

Dementia Policy for an Inclusive Society 2024

HGPI Recommendations on the Basic Plan on Dementia to Promote an Inclusive Society (Draft) and Basic Measures (Draft)

August 2024



HGPI Health and Global
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Introduction

Devoted efforts from all related parties have resulted in steady progress in Japan's dementia policy. Beginning with the establishment of the Long-Term Care Insurance System in 2000, emphasis has been placed on upholding the dignity of people living with dementia and their families, and based on the concept of the Integrated Community Care System, advances are also being made in multi-stakeholder cooperation, particularly that involving healthcare and long-term care. Japan's past dementia policies include the Five-Year Plan for the Promotion of Dementia Measures (the Orange Plan) of 2012; the Comprehensive Strategy to Accelerate Dementia Measures (the New Orange Plan) of 2015; and the National Framework for Promotion of Dementia Policies of 2019, which was Japan's first national dementia plan. Globally, rising life expectancies have made dementia measures an urgent issue for each country, and a major step forward was taken with the G8 Dementia Summit held in London in December 2013. That Summit led to the establishment of the World Dementia Council (WDC) and each nation has worked to develop policies for dementia in accordance with the G8 Declaration and Communiqué. In 2017, the World Health Organization (WHO) presented "Global action plan on the public health response to dementia 2017-2025," which also encouraged countries to formulate and advance policies for dementia. As we can see, there has been great momentum for dementia policy development in the international community in recent years. Now that we have overcome the COVID-19 pandemic, there are growing expectations for Japan to step once again into a leadership role in addressing dementia as a shared item on the global health agenda.

The year 2023 was a landmark year for dementia policy in Japan. Japan served as G7 President in 2023, marking one decade since the 2013 G8 Dementia Summit. To commemorate the G7 Health Ministers' Meeting in Nagasaki, a dementia symposium called "Collaboration in the International Community for Advancing Dementia Measures in a New Era" was held in May 2023 (with HGPI and WDC serving as supporting organizations). Then, the voices of civil society—namely, people living with dementia, their family members, and others close to them—played a major part in the development of dementia policy with the enactment of The Dementia Basic Act for an Inclusive Society (or, the Dementia Basic Act) on June 14, 2023.

The Government of Japan recently gathered public comments for the Basic Plan on Dementia to Promote an Inclusive Society, which will be Japan's first plan to be based on the Basic Act on Dementia. HGPI believes this Basic Plan will be crucial for providing a foundation for domestic dementia policies moving forward. The intent of these recommendations is to inform society of the content of the HGPI Dementia Policy Project's response to that call for public comments to provide society with policy options in the discussion on the Basic Plan on Dementia to Promote an Inclusive Society, which will soon come to a close, as well as in discussions on future versions of the Basic Plan.

Specific clauses and page numbers below are based on reference materials included in “Request for Opinions Regarding the Basic Plan on Dementia to Promote an Inclusive Society (Draft) and Basic Measures (Draft),” which was published on the “e-gov Public Comment” website on July 10, 2024.

URL : [https://public-comment.e-](https://public-comment.e-gov.go.jp/servlet/Public?CLASSNAME=PCMMSTDETAIL&id=495240094&Mode=0)

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Depending on the timing of the publication or viewing of this proposal, the source materials may not be verifiable in some cases.

Proposal regarding the Basic Plan on Dementia to Promote an Inclusive Society (Draft)

● The necessity to constantly review and update existing policies based on the "perception of dementia" in society

(Specific proposals)

- Regarding the 2nd point under "Promotion of an inclusive society" on Page 2, which states that "All efforts related to dementia policies are aimed at achieving this inclusive society...formulate, implement, and evaluate policies, and the national and local governments, etc." It is important to constantly review the already formulated policies based on the "new perspective on dementia". It is suggested to reword it as "formulate, implement, evaluate, review the policies in a timely and appropriate manner, and the national and local governments, etc."

- Regarding the 4th line on Page 7 "Treating formulation, implementation, and evaluation as a continuous process", it is suggested to reword it as "Treating formulation, implementation, evaluation, and review as a continuous process".

● The necessity to establish a permanent system to ensure the participation of people with dementia and their families in the policy-making process at the local government level

(Specific proposals)

- Regarding the 2nd priority goal on Page 12, the indicator "the number of local governments that reflect the opinions of people with dementia and their families in the planning of dementia policies" may be interpreted as merely requiring the reflection of opinions at least once, and the less discussed opinions may be intentionally selected. Instead of a temporary system of opinion gathering during the planning process, a permanent system to incorporate opinions is necessary. For this purpose, in addition to the 2nd indicator "the number of local governments that have listened to opinions", the indicators should be reorganized, and based on Arnstein's "Ladder of Participation", multifaceted and layered evaluation indicators are required, such as the methods used to listen and the participation status in expressing opinions. However, due to the lack of time to develop such indicators by the first plan, as a discussion topic for the future, it is suggested to use the indicator "the number of local governments that have established a permanent system to listen to the opinions of people with dementia and their families and to consider them in the discussion of policies and plans related to dementia" in the current plan, and to mention the future development of layered indicators regarding the manner of participation.

● **The importance of the voluntary and autonomous participation of stakeholders in research and clinical trials, and the necessity to initially focus on their involvement in the planning of such research and trials in the field of dementia that requires further discussion**

(Specific proposals)

• Regarding Priority Goal 4 on Page 14, the output indicator "the Number of people with dementia and their families who have participated in research and clinical trials" is insufficient, as participation in research and trials should be left to the voluntary and autonomous decision of the stakeholders, and as well as this, the level of discussion on research participation is not yet mature enough. Considering the incorporation in the second plan and beyond, it is suggested to use the process indicator "the Number of research and clinical trials in which people with dementia and their families have been involved in the planning, etc." as the output indicator for the current plan.

● **The necessity to incorporate the feedback from local governments, which are the foundations of the living environment for people with dementia and their families, in the review of the national basic plan**

(Specific proposals)

• Regarding "2. Review of the Basic Plan" on Page 17, it is suggested to include a statement emphasizing the consideration of feedback from local governments. Dementia policies are not limited to healthcare and long-term care, but broadly relate to various aspects of daily life. It is important to share and discuss the issues that have emerged through the discussions and policy implementation at the prefectural and municipal levels. Therefore, in addition to the second item where local governments modify the content based on the national basic plan, it is necessary to create opportunities and raise awareness for local governments to provide feedback to the national government.

Comments on the Basic Policy Measures (Draft)

The following are specific proposals regarding the "Basic Policy Measures (Draft)".

● Regarding the 2nd item under the title "1. Promotion of public understanding of people with dementia" and the subtitle (2) on Page 3, which states "Based on the formulation of the basic plan, etc., dementia supporters' activities will lead to helping people with dementia and their families". Considering the recent roles expected of dementia supporters, it is suggested to rephrase it as "dementia supporters' activities to help people with dementia and their families and to work together on community development will lead to helping them in a tangible way".

● Under the title "2. Promoting barrier-free lives for people with dementia", and the subtitle (5), on Page 7, the appropriate response training is limited to only public transportation operators, but there are other necessary businesses such as various retail businesses, so it may be appropriate to expand the scope to a certain extent.

- Regarding the 2nd item under the title "6. Establishment of a consultation system", and the subtitle (2), on Page 14, "the appropriate placement of dementia community support promoters", the expression should be "the appropriate placement of 'the' dementia community support promoters" for accuracy.
- Regarding the 3rd item under the title "7. Promotion of research", and the subtitle (1) , on Page 15, "Promote research leading to the elucidation of the pathology, diagnostic methods, and treatment methods of dementia such as Lewy body dementia, frontotemporal dementia, cerebral small vessel disease, and elderly tauopathy, whose pathology remains unknown", since the pathology of Alzheimer's disease, which accounts for the majority of dementia cases, is also not fully elucidated, it is suggested to rephrase it as "Promote research leading to the elucidation of the pathology, diagnostic methods, and treatment methods of not only Alzheimer's disease, but also Lewy body dementia, frontotemporal dementia, cerebral small vessel disease, and elderly tauopathy, whose pathology remains unknown".
- Regarding the 3rd item under the title "7. Promotion of research", and subtitle (2), on Page 16, "Disseminate indicators to verify and evaluate the effectiveness of technologies, services, and equipment related to dementia prevention and care", since rehabilitation to improve the functional impairment based on cognitive impairment is also important to promote social participation and employment support for people with dementia. Thus, it is suggested to rephrase it as "Disseminate indicators to verify and evaluate the effectiveness of technologies, services, and equipment related to dementia prevention, care, and rehabilitation".
- Regarding the 1st item under the title "7. Promotion of research", and subtitle (3), on Page 16, "Develop the research and clinical trial environment so that people with dementia and their families can actively participate in the research and clinical trials that they hope for", in order to promote participation in research and clinical trials, it is also necessary to disseminate and promote the necessary knowledge about the importance of research and clinical trials, so it is suggested to rephrase it as "Develop the research and clinical trial environment so that people with dementia and their families can deepen their understanding of the importance and necessary knowledge of research and clinical trials, and those who wish to do so can participate in them proactively".
- Regarding the 2nd item under the title "7. Promotion of research", and the subtitle (3), on Page 16, "While continuously promoting the development of registries and cohorts that serve as the foundation for dementia clinical research, including drug development and international collaboration, it is vital to further promote public-private partnerships between academia and private companies including pharmaceutical companies. Since the sustainability of registries and cohorts that have been long-term continued in other countries, such as the AIBL in Australia, BioFINDER in Sweden, and ADNI in the US, is important as the foundation for generating new knowledge, it is suggested to rephrase it as "While continuously promoting the development of sustainable registries and cohorts that serve as the foundation for dementia clinical research, including drug development and international collaboration, it is vital to further promote public-private partnerships between academia and private companies including pharmaceutical companies by utilizing ".

- Regarding the 1st item under the title "8. Risk reduction of dementia", and the subtitle (1) , on Page 18, "Along with the accumulation of scientific knowledge on the prevention of the progression of dementia/MCI, such as exercise habits, proper nutrition intake, psychological support, and social participation". Since prevention should encompass primary to tertiary prevention, it is suggested to rephrase it as "Along with the accumulation of scientific knowledge on the prevention of dementia/MCI, such as exercise habits, proper nutrition intake, psychological support, and social participation".
- Regarding the 1st item under the title OR subtitle "8. Risk reduction of dementia", and the subtitle (2) "Dementia prevention, etc." on Page 18, "Establish a support model that consistently provides early detection, early response, and post-diagnosis support", as the actual system built in each region will be greatly influenced by the resources available in that region., It is suggested to rephrase it as "Establish a support model that consistently provides early detection, early diagnosis, early response, and post-diagnosis support, and promote the implementation tailored to the local context ."
- Regarding the 2nd item under the title "8. Risk reduction of dementia", and the subtitle (2), on Page 18, "To promote early detection and early intervention, strengthen the collaboration between primary care physicians, community general support centers, and specialized medical institutions including dementia medical centers. To clarify the purpose, it is suggested to rephrase it as "To enhance early detection, early diagnosis, early response, and post-diagnosis support, strengthen the collaboration between primary care physicians, community general support centers, and specialized medical institutions including dementia medical centers in order to develop an integrated healthcare system that ensures seamless support from detection, diagnosis, and treatment to subsequent medical and life-related follow-up, respecting the individual's will".

Perspectives to be additionally incorporated into the plan and basic policies

- In this draft, the descriptions regarding the burden reduction for family caregivers are generally insufficient. It has been discussed that the burden reduction for family caregivers is an imperative element for the person with dementia to live a vibrant life, so it may be appropriate to clearly state this point.

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