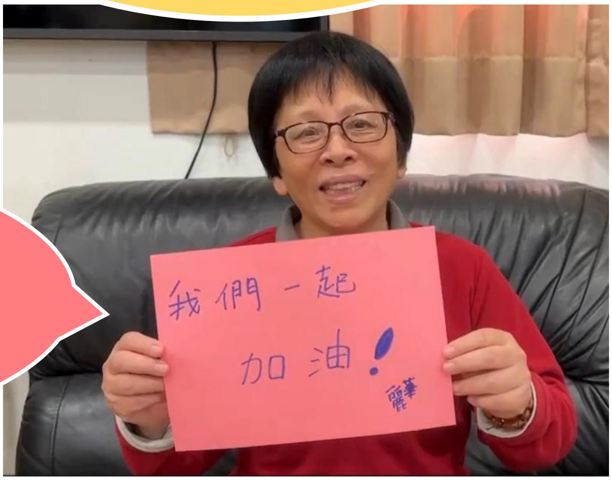
We have messages we’d like to share with you!

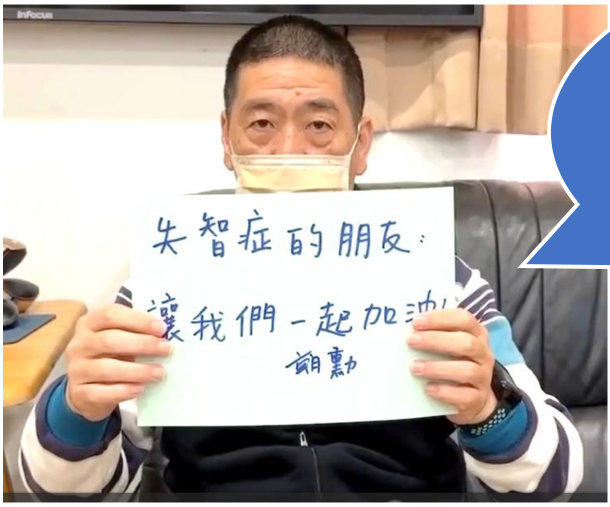

Dear日本的好朋友：
感謝您們對我們的
關心，這個疾病讓我失去一
些東西，但也讓我得到更多
真、善、美、愛、覺的部份！ 雅慧
Stella

We sincerely thank you for
your warm interest in us.
While this disease has taken many
things from us, it also allowed us
to feel truth, goodness,
beauty, and love more deeply.

Cai Yaqiang

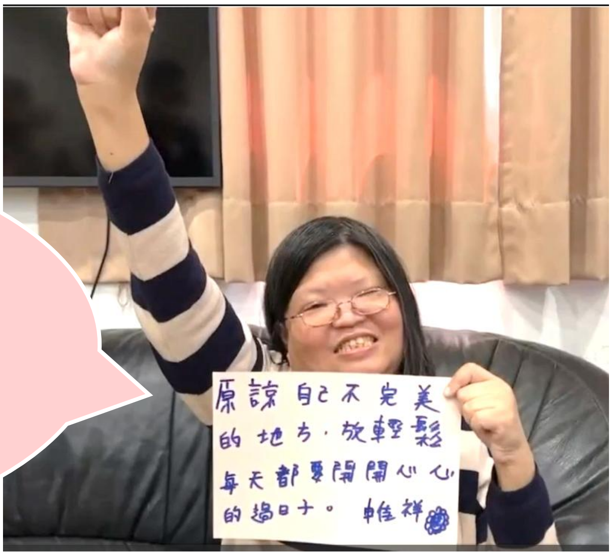
Let’s all do our best together!
CHOI Lai-wah


我們一起
加油！
麗華



To all our fellows living with dementia, let's keep going strong together!

CHAN CHIU FUN

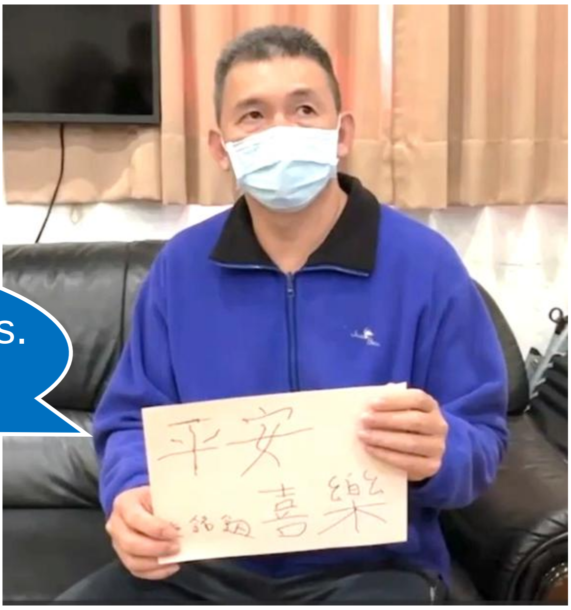


Allow yourself to accept your imperfections and take it easy. Spend each day with a smile and enjoy life to the fullest.

Shen Jiaxiang

Please take better care of yourself. Live true to your heart, cherish your body, and stay well.

Lau Kok Tong



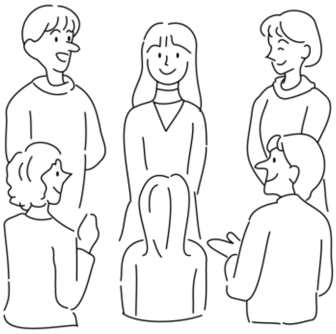
I pray for your peace and happiness.
SZE MING NIU

Part 2. Talk session

with Kate and Japanese people with dementia

■ What is needed to increase the participation of people living with dementia?

～ Including expectations for an international network of people living with dementia ～



Tomofumi Tanno

Residing in Sendai City, Miyagi Prefecture

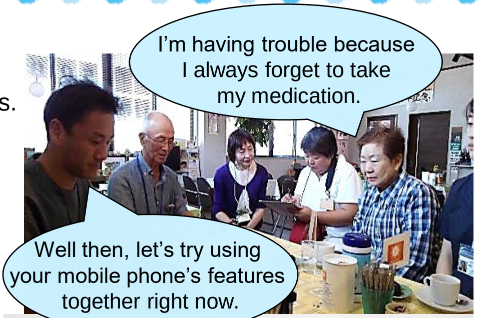
- Representative of Orange Door
- Representative of the Miyagi Network for People Living with Dementia
- Vice-representative Director, Japan Dementia Working Group
- Ambassador of Hope appointed by the Ministry of Health, Labour and Welfare, Ambassador of Hope appointed by Miyagi Prefecture

My journey with dementia

- In 2013, I was diagnosed with early-onset Alzheimer's disease at the age of 39, while working as a successful sales representative at Netz Toyota Sendai.
- After being diagnosed with dementia, all the information I heard was depressing.
- When I couldn't see a future for myself, I met cheerful and energetic peers living with dementia. This encounter inspired me to regain my own vitality and aspire to give courage to others facing dementia.
- After transitioning from a sales position to an administrative role, I continue working at the company, while actively engaging in activities to promote social understanding of living well with dementia.
- In 2014, I joined the Japan Dementia Working Group.
- In 2015, I established a consultation service run by people living with dementia, called Orange Door.
- In 2019, I established the Miyagi Network for People Living with Dementia.
- I was appointed as an Ambassador of Hope by the Ministry of Health, Labour and Welfare in 2020 and as an Ambassador of Hope by Miyagi Prefecture in 2024.

Challenges

- ■ I travel throughout Miyagi Prefecture and across Japan, engaging with local communities. Through these activities, I continue to convey the message that it is possible to maintain a life filled with smiles even after being diagnosed with dementia.
- ■ I continue to visit people living with dementia who are currently struggling, offering encouragement to help each person regain their strength and spirits.
- ■ In Miyagi Prefecture, I have been holding monthly gatherings where people living with dementia come together to have open and honest discussions. Through these gatherings, an increasing number of participants have gone on to become public speakers or active peer supporters.
- ■ I was involved in the production of the film *Orange Lamp*, which is based on my own experiences. Independent screenings of the film continue to expand across Japan.
- ■ I have continued to voluntarily interact with people with dementia in Scotland, Australia, and in recent years, in Asia.




©2022 Orange Lamp Production Committee

Many peers from all over Japan have contributed to and participated in the production.

Message

◆ **Even with dementia, we can still live with a smile. It's time for everyone—especially those living with dementia—along with their families and society at large, to break free from old preconceptions. Let's quickly shift toward a new perspective on dementia—one where we can live authentically with a smile, even while facing dementia!**

◆ **I receive calls and consultations from people living with dementia from all over Japan every day. Before attempting the grand task of changing society as a whole, I want to focus on working together to do what I can now to help those who have reached out to me find their smiles again.**

Major partners

- ☐ Many peers I have been working with in Miyagi.

Kazuko Fujita

Residing in Tottori City, Tottori Prefecture

- Representative Director, Japan Dementia Working Group
- Ambassador of Hope appointed by the Ministry of Health, Labour and Welfare
- Ambassador of Hope appointed by Tottori City

My journey with dementia

- Born in Tottori City in 1961.
- In 2007, I was diagnosed with early-onset Alzheimer's disease at the age of 45 while working as a nurse. Afterward, I voluntarily resigned from my job.
- In 2010, I established Clover, an association addressing the issue of early-onset dementia with my local peers.
- In 2014, I participated in the establishment of the Japan Dementia Working Group.
- In 2017, The Japan Dementia Working Group was incorporated as a general association and renamed the Japan Dementia Working Group. I was appointed as a Representative Director of the Group.
- I was appointed as an Ambassador of Hope by the Ministry of Health, Labour and Welfare in 2020 and as an Ambassador of Hope by Tottori City in 2021.
- In 2024, I participated in the formulation of the basic plan as a member of the meetings consisting of representative persons with dementia, their family members.
- In 2024, I received the Healthy Society Award hosted by Japanese Nursing Association.
- Member of research projects, etc., at the Ministry of Health, Labour and Welfare and the Ministry of Economy, Trade and Industry.

Challenges

- ■ At one point, I realized that unless we, as people living with dementia, speak out for ourselves, others will not truly understand the reality of our situation, and we will not be able to create a society where people with dementia can live comfortably. Since then, I have continued to convey my thoughts and opinions as a person living with dementia.
- ■ I hope to encourage as many people living with dementia as possible to raise their voices and increase the number of people working together to improve society. To this end, I have been persistently continuing my activities both in my hometown of Tottori and across Japan.
- ■ After the enactment of the Basic Act on Dementia to Promote an Inclusive Society, I participated as a committee member in the formulation of the government's basic plan.
- ■ I am calling for an experiential understanding of the ‘new perspective on dementia.’

Participated in the formulation of the government's basic plan with my peers.

My husband and dog, who support me in my daily life.

Message

- ◆ **Even after being diagnosed with dementia, I have continued to make various efforts and take on challenges. Now, I am deeply grateful to everyone who has been supporting me along the way.**
- ◆ **I hope that more people living with dementia will continue to walk their own unique paths, and I believe that the Basic Act will help support this.**
- ◆ **Let's show how we face dementia and live authentically while making various efforts, and inspire more people to think about dementia positively and take it as their own issue!**

Major partners

- ☐ Members of the JDWG and the secretariat
- ☐ Supporting network promoters for dementia in local communities in Tottori City
  ‘Let's create a society where people feel reassured even if they are diagnosed with dementia, together with the people with dementia themselves!’
- ☐ Local people who have been long-time friends and are now working with me on community center salons and other activities.

Shinobu Yamanaka

Residing in Nankoku City, Kochi Prefecture

- Representative Director, Second Story, a general incorporated association
- Director, Kochi Prefecture Association for People with Young-Onset Dementia, Their Family Members and Supporters
- Ambassador of Hope appointed by Kochi Prefecture
- Member, Japan Dementia Working Group

My journey with dementia

- Born in Kochi in 1977.
- I was diagnosed with early-onset Alzheimer's disease in February 2019, after 15 years of working as a sales representative for mobile phones.
- I resigned from the company at the end of June 2021.
- The presence of my beloved family gave me great strength. In addition, my encounter with the book *Living with a Smile* by Tomofumi Tanno, an Ambassador of Hope appointed by the Ministry of Health, Labour and Welfare, became the turning point that allowed me to move forward with a smile.
- I established Second Story, a general incorporated association, in April 2022.
- I was appointed as Ambassador of Hope by Kochi Prefecture in July 2022.
- I opened the Happy Day Service Center in October 2022.
- To Present: I have expanded the scope of my activities not only within the prefecture and across Japan but also internationally. I not only convey my thoughts as a person living with dementia but also engage in various activities, including paid volunteer work.

Challenges

- I established a day service center with a strong desire to create a place where no one feels alone and to build a community where people can live together with their companions in their familiar neighborhoods. I collaborate with local businesses and engages in various activities, including paid volunteer work. In addition, through the meeting center where people living with dementia and their family members can work together, I continue to realize the wishes and aspirations of my peers.
- Since being diagnosed with dementia, I have experienced many difficult emotions. Driven by my desire to ensure that no one else with dementia has to endure the same pain and to convey the message, 'You are not alone,' I actively engage in awareness-raising activities and peer support activities both within and outside the prefecture.

I helped to harvest mandarin oranges with my favorite companions from the Happy Day Service Center.

Note: This was selected as a photo for the poster of the 2024 World Alzheimer's Month.

At the Run Tomo Kochi 2024, an event where people connect and pass on a *tasuki* sash and thoughts.

Message

For us, meeting other people living with dementia can be a turning point that helps us look forward. However, to truly continue living with hope and positivity, the support of the communities we live in is essential.

When people in the community connect and engage in activities, new discoveries and insights emerge.

I believe that by building upon each of these small steps, we can create a more livable environment for the entire community.

Major partners

- ◻ Family members, and peers and companions I work with through activities at the Kaientai, the Happy Day Service Center, and the meeting center
- ◻ Staff members of the Dementia Disease Medical Center (peer support activities), early-onset dementia coordinators and other people

'The words and perspectives of people living with dementia themselves provide us with insights and opportunities to reflect on our current state and approach. Moreover, they teach us how to face (and live with) dementia.'

Haruko Sunohara

Residing in Ueda City, Nagano Prefecture

- Member, Japan Dementia Working Group
- Ambassador of Hope appointed by the Ministry of Health, Labour and Welfare
- Representative of a dementia salon ‘hinata bocco’

My journey with dementia

- 2004 (60 years old): I served as a children’s social worker for nine years after retiring from my teaching career. I then attended a local community development seminar. I started volunteer activities at Intensive Care Home for the Elderly, elementary schools, and in the local community.
- 2013 (69 years old): At a community development seminar, I learned about people living with dementia who continue to live authentically and stay positive despite their diagnosis.
- 2014 (70 years old): The local community association established Apron Club, a gathering place for the elderly. With fellow members, I began sharing what we learned about dementia with seminar participants. We also started to monitor and visit households where people live alone. We continue our activities in collaboration with intensive care homes for the elderly, the community comprehensive support center, and the local government.
- In 2017, I was diagnosed with Alzheimer's disease at the age of 73.
- I was appointed as Representative of a dementia salon ‘hinata bocco,’ a source of support for the people in the Hoden Area in 2018.
- I was appointed as an Ambassador of Hope by the Ministry of Health, Labour and Welfare in 2020.
- In 2024, I participated in meetings consisting of representative persons with dementia, their family members for the government's Basic Plan for the Promotion of Policies on Dementia.

Challenges

- Getting rid of the fear and prejudice about dementia, even before being diagnosed, is the best way to prepare yourself in case it ever happens. That is why I convey my personal experiences to show how important it is to build a community where people can live openly and authentically, even after being diagnosed with dementia.
- We provide persons living with dementia and their families the opportunity to experience, here at hinata bocco, how they can live freely and joyfully with their community, while openly embracing their condition. Through offering this experience, we support them in taking the first step toward a new and hopeful chapter in their lives.

I shared my thoughts and experiences as a person living with dementia with medical and care professionals who visited Japan.

With the members of hinata bocco.

Message

◆ **To the people of the community**

Let's work together to build a community based on the ‘new perspective on dementia’ with people living with dementia.

◆ **To people living with dementia**

Aging and forgetfulness are part of nature's plan—let’s embrace them!

And let’s enjoy new experiences while staying connected with our peers.

◆ **To family members of people living with dementia**

I hope that family members of people living with dementia will support us as we connect with our peers and the community.

Major partners

☐ A few words from the members of the Community Development Seminar Alumni Association, hinata bocco volunteers, and local mutual support salon members

‘Let’s share how people living with dementia are thriving together with their peers and companions in the community!’ (Mr. Yoshihisa Kanbayashi)

Mamoru Toue

Residing in Bungo Ono City, Oita Prefecture

- Oita Prefecture Peer Support Counselor
- Ambassador of Hope appointed by Oita Prefecture
- Ambassador of Hope appointed by the Ministry of Health, Labour and Welfare
- Director, Japan Dementia Working Group

My journey with dementia

- I began experiencing forgetfulness and poor physical health in 2016 at around the age of 56, while working as a local government employee. I was later diagnosed with frontotemporal dementia.
- After being diagnosed with dementia, I withdrew at home for about one year. However, I was able to regain a sense of self after connecting with a day service in Oita City where people with early-onset dementia use their strengths and play active roles.
- I was appointed as an Ambassador of Hope by Oita Prefecture in 2021.
- I was appointed as an Ambassador of Hope by the Ministry of Health, Labour and Welfare in 2024.

People living with dementia, medical students, graduate students, professors, and doctors played a baseball game together. We were able to see many expressions that we usually don't get to see from each other!

Challenges

- ■ Playing softball with students
- ■ Growing seasonal vegetables
- ■ Building relationships through peer support activities
- ■ Taking on challenges in the transportation job and new work opportunities
- ■ Building up my strength through activities such as walking, table tennis, and fishing
- ■ Watching baseball games at stadiums

Sharing authentic and fun stories of my journey, including my challenges and failures!

Message

- ◆ **Dementia is not necessarily a scary disease. We have peers who support each other along the way.**
- ◆ **I gave up work once, but I want to try again!** ◆ I gave up work once, but I want to
- ◆ **As our community transforms into an environment where 'it's okay to fail,' we can once again take on challenges and gain successful experiences. This, in turn, builds our confidence. As we regain our confidence, we regain a sense of self, and our world expands.**
- ◆ **I want to share the joy of work.**
- ◆ **Getting dementia is also an opportunity to reflect on what truly matters to you and to live your life authentically.**

Major partners

- ☐ President, Dementia Care Instructors, and chief care manager of the Outpatient Day Long-Term Care Center

  'We are on a journey with Mamoru. We laugh together through good days and bad days.'
- ☐ Supporting network promoters for dementia in local communities in Oita City

  'Working with Mamoru has made our job more fun!'

Hitoshi Fukuda

Residing in Sasebo City, Nagasaki Prefecture

- Director, Japan Dementia Working Group
- Dementia Support Ichigyou No Kai

My journey with dementia

- Born in Iwakuni City, Yamaguchi Prefecture in 1962.
- In 2014, I was diagnosed with early-onset Alzheimer's disease at the age of 51 while working as a licensed cook. After that, I chose to resign from my job. With the unwavering support of my partner and those around me, I found new hope in life.
- In 2015, I set up the Dementia Support Ikko No Kai with my partner and others. We have continued to engage in exchange activities within and outside the prefecture.

  In 2016, I host Cafe Toge No Chaya every month with my local friends.
- In 2018, I joined the Japan Dementia Working Group.
- From 2021 to 2023, I served as an Ambassador of Hope appointed by Nagasaki Prefecture.
- In 2025, I serve as a committee member for research projects conducted by the Ministry of Health, Labour and Welfare.

Challenges

- I believe that when we, people living with dementia, take a step forward in our community, it becomes a step forward for Nagasaki Prefecture. Eventually, this step can connect to the entire nation, transforming society into a better environment for everyone to live in. To realize this belief, I think the starting point of our activities lies in meeting other people living with dementia, sharing our thoughts, and listening to the voices of their families and various other people. By doing so, we can work together to transform the community we live in into a better place.
- While continuing to work together with everyone in the JDWG, I want us to collectively envision and realize a concrete framework for the future that allows us to live authentically. We aim to create a community where we can take walks safely and with peace of mind, even if communication becomes challenging in the future.

At a consultation meeting held in our community.

Message

◆ **The people with dementia who are members of the JDWG and who live in various regions have a lot of potential. What's the most important is to make sure that the discussions held with people living with dementia at peer support meetings, dementia cafes, or local social gatherings are not wasted, and that their thoughts and feelings are turned into tangible results.**

◆ **To make this happen, it is important that people living with dementia choose a place for themselves where they feel comfortable talking. This is really the first step in building good communication.**

Major partners

- ☐ Members of the JDWG and the secretariat
- ☐ Members of the Dementia Support Ikko No Kai

  （Staff members of Toge No Chaya in Sasebo and Mito）

  'Although we are in different regions, with the support of Hitoshi, the Toge No Chaya in Mito is open and thriving every month.'
- ☐ Supporting network promoters for dementia in local communities in Sasebo and staff members of the Community Comprehensive Support Center

Miki Taira

Residing in Ishioka City, Miyagi Prefecture

- Director, NPO Dementia Association Walking Together, Ibaraki
- Advisor, Support Network for Dementia with Lewy Bodies
- Member, Japan Dementia Working Group

My journey with dementia

- Born in Ibaraki Prefecture in 1958.
- I was diagnosed with Lewy body dementia at the age of 52.
- I met my current attending physician, and that encounter marked the beginning of a life where I could live positively with dementia.
- I met caregivers of people with dementia, and this encounter inspired me to participate in the establishment of the Dementia Support Group Walking Together, Ibaraki in 2015.
- In 2017, the Dementia Support Group Walking Together, Ibaraki was incorporated as an NPO.
  I was appointed as a director of the NPO.
- I encountered with the Japan Dementia Working Group.
- I was appointed as an advisor to the Support Network for Dementia with Lewy Bodies
- I give lectures across various regions.

NPO members and a dementia cafe activity for people with dementia. We had a lunch-making and chatting get-together.

Challenges

- I share my symptoms, feelings, and experiences as a person living with dementia, particularly Lewy body dementia, through lectures held at dementia cafes and nationwide to deepen understanding of the disease.
- I am actively engaged in raising awareness of the Help Mark and Help Card. I also actually carry them myself. With them in hand, I'm now enjoying new experiences like traveling alone to different parts of Japan (I like castles) and going to concerts—things I've never done before.

「思いやりあれば共存」

レビー小体型患者語る

自身の体験を語る平みきさん＝水戸市緑町

レビー小
日本認知

講演では、レビー小体型認知症を患う平みきさんも登壇。「認知症を怖いと思わないで。思いやりがあれば共存できる」と明るく語った。

レビー小体型はアルツハイマー型に次いで2番目に多い。認知機能が良いときと悪いときの波があり、幻視や睡眠時の異常行動などの症状が出る。平さんは幻視・幻聴の症状が最も強く、亡くなった両親をよく見るという。「怖いじゃなく、会えてうれしい」と考え方を転換し、ポジティブに捉えていると明かした。

最近はヘルプマークを身に着けているが、「突然後ろから声をかけられたり、大きな声を出されたりするとすごく怖い。小さなことに目を向けてほしい」と配慮を求めた。

「正直楽な病気ではない」と本音も。だが「苦しくもない。（啓発活動などで）全国に友達ができた。今度は広島に遊びに来いって誘われているんです」と笑顔で締めた。

A Lecture titled 'Dementia Is Not Scary' hosted by the NPO Dementia Association Walking Together Ibaraki (article published in the Ibaraki Shimbun on November 1, 2023).

Message

◆ **Dementia is not necessarily a scary disease.**

◆ **I believe we can live enjoyably if we have the courage to acknowledge our weaknesses and limitations, to ask for help when needed, and to express our gratitude both in feelings and words.**

Major partners

- Members of the NPO Dementia Association Walking Together, Ibaraki
- Members of the Support Network for Dementia with Lewy Bodies

'We are always encouraged by your positive words.'
Fumiko Shibuya, Representative, NPO Dementia Association Walking Together, Ibaraki

Toru Katagiri

Residing in Eniwa City, Hokkaido

- I am engaged in advocacy and awareness-raising activities as a person living with dementia in Eniwa City.

My journey with dementia

- In 2023, at around the age of 58, I found myself unable to solve an entrance exam question from a certain university while working as a teacher. Following the advice of my colleague, I decided to seek medical attention and was subsequently diagnosed with early-onset Alzheimer's disease.
- After being diagnosed with dementia, I searched the internet for information about dementia, but I was overwhelmed by the abundance of negative information and ended up leading a withdrawn and gloomy life. However, I learned that walking and interacting with others could help prevent the progression of the disease. This led me to participate in family support groups, walking clubs, and yoga classes. Living with dementia has also allowed me to find new sources of joy and meaning in life.

A training course for dementia supporters for nursing students. I was nervous but I was so comfortable with teaching that I was able to speak with great energy and enthusiasm.

Challenges

- **■** New hobbies and involvement
  - Walking, yoga classes
  - Dementia family support group
  - Social gatherings for people living with dementia
- **■** Activities
  - Lecturer at the dementia supporter training courses (Nursing department)
  - English reading sessions
  - Children's cafes, learning support teachers
  - Dementia cafe staff
- **■** Things I want to do
  - Teach English to children

I enjoyed interacting with children and an ALT at English reading sessions at the library.

Message

◆ **Having dementia has made me realize once again that living is not something to be taken for granted, and that I should be grateful for living to this age. I now live with the motto 'Be grateful for everything' close to my heart.**

◆ **I knew about dementia, but I didn't have accurate knowledge about it. I believe that it is important to have accurate knowledge about dementia from a young age. Drawing from my own experience, I hope to create opportunities to learn about dementia, starting in educational settings.**

◆ **Even after being diagnosed with dementia, I still have many things I want to do.**

I want to continue holding onto my dreams for the future.

Major partners

□ Kei Okumiya (Supporting network promoter for dementia in local communities, Community Comprehensive Support Center, Eniwa City)

'When I work with you, I realize that there is a lot to do. I would like to continue supporting your activities and dreams, and I look forward to continuing to work together with you.'

Shigeyuki Kanbara

Residing in Yokote City, Akita Prefecture

- Ambassador of Hope appointed by Akita Prefecture

My journey with dementia

- Born in Yokote City, Akita Prefecture in 1962.
- In 2022, I was diagnosed with early-onset Alzheimer's disease at the age of 58. At that time, I was working as the head of the nursing department at the psychiatric hospital where I still work. I stepped down from this position but transferred to the rehabilitation department, where I continue to work full-time. Using my personal skills as a nurse, I am involved in rehabilitation work and awareness-raising activities on dementia in collaboration with Yokote City.
- In 2024, I was appointed as an Ambassador of Hope by Akita Prefecture.
- With the motto of accepting requests whenever possible, I am amplifying the voices of people living with dementia.

Dementia Month event 'Yokote Castle Orange Illumination' held in September 2024.

Challenges

- I still hope to continue living my current life—just myself and my pet—while receiving support from the friends around me.
- We are currently holding preliminary peer support meetings, which originated from a local dementia cafe in the city.
- I believe we must not be like 'a frog in a well that knows nothing of the great ocean.' So, I am currently taking on challenges in my work, awareness-raising activities, and other things, while enjoying myself.

'Youthful moments?'

Message

◆ **I have been involved in psychiatric care for many years. During this time, I have consistently told patients with mental disorders that dementia is not a shameful disease.**
This belief remains unchanged even now that I am living with dementia myself.

◆ **Que será será—I want to enjoy living in the moment.**

Major partners

- Colleagues from Yokote-Kohsei Hospital
- Members of the Yokote City Welfare Department and fellow supporting network promoters for dementia in local communities
- Friends for decades
- Neighborhood association members and others.

'From your positive approach to living, I am learning what it means to 'live my own life.'

Akio Kakishita

Residing in Shinagawa Ward, Tokyo

- Member of the Minna No Dangisho (Everyone's Discussion Place) Shinagawa
- Ambassador of Hope appointed by the Ministry of Health, Labour and Welfare
- Member, Japan Dementia Working Group

My journey with dementia

- Born in Shizuoka Prefecture in 1953. During my university years, I served as a coxswain in rowing and competed in the 1976 Montreal Olympics.
- I worked at the Ota Market, Tokyo Metropolitan Central Wholesale Market for 40 years.
- Around 2014 (at the age of 61), I started to feel that something was not quite right.
- I was encouraged by my rowing friends to seek medical attention and was diagnosed with mild cognitive impairment (MCI). I later resigned from my job in 2016.
- I started attending day care and day services specialized for early-onset dementia.
- I met Mr. Tanno and Ms. Fujita. They are always smiling and cheerful! I was inspired by their activities driven by a sense of mission to support others with the same disability. It made me feel strongly motivated to do something myself.
- In 2020, I was appointed as an Ambassador of Hope by the Ministry of Health, Labour and Welfare.
- I am continuing my activities cheerfully and energetically with my fellow members of the Minna No Dangisho Shinagawa, the Meeting Center Medaka-no-kai, and peer support.

Challenges

- When I do something I enjoy, my brain feels happy and I become more energetic!
- Together with my peers and fellows, I try engaging in a range of activities—running, playing baseball, and even participating in the planning and holding festivals, events, and creating accessible work opportunities.
- Hope Lights Our Way!
  ⇒I was selected as a torch bearer for the Tokyo 2020 Olympic Games held in 2021.
- I started painting after being diagnosed with dementia and held a solo exhibition in 2023.
- With the belief that there is still so much to do, I continue to share my feelings and experiences across Japan.
- I am taking on new challenges to create accessible work opportunities, places to belong, and peer support spaces for those living with dementia. Let's have fun together!

Run Tomo Shinagawa is back!
I'm running with my fellow, so my smile is shining!

My hand moves on its own!
It's a time of deep concentration.

Message

- **There are things I have felt and experienced because I went through this illness. I believe there is meaning in sharing these experiences.**
- **It is impossible to climb Mount Fuji from the start. So, begin with a nearby hill. Take one step forward, then another. Each step builds your confidence. Your sensitivity will continue to grow!**
- **Let's expand our circle of friendship—one by one, in our local communities—with people we can laugh wholeheartedly with and enjoy life together!**

Major partners

- Various people are involved in my life, including members of the Minna No Dangisho Shinagawa, members of the Meeting Center Medaka-no-kai, and members of the brain activation art group ARTMaN.
  Our relationship goes beyond just giving and receiving favors.

'Live vibrantly and true to yourself in the present moment! I'll enjoy it together with you.' (Ms. Fuayo Kakishita)

Relay of Hope, your message.

Tokyo Center for Dementia Care Research and Practice

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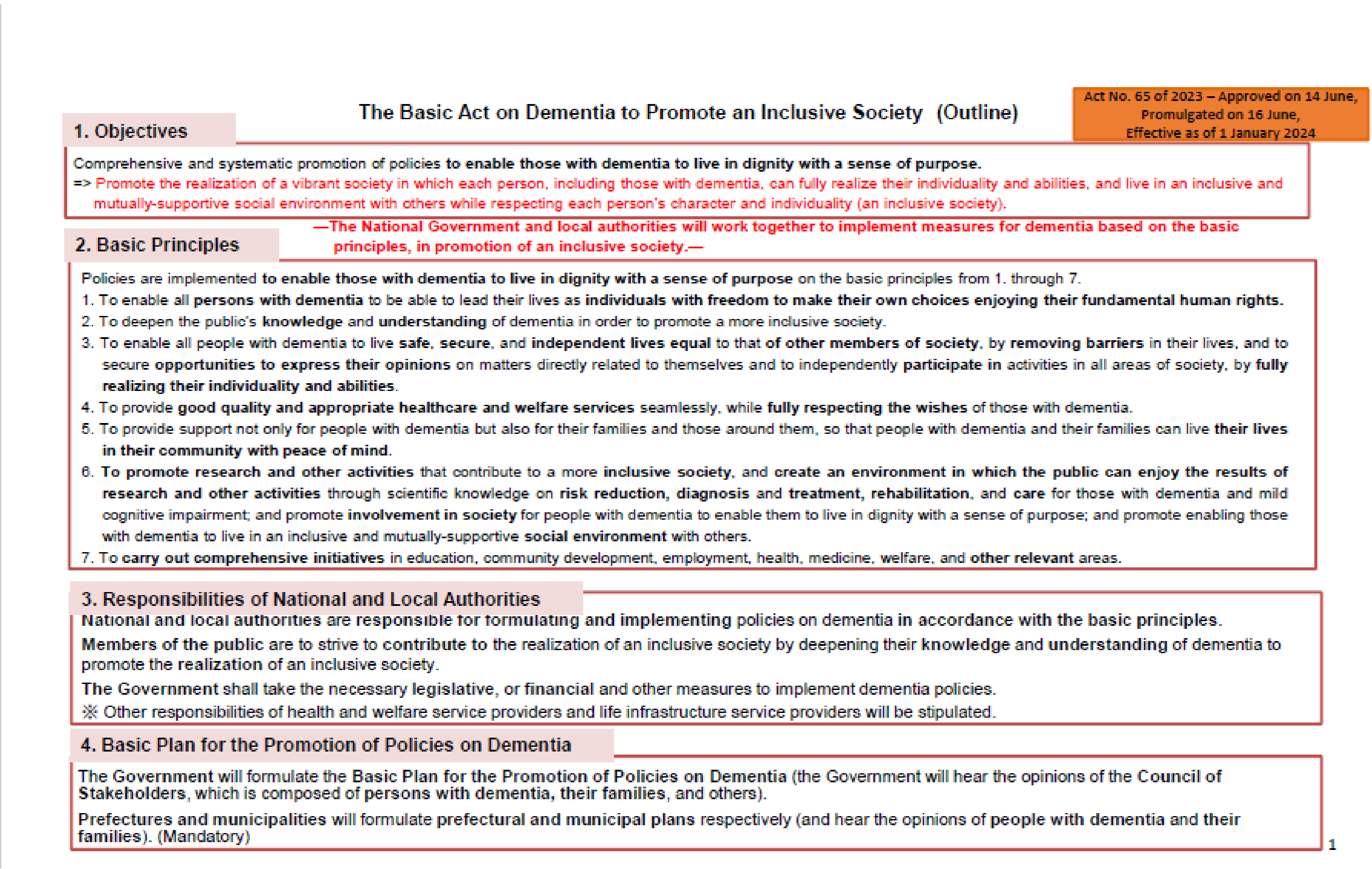
the reference materials

- The Basic Act on Dementia to Promote an Inclusive Society (Outline)
- Declaration of Hope for Living with Dementia



The Basic Act on Dementia to Promote an Inclusive Society (Outline)

Act No. 65 of 2023 – Approved on 14 June,
Promulgated on 16 June,
Effective as of 1 January 2024

1. Objectives

Comprehensive and systematic promotion of policies **to enable those with dementia to live in dignity with a sense of purpose.**

=> Promote the realization of a vibrant society in which each person, including those with dementia, can fully realize their individuality and abilities, and live in an inclusive and mutually-supportive social environment with others while respecting each person's character and individuality (an inclusive society).

—The National Government and local authorities will work together to implement measures for dementia based on the basic principles, in promotion of an inclusive society.—

2. Basic Principles

Policies are implemented **to enable those with dementia to live in dignity with a sense of purpose** on the basic principles from 1. through 7.

1. To enable all **persons with dementia** to be able to lead their lives as **individuals with freedom to make their own choices enjoying their fundamental human rights.**
2. To deepen the public's **knowledge** and **understanding** of dementia in order to promote a more inclusive society.
3. To enable all people with dementia to live **safe, secure,** and **independent lives equal** to that **of other members of society**, by **removing barriers** in their lives, and to secure **opportunities to express their opinions** on matters directly related to themselves and to independently **participate in** activities in all areas of society, by **fully realizing their individuality and abilities**.
4. To provide **good quality and appropriate healthcare and welfare services** seamlessly, while **fully respecting the wishes** of those with dementia.
5. To provide support not only for people with dementia but also for their families and those around them, so that people with dementia and their families can live **their lives in their community with peace of mind**.
6. **To promote research and other activities** that contribute to a more **inclusive society**, and **create an environment in which the public can enjoy the results of research and other activities** through scientific knowledge on **risk reduction, diagnosis** and **treatment, rehabilitation**, and **care** for those with dementia and mild cognitive impairment; and promote **involvement in society** for people with dementia to enable them to live in dignity with a sense of purpose; and promote enabling those with dementia to live in an inclusive and mutually-supportive **social environment** with others.
7. To **carry out comprehensive initiatives** in education, community development, employment, health, medicine, welfare, and **other relevant** areas.

3. Responsibilities of National and Local Authorities

National and local authorities are responsible for **formulating and implementing** policies on dementia **in accordance with the basic principles.**

Members of the public are to strive to **contribute** to the realization of an inclusive society by deepening their **knowledge** and **understanding** of dementia to promote the realization of an inclusive society.

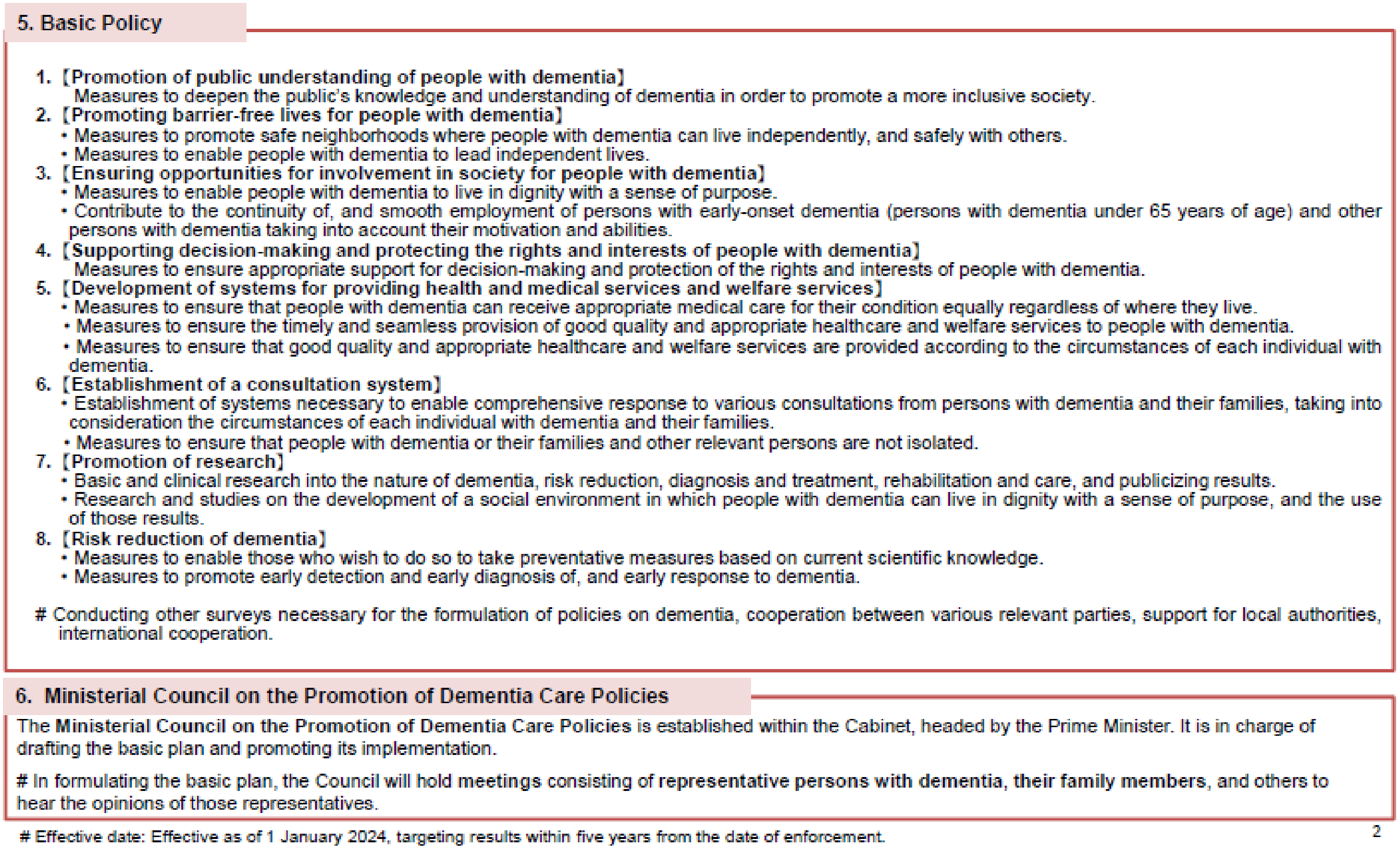
The Government shall take the necessary **legislative**, or **financial** and other measures to implement dementia policies.

※ Other responsibilities of health and welfare service providers and life infrastructure service providers will be stipulated.

4. Basic Plan for the Promotion of Policies on Dementia

The Government will formulate the **Basic Plan for the Promotion of Policies on Dementia** (the Government will hear the opinions of the **Council of Stakeholders**, which is composed of **persons with dementia, their families**, and others).

Prefectures and municipalities will formulate **prefectural and municipal plans** respectively (and hear the opinions of **people with dementia** and **their families**). (Mandatory)



5. Basic Policy

1. **［Promotion of public understanding of people with dementia］**
   Measures to deepen the public's knowledge and understanding of dementia in order to promote a more inclusive society.
2. **［Promoting barrier-free lives for people with dementia］**
   - Measures to promote safe neighborhoods where people with dementia can live independently, and safely with others.
   - Measures to enable people with dementia to lead independent lives.
3. **［Ensuring opportunities for involvement in society for people with dementia］**
   - Measures to enable people with dementia to live in dignity with a sense of purpose.
   - Contribute to the continuity of, and smooth employment of persons with early-onset dementia (persons with dementia under 65 years of age) and other persons with dementia taking into account their motivation and abilities.
4. **［Supporting decision-making and protecting the rights and interests of people with dementia］**
   Measures to ensure appropriate support for decision-making and protection of the rights and interests of people with dementia.
5. **［Development of systems for providing health and medical services and welfare services］**
   - Measures to ensure that people with dementia can receive appropriate medical care for their condition equally regardless of where they live.
   - Measures to ensure the timely and seamless provision of good quality and appropriate healthcare and welfare services to people with dementia.
   - Measures to ensure that good quality and appropriate healthcare and welfare services are provided according to the circumstances of each individual with dementia.
6. **［Establishment of a consultation system］**
   - Establishment of systems necessary to enable comprehensive response to various consultations from persons with dementia and their families, taking into consideration the circumstances of each individual with dementia and their families.
   - Measures to ensure that people with dementia or their families and other relevant persons are not isolated.
7. **［Promotion of research］**
   - Basic and clinical research into the nature of dementia, risk reduction, diagnosis and treatment, rehabilitation and care, and publicizing results.
   - Research and studies on the development of a social environment in which people with dementia can live in dignity with a sense of purpose, and the use of those results.
8. **［Risk reduction of dementia］**
   - Measures to enable those who wish to do so to take preventative measures based on current scientific knowledge.
   - Measures to promote early detection and early diagnosis of, and early response to dementia.

Conducting other surveys necessary for the formulation of policies on dementia, cooperation between various relevant parties, support for local authorities, international cooperation.

6. Ministerial Council on the Promotion of Dementia Care Policies

The **Ministerial Council on the Promotion of Dementia Care Policies** is established within the Cabinet, headed by the Prime Minister. It is in charge of drafting the basic plan and promoting its implementation.

In formulating the basic plan, the Council will hold meetings consisting of **representative persons with dementia, their family members**, and others to hear the opinions of those representatives.

Effective date: Effective as of 1 January 2024, targeting results within five years from the date of enforcement.

Japan Dementia Working Group

Declaration of Hope for Living with Dementia

1

We will break free from the shell of common sense that has trapped us and go on living facing forward.

2

We will continue to live the lives we want to live, making the most of our abilities, and as members of society, we will take on challenges while enjoying ourselves.

3

We will meet each other, connect with each other, inspire the power of life, and go on living

4

While conveying our thoughts and hopes, we will find people in our local community who will become our allies, and we will walk together with them.

5

Making use of our experiences and ideas regarding living with dementia, we will work together to create a community where it is easy to live.

＊The Government's Dementia Policy Promotion Plan, based on the Basic Law, states that this Declaration of Hope is to be disseminated throughout the country.

- The Declaration of Hope for Living with Dementia was born out of each of us living with dementia putting our experiences and thoughts into words, bringing them together and overlapping them.
- We hope that as many people as possible will join us in making this declaration in order to live with dementia now and in the future.
- We sincerely hope that this Declaration of Hope will spread like a ripple and become a great swell towards the days of hope.
- We hope that you will join us in the towns where you live and across the country.

Kazuko Fujita, Representative Director,
Japan Dementia Working Group

We are developing the Relay of Hope project throughout Japan based on the Declaration of Hope for Living with Dementia.

the Japan Dementia Working Group
hope@jdwg.org♦http://www.jdwg.org
JDWG

Nov
2018.

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