

The Future of Dementia Policy 2022:

Deepening Dementia Policies Centered on People Living
with Dementia and their Families to Lead Global Society

Health and Global Policy Institute (HGPI) Dementia Policy Project Policy Recommendations

July 2022



Background of these recommendations

In Japan, devoted efforts from people involved in the field of dementia have resulted in steady progress for domestic dementia policy. Since the Long-Term Care Insurance System was established in 2000, there has been particular emphasis placed on upholding the dignity of people living with dementia and their families, and we have seen progress in multi-stakeholder cooperation encompassing healthcare and long-term care under the concept of the Integrated Community Care System. Past domestic dementia policies include the Five-Year Plan for the Promotion of Dementia Measures (the Orange Plan), which was enacted in 2012; the Comprehensive Strategy to Accelerate Dementia Measures (the New Orange Plan), which came into effect in 2015; and the National Framework for Promotion of Dementia Policies, Japan's first national strategy for dementia, which was introduced in 2019. Average life expectancies in each country are growing, making measures for dementia an urgent issue in the global community. The G8 Dementia Summit, which was held in London in December 2013, marked a major step forward in dementia policy for the international community. The World Dementia Council (WDC) was established as a result of that summit, and each country has been working to expand policies for dementia according to its Declaration and Communique. Then, in 2017, the World Health Organization (WHO) released "Global action plan on the public health response to dementia 2017-2025," which called on each country to formulate and advance dementia policies. While the past decade has seen much growth in momentum for dementia policies in the global community, these efforts have been impacted by the COVID-19 pandemic. We must now acknowledge the need to redouble our efforts. It will soon be a decade since the G8 Dementia Summit, and the 2023 G7 Summit will be held in Japan. Given this opportunity, Health and Global Policy Institute (HGPI) has developed the following policy recommendations based on knowledge gained over many years of Dementia Policy Project activities to indicate the direction for Japan to take to further strengthen dementia policy in the global community.

The Social Environment

Transition from “Understanding, watching over, and providing support” to “Coexisting and co-creating with people living with dementia”

After the official term for “dementia” in Japan was revised in 2004, measures to build awareness, eliminate stigma and prejudice, and promote accurate understanding toward dementia have been implemented on a national scale. The Dementia Supporter Training Program began in 2005 and is central to these efforts. As of the end of March 2022, this program has trained approximately 13.8 million Dementia Supporters, meaning their number already exceeds 10% of the population of Japan. The Dementia Supporter Training Program has attracted much global attention and more and more countries and regions are introducing similar programs. Such efforts to build awareness have resulted in great changes in society’s perception of dementia. However, just training more Dementia Supporters will not be enough to build a dementia-inclusive society. There is a gap between understanding dementia and living alongside dementia, and bridging that gap requires changes in attitudes. Instead of viewing our roles as solving the problems faced by people living with dementia, we must see ourselves as partners who help them achieve their goals. Continuously accumulating experiences together will help us transition into a phase in which we are the co-creators of a dementia-inclusive society. To do this, we must not limit ourselves to existing awareness-building measures targeting society as a whole. Instead, we must implement measures that encourage people living with dementia to take more active roles in society.

Go beyond the healthcare, long-term care, and welfare sectors to co-create a dementia-friendly society with people living with or affected by dementia and retailers, public transport organizations, and other companies

In the past, community development efforts have been primarily led by the Government and the healthcare and welfare sectors. These efforts have improved understanding toward dementia in many communities and have led to ongoing change. In addition, based on the concept of promoting barrier-free living for people with dementia outlined in the National Framework for Promotion of Dementia Policies, recent years have also seen growing momentum for participation from various actors in the private sector. To keep pace with these trends, it will be necessary to promote community development at the local level with businesses involved in the lives of people with dementia including retailers, public transportation, and the housing industry. In particular, there are great differences among regions in issues and necessary initiatives in sectors like shopping and transportation. With support from the Government and the healthcare and welfare sectors, opportunities must be created at the local level in each community so people living with dementia, their families, and businesses can collaborate on building a barrier-free society for dementia.

Provide support to energize activities from civil society starting with patient advocate organizations and train patient advocate leaders at the community level

For people living with dementia and their families to proactively get involved in creating policy, it is not only necessary for them to do so on an individual basis, it is also vital for there to be active efforts from patient advocacy organizations that provide the foundation for their activities. When engaging in such activities, they must also learn how to collaborate with various stakeholders involved in creating policy and improve their advocacy skills. Patient advocate leaders in each community will serve essential roles in identifying challenges in their communities and in linking those insights to improvements. The national and local governments must provide the necessary support and information focusing on patient advocacy organizations to enable people living with dementia and their families to maintain these activities. In particular, the Government should promote cooperation with global organizations for dementia like Alzheimer’s Disease International (ADI), the WHO, the WDC, and NGOs that provide dementia support in countries around the world; actively disseminate good examples and innovative practices from Japan; and create opportunities for civil society to learn best practices from overseas.

Expand evidence-based risk reduction initiatives for dementia risk factors

Comprehensive evidence regarding risk factors for dementia has been presented in sources like 2019's "Risk reduction of cognitive decline and dementia: WHO guidelines" or "Dementia prevention, intervention, and care: 2020 report of the Lancet Commission" from a team at University College London led by Professor Gill Livingston. Steps to build various forms of evidence are also underway at domestic universities and research institutions. Risk factors for dementia are wide-ranging and many of them can affect people over long periods of time, meaning it will be necessary to continuously advance academic research, centered on academia. In addition to bridging research, which enables findings to be applied throughout society in practical terms, as well as existing initiatives from the national and local governments for exercise and social participation based on those findings, it will be necessary to remain aware of how to link those efforts to efforts for non-communicable disease (NCD)* control and to implement risk reduction initiatives based on the needs of community members.

There are many products and services for dementia risk reduction and prevention on the market today, but from the user's perspective, there are many points of uncertainty regarding which criteria to apply when selecting one. Industry, Government, academia, and civil society should consider establishing standards and certification systems together to guarantee or improve the quality of such products and services.

*Non-communicable diseases (NCDs): A collective term for chronic diseases such as cancer, diabetes, cardiovascular disease, respiratory disease, and mental disorders that occur due to causes like unhealthy diets, insufficient exercise, smoking, excessive alcohol consumption, or air pollution.

Promote practices for early detection and diagnosis that are based on the needs of people with dementia

While it goes without saying that it is essential for people with dementia to be provided with the right medical and long-term care services at the right times, it is also essential for them to receive appropriate diagnoses and recognize the signs of dementia early so they can continue living in familiar environments as long as possible. To this end, it will be necessary to improve the examination, diagnosis, and consultation systems while working to sweep away the stigma toward dementia and establish a social environment where people can seek diagnoses with peace of mind. Accurate, easy-to-use diagnostic techniques must be developed and preparations must be made so they can be incorporated into all types of medical checkups and examinations. Expectations are also high for the effective utilization of existing cognitive function tests. In particular, it is urgent that biomarkers are developed and testing and diagnostic technologies are improved. Some promising areas where future developments in digital technology can contribute to dementia diagnosis include analyzing facial expression, bodily movement, and gaze to assess cognitive function or detecting cognitive decline based on operational errors when using smartphones or other electronic devices.

It will also be necessary to establish consultation and psychological care systems together. Such systems will be used to help prevent anxiety among people with dementia or their families after an examination or diagnosis. For example, one outcome indicator for Initial-Phase Intensive Support Teams for Dementia, which are to be established in every municipality, is introducing people to healthcare and long-term care services. In addition to that, however, there are also high expectations for these teams to connect people to peer support networks, dementia cafés, and post-diagnosis support services from medical centers for dementia. Based on the experiences of people living with dementia or those close to them, it will be necessary to build an integrated early response system that includes healthcare and long-term care services as well as consultation and psychiatric care systems.

Consider evaluation indicators for care quality and degree of specialty and the ideal evaluation system so the value and importance of long-term dementia caregivers and other forms of care work is communicated throughout society

The socialization of care has been the objective of the Long-Term Care Insurance System since it was first established, but care provided by professionals and informal care provided in the home have not received sufficient social recognition or appropriate value assessment. In the past, caregiving was the responsibility of family members, including caregiving for dementia, and there is a lingering misconception that the duties of caregiving can be taken on without first acquiring any applicable knowledge or experience. In practice, caregiving is highly individualized, it is difficult to define what forms of care are optimal for the person receiving it, and it is not easy to capture that expertise in objective terms and systematize it. Still, evaluation indices of some type are needed so care can be assigned appropriate value. To promote care that contributes better quality of life (QOL) for older adults and ensure equitable access to that care, we must examine how to design and institutionalize criteria for evaluating care effectiveness from broad perspectives, like social care-related QOL.

Perspective

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Research

Secure continuous funding and drive medium- to long-term development in domestic dementia research

Current initiatives in dementia research span various fields and include promoting basic research to elucidate the underlying mechanisms of the diseases that cause dementia, establishing clinical research platforms that make it possible to rapidly implement treatments that are considered effective, and conducting studies that verify findings on risk reduction. Furthermore, many of these initiatives are planned with medium- to long-term perspectives, so they require medium- to long-term research strategies that cover items like securing continuous research funding or training researchers. As such, there are high expectations for the establishment of public private partnerships (PPPs) that can utilize both public and private funds in a balanced manner and foster collaboration to promote dementia R&D. Such collaboration should include the sharing of data and research personnel and involve industry, Government, academia, and civil society, including people living with or affected by dementia.

Utilize real-world data (RWD) and promote global joint studies and data-sharing

R&D using real-world data (RWD) from healthcare and long-term care must be advanced in dementia research. In the fields of healthcare and long-term care, RWD is being gathered in vast amounts through regular examinations and checkups in the form of test results and care records created by medical and long-term care specialists. In addition to this data, it will be also necessary to gather data using sensors and IoT technology and use it effectively in R&D by analyzing it using AI and other technologies. Dementia is not only a key policy issue for Japan, it is important for other countries, as well. Sharing big data and analysis results globally and promoting international joint research using shared data is likely to make R&D more effective and efficient.

Construct an R&D platform that facilitates citizen participation

Involving people with dementia, their families, and members of the general public before they have symptoms will be essential to rapidly advance research. In the U.K., the National Health Service (NHS) operates an open platform called “Join Dementia Research,” which allows volunteers to register for single clinical trials and matches them to appropriate R&D efforts based on their own interests. While referring to that system or others like it, we must establish a platform that facilitates participation from people living with or affected by dementia in clinical research and care-related research. Building an integrated dementia registry is likely make it possible to predict and identify the number of people with dementia in a timely and accurate manner, to identify the underlying diseases causing forms of dementia that improve with treatment (such as idiopathic normal pressure hydrocephalus (iNPH) and thyroid disease), and to address various unmet needs for forms of dementia with no registry, such as familial dementia or early-onset dementia.

Establish evaluation criteria that encompass user perspectives for products and services that support the daily lives of people with dementia to create a market for dementia-friendly products and services

R&D in the field of dementia is not only important for developing pharmaceuticals and treatment methods. Promoting R&D for dementia-friendly products and services can enable people to continue living true to themselves even if they develop dementia and enrich the lives of people living with dementia and their families. In the future, there are high expectations for the creation of evaluation criteria for determining the effectiveness of such products and services and for methods of verifying their results based on those criteria. There are also high expectations for the development of a market for dementia-friendly goods and services in which quality is assured by granting a “dementia-friendly certification” (a tentative name) from a third party organization to goods and services that meet certain standards. Such a certification would provide civil society with a baseline for selecting appropriate products and services. Expectations are also high for those in the private sector to clearly present their target values when developing products or services and to adopt dementia-friendly initiatives as sustainable parts of their core businesses instead of considering them as efforts made out of goodwill.



Political leadership

Make dementia a central agenda at the 2023 G7 Summit in Japan

Almost a decade has passed since the G8 Dementia Summit was held in the U.K. in 2013. Since then, significant progress has been made in dementia policy around the world. There would be great significance to once again focus on dementia as a key agenda at the G7 Summit held ten years later in Japan, the country where population aging has advanced the most. The Communique issued after the G8 Dementia Summit and the WHO Action Plan have both identified 2025 as a milestone year. The upcoming Summit presents an excellent opportunity for Japan to demonstrate its leadership in dementia policy to the global community in 2025 and beyond.

Enact the Basic Act for Dementia as soon as possible

Government leadership led to the formulation of a national strategy cutting across ministries and agencies called the National Framework for the Promotion of Dementia Policies in 2019. The bipartisan Parliamentary Association for Promoting Dementia Policies for an Inclusive Society was then established in 2021, and discussions on enacting the Basic Act for Dementia are now underway. The Basic Act for Dementia, which was submitted to the Diet in 2019 and has been the subject of ongoing discussion, calls for emphasis to be placed on upholding dignity for people living with dementia and their families and guaranteeing them a spot in the policy-making process. It also obligates the Government to formulate a Basic Plan for the Promotion of Policies for Dementia and to review that plan at a minimum of every five years. When enacted, it is anticipated that the Basic Act for Dementia will guarantee participation for people living with dementia, sustain momentum in dementia policy, and ensure continuous funding. Through future discussions in the legislature, there are high hopes that the rapid enactment of the Basic Act for Dementia will help dementia policy take the next step forward.

Promote public understanding toward reforms that distribute burdens to stabilize social security finances

In an era that demands fiscal restructuring, there is particularly strong pressure to cut back on social security spending, which accounts for a significant proportion of national expenditures. It is urgent that financial resources are secured for the healthcare and long-term care insurance systems, which are the foundation of dementia policy. It is inevitable that the burden placed on citizens will continue to increase, and like when the tripartite agreement on the Comprehensive Reform of Social Security and Tax was made in 2012, the Government should go beyond partisan conflicts and make persistent efforts to gain understanding toward increased public burden in the form of taxes and social insurance premiums to secure the financial resources needed for social security.

Bolster community development through regulations for dementia from local governments

Communities provide the foundation for our lives, including for people living with dementia and their families. Municipal governments bring together these communities and hold great influence over them. For each municipality to make progress in creating dementia-friendly communities under the concept of the Integrated Community Care System, dementia policies established through local regulations for dementia must be developed and subjected to continuous review. A growing number of municipal governments have been enacting local regulations for dementia since 2017, with people with dementia and their families participating in various ways throughout that process. Their participation includes joining review meetings, attending workshops and hearings, and submitting public comments. There are high expectations for municipal governments to refer to innovative examples of participation and to actively collaborate with people living with dementia and their families to formulate policies. Unified local elections will be held in the near future, in 2023. We hope many candidates aiming to become local leaders and councilors take this opportunity to recognize dementia as a high-priority policy issue and take action.

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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