

Health and Global Policy Institute (HGPI) Dementia Policy Project
Urgent Recommendations: Enact the Basic Act for Dementia to Reshape Perceptions
of Dementia
(September 27, 2022)

Introduction

Due to various circumstances including the Coronavirus Disease 2019 (COVID-19) pandemic, discussions have yet to conclude on the Basic Act for Dementia which was submitted to the Diet by representatives of the Liberal Democratic Party and Komeito in 2019. In 2021, a bipartisan Diet caucus called the Parliamentary Association for Promoting Dementia Policies for an Inclusive Society was established and discussions on the Basic Act for Dementia have now resumed. These urgent recommendations call for concrete discussions on revising the Basic Act for Dementia and ensuring it is enacted during the next ordinary session of the Diet in 2023.

It is estimated that over 6 million people in Japan currently live with dementia, and their number is projected to increase together with the rate of population aging. The estimated annual social cost of dementia in 2014 was 14.5 trillion yen (healthcare: 1.9 trillion yen; long-term care: 6.4 trillion yen; and informal care: 6.2 trillion yen). Given these circumstances, the social impacts around dementia are enormous, especially for people living with dementia and their families, and it is a very high priority policy issue. Although the priority of dementia as a policy issue was lowered temporarily as society grappled with the effects of the COVID-19 pandemic starting in late 2019, as a super-aging society, it was originally the top priority policy issue for Japan. Even more importantly, the parties most affected have expressed high expectations for the Basic Act for Dementia, and organizations representing people living with dementia or their families starting with the Japan Dementia Working Group (JDWG) and Alzheimer's Association Japan have issued proposals and statements calling for its enactment. Similar opinions have also been expressed by those in academia and industry. Health and Global Policy Institute (HGPI) has been advocating for the enactment of the Basic Act for Dementia for many years through activities that have included co-hosting the Diet Study Group on Dementia, organizing multiple symposiums, and presenting policy recommendations.

The outbreak of COVID-19 occurred shortly after the Basic Act for Dementia was submitted, and this may have had an effect on discussions. Discussions are now finally turning toward issues that we must face in a post-COVID-19 world. The time has come to return our focus to dementia as an issue of the highest priority. Although previously mentioned in policy recommendations presented by HGPI in July 2022 titled, "The Future of Dementia Policy 2022: Deepening Dementia Policies Centered on People Living with Dementia and their Families to Lead Global Society," as a country with advanced population aging and the host of the 2023 G7 Summit in Hiroshima, Japan must demonstrate leadership to the international community and guide discussions on dementia policy. To succeed in that, the Basic Act for Dementia must be enacted during the ordinary session of the Diet in 2023. In these recommendations, HGPI would like call for careful, non-partisan deliberations so an updated Basic Act for Dementia that is based on the opinions and latest discussions of people living with dementia and their families, related parties in healthcare and long-term care, representatives of academia, and other multi-stakeholders can be presented to and enacted by the Diet.

Why a Basic Act for Dementia is necessary

The Basic Act for Dementia is needed to fulfill two objectives: (1) shifting perceptions of dementia and (2) achieving an inclusive and dementia-friendly society. Starting with “Caring for Elderly People in 2015: Establishing Forms of Care that Uphold the Dignity of Elderly People,” a report from the Ministry of Health, Labour and Welfare (MHLW) published in 2003, policies for long-term care for elderly people and dementia measures have included clear mention that the dignity of people with dementia must be upheld and they should be respected as full members of society. To do so, it will be essential for us to escape or reshape the notion that “people with dementia lose their ability to understand anything” (which might be considered the “outdated perception of dementia”). This was already stated in discussions that took place in 2004, when the previous term for dementia was deemed derogatory and was revised to “ninchi-sho” (“Report of the MHLW Committee for Examining Affairs Concerning the Term ‘Chiho’”). A proposal published in June 2021 by the JDWG (which was established in 2017) titled “Expectations and Requests for the Basic Act to Realize an Inclusive and Dementia-Friendly Society” recommended that “outdated views on dementia should be left behind and a Basic Act should be enacted so an inclusive society filled with hope and energy can be created.” However, this vision has yet to be realized. The Basic Act for Dementia will lay the groundwork for all dementia policy moving forward, so it should clearly state that it aims to transform existing perceptions of dementia.

Accomplishing that will require a Basic Act for Dementia that emphasizes building an inclusive society. A bipartisan caucus of Diet Members established in 2021 with the name, “Parliamentary Association for Promoting Dementia Policies for an Inclusive Society,” which is also in line with that concept. The National Framework for Promotion of Dementia Policies adopted by the Government of Japan in 2019 also positions inclusion and prevention as two items to advance in parallel, but the prevention of dementia within dementia policy is only one step toward the goal of creating a society where people can lead lives that are true to themselves even if they develop dementia. As for HGPI, which advocates “citizen-centered health policy,” we believe a key element of building an inclusive society will be having participation from people with dementia and their families when formulating and promoting policy. Another important item to keep within our field of vision moving forward will be how to fully equip society with the latest diagnostic and therapeutic methods produced by advances in R&D to achieve health equity.

Transitioning from the current goal of attaining inclusion and prevention as outlined in the current National Framework for Promotion of Dementia Policies to the goals of implementing comprehensive and well-planned measures for building an inclusive society and shifting the direction of the government will require a law created by the Diet, which is the highest organ of national power and the sole legislative body of the Government of Japan. The Basic Act for Dementia is significant as a paradigm shift in dementia policy that will encourage a reshaping of how society perceives dementia while driving the creation of an inclusive society.

Recommendation 1: The Basic Act for Dementia should be centered on inclusion

1-1: Rather than “prevention,” the stated obligation of citizens should be to “Participate and cooperate in building an inclusive society”

In the current proposed version of the Basic Act for Dementia, the purpose of the provision for Article 1 states “promote prevention, etc.” while Article 8 obligates citizens to endeavor to “devote the necessary attention to the prevention of dementia.” As covered during debates on “inclusion and prevention” that occurred during the formulation of the National Framework for Promotion of Dementia Policies in 2019, the purpose of the Basic Act for Dementia and the obligations of citizens should be centered around “building an inclusive society.”

There are also high expectations that advances in medical research will make it possible to prevent dementia and its underlying causes. Additionally, the term “prevention” covers a broad range of actions. It includes “primary prevention,” which aims at risk reduction; “secondary prevention,” which aims to provide early interventions; and “tertiary prevention,” which emphasizes preventing progression and maintaining functions. These are all important from the perspective of building an inclusive society, as well. As such, sufficient resources must be invested in R&D, especially in dementia prevention and particularly for establishing evidence. However, the prevention of dementia is only one step toward the goal of building an inclusive society. The objective of the Basic Act for Dementia should be encouraging a shift in perceptions of dementia in society and the creation of an inclusive society, and to do that, we request that this article be revised to ask citizens to participate and cooperate in building an inclusive society.

1-2: “Early detection, diagnosis, and response” and “Establishing consultation systems” should be clearly stated as integral parts of the Basic Act for Dementia

The proposed Basic Act for Dementia mentions “early detection and early response” in “Article 17: Dementia prevention, etc.” However, the main reason these are important is not to prevent dementia, it is ensuring people living with dementia and their families are adequately prepared to live alongside dementia. Because that Article may give the impression that its mention of “early detection and early response” places prevention as its primary objective, it requires revision. While this will be discussed further below, this provision mentions “early detection and early response,” but it makes no mention of “early diagnosis.” Early diagnosis of dementia is internationally recognized as an important measure and should be included as “early detection, early diagnosis, and early response.” Early detection, diagnosis, and response provide a number of benefits. Connecting people with dementia and their families to support systems at early stages is likely to help alleviate anxiety. Early diagnosis is also likely to help create a system that enables people to continue living in the communities they are used to by linking them to health and long-term care services as well as to informal care. In addition, if dementia can be diagnosed very early, such as at the stage of mild cognitive impairment (MCI), it becomes possible to grasp the risks of developing symptoms and helps people start preparing early. At the same time, to avoid what we might refer to as “early diagnosis and early despair,” it will be essential to expand systems for providing consultations and to state these items in an integrated manner.

Recommendation 2: The Basic Act for Dementia should encourage proactive participation from people living with dementia and their families

2-1: Make clear mention of the establishment of a “Committee for the Promotion of Dementia Policies” (tentative name) that includes affected parties among its members

Since our establishment, HGPI has advocated for “citizen-centered health policy” and has worked for policy reform by bringing together and providing opportunities for discussions among patients and affected parties in dementia policy and in many other areas of health policy. Based on those initiatives, the most important element is involving patients and other affected parties from the outset when formulating and assessing policies. We would like to request for the Basic Act for Dementia to make clear mention of the establishment of a “Committee for the Promotion of Dementia Policies” (tentative name), and for that committee to include people with dementia or their family members, parties involved in healthcare and long-term care, and representatives from academia and other such experts. There is a similar clause in the Cancer Control Act and Basic Act on Countermeasures for Stroke, Heart Disease and Other Cardiovascular Diseases, and such a clause is also necessary based on global trends.

2-2: Mention that there will be “collaboration with people living with dementia, their families, and similar parties” during policy formation, implementation, and assessment

In the proposed version of the Basic Act for Dementia, there is no mention of conducting opinion hearings with people living with dementia or their families in the Government’s Basic Plan. It also states that when regional or municipal governments formulate plans, they must “endeavor to gather opinions from persons with dementia, their families, and similar parties.” To reflect the voices of the parties most affected in policy, instead of taking minor, short-term actions like “gathering their opinions,” it will be necessary to involve them from the planning stages and build those plans together. We request for the Basic Act for Dementia to be revised so this concept is clearly conveyed in its articles.

2-3: Clearly state the need for Patient and Public Involvement (PPI) in R&D

It will also be important to have proactive participation from people living with dementia and their families in R&D. In medical research, this concept is known as Patient and Public Involvement (PPI), and great advances in PPI have already been made in the field of oncology. Efforts aiming to encourage PPI are underway at the Japan Agency for Medical Research and Development (AMED), and this is also in line with Japan’s overall strategy for R&D in the field of medicine. Notable characteristics of dementia R&D are that it must involve people who have not yet developed dementia and that research in this area requires greater lengths of time than general research. From that perspective, as well, it will be important for preparations to be made for deepening mutual understanding and maintaining close communications among research institutions or researchers and civil society, starting with people living with dementia and their families. We would like these concepts to be clearly stated in articles related to R&D in the Basic Act for Dementia.

While the concept of PPI is currently being emphasized at the Japan Dementia Public-Private Council (and at the Dementia Innovation Alliance Public and Private Sector Working Group in particular), the scope of that PPI is limited. This concept should be applied to R&D in a broader, more general sense, and this direction should be set within the Basic Act for Dementia.

When promoting PPI, those from academia who are involved in each research program must diligently provide information to those who will be participating in that research – namely, patients and members of the public. Steps to ensure ample mutual communication must also be taken. To meet these needs, expanding and reinforcing human resources at each research institution will be essential, and that will require support in the form of investments in R&D. Japan invests much less in dementia research compared to other developed countries, so anticipation for investments made through public-private collaboration is high. It will be important to start a virtuous cycle in which the results generated through increased investments are utilized to give back to society, which will then encourage even greater investment. In addition to increasing funding for research, it will also be necessary to establish systems for providing said funding in a manner that accommodates studies spanning long periods.

Recommendation 3: The Basic Act for Dementia should reflect the paradigm shift occurring due to advances in R&D

3-1: Clearly state the need for early diagnosis and health equity in health, medicine, and welfare services that look toward implementing the use of new preventive, diagnostic, and treatment technologies in society

Right now, Disease Modifying Therapies (DMTs) for many of the underlying causes of dementia have yet to be developed, approved, or granted insurance coverage. This may be the reason that the National Framework for Promotion of Dementia Policies and proposed Basic Act for Dementia mention, “early detection and early response.” However, there are various underlying causes that can result in dementia. For conditions referred to as “forms of dementia that can be treated,” starting with idiopathic normal pressure hydrocephalus (iNPH), treatment becomes more difficult once the condition progresses, making early diagnosis and treatment extremely important. Furthermore, expectations are high for significant future progress in medical research, particularly the development of DMTs for Alzheimer’s disease. To ensure DMTs for treatable forms of dementia or which are likely to appear in the future are implemented in society in a stable manner, it will be important to develop diagnostic methods (using tools like PET scans and blood biomarkers) which can accurately detect pathology and to secure access to them. As we can see, there are significant benefits to providing early diagnosis, so Article 18 paragraph (1) should state that early detection and early diagnosis shall be the basis.

Looking at the social costs of dementia, in the past, long-term care and informal care have comprised large proportions, while the absence of fundamental treatment methods mean the proportional costs of healthcare have been relatively small. Of the 14.5 trillion yen in social costs mentioned above, long-term care accounted for 44%, informal care accounted for 43%, and healthcare accounted for 13%. When new technologies are developed for the prevention, diagnosis, and treatment of dementia and MCI, the role of healthcare is likely to grow as it has for other diseases. In the future, systems must be developed to facilitate approval and coverage of the results of R&D and enable their use in society, and care delivery systems must be established so every affected person can enjoy the benefits of early detection and diagnosis in an equitable manner, regardless of where they live. The systems and regulations needed to implement the use of new prevention, diagnosis, and treatment technologies in society must be created, specialists must be trained, institutions providing those technologies must be established, steps must be taken to maintain and enhance overall quality, and structures for aggregating and providing information must be built.

In articles concerning the healthcare and long-term care systems, we would like the Basic Act for Dementia to clearly state, as a set, (1) it will be important to establish systems for early detection, diagnosis, and response that keep R&D progress in view and (2) equity in health, medicine, and welfare services must be promoted.

Reference: Urgent recommendations and articles referenced

Recommendation	Articles referenced
<p>1-1: Rather than “prevention,” the stated obligation of citizens should be to “Participate and cooperate in building an inclusive society”</p>	<p>The proposed Basic Act for Dementia (Objectives) Article 1: With an increasing number of persons with dementia accompanying the rapid aging of the Japanese population, the purpose of this Act is to create a society in which persons with dementia (hereinafter referred to as “persons with dementia”) are respected as members of society while upholding their personal dignity and while promoting measures for dementia, including for its prevention, etc. (hereinafter referred to as “measures for dementia”). This Act will promote measures for dementia in a comprehensive and systematic manner by defining basic principles for said measures; clarifying the responsibilities of the national Government, local governments, and similar bodies; and providing items to be included during formation of Plans for the Promotion of Dementia Measures and basic items to be included in measures for dementia. (Obligations of citizens) Article 8: Citizens shall endeavor to obtain accurate knowledge regarding dementia, to devote the necessary attention to the prevention of dementia, and lend their cooperation in enabling persons with dementia to exercise independence and engage in social participation.</p>
<p>1-2: “Early detection, diagnosis, and response” and “Establishing consultation systems” should be clearly stated as integral parts of the Basic Act for Dementia</p>	<p>The proposed Basic Act for Dementia (Prevention, etc. of dementia) Article 17: The national Government and local governments shall undertake necessary measures to promote the prevention of dementia and mild cognitive impairment, including measures to raise awareness and disseminate knowledge regarding prevention, to promote activities in communities that may contribute to prevention, and to gather information related to prevention. (2) The national Government and local governments shall undertake necessary measures to promote early detection and early response for dementia and mild cognitive impairment including for the development of cooperative or collaborative systems that include Integrated Community Support Centers described in Article 115-46, paragraph (1) of the Long-Term Care Insurance Act, health institutions, civil society organizations, and similar organizations.</p>
<p>2-1: Make clear mention of the establishment of a “Committee for the Promotion of Dementia Policies” (tentative name) that includes affected parties among its members</p>	<p>The Cancer Control Act Article 24: A Committee for the Promotion of Cancer Control (hereinafter referred to as “the Committee”) shall be established in the Ministry of Health, Labour and Welfare to respond to matters described in Article 10, paragraph (4) (including cases that apply mutatis mutandis to paragraph (8) of the same Article) with regard to the Basic Plans to Promote Cancer Control. Article 25: The Committee shall include no more than 20 members. (2) Committee members shall be appointed by the Minister of Health, Labour and Welfare from among cancer patients, their families, their surviving family members, or persons representing them; and persons engaged in providing cancer treatment or possessing relevant education and professional experience.</p>
<p>2-2: Mention that there will be “collaboration with people living with dementia, their families, and similar parties” during policy formation, implementation, and assessment</p>	<p>The proposed Basic Act for Dementia (Plans for the Promotion of Dementia Measures in each prefecture) Article 12: Prefectural governments shall endeavor to formulate Prefectural Plans for the Promotion of Dementia Measures (hereinafter referred to as “Prefectural Plans” in this Article and in paragraph (1) below) that are based on the Basic Plan and are in accordance with conditions in their respective prefectures. (2) (Omitted) (3) When formulating Prefectural Plans, prefectural governments must endeavor to gather opinions from persons with dementia, their families, and similar parties in advance.</p>

	<p>(Plans for the Promotion of Dementia Measures in municipalities)</p> <p>Article 13: Municipalities (including special wards) shall endeavor to formulate Municipal Plans for the Promotion of Dementia Measures (hereinafter referred to as “Municipal Plans” in this Article) that are based on the Basic Plan (or in the event a Prefectural Basic Plan has been formulated, the Basic Plan and the Prefectural Basic Plan) and are in accordance with conditions in the municipality in question.</p> <p>(2) (Omitted)</p> <p>(3) The provisions of paragraphs (3) through (7) of the preceding Article shall apply mutatis mutandis to Municipal Plans.</p>
<p>2-3: Clearly state the need for Patient and Public Involvement (PPI) in R&D</p>	<p>The proposed Basic Act for Dementia</p> <p>(Promotion, etc. of research and development)</p> <p>Article 22: The national Government and local governments shall promote basic and clinical research aiming to develop prevention, diagnosis, or treatment methods for dementia or mild cognitive impairment, or on other items that contribute to prevention including efforts to elucidate the underlying causes of dementia; that aim to develop rehabilitation or long-term care methods that are applicable to the conditions of persons with dementia; or that aim to improve or maintain quality of life for persons with dementia. In addition, they shall take measures to ensure the results of such research efforts are utilized effectively.</p> <p>(2) When taking measures described in the preceding paragraph, while promoting public-private cooperation, the national Government shall undertake necessary measures to build a foundation for dementia research and development on dementia including promoting the implementation of nationwide follow-up studies and establishing an environment for conducting clinical trials in a rapid and easy manner.</p>
<p>3-1: Clearly state the need for early diagnosis and health equity in health, medicine, and welfare services that look toward implementing the use of new preventive, diagnostic, and treatment technologies in society</p>	<p>The proposed Basic Act for Dementia</p> <p>(Establishment, etc. of provision systems for health, medical, and welfare services)</p> <p>Article 18: The national Government and local governments shall undertake necessary measures to establish healthcare institutions providing specialized medical care for dementia to enable all persons with dementia to receive appropriate care according to their condition in an equitable manner regardless of their location of residence.</p> <p>(2) The national Government and local governments shall undertake necessary measures to provide persons with dementia timely and appropriate healthcare and welfare services in a comprehensive manner by building an Integrated Community Care System in accordance with Article 2, paragraph (1) of the Law to the Related Acts for Securing Comprehensive Medical and Long-Term Care in the Community (Act No. 64 of 1989) that provides organic coordination among health, medicine, and welfare.</p> <p>(3) The national Government and local governments shall undertake necessary measures to ensure the provision of health and welfare services that are in accordance with the conditions of persons with dementia, including by providing training for healthcare and long-term care professionals to enhance their ability to respond to persons with dementia, as well as securing, developing, and enhancing the quality of human resources for healthcare and long-term care.</p>

Conclusion

In July 2022, HGPI published policy recommendations titled, “The Future of Dementia Policy 2022: Deepening Dementia Policies Centered on People Living with Dementia and their Families to Lead Global Society,” which included general recommendations on the future direction to set for dementia policy ahead of the 2023 G7 Summit in Japan. The urgent recommendations offered by this document were compiled to focus on the Basic Act for Dementia just as discussions on the Basic Act for Dementia begin in earnest to energize further discussions in the legislature and to build social momentum for dementia policy. Actions described in these recommendations will be particularly important for the Basic Act for Dementia. At the same time, however, enacting the Basic Act for

Dementia is not the goal; rather, it is the starting line. Many discussions must be held in the future for the second phase of the National Framework for Promotion of Dementia Policies and to determine the details of how the national and local governments' plans based on the Basic Act for Dementia should be organized. To that end, HGPI will continue to provide forums for discussions and deliberation that include items described in these urgent recommendations to continue communicating the voices of civil society to make concrete progress.

We would like to express our deepest gratitude to everyone who took part in compiling these urgent recommendations for providing opinions from various perspectives despite the extremely tight schedule.

About Health and Global Policy Institute

Health and Global Policy Institute (HGPI) is a non-profit, independent, non-partisan health policy think tank established in 2004. In its capacity as a neutral think-tank, HGPI involves stakeholders from wide-ranging fields of expertise to provide policy options to the public to successfully create citizen-focused healthcare policies. Looking to the future, HGPI produces novel ideas and values from a standpoint that offers a wide perspective. It aims to realize a healthy and fair society while holding fast to its independence to avoid being bound to the specific interests of political parties and other organizations. HGPI intends for its policy options to be effective not only in Japan, but also in the wider world, and in this vein the institute will continue to be very active in creating policies for resolving global health challenges. HGPI's activities have received global recognition. It was ranked second in the "Domestic Health Policy Think Tanks" category and third in the "Global Health Policy Think Tanks" category in the Global Go To Think Tank Index Report presented by the University of Pennsylvania (as of January 2021, the most recent report).

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