

# Towards a Society in which Dementia Sufferers can live their Lives as they wish

As the aging of Japan's society advances, the number of dementia sufferers is increasing. Is modern Japan making the necessary preparations to allow these people to continue living their lives in the way that they wish? Urgent measures are required. In this issue of *My Vision*, we discuss what will be necessary.

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### Towards a society in which dementia sufferers can live their lives as they wish – What is the direction for a society that allows dignity to be maintained?

Yuri Okina

NIRA Executive Vice President / Chairperson of The Japan Research Institute, Limited

Keywords...Super-aged society, dementia, decline in sufferers' quality of life, effect on society and the economy, creation of a society in which we are able to coexist with dementia sufferers via cooperation across boundaries

## Expert Opinions

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Professor, Department of Neuropathology, Graduate School of Medicine, The University of Tokyo

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Director, AI Care Division, Care Tech Dept. Exawizards Inc.

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#### A society that learns from people with dementia

Tadamichi Shimogawara

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Keywords...Correct understanding of dementia, social tolerance, troubled, unhappy, rational consideration applied to the prevention of mistakes

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About this Issue

# Towards a Society in which Dementia Sufferers can live their Lives as they wish

– What is the Direction for a Society that allows Dignity to be maintained?



**Yuri Okina**

NIRA Executive Vice President /  
Chairperson of The Japan  
Research Institute, Limited

Five years from now, in 2025, all of Japan's baby boom generation will be aged over 75, and Japan will become a "super-aged" society. It is predicted that there will be 7 million dementia sufferers in Japan in 2025, and that following this the number will increase rapidly with the increase in the number of elderly citizens. If we do not consider as a society how to best respond to this situation, not only might the quality of life of dementia sufferers decline, but the ability of their family members to work may also be affected. In addition, the increase in the number of dementia sufferers will have a significant impact on Japan's society and economy, presenting a range of issues including the maintenance of the system of nursing care with shortages of staff, an increase in the number of traffic accidents, and the necessity of responding to the

immobilization of financial assets. The question of how to coexist with a rapidly increasing number of dementia sufferers will be an important one for the Japanese society of the future. In Japan, the importance of creating a society in which we are able to live together with dementia sufferers, through the efforts not merely of government ministries and agencies, local administrations and the medical community, but through cooperation between industry, government and academia across diverse fields, is recognized in growth strategies and the like, but concrete studies and practical measures will be tasks for the future. In this issue of *My Vision*, we canvas opinions from specialists in a range of fields who are working to address these issues regarding what they feel is lacking in current responses to the care of dementia sufferers, and how we should go about creating a society in which we are able to coexist with dementia sufferers.

## Potential for the Development of Drugs to treat Cognitive Decline

First of all, how does the medical community understand dementia? The view that it will be difficult to develop drugs to prevent or specifically target dementia is frequently expressed, but is this view correct? Leading off this issue, Professor Takeshi Iwatsubo of The University of Tokyo, who is noted for his research on dementia, informs us that Alzheimer's-type dementia is caused by the buildup of certain types of protein in the brain due to its aging. While emphasizing the difficulty of developing therapeutic drugs, Professor Iwatsubo also indicates the potential for the development of drugs to treat the cognitive decline associated with Alzheimer's in the near future. There is also some hope that administration of these drugs at an early stage may have a preventive effect. We must accept that dementia is a natural phenomenon associated with aging, and that we are all at risk of it. The development of drugs that target dementia is a task of the highest priority considering our future super-aged society, and policy support will be essential in this area.

In the developed nations, the movement to realize societies in which it is possible to coexist with dementia sufferers has expanded in recent years. Sweden's Dementia Forum X is arguably the most advanced movement in this direction. With strong support from Sweden's Queen Silvia, the Karolinska Institute (recognized as one of the world's most advanced centers of medical

research) is supplying a diverse range of evidence-based findings regarding dementia sufferers, and industry-government-academia cooperation is being mobilized in order to create an environment in which dementia patients are readily able to live independent lives. An example of efforts in this area are initiatives by the Swedish furniture manufacturer Ikea to contribute to the realization of housing that is easier for the elderly to live in. In this issue, Sweden's ambassador to Japan, H.E. Pereric Högberg, describes the spirit of these measures as being a belief that people with dementia have a right to support. These measures treat dementia sufferers with respect, and provide support for their families. The spirit of Sweden's approach is being realized in the national rollout next year of an initiative in which, as H.E. Högberg states, "If a dementia sufferer has no family and no-one to rely on, then the local authorities will step in and support that person in their daily life". This is an initiative which Japan should study very attentively.

## **Towards a Society that respects the Intentions and the Desires of the Individual**

One concrete issue that dementia sufferers face is how to manage their assets in order to finance their lives. In Japan, the assets held by elderly citizens with dementia exceeds 100 trillion yen, and the immobilization of these funds represents a huge loss for the Japanese economy. In this issue, Professor Kohei Komamura of Keio University proposes that we should create more "dementia-friendly" social mechanisms, which would assist the decision-making processes of dementia sufferers, throughout society as a whole. Professor Komamura also points out that in Japan, support for dementia sufferers in the "grey zone" is particularly lagging behind. Initiatives such as those undertaken by certain British banks, in which the accounts of dementia sufferers are protected by voice recognition even if they forget their passwords, are richly suggestive for Japan.

Exawizards, Inc. is a company that is similarly applying technical innovations, this time at the site of nursing care. Mr. Tomoaki Maekawa, Director of the company's AI Care Division, points out that in many cases carers are too busy to devote time to improving their caring skills. Realizing the more widespread use of "templates" for high-quality nursing care will be an important factor in reducing the burden on carers. In addition to conducting training throughout the country, Exawizards is engaged in the development of applications that make it possible to provide instruction to carers from remote locations using AI. In the future, the company is also seeking to enable the details of care to be changed in response to the behavior of the specific patient, and is collecting data in order to make this a reality. It may be the case that technological innovation in the form of data and AI will be the key to the solution of a range of issues affecting the provision of care.

Mr. Tadamichi Shimogawara, President of Silverwood Co., Ltd., a company that provides housing facilities for dementia sufferers, tells us that it will be necessary for us to create a tolerant society that allows those with dementia to make mistakes. At the senior living facilities managed by his company, residents who so desire are able to be independent, perform jobs, and live vital lives. We can consider the idea of seeking to realize a society in which the intentions and desires of the elderly are respected to be the foundation of the creation of a society in which we coexist with dementia sufferers. The opinion that we should transform the system of paid nursing care into a paradigm that promotes self-reliance has long been bruited. It is time for the government to take such proposals from the frontline of care as seriously as they deserve.

Dr. Okina is an Executive Vice President of NIRA and the Chairperson of the Japan Research Institute (JRI). She holds a Ph.D. in economics from Kyoto University. She holds numerous public offices, including as a member of the Ministry of Economy, Trade and Industry's Industrial Structure Council.

# Working towards the Preventive Treatment of Dementia



**Takeshi Iwatsubo**

Professor, Department of  
Neuropathology, Graduate  
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The greatest risk factor for the development of Alzheimer's disease, which accounts for the majority of dementia, is the aging of the brain. As the brain ages, amyloid- $\beta$  proteins are prone to accumulate in the brain, and become triggers for disease. It is believed that these pathogenic proteins accumulate in the brain causing nerve cells to die. The brain atrophies, resulting in Alzheimer's disease.

Research is being conducted throughout the world towards the development of antibody drugs that will bond with amyloid- $\beta$  proteins and promote their elimination from the brain. If such drugs can be developed, they will represent a fundamental treatment modality that acts directly on the mechanism causing the death of nerve cells. However, the development of such drugs has faced difficulties to date. Despite the fact that it has been possible to reduce amyloid- $\beta$  proteins, we have not been able to

develop drugs that are effective in relation to core cognitive functions. Against this background, a new drug called aducanumab displayed an effect on cognitive decline in tests conducted by fall 2019, and is attracting attention as potentially the world's first therapeutic drug for Alzheimer's disease. Whether or not this drug will be approved will be determined by examinations conducted throughout this year by regulatory authorities in the US and elsewhere.

My own focus is on preventive treatment. The symptoms of Alzheimer's first appear when the number of nerve cells has been reduced to the point that the brain can no longer compensate for the decline in number. At this point, the loss of nerve cells is already irreversible. Following the commencement of accumulation of amyloid- $\beta$  proteins in the brain, cognitive function will not be impaired for between 10 to 15 years. If it was possible to halt the accumulation of amyloid- $\beta$  proteins within this period through the application of medication or by some other means, we could slow down the loss of nerve cells before it reached a critical level, and realize prevention of the disease to some extent.

In the western nations also, the most advanced researchers are beginning to consider that we should make serious efforts to develop preventive treatments. In order to develop new drugs, it will first be necessary to conduct clinical trials with subjects who are asymptomatic but whose brains have begun to change. However, precisely because they are at the stage at which symptoms have not yet appeared, it is difficult to find such test subjects. Given this, we have decided to call for research volunteers in order to find appropriate candidates for trials. We commenced the "Trial-Ready Cohort" (J-TRC)\* Project in fall 2019. This project calls for healthy individuals between the ages of 50 and 85 to take part in clinical trials. It is estimated that in 2025, there will be 7.3 million dementia sufferers in Japan. I want to devote my full energies to the realization of a future in which we are able to prevent this disease.

(\* ) See <https://www.j-trc.org>

Professor Iwatsubo conducts research on the pathogenic mechanisms of Alzheimer's disease and Parkinson's disease, attempting to develop fundamental therapeutic drugs. Following his graduation from The University of Tokyo's Faculty of Medicine and his taking of the degree of Doctor of Medicine, he entered the university's Department of Neurology. Professor Iwatsubo took his present position in 2007, following a period as a professor in the university's Graduate School of Pharmaceutical Sciences. Since 2011, he has also been Director of The University of Tokyo Hospital's Unit for Early and Exploratory Clinical Department. Professor Iwatsubo holds numerous public positions as a member of government committees, etc. The J-TRC, which the professor serves as a research representative, is Japan's largest project for the online recruitment of research participants, and is seeking to develop preventive drugs for dementia. Professor Iwatsubo's Tokyo University team forms the core of his research activities, but his research is also being advanced in collaboration with academic societies, medical research institutes throughout Japan, pharmaceutical companies, and relevant parties in other countries.

# You are not Alone



**Pereric Högberg**

Ambassador of Sweden to Japan

In both Japan and Sweden, our average ages have gone up, and there are large numbers of elderly people. Sweden has a population of 10 million, of which about 160,000 people are living with dementia. The government has invested resources and funds to increase the staff involved in care for older people. If a dementia sufferer has no family and no-one to rely on, then the local authorities will step in and support that person in their daily life, taking care of everything from housing, hygiene, and shopping, to financial and asset management. In the coming year, the government plans to adopt a more comprehensive approach to dementia care, ensuring that people with dementia are offered the right support and the

right interventions across the whole country.

In Sweden, such conditions as handicaps and HIV/AIDS and other sexually transmitted diseases have been regarded as stigmas. Dementia has also been stigmatized. The government provides a variety of forms of support for dementia care, but if there are still cases in which dementia patients disappear from society and it becomes the business of the family to look after them, then the situation must be changed. The importance of Dementia Forum X, which I will discuss here, basically lay in making it possible to talk about dementia as a natural part of life.

Dementia Forum X is a non-governmental conference concerning dementia which has been held in Sweden since 2015. In 2018, the 150th anniversary of the establishment of diplomatic relations between Sweden and Japan, it was also held in Tokyo. The Forum was founded by private organizations including the Forum for Elderly Care, the Swedish Care International, and the Silviahemmet Foundation, and is operated by the Karolinska Institute. It is attended by experts and stakeholders from diverse sectors, including representatives of support organizations, government officials and researchers from various nations, representatives of international organizations such as the WHO and the OECD, and world-leading business executives.

The involvement of social role models in the Forum sends the message that dementia is not a stigma that should be hidden, but rather something that should be spoken about openly. You are not alone, and you have the right to receive support. The fact that Queen Silvia, whose mother has dementia, has supported the activities of the Forum, has been a major driving force for realizing change in social awareness. We must create a society in which dementia sufferers are treated with respect, and in which their families receive support.

Ambassador Hogberg was appointed Sweden's ambassador to Japan in fall 2019. He has served in positions including as First Secretary of the Embassy of Sweden in South Africa, Director of the International Division of the Swedish Arts Council, Director of the Africa Department of the Swedish Ministry for Foreign Affairs, and as Sweden's Ambassador to Japan. Sweden established national guidelines for dementia care in 2010. In addition to setting forth the principle of "Person-centered care," which emphasizes taking the perspective of the person with dementia, the Guidelines define methods of care that are recommended and methods that are not, based on evidence, provide appropriate indicators of quality and effectiveness, and indicate expected results.

## Make Finance and Other Social Systems “Dementia-friendly”



**Kohei Komamura**

Director, Institute for Economic  
Studies Research Center for  
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Currently, it is estimated that one person in four people over the age of 75 in Japan has dementia. Issues related to money and financing, including medical and nursing care, housing, asset management, business succession, and inheritance cluster in the second half of life. These are issues regarding which it is difficult to make decisions even if one does not have dementia. 25% of the balance of household assets in Japan is in the hands of people aged over 75. A simple estimate indicates that more than 100 trillion yen of these assets are possessed by individuals suffering from dementia. Who will provide support for these dementia sufferers in possession of significant assets, and how will they do so? It is important for each individual to prepare early, but there are limits to this. It will be essential for financial institutions and society as a whole to create new systems, environments and business models in order to support decision-making by the elderly.

An Adult Guardianship System is available for individuals who are no longer able to make rational decisions due to the progression of their dementia. However, this system does not provide support for individuals in the “grey zone,” the period in which neither they nor the people around them are certain that they have dementia. Our ability to make judgments regarding our economic activities changes as we age, reaching its peak in our 40s and 50s. Following this, with the slow decline in our cognitive abilities, it becomes more difficult to compare and examine complex alternatives, and we can become over-confident, placing too much trust in our own abilities. In addition, it has been scientifically proven that our decision-making is more readily affected by other people’s explanations as we age. It will be important for financial institutions to determine the level of ability to make judgments possessed by individuals using banking services. Additionally, rigorous ethical standards will be essential to ensure that financial institutions do not engage in transactions that take advantage of a decline in the ability to make decisions among their customers.

The Adult Guardianship System protects and supports people with insufficient powers of judgment, but it also restricts the rights of the individuals subject to the system to make decisions. Financial institutions will currently freeze the accounts of individuals diagnosed with dementia, but this is merely a measure for the avoidance of lawsuits and other claims against them. What would be desirable, rather, is a more friendly society that respects the will of the individual even if they have dementia. In Britain, some banks make it possible to protect accounts by voice recognition even if the account holder has forgotten their password. Taking into consideration the remaining ability of the individual to make decisions, they are making efforts to provide support in order to enable dementia sufferers to use their services despite the decline in their cognitive abilities. It will be essential to provide support that is not restricted to bank withdrawals, but which spans the entire range of economic activities, including, in addition to arrangements for medical and nursing care, the arrangement of non-insurance-related services such as support for daily life.

Professor Komamura researches reform of the social security system in societies with declining birthrates and aging populations. He graduated from Keio University’s Graduate School of Economics, and holds a Ph.D. in economics. He has been a Professor in Keio University’s Faculty of Economics since 2007, following periods as a researcher at the National Institute of Population and Social Security Research and a Professor at Toyo University. The Research Center for Financial Gerontology was established in 2016. The research conducted by the Center incorporates results from gerontology, cognitive science and brain and neuroscience in order to study the social problems caused by decline in cognitive ability. Professor Komamura holds numerous public positions, including as a member of the Social Security Council and the Working Group on Financial Markets of the Financial Services Agency’s Financial System Council.

Expert Opinions

## Increasing the Number of Providers of High-quality Dementia Care through Humanitude and Remote Care Coaching



**Tomoaki Maekawa**

Director, AI Care Division, Care Tech Dept., Exawizards Inc.

Dementia is a social issue that it will not be possible to avoid in our future super-aged society. In response to this issue, Exawizards Inc. is utilizing technology in order to expand the use of “templates” for the provision of high-quality care. In many cases, caregivers are extremely busy providing care, and they do not have the time to devote to improving their care skills. While they may provide care in their own fashion, this may not produce the appropriate results. The provision of a “template” can sometimes be surprisingly effective. Our goal is to offer a platform that teaches better approaches to care, in order to increase the number of providers of high-quality care in the community.

What we focused on first was a method of communication known as “Humanitude,” which emerged from France. Humanitude makes the purpose of care the creation of a good relationship between the caregiver and the recipient of care by means of communication. The method is employed in a wide range of fields of nursing care, and is effective in cases of dementia. Exawizards conducts training in Humanitude throughout the country, and we are also working in cooperation with local governments to verify the effect of introduction of the method. For example, in the case of an initiative conducted with Fukuoka City, it was shown that two hours of training for family caregivers resulted in a 30% reduction in the burden on caregivers one month after the training.

There is a limit to the “templates” that can be provided using this Humanitude training alone. Because of this, we have also started offering a video communication (remote care coaching) application called “Care Coaching,” which utilizes AI. Using this application, caregivers video actual scenes of care in the location in which it is provided, and veteran staff and specialists in remote locations are able to check the details of care and make comments. The application is used not only for care, but also to allow easy sharing of any items that need to be reported. We intend to further evolve the application. For example, by employing AI to analyze the video data accumulated in the application, we will enable the AI to provide care guidance itself, and by analyzing specific video scenes, we will make the application easier for users to employ.

Another of the goals of the Care Tech Dept. is to provide support for changing the details of care depending on the context of the behavior of the recipient of care. With the help of sufferers of dementia, we aim to create a database that will allow us to understand the context behind specific behaviors, and to link this understanding with the details of care. We seek to increase the quality of care across the care industry by creating a database that can be utilized by any division of the industry.

Mr. Maekawa is the Director of Exawizards Inc.’s Care Tech Dept. Established in 2016, Exawizards is a company that promotes industrial innovation and the solution of social problems through the development of services utilizing AI. The Care Tech Dept. seeks to apply technology in order to realize a society in which people are able to receive care with peace of mind in any part of the country, allowing them to grow old in good health. Among its other projects, the Care Tech Dept. is also conducting gait analysis and developing AI to visualize the impact of actual care on controlling the future need for nursing care. Mr. Maekawa completed the Tokyo Institute of Technology’s specialized course in Mechanical and Intelligent Systems Engineering. He took his present position in 2019, following periods of employment with Sony Corporation and the Boston Consulting Group.

# A Society that learns from People with Dementia



**Tadamichi Shimogawara**

President, Silverwood Co., Ltd.

When they hear the word “dementia,” people who do not possess a correct understanding of the condition exclusively imagine severe symptoms due to progressive atrophy of the brain. What happens as a result is that both society at large and the individual’s family sees that individual only as “a person with dementia.” And then they steadily rob that person even of things that they are able to do before it is necessary – “Don’t carry a wallet,” “Don’t go out,” etc. But there are numerous things that many sufferers of dementia are still able to do, and they can lead enjoyable lives. Of course, they will sometimes make mistakes. The important thing is for society to have tolerance for mistakes caused by dementia. The concept here is that we learn this tolerance from people with dementia.

I developed a virtual reality (VR) apparatus in order to enable the people around dementia sufferers to understand what type of world they lived in, and what it was that troubled them. We have provided this vicarious experience of the feelings of dementia sufferers to 60,000 family members, personnel of medical institutions, and representatives of companies and local governments. Everyone has said that it touched a deep chord within them and allowed them to really feel the emotional state of dementia sufferers. The thing that I most want them to become aware of is the fact that dementia sufferers are innately confused and troubled. Say that you have taken your usual train, but suddenly you do not know the station at which you should get off. It is difficult for others to understand the fear felt by the dementia sufferer when the world that has previously been taken for granted becomes uncertain. They might ask their family numerous times whether they have eaten lunch. It is not that they wish to cause anyone trouble. But despite the fact that it is the person who is forgetting who is most troubled, it is they who others become angry at. How many times have I heard “Why do they get so angry at me, it makes me so unhappy.”

The senior living facilities operated by Silverwood Co., Ltd. may be described as senior living facilities with an option for work. If we include cases of Mild Cognitive Impairment (MCI), 90% of our residents have dementia. Nevertheless, any resident who wishes to is able to work at the restaurants or the candy stores in the facilities. If the work is divided up according to ability, even people with dementia are able to perform it adequately. Sometimes one of our residents goes missing, but in these cases everyone goes looking for them. It is not our role to feed anxiety on the part of someone who may make a mistake, but rather to be tolerant, and to engage in rational consideration in order to ensure that our elderly workers do not make mistakes. It is my hope that businesses that incorporate welfare-related elements of this type will be further developed, enabling us to create a society and systems that respect the intentions and desires of the elderly, whether they have dementia or not. While the government is talking about measures to support self-reliance, in actual fact the system remains one in which more nursing care equals more profits for the operator. This system that ensures that remuneration will accrue in proportion to the degree of nursing care must itself be reformed.

Mr. Shimogawara is the President of Silverwood Co., Ltd., a company that he founded in 2000 to work in the field of thin and lightweight steel beams. When his company began receiving orders for the construction of housing for seniors, Mr. Shimogawara was inspired to commence the design and development of senior living facilities. Silverwood manages the serviced senior living facilities “Gin·Moku·Sei,” which have grown to 12 branches. In addition to respecting the freedom and independence of residents, the high-quality interiors and superior architecture offer an elegant environment, ensuring their popularity. The “VR Dementia Experience” is a project inspired by the opinions and experiences of the residents of the Gin·Moku·Sei facilities. Mr. Shimogawara is a businessperson whose freedom of thought enables him to transcend the conventional frameworks of his industry. He also serves as the President of the Senior Housing Association.