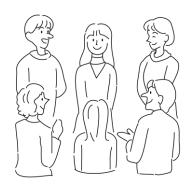
### Part 2. Talk session

with Kate and Japanese people with dementia

- What is needed to increase the participation of people living with dementia?
- $\sim$  Including expectations for an international network of people living with dementia  $\sim$





### 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.



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.



■ 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.



- 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 awarenessraising 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.'

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### 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!
- ♦ 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 lunchmaking 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.



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

# K

#### 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.



### 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



- 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!



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 r.tokyo@dcnet.gr.jp



	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
Г	Substay for electry fleath promotion project, etc. In 1 12024.
	Connecting the baton for people with dementia at home and abroad
	The 'Relay of Hone' International Forum 2025
	The 'Relay of Hope' International Forum 2025
	The 'Relay of Hope' International Forum 2025  ~Promoting an inclusive society by valuing the voice, power and connection

Tokyo Center for Dementia Care Research and Practice

14 February 2025.