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## Special Feature Article

### Self-stigma in the Context of Dementia

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#### Abstract

Important movements related to reducing self-/public stigma in the context of dementia after the year 2000 are summarized in this overview: 1) In 2004, the Japanese government changed the previous term of dementia "Chiho" to the present term "Ninchi-sho". After sixteen years of this symbolic decision, a recent survey revealed that over 70 percent of the family members of people living with dementia considered that the present term ("Ninchi-sho") caused them less discomfort than the previous one ("Chiho"). Effective educational strategies for reducing stigma in the context of dementia have been developed alongside this change of terminology. 2) There has been little evidence regarding proper self-stigma outcome measures for people with living with dementia. According to the recent review, the only scale is the self-stigma scale, which was previously tested quantitatively in populations living with dementia. Stigma scales from mental health appear not to be readily adapted for use with people with dementia. 3) Protest/social activism for people with dementia has progressed in these two decades. During the 2010s, personal activism of people with dementia had been organized gradually, and the Japan Dementia Working Group (JDWG) was founded in 2014 by people with living with dementia. In recent years, JDWG members' opinions are reflected in government policies related to dementia. In this context, I briefly mention the concept

of "dementia-friendly community". Although there has been progress, even today, self-/public stigma in the context of dementia remains to some extent in our society; therefore, accepting a diagnosis of dementia is still something that patients need courage to do. Our goal regarding reducing stigma in the context of dementia has not been completely achieved. The modern paradigm of "living together with dementia" continues to be our key concept.

**Keywords:** dementia, self-stigma, dementia friendly community

## Introduction

Trends to reduce the self-stigma and public stigma associated with dementia have been active since the 2000s. As an early symbolic achievement, the term "Chiho" for dementia was changed to "Ninchi-sho" in 2004.<sup>14)</sup> This name change was a semi-strategic administrative move, intended to dispel the dark image historically associated with the term "Chiho" and change the nature of "dementia" in society. From the following year, the concept of "mild cognitive impairment" began to be promoted and disseminated, and, at the same time, the importance of early diagnosis has been emphasized and educational activities have become more active. This paper will first discuss the pre-history of this name change, give a brief history of the change, and consider how much the name change has altered family perceptions, followed by a brief overview of the stigma attached to dementia in general in the subsequent

subsections. A movement even more important than the change in the name itself, in relation to self-stigma, is the "increased activity of people with dementia" since the 2000s. This trend is also related to the recent key concept of a "dementia-friendly community,"<sup>1)27)</sup> which will be discussed in the latter half of this paper.

## I. Pre-history of the Name Change from "Chiho" to "Ninchi-sho"<sup>10)11)</sup>

The term "Chiho (dementia)" may only create a negative image for the younger generation of psychiatrists, but I would like to explain the original intention behind this academic term. It was Shuzo Kure, the father of modern psychiatry in Japan, who officially introduced the name "Chiho" to psychiatry as an academic term.<sup>19)</sup> In 1909, in his book, "精神病ノ名義ニ就キテ," the term "Chiho" was used for the three diagnostic categories: "Souhatsu-sei-Chiho (i.e., "Praecox dementia" in

Germany, corresponding schizophrenia in modern category), “Roumou-sei-Chiho (i.e., senile dementia),” and “Mahi-sei-Chiho (i.e., paralytic dementia due to neurosyphilis)” in the classification of psychiatric disorders. Kure considered the negative image of the characters “癡 (mad)” and “狂 (crazy),” which had been used earlier, to be problematic, and selected and adopted “Chiho (dementia)” as a technical term in the medical field.<sup>9)</sup> It is considered that Kure did not intend “Chiho” to have negative connotations, but rather, he chose it as a softer expression than the other terms, and assigned it to the translation of “dementia.”

However, the image commonly created by the word “Chiho” was different from that of the medical term. Sekiya retrospectively examined the nuances of the word “Chiho” as used in general society from a sociological perspective, using newspaper articles archived from the Taisho era (1912-1926) to before the end of World War II.<sup>24)</sup> It should be pointed out that, at that time, the terms “Souhatsu-sei-Chiho (schizophrenia)” and “Mahi-sei-Chiho (paralytic dementia due to neurosyphilis)” were often used to refer to cases of criminal or deviant behavior, and the word “Chiho” in general society first reminded people of both of these two. Dementia in old age was described as “Roumou-sei-Chiho

(senile dementia)” at that time, and there were many reports of cases of elderly people who received police protection due to wandering caused by the disease. Compared with articles on “Souhatsu-sei-Chiho (schizophrenia)” and “Mahi-sei-Chiho (paralytic dementia due to neurosyphilis),” the tone of this article was milder. The concept of “Chiho (dementia)” as a social term was considered a mixture of these two, and this concept was spreading, incorporating many things that differ markedly from what is included in “senile dementia” today. It gradually took root as “dangerous” and “something with a negative impression.” By the 1960s, the number of new patients with Mahi-sei-Chiho (paralytic dementia) had decreased due to advances in treatment, and the public perception of “Chiho” changed to mean senile dementia. The popular image of “senile dementia” at this time was well-expressed in the description of an elderly man with dementia named “Shigezo” who appears in Sawako Ariyoshi's “Koukotsu no Hito (The Twilight Years)” (1972).<sup>2)</sup> “Shigezo” is almost never seen as a subject with a disease who reveals his feelings, but rather is depicted as a ‘frightening being’ who acts in ways that make no sense to those around him. By skillfully depicting the turmoil of surrounding people, Ariyoshi raises the issue of the

current state of “Chiho” in an aging society. The reaction to this work altered public opinion and led to the promotion of relevant measures and legislation.<sup>13)</sup>

## II. The Name Change in 2004 and Family Survey Report in 2020<sup>28)</sup>

Around the year 2000, the fact that the term “Chiho” made it difficult to conduct awareness-raising activities was reported, and there was growing momentum for the term be changed. In 2004, the three directors of the Center for Dementia Care Research and Practices submitted a request to the government to review the name “Chiho.” In the same year, the Ministry of Health, Labour and Welfare (MHLW) formed a “Study Group on a New Terminology to Replace ‘Chiho’ (hereinafter referred to as the Study Group on Terminology) to examine the name change through a review by experts and public solicitation. The committee discussed the issue four times, and decided to change the name from “Chiho (dementia)” to “Ninchi-sho (progressive cognitive decline)” on December 24 of the same year.<sup>14)</sup> Unfortunately, the terminology review meeting in 2004 did not provide an opportunity for people with dementia to directly express their opinions. As one of the activities of people with dementia, a video interview with Christine Bryden, a well-known person with dementia,<sup>3)</sup>

who had already begun actively communicating from Australia to the world, was presented as “reference material” by Dr. Kazuo Hasegawa, a member of the Terminology Committee.<sup>14)</sup> As described below, it has become routine these days to reflect the will of people with dementia in measures, but at that time, the idea of involving those people in the decision-making process did not exist.

Regarding awareness of the name and subsequent changes, the results of a public awareness survey conducted in 2004 as part of the activities of the Terminology Committee and a survey on the awareness of the name “Ninchi-sho” conducted in 2020 among family members of persons with dementia<sup>28)</sup> are presented below. In 2004, the Terminology Committee examined the public's opinion on the term “Chiho” in terms of: (i) general terminology and administrative terms, and (ii) usage as a diagnosis and disease name, and asked the respondents whether they felt offended or contemptuous by the term “Chiho.” The results showed that 56% of the respondents answered “yes” and 37% “no” to (i), and 49% “yes” and 44% “no” to (ii). In a cross-sectional study conducted in 2020 by Yamanaka, K. et al. on “Family Perspectives of People with Dementia” on the name change, 72% of family members answered that “Ninchi-sho” was less offensive than

“Chiho.” However, 13% said they felt that “Ninchi-sho” was discriminatory.<sup>28)</sup> The study analyzed the concepts that make up emotions, and identified “reluctance to be open with others” as a factor that causes negative feelings toward the term “Ninchi-sho.” This hesitancy is considered to be caused by public stigma related to dementia. The results of this study are important as they show both that the name change had a certain effect in reducing stigma, and that the current situation cannot be improved by the change alone.

### III. The Concept of Stigma Surrounding People with Dementia

Regarding dementia, as in other mental disorders, the presence of stigma has been found to be a factor that hinders a patient's behavior to receive treatment, desire for assistance after diagnosis, and willingness to participate in research.<sup>25)</sup> The two-path model<sup>7)12)</sup> showing the three dimensions to public stigma of mental illness: respective associations among “cognition,” “emotion,” and “behavior,” is shown in Figure 1. This model is also applicable to dementia. As an example of the path model shown in column B of Figure 1, cases influenced by fragmentary and biased information, such as “cases showing easy anger and violence” or “family members having trouble dealing with wandering,” which are perceived

as “dangerous” and generate feelings of “fear,” result in negative behaviors such as “avoidance of contact” and “suppression.” Tokuda<sup>27)</sup> stated that his experience of reporting on dementia while working for a broadcasting station made him keenly aware of how people have a distorted and fictional image of “those with dementia,” and how different this image is from their actual condition (Table 1). Even more troublesome than ignorance are the fictional images that arise from biased knowledge and the stigma that is formed from them.

Meta-analyses of public stigma amelioration and intervention have shown that education, interpersonal interaction with people with dementia (contact), and social movements and appeals (protest/social activism) by people with dementia themselves are effective.<sup>8)</sup> As a movement related to education among these three aspects of dementia, the Ministry of Health, Labour and Welfare (MHLW)-led “10-year project to understand dementia and build communities” was launched in the year following the name change in 2004.<sup>15)</sup> (Table 2) One of the main goals of the project was to “train 1 million dementia supporters”; as of October 2021, more than 13 million people had taken training courses, far exceeding the initial target.<sup>6)</sup> Regarding contact, one example is the “Dementia

Cafe,” which was first introduced in the “Five-year Plan to Promote Dementia Policies (Orange Plan)” formulated in 2012.<sup>16)</sup> Dementia cafes are places where people with dementia and their families gather with local residents and professionals to exchange information through talks and lectures. The “Comprehensive Strategy to Accelerate Dementia Measures” formulated (New Orange Plan) in 2015 set a goal for dementia cafes to be placed in each municipal municipality; as of 2017, 1,265 of the 1,747 municipal municipalities (72%) nationwide had completed their establishment.<sup>17)</sup> However, it is difficult to say that enhancing the number of dementia supporters and dementia cafes is the essential goal to be achieved, and the issue is how to promote their qualitative maturation. As for protest/social activism, the history of activities of people with dementia will be discussed in the next section, but it is important to consider “how they perceive stigma, the degree of self-stigma they already harbor, and how it is being resolved.” (Figure 2)

There is very little evidence regarding the appropriateness of self-stigma assessment methods in dementia. According to a 2020 systematic review,<sup>22)</sup> there were only nine studies worth reviewing in both quantitative and qualitative categories, including

only two longitudinal studies by the same group in the United States that included quantitative studies.<sup>4)5)</sup> The study used a self-administered questionnaire, the modified Stigma Impact Score (SIS), which scores “quality of life,” “family relationships,” “social contact,” and “self-esteem” on a scale of 0 to 10 (zero to maximum impact) and assesses four stigmas: (i) economic instability, (ii) social rejection (iii) internalized shame, and (iv) social isolation. The results showed that the stigma perceived by the patients and their families did not decrease over 18 months and four measurements.<sup>22)</sup> However, a qualitative study of self-stigma in dementia identified “fear, frustration, anger, sadness, self-doubt, and depression” as the most common emotions felt by patients, and “negative thoughts, fear, guilt, distress, bewilderment, and embarrassment” were reported by family members who provide care. The presence of “anxiety” causes rejection, disengagement from society, and delays in assistance-seeking by people with dementia. Overall, similar to what has been conventionally pointed out in psychiatric disorders regarding internalized stigma, a review of dementia also indicates that psychological factors (perception of public stigma, self-esteem) have a stronger influence on the formation of

self-stigma than sociodemographic factors.<sup>22)</sup>

#### IV. Increased Activities of People with Dementia and Dawn of "Dementia-friendly Society" (Table 2)

The changes in administrative policies since the alteration in the term "dementia" to the present day can be said to have strengthened the attitude of reflecting the voices of people with dementia in the policies on an annual basis. As shown in Table 2, in 2005, the "One Year to Know Dementia" and "Ten Years to Know Dementia and Create a Community"<sup>15)</sup> were launched, with the two main objectives of promoting an accurate understanding of dementia and creating a community where people with dementia can live with peace of mind. In 2012, the Project Team for the Study of Dementia Policies formulated the "Orange Plan," and one of the goals of the plan was to establish care services to enable people with dementia to continue living in the community and at home, instead of the former path of isolating people from society and living mainly in medical institutions and facilities.<sup>16)</sup> The New Orange Plan formulated in 2015 emphasized the promotion of measures that emphasize the perspectives of people with dementia and their families, and several ministries and agencies were involved in its formulation.<sup>17)</sup> In 2019,

the new plan was succeeded by the current "Framework for promoting dementia care," which has two major concepts of "prevention and symbiosis."<sup>18)</sup> These measures have been accompanied by increased activities of people with dementia. According to the book<sup>23)</sup> by Masahiko Sato, who continues to lead activities of people with dementia, he began talking with other people with dementia in 2007, two years after he was diagnosed, and after subsequent lecture activities, he participated in the Ministry of Health, Labour and Welfare's "Opinion Exchange Meeting to Promote Measures for Juvenile Dementia" in 2009. In 2013, the importance of the role of policy in reducing stigma was discussed at the World Psychiatric Association's Anti-Stigma Subcommittee, and around the same time, the NPO "Association of People with Dementia" (established in 2012), which includes him, advocated the need for support systems that facilitate self-reporting for people with dementia, in order to revise the Road Traffic Law. These meaningful actions resonated with Kazuko Fujita, Shigenobu Nakamura, and others, leading to the establishment of the Japan Dementia Working Group (now the Japan Dementia Working Group [JDWG]), a national organization of people with dementia, in 2014. In recent years,

JDWG's recommendations and the participation of its members have become part of the policy-making process (e.g., JDWG presented the views of its members to the Ministry of Health, Labour and Welfare when formulating the New Orange Plan; JDWG Representative Director Fujita and others attended the "Experts' Meeting to Promote Dementia Policy" that preceded the formulation of the National Outline for Dementia Policy Promotion. In June 2021, JDWG submitted "Expectations and Requests for a Basic Law to Realize a Dementia-symbiotic Society" to the Diet Members Caucus for the Promotion of Dementia Policies, a cross-party organization for realizing a symbiotic society.<sup>20)</sup> Such activities constitute protests/social activism, as described in the previous section, and are important from the perspective of reducing stigma.

With the increased activities of people with dementia, the concept of a "dementia-friendly community" has been attracting attention in recent years, in which the social phenomenon of "dementia" is viewed from a community model, breaking away from the medical and care models.<sup>1)27)</sup> It is a social concept in which people with dementia themselves are the main actors, unlike the traditional structure of "those without dementia reaching out to those with dementia." Needless to say,

the prevalence of dementia increases with age, and dementia is a social phenomenon with the perspective that "anyone can eventually become a sufferer." Thus, the relationship between people with dementia and those without dementia is not fixed, and dementia patients can be described as "having a continuous or horizontal relationship on a time axis. This aspect is a unique characteristic of dementia compared with other mental disorders, and may be a clue to reducing stigma. The concept of a "dementia-friendly community" is based on the idea that all people who participate in society should understand the issues surrounding dementia, and that all sectors, not just the medical care industry or specific ministries and agencies, should proactively participate in building a user-friendly society adapted to the lives of people with dementia. (Table 3) Although specific case studies have been omitted from this report for reasons of space limitation, examples from Japan and overseas are introduced in Takehito Tokuda's book for the general public: "Dementia-friendly community."<sup>27)</sup>

## Conclusion

Tomofumi Tanno, a leading figure in activities for people with dementia in Japan, wrote in "Tomofumi Tanno: Living with Dementia with a Smile"<sup>26)</sup>

about the psychological resistance he faced immediately after his diagnosis:

“I think everyone with dementia and their family members feel this way, but it takes a lot of courage to talk to others about the disease of dementia; but think about it, why is it so difficult to talk about dementia? Why do we feel embarrassed? If you have a cold or the flu, you can laugh about it, but dementia requires courage to even openly talk about the disease. I think this is because there is a prejudice against dementia.”

“I took the plunge and opened up about my illness. As a result, I rarely feel prejudiced by being open about it, and on the contrary, many supportive people have come to me. From this experience, I came to this conclusion: ‘Prejudice is within ourselves.’”

As outlined in this article, there has been progress in reducing the public stigma and self-stigma associated with dementia, but “being open about dementia” is still not easy, as can be noted in Tanno's early struggles. One of the challenges related to assistance-seeking before and after a dementia diagnosis is the existence of a time lag, called the “blank period”<sup>21)</sup> (i.e., two delay periods): (i) the period between the time a person becomes concerned or uncomfortable about dementia and the

time they receive a diagnosis, and (ii) the time between the diagnosis and start of long-term care insurance services. However, a common underlying factor is the “hesitation” that prevents self-determination, and there is no doubt that stigma is related. As the system matures, it is hoped that the concept of “symbiosis” described in the 2019 Framework for promoting dementia care will spread even more strongly in the future as a “substantive activity” that everyone can experience on a daily basis.

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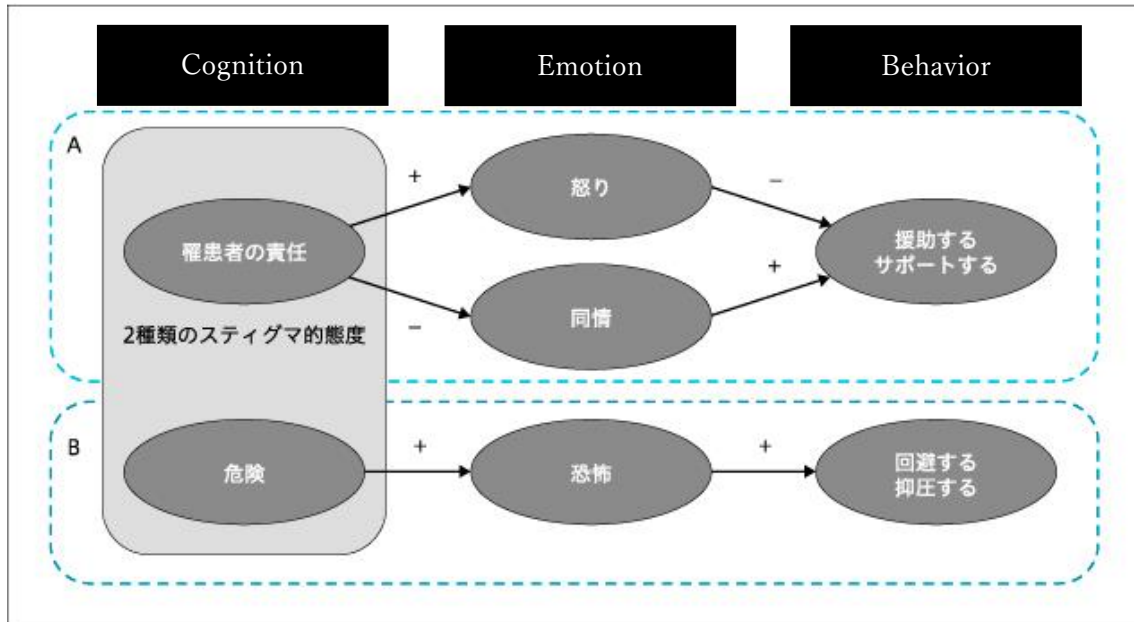


図1 スティグマ三次元（認知・感情・行動）間の関連を示すパスモデル

A：支援モデル，B：回避モデル。（文献7，12をもとに著者が作成）

Figure 1 Path model showing the relationships among the three dimensions of stigma (cognition, emotion, and behavior).

A: Support model, B: Avoidance model. (Prepared by the author based on references 7 and 12)

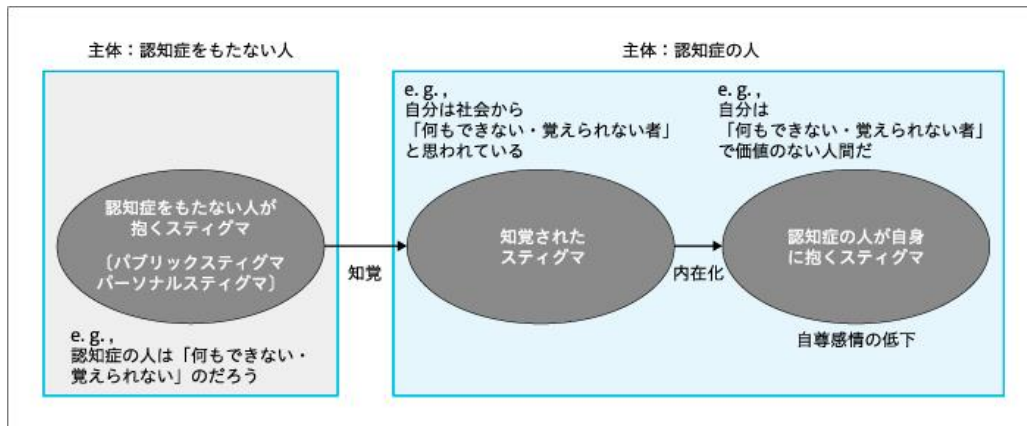


図2 認知症の人をめぐるスティグマ概念  
(文献 12 をもとに著者が作成)

Figure 2 Conceptualized image of stigma against people with dementia.  
(Prepared by the author based on ref. 12)

表 1 認知症の人の“虚構のイメージ”と「実際」の乖離

“虚構のイメージ”	実際
認知症かどうかは、1か0か境界は明確	認知症かどうかは連続的
認知症になると何もわからなくなる	変化を一番自覚しているのは本人
認知症の人には単一の行動パターンがある	行動は多様
多くが介護施設に暮らしている	多くが在宅生活、まちで暮らしている
医師などの専門家が答えを知っている	課題を独力で解決できる専門家はいない

(文献 27 をもとに著者が作成)

Table 1 Discrepancy between “Fictional image” and “Reality” of people with dementia

“Fictional image”

Dementia or not, the boundary is as clear as 1 or 0

Dementia makes a person unable to understand anything

People with dementia have a single pattern of behavior

Many live in nursing homes

Doctors and other experts know the answers

Reality

Dementia is continuous

It is the patient himself/herself who is most aware of his/her changes

Behavior is diverse

Many live at home or in the community

No specialist can solve the problem on his/her own.

(Prepared by the author based on reference 27)

表 2 認知症当事者の活動や関連する施策等

1998年	豪州の当事者クリスティーン・ブライデン著 “Who will I be when I die?” が出版
2003年	上記ブライデン氏著書の邦訳『私は誰になっていくの?』出版
2004年	「痴呆」の用語廃止, 「認知症」への名称変更
2005年	「認知症を知り地域をつくる10ヵ年」の構想
2008年	「認知症の医療と生活の質を高める緊急プロジェクト」
2012年	「今後の認知症施策の方向性について」
2012年	「認知症施策推進5ヵ年計画(オレンジプラン)」
2012年	国際アルツハイマー病学会 “Overcoming the Stigma of Dementia” (認知症に関連する偏見を克服するための10ヵ条提案)
2013年	佐藤雅彦氏, 第6回世界精神医学会アンチスティグマ分科会(東京)で講演
2013年	G8 認知症サミットが英国ロンドンで開催
2014年	認知症の人による全国組織「日本認知症ワーキンググループ」設立(現「日本認知症本人ワーキンググループ(JDWG)」)設立
2014年	認知症サミット日本後継イベント
2015年	「認知症施策推進総合戦略——認知症高齢者等にやさしい地域づくりに向けて——(新オレンジプラン)」
2018年	「認知症の人の日常生活・社会生活における意思決定支援ガイドライン」(厚生労働省)
2019年	「認知症施策推進大綱」(厚生労働省)
2019年	認知症未来共創ハブ
2021年	認知症共生社会を実現する基本法への期待と要望(JDWG)

(文献11をもとに著者が作成)

Table 2 Activities of people with dementia and related policies

1998

“Who will I be when I die?” written by Christine Bryden, an Australian dementia patient, was published.

2003

The Japanese edition of “Who will I be when I die?” written by Christine Bryden, an Australian dementia patient, was published.

2004

The term “Chiho” was abolished and a new term, “Ninchi-sho,” was adopted.

2005

“Ten-year Plan for Understanding Dementia and Building Communities

2008

Urgent project to improve medical care and quality of life for people with dementia

2012

“Future Direction of Dementia Policies” (in Japanese)

2012

Five-year Plan for the Promotion of Dementia Policies (Orange Plan)

2012

“Overcoming the Stigma of Dementia” (Ten Proposals to Overcome Dementia-related

Prejudices), International Alzheimer's Association

2013

Dr. Masahiko Sato, Lecture at the 6th World Psychiatric Association Anti-stigma Section Meeting, Tokyo, Japan

2013

G8 Dementia Summit held in London, UK

2014

Establishment of the Japan Dementia Working Group (now the Japan Dementia Working Group (JDWG)), a national organization of people with dementia

2014

Dementia Summit Japan successor event

2015

“Comprehensive Strategy to Accelerate Dementia Measures (New Orange Plan)”

2018

“Guidelines for Decision-making Support in Daily Life and Social Life for People with Dementia” (Ministry of Health, Labour and Welfare)

2019

“Framework for promoting dementia care” (Ministry of Health, Labour and Welfare)

2019

Dementia Future Co-creation Hub

2021

Expectations and Requests for the Basic Act for Realizing a Society in Harmony with Dementia (JDWG)

(Prepared by the author based on Reference 11)

表3 認知症フレンドリー社会と従来型の認知症対処社会

	認知症対処社会 (従来)	認知症フレンドリー社会 (現在～今後)
基本理念	社会的負担の軽減	誰もが普通に暮らせる社会の設計
活動の主体	専門家	当事者・家族・自治体・企業・福祉など
活動の内容	正しいケア 住民の啓発・活用 企業は社会貢献アプローチ	当事者と一緒に考える各セクターの挑戦 商品サービスの創出
成果指標	事件・事故や“問題行動”の減少 介護者の負担軽減	当事者のQOL 社会環境のフレンドリー度 当事者の声の反映度

(文献 27 をもとに著者作成)

Table 3 Dementia-friendly community and conventional dementia-coping society

Dementia-coping society (Conventional)

Dementia-friendly community (present - future)

Basic philosophy

Reduce social burden

Design a society where everyone can live normally

Actors

Experts,

People with dementia, family members, local governments, companies, welfare, etc.

Content of activities

Correct care, enlightenment and utilization of residents, approach of companies to social contribution

Challenges of each sector to think together with people with dementia, creation of products and services

Performance indicators

Reduction of incidents, accidents, and “problematic behaviors”, Reduction of caregiver burden

Quality of life, Degree of friendliness of social environment, Degree of reflection of caregivers' voices

(Prepared by the author based on reference 27)