

POLICY RECOMMENDATIONS

**The Future of Dementia Policy Surrounding Families
and Others Who Care for People with Dementia**

April 2026

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Health and Global Policy Institute (HGPI) Dementia Project FY2025

Policy Recommendations:

The Future of Dementia Policy Surrounding Families and Others Who Care for People with Dementia

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Introduction

The Basic Act on Dementia (Dementia Basic Act), enacted in 2023, is grounded in a "new perspective on dementia" that aspires to realize a society in which people with dementia can continue to live with hope. The Act usher's dementia policy into a new phase. In 2024, the Basic Plan for the Promotion of Dementia Policies was formulated, calling for the development of comprehensive measures that extend beyond medical care, long-term care, and welfare.

Despite these advances in dementia policy, support for families and caregivers who support people with dementia in their daily lives remains far from adequate. Although the Long-Term Care Insurance System was introduced in 2000 with the goal of "socializing long-term care," families and caregivers continue to shoulder roles that public services cannot fully cover, such as coordinating services, accompanying the person to medical appointments, and providing day-to-day supervision. Moreover, the circumstances surrounding families and caregivers have changed dramatically. According to the Comprehensive Survey of Living Conditions conducted by the Ministry of Health, Labor and Welfare (MHLW) (2022), single-person households increased from approximately 15% to approximately 30%, and elderly-only households nearly doubled from approximately 35% to approximately 62%. During the same period, the proportion of three-generation households among those with a person requiring care dropped sharply from approximately 33% in 2001 to approximately 11% in 2022. Caregiving roles that were once shared within extended families are now increasingly concentrated on a single primary caregiver. Furthermore, the profiles of families and caregivers have diversified, comprising of those who work while providing care, male caregivers, young carers, double carers, and caregivers with their own health conditions, thus giving rise to needs that one-size-fits-all support cannot address. We must also recognize that while "care" should be understood as a matter for institutional design, it also carries a deeply private dimension, and that both the "right to provide care" and the "right not to provide care" are inherent in any discussion of caregiving.

Against this backdrop, the HGPI Dementia Project designated "The Future of Dementia Policies Surrounding Families and Caregivers of People with Dementia" as the theme for FY2025. The project conducted a literature

review and interviews with relevant stakeholders and convened a multi-stakeholder Advisory Board. Through multiple rounds of deliberation and individual consultations, the project engaged in wide-ranging discussion and analysis. As a result, this set of policy recommendations brings together five thematic pillars of concern and corresponding policy directions that emerged over the course of one year of research and deliberation.

It should be noted at the outset that these recommendations do not frame the issue as a binary opposition between "the person with dementia" and "the family." People with dementia and their families and caregivers share the same daily lives, and the condition of each inevitably affects the other. For people with dementia to continue living with hope, an environment must be created in which families and caregivers can also continue to live their own lives, built on mutual respect for one another's life trajectories. Support for both must be advanced as the two wheels of the same cart. These recommendations are grounded in that awareness, while placing a particular focus on policies for families and caregivers, an area where support has long been considered insufficient.

The structure of these recommendations is as follows. Chapter 1 provides an overview of the five thematic pillars identified through this year's research and deliberation, along with the envisioned directions for each. Chapter 2 presents specific policy proposals corresponding to each pillar. It is our hope that these recommendations will be utilized by a broad range of stakeholders in contexts such as the interim review of the Basic Plan for the Promotion of Dementia Policies, revisions to medical fee reimbursement and nursing care compensation schedules, and the design or review of related systems.

Finally, one caveat should be noted. In general, welfare services are prone to a structural challenge whereby an increase in the supply of services in response to needs may itself generate new demand. Additionally, the expansion of public services naturally requires securing the necessary financial resources; however, amid growing pressure to contain tax revenues and social insurance premiums, securing additional funding is by no means straightforward. While these recommendations focus on the specific topic of support for families and caregivers, we wish to note that the broader debate over financing remains an indispensable issue in the design of future systems.

Chapter 1: Overview

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Chapter 1: Overview

Pillar 1: Promoting the Physical and Mental Well-being of Families and Caregivers (Direct Support)

Background and Challenges

The establishment of the Long-Term Care Insurance System in 2000 was premised on "socializing long-term care," yet families and caregivers left to and continue to bear a significant share of roles that the system cannot fully cover, such as day-to-day supervision, accompanying the person to medical appointments, and responding to the behavioral and psychological symptoms of dementia (BPSD). Yet this is not a problem unique to long-term care; it reflects a broader challenge facing all forms of "care" today. From the standpoint of institutional positioning as well, direct support for families and caregivers under the Long-Term Care Insurance System, for example, remains situated merely as an optional program within Community Support Projects. While this partly reflects the origins of the system itself, support for families and caregivers has not necessarily been placed at the center of policy.

In addition to these structural issues, a point repeatedly raised during the interviews and Advisory Board deliberations conducted for this project was the difficulty families and caregivers face in recognizing that they themselves are entitled to receive support. Despite the growing diversity of caregiving circumstances, including those who work while providing care, male caregivers, young carers, and caregivers with their own health conditions, many perceive seeking help as "causing trouble for others" and end up cutting themselves off from available support.

As a consequence, depression and physical and mental exhaustion among families and caregivers have become serious concerns. It has been noted that a major contributing factor is "anxiety stemming from uncertainty", the uncertainty caused by the unpredictable progression of dementia and the inability to foresee the future. Indeed, among consultations related to long-term care insurance, a large proportion involve concerns such as "not knowing what to do about the current situation," and the inability to obtain the necessary information or a concrete outlook significantly heightens psychological burden. In such circumstances, supportive listening alone is often insufficient, and the buildup of fatigue can lead to inappropriate responses to BPSD, which in turn further worsens the person's condition,

creating a vicious cycle. Moreover, as the wishes of the person with dementia to continue living at home or to receive end-of-life care at home are increasingly respected, families and caregivers are prone to inner conflict between sustaining care and maintaining their own lives; understanding and providing support for this dilemma is also an important challenge. Continued employment and the maintenance of social activities are thus essential to the physical and mental health of families and caregivers, yet the existing care leave system, for example, is designed solely for the purpose of "securing time for caregiving" and does not extend to support the caregiver's own rest, continued employment, or social participation. Furthermore, after dementia care comes to an end, caregivers experience the loss of social relationships and roles they had acquired through their involvement with the person with dementia. This transition is a risk factor for cognitive decline and deterioration of mental health in the caregivers themselves, yet the caregiving period is treated merely as a gap in individual careers and social participation, and no support framework exists from the perspective of rebuilding life after caregiving.

Envisioned Directions

The starting point for a policy shift is to position families and caregivers not solely as those who support the person with dementia, but also explicitly as individuals who themselves require support. This trend is gaining ground internationally, and in Japan, one example is the enactment of Carer Support Ordinances at the municipal level. Although these ordinances are not specific to dementia, they clearly position those involved in caregiving as individuals whom the entire community should support and provide a framework to promote municipal policy initiatives; for municipalities that have not yet adopted such ordinances, consideration of their enactment is worthwhile. At the same time, seeing as optional programs under Community Support Projects are largely at the discretion of each municipality and the quality of measures varies significantly depending on how they are implemented, a support structure should be established in which Regional Bureaus of Health and Welfare, prefectures, universities, and other institutions collaborate to help municipalities make effective use of these programs.

At the frontline of support, what is needed first is a mechanism for assessing the physical and mental condition of families and caregivers adequately. By

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identifying "where the difficulties lie," intervening based on assessment results, and re-evaluating outcomes, it becomes possible to institutionally guarantee a cycle of continuous support that does not depend on individual discretion or personal commitment.

A shift in perspective is also needed toward protecting the overall lives of families and caregivers, including continued employment and the maintenance of social participation. From the period around diagnosis through bereavement and the end of the caregiving role, it is necessary to build a seamless support system responsive to each stage of progression, while also making visible the day-to-day burdens of "invisible care" and constructing pathways that connect families and caregivers to diverse forms of support, including consultation services and peer support. In addition, to alleviate the financial burden on families and caregivers arising from the use of out-of-pocket services that fall outside the scope of public benefits, it is worth considering making such expenses eligible for income deductions or tax credits. The proliferation of such non-insured services is a priority issue for the Ministry of Economy, Trade and Industry (METI) as well, and in practice, a wide variety of services are already in use across all forms of care, not limited to long-term care. From the perspective of giving economic recognition to the reality that families and caregivers have been filling the gaps in public systems at their own expense, and of broadening the range of support options available, tax-based measures can serve as an effective instrument.

As a specific measure for maintaining the physical and mental health of families and caregivers, the next chapter discusses a proposal (Recommendation 5) to establish evidence-based psychological support, including cognitive behavioral therapy (CBT), as a standard component of family and caregiver support, and to develop pathways for access to such services.

Pillar 2: Strengthening the Capacity of Families and Caregivers by Providing Information and Enhancing Knowledge

Background and Challenges Institutional frameworks have yet to ensure that people diagnosed with dementia and their families can reliably access the information they need. During Advisory Board deliberations, drawing on the prior surveys, it was noted that only 10–20% of families and caregivers had

received information about how to use the Long-Term Care Insurance System or about peer support following a diagnosis. Less than 30% felt they had received sufficient information from their primary care physician, and only about 40% felt that information on available consultation services and support was easily accessible immediately after diagnosis. These and other observations pointed to significant challenges in accessing information and local resources in the immediate aftermath of a diagnosis. Such observations were also confirmed in multiple interviews conducted beyond the Advisory Board members, reaffirming the magnitude of the issue.

This failure of information to reach those who need it has structural roots. While information is disseminated by a wide range of actors, including the national and local governments, medical institutions, long-term care providers, and patient/family organizations, there is no mechanism for consolidating and presenting this information in an integrated manner. Although this structure can be viewed positively as enabling access through diverse channels, the provision of existing support tends to be passive in nature, structured to "respond to those who come seeking help", making it difficult to reach people who are unaware of the need for support, or who cannot actively access information due to constraints such as busyness, psychological strain, or unfamiliarity with digital environments. Those most in need of support are often the most isolated and the most likely to fall through the cracks. In interviews conducted for this project, the observation that "the families and caregivers who are truly struggling are the farthest from information" was repeatedly cited from multiple perspectives.

Moreover, a lack of information and adequate knowledge directly undermines the capacity of families and caregivers themselves. Continuing to provide care without knowing the appropriate methods of caregiving or how to utilize available systems heightens the risk of inappropriate care, increased physical and mental burden on families and caregivers, and even abuse.

Envisioned Directions

Firstly, what is needed is the establishment of a system that ensures families and caregivers are reliably and adequately connected to support, from the stage at which dementia is suspected through the period following diagnosis. In Japan, Community Comprehensive Support Centers function as public

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consultation points, but they are not sufficient as a mechanism for ensuring reliable connection at the critical moment immediately following diagnosis, and strengthening the initial link with medical institutions remains a challenge. The period immediately after diagnosis is one of significant psychological distress, during which there is often restrictions in the capacity to research available systems and services. During this period, it is essential to standardize a "post-diagnosis initial package" that provides an overview of available consultation services, long-term care services, peer support, legal and financial advice, and other resources, and that connects families and caregivers to local social resources. This package should be disseminated with accompanying budgetary provisions. Other countries have established systematic public consultation systems, such as Scotland's Post-Diagnostic Support (PDS) system in the United Kingdom and Australia's Carer Gateway that can serve as valuable precedents. Drawing on such examples, it is important to develop a system that provides comprehensive support from the pre-diagnostic stage through the immediate post-diagnostic period, built upon the community-based integrated care system and local communities. Secondly, it is necessary to institutionalize proactive outreach to those who are not utilizing existing systems or are unaware of their existence, as well as to those prone to isolation. It is important to move beyond "disseminating information only in venues where interested individuals gather" and to incorporate proactive, push-based outreach that delivers information naturally along people's daily routines. To address information disparities arising from differences in digital literacy, it is also essential to develop multiple channels combining in-person, telephone, and online formats. However, barriers to information reaching those who need it exist not only on the provider side but also on the recipient side. Given that people tend not to take action until they are facing genuine difficulties, information delivery and intervention design must be designed with this tendency in mind.

As a specific measure, the next chapter discusses a proposal (Recommendation 1) to build an online navigation site that ensures families and caregivers are reliably connected to the information, consultation services, and local resources they need, starting from the point immediately after diagnosis.

Pillar 3: Building Supportive Communities and Workplaces for Families and Caregivers

Background and Challenges

For families and caregivers of people with dementia to continue providing care without becoming isolated, a supportive environment in their two primary life settings, the community and the workplace, is indispensable. However, at present, structural challenges are accumulating in both domains. In communities, while Dementia Cafes and family support groups, places where those affected can connect, have been expanding across the country, most depend on the goodwill for their operation, and ensuring continuity and the quality of support remains a challenge. According to an MHLW survey (2022), more than 8,000 Dementia Cafes exist nationwide, but the content and functions of these cafes vary widely, and no shared understanding has been formed regarding the type of support one can expect and the type of venue. As a result, those in need continue to become isolated, because they cannot identify where to go is more correct here. During the Advisory Board deliberations for this project, it was repeatedly noted that people who want to participate but cannot, particularly male caregivers and those who are employed, face difficulty attending cafes and family support groups. The high psychological barrier of not being able to take the first step, even when one knows it would be beneficial was raised as a common concern.

According to the MHLW Comprehensive Survey of Living Conditions (2022), dementia is the leading cause of the need for care or support, yet employers' responses in the workplace lag significantly behind those for childcare support. Given that the vast majority of Japan's workforce belongs to organizations such as companies, and workplace-based approaches have the potential to reach a very large number of people. Despite this potential, it has been noted that "hidden caregiving" in which employees conceal their caregiving responsibilities for fear of career repercussions, is widespread, and cases of sudden job departure following a period of isolated caregiving are not uncommon. While awareness of the need for support is growing among employers, small and medium-sized enterprises (SMEs) in particular lack the resources to take concrete action, and disparities in support by company size area serious concern. Furthermore, the connection between workplaces and community-based long-term care and welfare resources is

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weak, and a structural problem has been identified in which workplace consultations fail to link employees to community support.

Envisioned Directions

In communities, it is necessary to optimize and make the functions and characteristics of local resources, such as Dementia Cafes and family support groups, more visible, so that people in need can more easily find venues that match their needs. Rather than applying standardized assessments, the use of flexible tagging by function and target demographic is considered effective, as it can foster a sense of "what to expect" among users without undermining the autonomy of individual cafes. At the same time, it is important to promote active referrals and linkages from medical institutions and Community Comprehensive Support Centers to cafes, thereby broadening the entry points through which isolated individuals can establish connections.

In the workplace, rather than expecting employers to "handle all aspects of caregiving," it is realistic and effective for them to assume the role of "gatekeepers who notice and connect", identifying employees in caregiving situations and linking them to appropriate resources. The starting point is to provide opportunities, from around the time of diagnosis onward, for employees to become informed about caregiving and to cultivate an organizational culture in which employees feel comfortable seeking advice. For SMEs, sustainable models that do not assume the assignment of dedicated personnel are needed, such as contracting with external professionals or establishing shared consultation services through health insurance societies or the Japan Health Insurance Association (Kyokai Kenpo). Furthermore, ensuring that workplace consultations are reliably connected to the community resources and services in the area where the person with dementia resides is key to making workplace-based support truly effective. As specific measures, the next chapter discusses proposals for making Dementia Cafe functions visible through functional tagging and developing a coordination platform (Recommendation 3), and for building a workplace-based family and caregiver support system through the establishment of insurer-level consultation functions (Recommendation 4).

Pillar 4: Support for Professionals

Background and Challenges

A wide range of professionals play an important role in supporting families and caregivers of people living with dementia. Tasks such as providing explanations to families, offering psychological support, assessing care burden, and connecting families and caregivers to local resources like peer support, family groups, and Dementia Cafes are indispensable elements that affect the quality of care for the person with dementia. Yet many of these activities are not adequately recognized under current medical fee reimbursement or nursing care compensation frameworks. As a result, support for families and caregivers has become structurally dependent on the discretion and goodwill of individual professionals, and the quality and volume of support provided vary greatly depending on the awareness of the practitioner, the policies of the institution, and the availability of local resources.

During interviews conducted for this project, urgent concerns about these challenges repeatedly captured. Physicians at memory clinics noted that despite low follow-up consultation fees, they spend considerable time on family consultations, effectively providing this service free of charge, making it difficult to justify from a hospital management perspective. Care Managers, although best positioned to understand the wishes of families, are overburdened and lack the time to provide adequate support. Home-visit nurses, who have the deepest contact with families in the home setting, pointed out that family support is not formally recognized. At Community Comprehensive Support Centers as well, there is growing pressure from being expected to serve as all-purpose consultation centers, and strong concerns were expressed about adding new responsibilities without accompanying improvements to compensation.

Challenges related to the quality of assessments for families and caregivers have also emerged from the field. Although current assessment frameworks include provisions for the circumstances of families and caregivers, the content remains abstract and insufficient to capture the actual care burden, emotional changes, and perceptions of support. It was also noted that, amid excessive workload, insufficient time to listen to families result in uneven quality of support.

The exhaustion experienced at individual sites overlaps with structural

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problems facing the field of dementia support as a whole. Dementia care involves a wide variety of actors spanning multiple institutional domains, namely medical, long-term care, welfare, and community. The national government has established mechanisms, such as Dementia Support Physicians and Initial-phase Intensive Support Teams (IPIST) for Dementia, but the level of their activities and the roles they actually play vary considerably across regions and institutions. In some cases, professionals who hold specialist credentials lack sufficient practical training in dementia-specific care, and in others, roles defined by the system are not backed by appropriate staffing or operational structures. These disparities in quality and function translate directly into regional inequalities in the support available to families and caregivers. The quality and equity of support cannot be ensured by relying solely on the commitment and skills of individual professionals.

In addition, there is a lack of adequate systematic education and training opportunities for professionals who support families and caregivers. While "person-centered care" has long emphasized support focused on the person with dementia, the perspective of viewing families and caregivers as recipients of support and assessing their needs has not been sufficiently considered among professionals. The growing complexity of care arrangements, involving multiple professions and multiple systems, has also contributed to the difficulty of delivering effective support.

Envisioned Directions

The envisioned direction, though difficult to implement, is to advance the institutional recognition and remuneration of support for families and caregivers, positioning such activities not as "peripheral tasks" but as "specialized support." Specifically, the development of mechanisms that enable billing under medical fee reimbursement and nursing care compensation frameworks for activities such as initial psychoeducation, assessment of care burden, and evaluation of support needs is called for. In doing so, it is important that the evaluation covers the entire process from assessment through intervention to re-evaluation, thereby ensuring quality beyond mere formalistic implementation.

Furthermore, the development of such mechanisms can also serve as a notable entry point for broadening the participation of diverse professions

in care. Among these, primary care physicians at clinics and small to mid-sized hospitals, along with their staff, represent the most accessible medical resource for people with dementia and their families and caregivers, and encouraging their involvement is particularly essential. By leveraging incentives within the medical fee reimbursement framework, it is desirable to build a system in which primary care physicians and other local multidisciplinary professionals collaborate to support families and caregivers, thereby enhancing comprehensive care within the local communities where they live

However, the introduction of remuneration must not simply be the addition of new responsibilities and tasks. It is essential that it be linked to improvements in the working conditions of professionals, and that the system design incorporates both compensation commensurate with the increased workload and the improvement of work environments. At the same time, the development of systematic education and training programs focused on assessment techniques and support skills for families and caregivers is a critical pillar of professional support.

As a specific measure, the next chapter discusses a proposal (Recommendation 2) to institutionally evaluate specialized support for families and caregivers based on assessment within the medical fee reimbursement and nursing care compensation frameworks, and to develop a system that enables professionals to engage in family support in a sustainable manner.

Pillar 5: Reducing the Burden on Families and Caregivers through Improved Support for the Person Living with Dementia (Indirect Support)

Background and Challenges

Support for the person with dementia and support for families and caregivers are inseparable, two sides of the same coin. Multiple studies have indicated that the quality of life (QOL) of the person with dementia also affects the QOL of families and caregivers, and creating an environment in which the person can live peacefully and securely functions as indirect support that

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directly reduces the burden on families and caregivers. According to estimates made in 2014 by Professor Mitsuhiro Sado of Keio University and colleagues ("Social Costs of Dementia"), the monetized impact of dementia on society was projected to reach approximately 19.4 trillion yen in 2025, of which 8.1 trillion yen was estimated to be borne by informal care provided by families and caregivers. These figures starkly illustrate the extent to which the current system is predicated on care provided by families and caregivers. However, the current system, including the Long-Term Care Insurance System, retains a structure that "assumes families and caregivers will fill the gaps and provide the bridges between institutional provisions." During interviews conducted for this project, a wide range of issues stemming from these systemic gaps were repeatedly raised: the isolation of families and caregivers during the gap period between diagnosis and the commencement of certified care services; the fact that families and caregivers are left to manage responsibilities outside the scope of long-term care insurance, such as accompanying the person living with dementia to medical appointments and sharing information with medical institutions; and the excessive burden placed on families and caregivers when the community cannot adequately support a person with dementia living alone at home.

In other words, while the current system has organized the scope, range, and standards of benefits from the perspectives of efficiency and uniformity based on a single metric, the "level of care needed", needs that cannot be fully addressed by standardized combinations of services remain. Dementia care, in particular, is heavily influenced by individual factors, including the kind of life the person has valued, and the nature of their relationships with families and caregivers. The protection of dignity and "continuation of a life true to that person" are principles explicitly stated in the Dementia Basic Act, yet they can hardly be said to have been sufficiently incorporated into the design of benefit systems or evaluation metrics. While uniform standards contribute to the stability of the system, they have also resulted in individualized, context-specific needs and quality-of-life concerns faced by the person and their families and caregivers being overlooked. To alleviate the burden on families and caregivers through enhanced support for the person living with dementia, a fundamental rethinking and reformation of this approach is indispensable.

Additionally, while it is widely recognized that behavioral and psychological

symptoms of dementia (BPSD) increase the care burden on families and caregivers, the creation of social roles for the person with dementia and the development of environments that support and promote their peaceful daily life, have not been adequately positioned within policy, even though this is important in reducing the occurrence of BPSD. When the quality of life of the person with dementia is compromised, this inevitably results in exhaustion for families and caregivers. If they are living together, it is essential to view the person and their families and caregivers as a single unit, and to adopt a system design grounded in the recognition that enhancing support for the person with dementia also protects the lives of families and caregivers.

Envisioned Directions

First, a shift toward system design that does not presuppose care by families and caregivers is necessary. The system's goal should be reframed and reoriented towards "a state in which the person living with dementia can live safely and securely even on their own," and systems must be built to ensure that the person receives appropriate support, irrespective of how families and caregivers are involved. It is urgent to develop a system in which local support resources are reliably connected to the person, even in cases where there is no designated key person or the key person lives far away. Such efforts would help create an environment in which diverse preferences can be accommodated, whether the preference is for services to cover care needs, or for the family to take on a caregiving role. However, there are also psychological and attitudinal factors that impede choice, such as when families feel resistance to using services or when the person with dementia does not wish to receive care services. Alongside institutional improvements, it is therefore necessary to also develop approaches that address these concerns through compassionate and continuous dialogue.

Second, it is necessary to strengthen coordination among medical, long-term care, welfare, and community services to ensure that the person with dementia and their families and caregivers do not fall through the gaps in the system. It is essential to clarify what support is available to the person and their families and caregivers at each stage, including the period between diagnosis and the commencement of Long-Term Care Insurance services, and to institutionally develop the functions that facilitate these connections.

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Third, the social participation of the person with dementia and the securing of their social roles should be actively positioned within policy. An environment in which the person can live actively within their community indirectly reduces the care burden on families and caregivers through the prevention and mitigation of BPSD, and is also aligned with the philosophy of the Dementia Basic Act, "realizing a society in which one can live with peace of mind even with dementia." The ultimate vision of this project is the creation of a society in which both the person with dementia and their families and caregivers can live with dignity.

As specific measures, the next chapter discusses proposals for developing an information-sharing platform among medical, long-term care, and family stakeholders to realize data-driven continuous support (Recommendation 6), and for building a support scheme aimed at sustaining and expanding community-based mutual aid (Recommendation 7).

Chapter 2: Specific Proposals

Concrete Recommendations for Immediate Implementation

Implementation Timeline: 1–2 Years

[Rec. 1] Online Link Worker: Building a Navigation Site Starting from the Point of Diagnosis

[Rec. 2] Remuneration for Family Support: Institutional Recognition of Professional Support Based on Assessment

[Rec. 3] Cafes of Choice: Visualizing Dementia Cafe Functions Through Tagging and Building a Coordination Framework

Recommendations Aiming for Institutionalization through Demonstration

Implementation Timeline: 3–5 Years

[Rec. 4] Reaching Families and Caregivers Through the Workplace: Developing Consultation Functions and Gatekeepers at the Insurer Level

[Rec. 5] Psychological Support for Families and Caregivers Standardizing Evidence-Based Psychological Support and Establishing Access Pathways

Recommendations Presenting a Future Vision

Implementation Timeline: 5+ Years

[Rec. 6] Connected Care through Digital Transformation: Building an Information-Sharing Platform Among Medical, Long-Term Care, and Family Stakeholders

[Rec. 7] Mutual Aid System for the Future: Building a Support Scheme for Sustaining and Expanding Community-based Mutual Aid

These recommendations are organized into three categories based on the readiness of each measure and the process required for implementation. These are not sequential stages; rather, they are to be advanced in parallel.

Recommendation 1: Online Link Worker

— Building a Navigation Site Starting from the Point of Diagnosis —

Implementation Timeline: 1–2 Years

Implementation Timeline: 3–5 Years

Implementation Timeline: 5+ Years

Key Players and Their Roles (Examples)

Ministry of Health, Labour and Welfare (MHLW)	Overall design, examination of standardizing post-diagnostic support, development of the navigation site
Municipalities / Community Comprehensive Support Centers	Coordination with the navigation site and local resources, consultation services
Medical Centers for Dementia and other specialized medical institutions	Conducting family education classes (municipalities), registering for the navigation site (diagnosis-linked individual support function), ongoing support during hospital visits
Primary Care Medical Institutions	Initial connection to Medical Centers for Dementia and the navigation site after diagnosis, ongoing support during hospital visits (after confirmed diagnosis)
Care Managers, Dementia Community Support Promoters, Young-onset Dementia Support Coordinators	Individual consultation, stakeholder coordination
Patient/family organizations, Dementia Supporters, etc.	Peer support, watching over, and provision of community-based support and care

Recommendation 1: Online Link Worker

— Building a Navigation Site Starting from the Point of Diagnosis —

Implementation Timeline: 1–2 Years

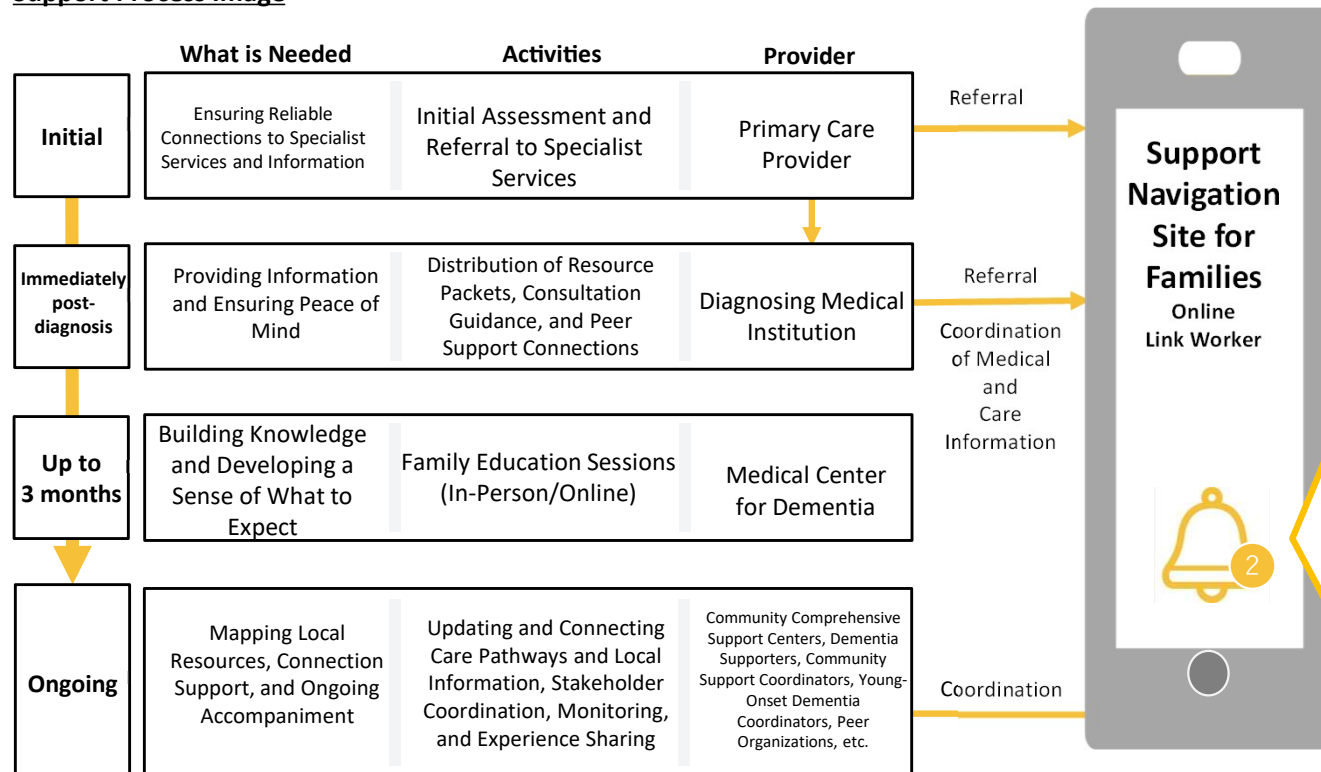
Implementation Timeline: 3–5 Years

Implementation Timeline: 5+ Years

Purpose and Overview of the Measure

Establish a system to ensure that families and caregivers of people newly diagnosed with dementia are reliably connected to support during the uncertain period immediately following diagnosis. Drawing on systems such as Scotland’s Post-Diagnostic Support (PDS), which provides accompaniment to help individuals plan for the future from immediately after diagnosis, and adapting such approaches to the Japanese context based on the community-based integrated care system, this recommendation proposes the construction of a navigation site rooted in Japan’s existing local communities and support infrastructure.

Support Process Image



- I. **Open Information Platform (accessible regardless of diagnosis status):** Aggregate existing support websites and care path information into a single resource providing FAQs on dementia, guidance on the Long-Term Care Insurance System, local resource information, online learning tools, connections to peer support, and more. A system that enables anyone to access the information they need at any time, regardless of whether they have received a diagnosis.
- II. **Diagnosis-linked Individual Support Function (initiated upon confirmed diagnosis):** Starting from the point of confirmed diagnosis, registered families and caregivers receive stage-appropriate information via push notifications. Consultation guidance and services (including online) provided by specialists such as Young-onset Dementia Support Coordinators are also made available. The system includes a triage function based on urgency level, connecting users to appropriate support resources.

Recommendation 1: Online Link Worker

— Building a Navigation Site Starting from the Point of Diagnosis —

Implementation Timeline: 1–2 Years

Implementation Timeline: 3–5 Years

Implementation Timeline: 5+ Years

Points Requiring Further Consideration

- **Reaching families and caregivers before diagnosis or who are not connected to support**

While this proposal designs support for families and caregivers starting from the point of diagnosis one must not overlook the fact that outreach to families and caregivers before diagnosis or those who have become isolated for various reasons is equally important.

- **Strengthening initial connections at medical institutions**

It has been noted that the push from the medical side to connect families to social resources and support after diagnosis is weak. The proportion of families who feel they have received adequate information is low, and information about how to use the Long-Term Care Insurance System and peer support is particularly difficult to reach. To ensure reliable connection to the navigation site, standardization of information provision at medical institutions and training for medical professionals, including primary care physicians, are necessary.

- **Assessment and support triage at the time of diagnosis**

It is necessary to develop a mechanism for at least briefly assessing the situation of families and caregivers at the time of diagnosis and triaging the direction of needed support (information provision, psychological support, connection to social resources, etc.). This point requires coordination with the family assessment proposed in Recommendation 2 (remuneration for professionals' support of families and caregivers).

- **Responding to families and caregivers who do not use support**

While respecting the choice to "not participate" or "not use services for now," a system that enables relevant parties to reach out when needed is necessary. In particular, for families and caregivers with significant time constraints, such as working carers, mechanisms that deliver information naturally along their daily routines and online support accessible at any time are important.

Recommendation 1: Online Link Worker

— Building a Navigation Site Starting from the Point of Diagnosis —

Implementation Timeline: 1–2 Years

Implementation Timeline: 3–5 Years

Implementation Timeline: 5+ Years

Points Requiring Further Consideration

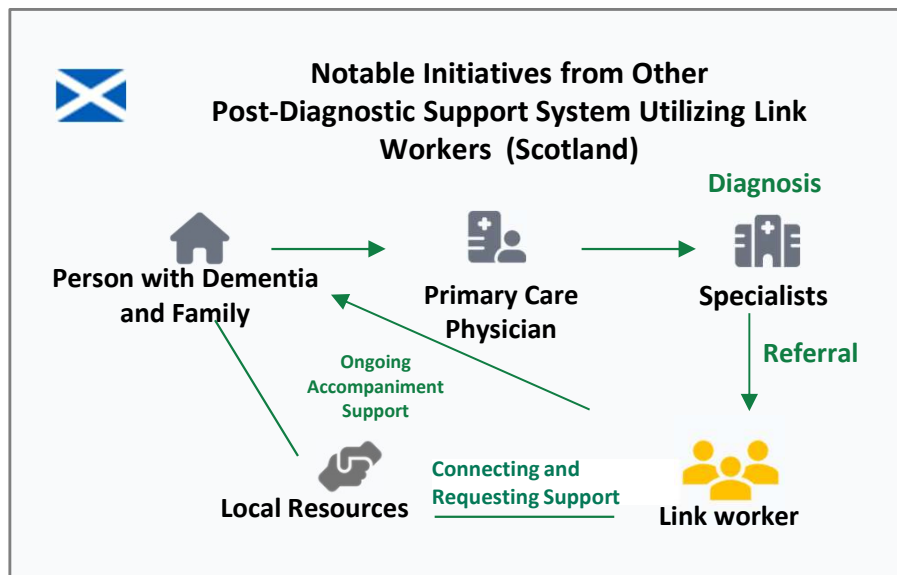
- **Alignment with existing initiatives**

Consolidation and integration of various websites need to be considered.

- **Addressing regional disparities in social resources and the digital divide**

Given regional disparities in available social resources, it is necessary to promote wide-area coordination and enrich online content. Measures to support those unfamiliar with digital devices should also be considered.

Reference



Recommendation 2: Remuneration for Family Support: Institutional Recognition of Professional Support Based on Assessment

Implementation Timeline: 1–2 Years

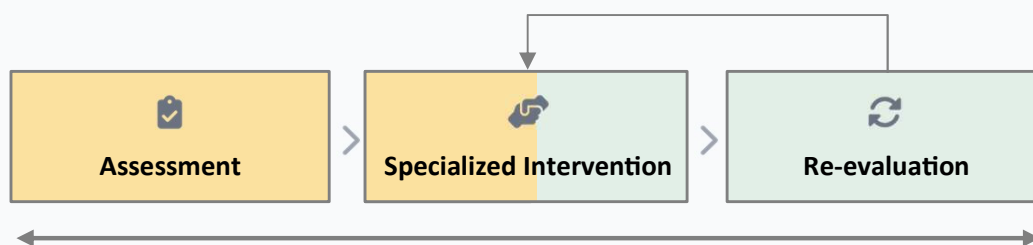
Implementation Timeline: 3–5 Years

Implementation Timeline: 5+ Years

Purpose and Overview of the Measure

This recommendation aims to embed family and caregiver support into the system as a sustainable mechanism by advancing the following three elements in an integrated manner.

- I. **Introduction of remuneration based on assessment and process evaluation: Establish new add-on fees under medical fee reimbursement and nursing care compensation for the entire process from assessment of families and caregivers through support provision and re-evaluation.**
- II. **Reducing practitioner burden and ensuring well-being: To ensure that family and caregiver support does not become an additional workload but is compatible with the well-being of professionals, the improvement of working environments and working conditions shall be a requirement for billing.**
- III. **Systematic education and assessment skill development for family support: Standardize the content and items of assessment items targeting families and caregivers, and develop training programs to support the acquisition of corresponding skills. Completion of such training shall be a facility requirement for billing.**



Conduct assessments of families and caregivers, and based on the results, consider and provide necessary support. Rather than a one-time evaluation, perform regular assessments and monitoring in both medical and long-term care settings, reviewing support content and connecting to continuous support. This enables appropriate tracking of changes in the condition and support needs of families and caregivers, delivering continuous and responsive support. Establish new add-on fees for this entire process.

Recommendation 2: Remuneration for Family Support: Institutional Recognition of Professional Support Based on Assessment

Implementation Timeline: 1–2 Years

Implementation Timeline: 3–5 Years

Implementation Timeline: 5+ Years

Key Players and Their Roles (Examples)

MHLW	Standardization of assessments, revision of medical fee reimbursement and nursing care compensation, design and notification of detailed billing criteria
Central Social Insurance Medical Council (Chuikyo)	Deliberation on medical fee reimbursement revisions
Medical institutions / Long-term Care Facilities, etc.	Implementation of assessments and provision of necessary care, improvement of working conditions and work environments
Professional Associations	Implementation of education programs for medical and long-term care professionals, involvement in standard-setting
Care Managers, Community Comprehensive Support Centers, etc.	Provision of necessary care based on assessments and coordination with medical institutions

Points Requiring Further Consideration

- **Distinguishing from routine duties and system design**

Since many professionals already provide family support as part of routine duties, the key challenge in system design is drawing the line for "what constitutes specialized support eligible for add-on fees." It is necessary to clearly define this as systematic support based on assessment, distinct from routine medical care and caregiving. At the same time, ensuring family understanding and acceptance of the user co-payment that accompanies the add-on fee is also required.

Recommendation 2: Remuneration for Family Support: Institutional Recognition of Professional Support Based on Assessment

Implementation Timeline: 1–2 Years

Implementation Timeline: 3–5 Years

Implementation Timeline: 5+ Years

Points Requiring Further Consideration

- **Incorporating process evaluation**

There is a risk that assessment implementation may become a formality without leading to improved quality of family support. Rather than measuring outcomes solely through short-term numerical indicators, a process evaluation perspective should be incorporated to assess whether families and caregivers feel comfortable seeking consultation and whether the support system is functioning effectively.

- **Understanding from medical institution leadership and organizational positioning**

A prerequisite is that the leadership and management of medical institutions understand the importance of family support in sustaining the lives of people with dementia and establish an organizational structure for this work. While maintaining a fundamental posture of community engagement regardless of remuneration, coordination with remuneration should be considered.

- **Specific mechanisms for improving working conditions**

A design ensuring that add-on fee revenue is reliably reflected in improved working conditions for professionals is necessary. Specific mechanisms such as incorporating working condition improvement requirements into facility criteria and allocating add-on revenue to working condition improvements should be considered.

- **Evaluation of family support under Community Support Projects**

For family support in areas that fall between systems or at the preventive stage, which cannot be fully evaluated under medical fee reimbursement or nursing care compensation frameworks, the approach to evaluation under frameworks, such as Community Support Projects should be examined.

Recommendation 2: Remuneration for Family Support: Institutional Recognition of Professional Support Based on Assessment

Implementation Timeline: 1–2 Years

Implementation Timeline: 3–5 Years

Implementation Timeline: 5+ Years

Points Requiring Further Consideration

- **Specifying and standardizing assessment items for families and caregivers**

Current assessments related to families and caregivers are highly abstract, and variation in evaluation tends to occur depending on individual expertise and experience. From the perspective of cross-disciplinary professional involvement in assessment, standardized evaluation items are needed to more concretely and consistently capture care burden, psychological state, and impact on daily life, while minimizing assessor-dependent variation. At the same time, standardization of assessment items should be positioned as a means of enhancing the quality and consistency of support, not as mere administrative formality.

- **Strengthening education and training for medical and long-term care professionals**

Systematic training for professionals, including Care Managers, on assessment and support techniques for family support is needed. In particular, the acquisition of practical skills for appropriately understanding the emotions and burdens of families and connecting them to support is important. Education and training should be paired with incentives for professionals and reduction or adjustment of workload.

- **Strengthening and using the primary care function**

Reaching a confirmed diagnosis of dementia typically requires multiple visits, and continuous assessment to ensure the quality of the diagnostic process, as well as evaluation of post-diagnostic follow-up, should be strengthened. Specifically, it is worth examining the addition of instruments such as the Functional Assessment Staging Test (FAST) and Dementia Assessment Sheet (DASC-21) to the billing requirements for the "Community Comprehensive Care Add-on" under the "A001 Follow-up Visit Fee" in the medical fee schedule.

Recommendation 3: Cafes of Choice: Visualizing Dementia Cafe Functions Through Tagging and Building a Coordination Framework

Implementation Timeline: 1–2 Years

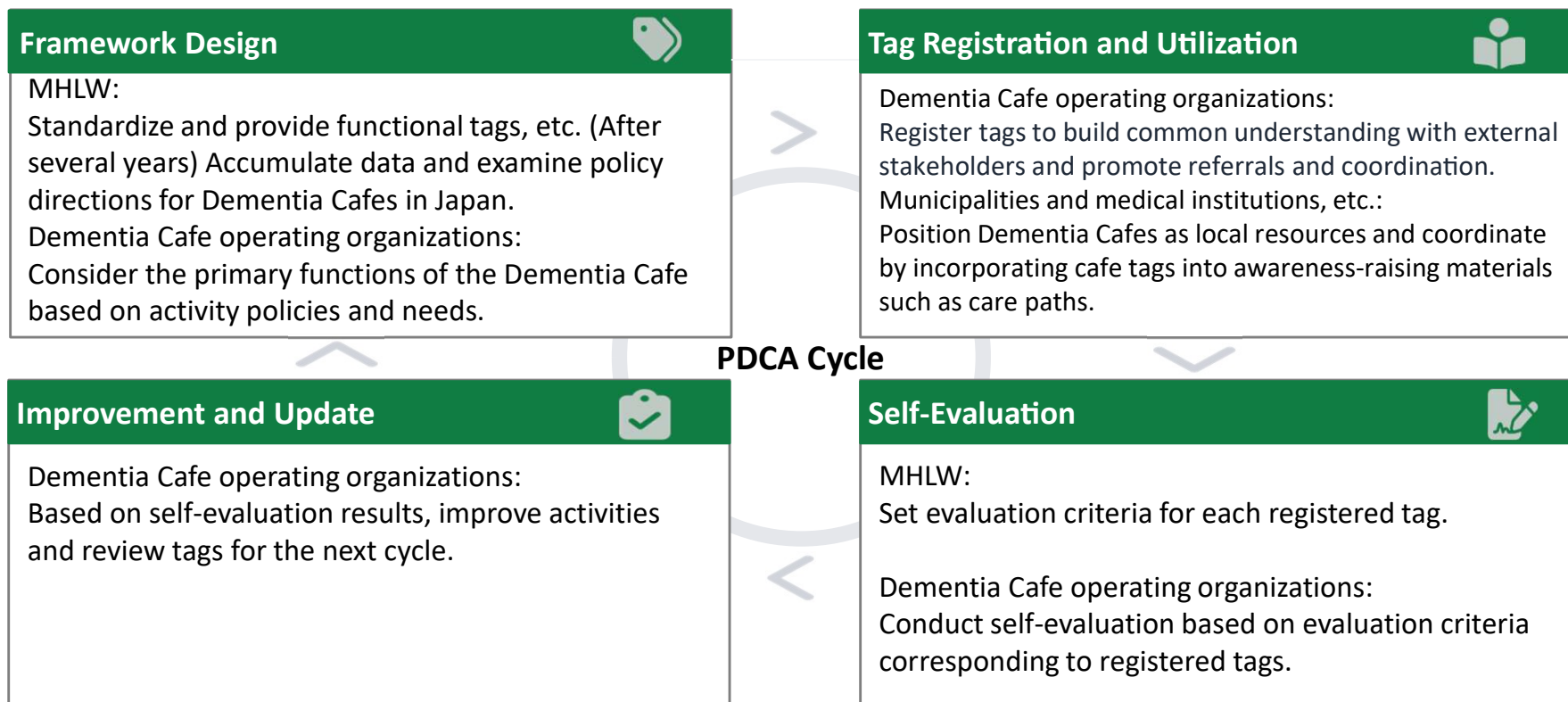
Implementation Timeline: 3–5 Years

Implementation Timeline: 5+ Years

Purpose and Overview of the Measure

Make visible the diverse functions that Dementia Cafes can serve in supporting families and caregivers, and develop an environment where families and caregivers and relevant parties can easily find cafes that match their needs. This will reduce the psychological and informational barriers to participation and promote coordination among medical, long-term care, and community stakeholders.

While respecting the autonomy and local character of each cafe, present a common organizing framework to foster a shared sense of "what to expect" from Dementia Cafes and to build a foundation for policy support.



Recommendation 3: Cafes of Choice: Visualizing Dementia Cafe Functions Through Tagging and Building a Coordination Framework

Implementation Timeline: 1–2 Years

Implementation Timeline: 3–5 Years

Implementation Timeline: 5+ Years

Key Players and Their Roles (Examples)

MHLW	Formulation of policy proposals including tags and supplementary display items
Municipal governments	Management and utilization of tagging, dissemination of the system to Dementia Cafe operating organizations and coordination
Dementia Cafe operating organizations	Selection and registration of tags, dissemination to local stakeholders

Points Requiring Further Consideration

- **Positioning Dementia Cafes within the overall care pathway**

Dementia Cafes are one of many community support resources, and their roles partly overlap with family groups, day services, and Community Comprehensive Support Centers. Using tagging as an opportunity, it is necessary to clarify the primary areas that Dementia Cafes serve within the care pathway and to organize their differentiation from and coordination with other support resources.

- **Balancing tagging operations with flexibility**

Dementia Cafes have expanded nationwide precisely because of their high degree of flexibility. To prevent tagging from leading to uniformity or excessive management, it should be operated as a flexible framework aimed at fostering a shared sense of "what to expect." Tags should not be fixed but designed to be flexibly updated as activities evolve.

Recommendation 3: Cafes of Choice: Visualizing Dementia Cafe Functions Through Tagging and Building a Coordination Framework

Implementation Timeline: 1–2 Years

Implementation Timeline: 3–5 Years

Implementation Timeline: 5+ Years

Points Requiring Further Consideration

- **Addressing the psychological barrier to participation**

While tagging is expected to lower informational barriers, the psychological barrier to attending a cafe for the first time remains high. Particular attention should be given to the fact that supplementary display items such as "stage of progression or type of dementia" may create resistance at early stages due to concerns about disclosing one's condition to the community. Outreach approaches beyond information dissemination, such as personal invitations by local stakeholders, should also be examined.

- **Integration with the perspective of the person with dementia**

This recommendation proposes tagging from the perspective of family and caregiver support, but Dementia Cafes also serve functions for social participation and empowerment of the person with dementia, as well as support for local residents. In the future, expanding the tagging system to incorporate the perspective of the person with dementia should be considered.

- **Deployment adapted to local characteristics**

Since the number and variety of available cafes differ between urban and rural areas, flexible approaches adapted to local conditions are needed in the operation of tagging. Where tagging reveals a shortage of cafes in specific areas, approaches such as establishing new cafes with financial support and creating diverse Dementia Cafe deployment models through public-private-academic-civic collaboration should be explored.

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Implementation Timeline: 1–2 Years

Implementation Timeline: 3–5 Years

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Recommendation 4: Reaching Families and Caregivers Through the Workplace Developing Consultation Functions and Gatekeepers at the Insurer Level

Implementation Timeline: 1–2 Years

Implementation Timeline: 3–5 Years

Implementation Timeline: 5+ Years

Purpose and Overview of the Measure

Establish consultation functions related to caregiving within companies, and by creating an environment where employees who provide care while working can feel secure in seeking advice from an early stage, promote the prevention of work separation due to caregiving and the stabilization of daily life in an integrated manner. The role of companies is not to take on all aspects of support, but to function as gatekeepers who notice employees' difficulties and connect them to appropriate resources.

However, to make such initiatives effective, it is necessary to recognize that dementia care can have characteristics that differ from childcare, such as the lack of a clear temporal endpoint; ambiguity about who holds decision-making authority regarding service introduction (the person themselves, spouse, children, etc.); and particularly in cases where children provide care for a parent, the difficulty of intervening in family relationships between parents and children, which adds complexity.

Recommendation 4: Reaching Families and Caregivers Through the Workplace Developing Consultation Functions and Gatekeepers at the Insurer Level

Implementation Timeline: 1–2 Years

Implementation Timeline: 3–5 Years

Implementation Timeline: 5+ Years

Purpose and Overview of the Measure

Overall picture of the support model

Clarify the first point of consultation (primary consultation) that employees access, based on their insurance enrollment and in-company resources, and build a structure that supplements gaps through industry- or joint-level frameworks. In primary consultation, the employee's situation is assessed through interviews and counseling, the direction of support is considered together with the employee, and when necessary, they are connected to community resources (Community Comprehensive Support Centers, medical institutions, long-term care services, etc.).

Scope of support

The target stage is not limited to the period after long-term care certification but extends from the unaware stage, around the time of diagnosis, and the period before long-term care certification. In addition to individual consultations, the approach includes raising basic awareness about caregiving and available systems through companies from the stage before caregiving begins, forming a foundation that enables employees to seek consultation and take action on their own when the need arises.

Recommendation 4: Reaching Families and Caregivers Through the Workplace

Developing Consultation Functions and Gatekeepers at the Insurer Level

Implementation Timeline: 1–2 Years

Implementation Timeline: 3–5 Years

Implementation Timeline: 5+ Years

Key Players and Their Roles (Examples)

MHLW / Ministry of Economy, Trade and Industry (METI)	Formulation of guidelines, implementation of model projects, coordination with KENKO Investment for Health policies
Insurers (health insurance societies, Japan Health Insurance Association, etc.)	Development of shared insurer consultation services, reflection in Data Health Plans
Companies	Establishment of consultation functions, cultivation of organizational culture, formulation of work-care balance plans
Municipalities / Community Comprehensive Support Centers	Connection to community resources, support for self-employed individuals, etc.
Industry Associations	Establishment and operation of shared consultation services for SMEs

Points Requiring Further Consideration

- **Avoiding excessive burden on Community Comprehensive Support Centers and examining bridging functions**

Community Comprehensive Support Centers are already overburdened. To ensure that consultations from the workplace do not become an additional burden, it is necessary to clarify the division of roles between primary workplace consultation functions and community resources, and to properly triage consultation destinations. At the same time, reviewing and optimizing existing duties, and strengthening the function of Community Comprehensive Support Centers as hubs that coordinate diverse professionals including lawyers and tax accountants, are necessary.

Recommendation 4: Reaching Families and Caregivers Through the Workplace Developing Consultation Functions and Gatekeepers at the Insurer Level

Implementation Timeline: 1–2 Years

Implementation Timeline: 3–5 Years

Implementation Timeline: 5+ Years

Points Requiring Further Consideration

- **Implementing a "translation" function between workplace and community**

There is a gap between the logic prioritized by companies (productivity, operational efficiency, etc.) and the logic of the community (welfare, daily living support, etc.), and a coordinating/translation function to bridge the two is essential. Furthermore, if personnel responsible for primary consultation are expected to play this role, ensuring their expertise becomes a challenge. As well as the clarification of roles vis-à-vis existing professionals (social insurance and labor consultants, occupational health professionals, etc.), it is important to pursue a direction of leveraging and enhancing existing resources rather than simply creating new qualifications or positions.

Recommendation 4: Reaching Families and Caregivers Through the Workplace

Developing Consultation Functions and Gatekeepers at the Insurer Level

Implementation Timeline: 1–2 Years

Implementation Timeline: 3–5 Years

Implementation Timeline: 5+ Years

Points Requiring Further Consideration

- **Approaches to supporting self-employed individuals**

Self-employed individuals are prone to falling outside workplace-based support frameworks, and they face unique challenge, such as the direct loss of income and risk of business closure when taking time off. As enrollees in the National Health Insurance, their primary point of consultation would be the Community Comprehensive Support Center, but as highlighted in the previous point, these centers are already overburdened. Concrete measures to support the balance of continued work and caregiving need to be developed.

- **Privacy considerations and entry point design for consultations**

Given the tendency of employees to avoid disclosing caregiving responsibilities for fear of career repercussions, consultation design that reconciles the need for privacy ("not wanting the company to know") with the need for early intervention is required. It should also be noted that families may not necessarily feel they "want to receive support," and entry points should be designed so that consultation feels natural, as part of health management or mental health support.

- **Responding to cases where the person and family do not reside in the same area**

With the increase in caregiving by family members who do not live together, there are many cases requiring coordination across the residential areas of the person with dementia and the caregiver, such as long-distance caregiving. It is necessary to build pathways for information sharing between workplace consultation functions and the Community Comprehensive Support Centers and medical/care services in the area where the person with dementia resides.

Implementation Timeline: 1–2 Years

Implementation Timeline: 3–5 Years

Implementation Timeline: 5+ Years

Purpose and Overview of the Measure

Establish a system for providing evidence-based psychological support, including cognitive behavioral therapy (CBT), to families and caregivers who support people with dementia, in a multi-component, multi-disciplinary, and phased manner. This aims to alleviate the psychological burden on families and caregivers, protect their well-being, and support the physical and mental stability and continued independent living of the person with dementia. At the same time, ensure that families and caregivers in need of support can access appropriate psychological support.

Standardization of psychological support: Develop and validate a standard model combining the following three elements, based on stratification according to burden levels and severity (indirect support, moderate support, intensive support);

- I. Provision of accurate knowledge about dementia (psychoeducation): Enable families and caregivers to gain a sense of perspective by understanding the condition, learning specific coping strategies for BPSD, and acquiring caregiving skills.
- II. Practical skills in caregiving and communication: Provide opportunities to learn tips for care, including environmental adjustments.
- III. Support for cognitive restructuring and emotional regulation: Support adaptive coping through shifting perspectives on dementia and care and adjusting how emotions are processed.

The support process consists of five stages: Screening (identification of high-risk groups) → Assessment (evaluation of burden and needs) → Intervention (implementation of psychoeducation, etc.) → Evaluation (outcome measurement and review) → Follow-up (ongoing support).

Implementation Timeline: 1–2 Years

Implementation Timeline: 3–5 Years

Implementation Timeline: 5+ Years

Purpose and Overview of the Measure

Establishing access pathways: Develop the following two pathways for families and caregivers to reach psychological support;

- a. Development of online programs: Provide short programs that families can view and experience in spare moments to strengthen stress management and related skills.
- b. Development of training in psychological care for professionals: With Medical Centers for Dementia serving as hubs, provide opportunities for various professionals to learn CBT-based approaches and intervention methods. Build a system enabling each professional to deliver support in their own practice setting.

Pathway from Demonstration to Institutionalization

This recommendation aims for institutionalization after verifying the effectiveness of intervention protocols through model projects. While coordinating with the process from assessment to support proposed in Recommendation 2 (remuneration for professionals' support of families and caregivers), the future positioning of specialized psychological interventions under medical fee reimbursement should be examined.

Points Requiring Further Consideration

- **Standardization of intervention protocols**

Standard protocols need to be developed through model projects regarding the components of multi-component interventions, criteria for allocating to each tier (indirect support, moderate support, intensive support), and the frequency and duration of interventions. In doing so, rather than making specific methods a billing requirement, the process itself, including assessment, intervention, and re-evaluation, should be made the basis of evaluation, allowing for phased refinement and the accumulation of evidence.

Implementation Timeline: 1–2 Years

Implementation Timeline: 3–5 Years

Implementation Timeline: 5+ Years

Points Requiring Further Consideration

- **Designing the professions responsible for support and the training system**

Clarification is needed regarding who will deliver each element of psychological support. While psychoeducation and practical skill provision can be delivered by home-visit nurses and care managers along daily routines, advanced psychological interventions, such as cognitive restructuring and emotional regulation will primarily be led by certified psychologists and other specialists. The content and standards of training required for each profession need to be specified, and for cases where empathetic listening alone is insufficient, the development of referral pathways to appropriate professionals is also necessary.

- **Methods for evaluating the subjective experience of families**

In addition to quantitative evaluation using standardized scales, how to incorporate family narratives and subjective experiences into the evaluation of support is a notable challenge. Qualitative evaluation methodologies for capturing changes such as "feeling reassured" or "being able to see a path forward" need to be examined within model projects.

- **Designing a system centered on the holistic well-being of family caregivers**

Families have historically been positioned as "caregiving capacity." To prevent the enhancement of psychological support from being perceived as a policy that presumes "families will continue to provide care," the design must make clear that the purpose of support is the protection of the well-being of the family themselves. There may also be cases where the perspective of supporting the person with dementia and the perspective of supporting the family are in tension, and thoughtful design is needed.

- **System design toward remuneration**

In positioning psychological support within the medical fee reimbursement framework in the future, it is necessary to specify target criteria (screening thresholds, etc.), billing frequency, and the range of eligible professions. While avoiding duplication with the assessment and support process remuneration proposed in Recommendation 2, the institutional framework under which specialized psychological interventions should be evaluated, needs to be examined.

Recommendation 6: Connected Care through Digital Transformation: Building an Information-Sharing Platform Among Medical, Long-Term Care, and Family Stakeholders

Implementation Timeline: 1–2 Years

Implementation Timeline: 3–5 Years

Implementation Timeline: 5+ Years

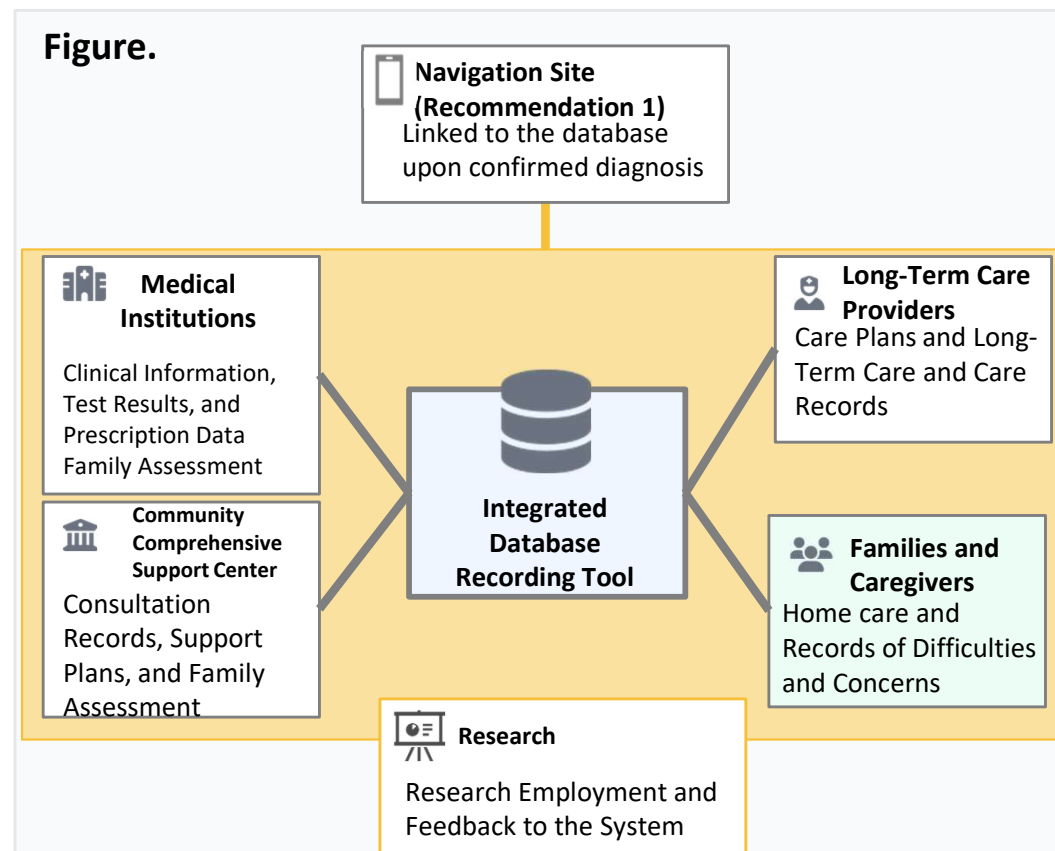
Purpose and Overview of the Measure

Develop a platform that promotes safe and seamless information sharing about the condition of people with dementia among medical, long-term care, family and stakeholders. Through the centralization, visualization, and organization of information, enable early detection and rapid response to changes, achieve burden reduction and isolation prevention for families and caregivers. Additionally, build a system for recording and sharing the actual care provided by families and caregivers on a daily basis, thereby enabling the visualization of "invisible care" and contributing to data-driven improvement in the quality of medical care and long-term care, as well as the advancement of research.

This recommendation envisions integrating the information provision platform developed in Recommendation 1 (navigation site), the family assessment introduced in Recommendation 2 (remuneration), and the screening conducted in Recommendation 5 (psychological support), and integrating them into a unified information-sharing platform over the long term.

What this recommendation aims for is the construction of a platform that enables the sharing and utilization of information, currently distributed across medical institutions, long-term care providers, Community Comprehensive Support Centers, and families—with the consent of the person with dementia and their families and caregivers. Specifically, this envisions a system for comprehensively managing and referencing medical records, prescription data, care plans, care records, consultation records, support plans, records of home care by families, and the health status of families.

Figure.



Expected outcomes

- Centralization and visualization of information
- Early detection and response to changes
- Peace of mind and reduced burden for families

Implementation Timeline: 1–2 Years

Implementation Timeline: 3–5 Years

Implementation Timeline: 5+ Years

Points Requiring Further Consideration

- **Consent and agency of the person with dementia**

As a prerequisite for the information-sharing platform, the principle of information sharing based on the person's consent must be established. Anticipating cases where expression of intent may become difficult as dementia progresses, system design should include mechanisms for advance confirmation of wishes and proxy consent. A framework that respects the person's agency in determining "who shares what and to what extent" should be examined.

- **Privacy protection and security**

Since this is a system for sharing information across medical, long-term care, and daily living domains, it is necessary to ensure alignment with legal frameworks including the Act on the Protection of Personal Information, and to design information management, access permissions, and security systems. Standards for how far life information recorded by families may be shared with professionals and research institutions should also be examined.

- **Alignment with existing information platforms**

Existing information platforms such as My Number Portal, electronic medical records, long-term care record systems, the Long-term Care Information system For Evidence (LIFE), long-term care information infrastructure, and municipal consultation record systems have been developed independently for each domain and purpose. In building this platform, the policy for linkage and integration with these existing systems needs to be clarified. The technical and operational connection with the navigation site constructed in Recommendation 1 should also be examined.

Recommendation 6: Connected Care through Digital Transformation: Building an Information-Sharing Platform Among Medical, Long-Term Care, and Family Stakeholders

Implementation Timeline: 1–2 Years

Implementation Timeline: 3–5 Years

Implementation Timeline: 5+ Years

Points Requiring Further Consideration

- **Addressing the recording burden on families and the digital divide**

To ensure that recording and sharing of care does not become an additional burden for families and caregivers, simple input methods and automated recording mechanisms need to be explored. Measures to support those unfamiliar with digital devices, such as the combined use of analog methods and the development of support systems, are also needed.

- **Units for wide-area coordination and operational systems**

How to define the geographic scope of information sharing (secondary medical care areas, municipal units, etc.) is an important issue that encompasses responses to long-distance caregiving. Sustainable structures for those who will operate, maintain, and update the platform also need to be examined.

Recommendation 7: Mutual Aid System for the Future:

Building a Support Scheme for Sustaining and Expanding Community-Based Mutual Aid

Implementation Timeline: 1–2 Years

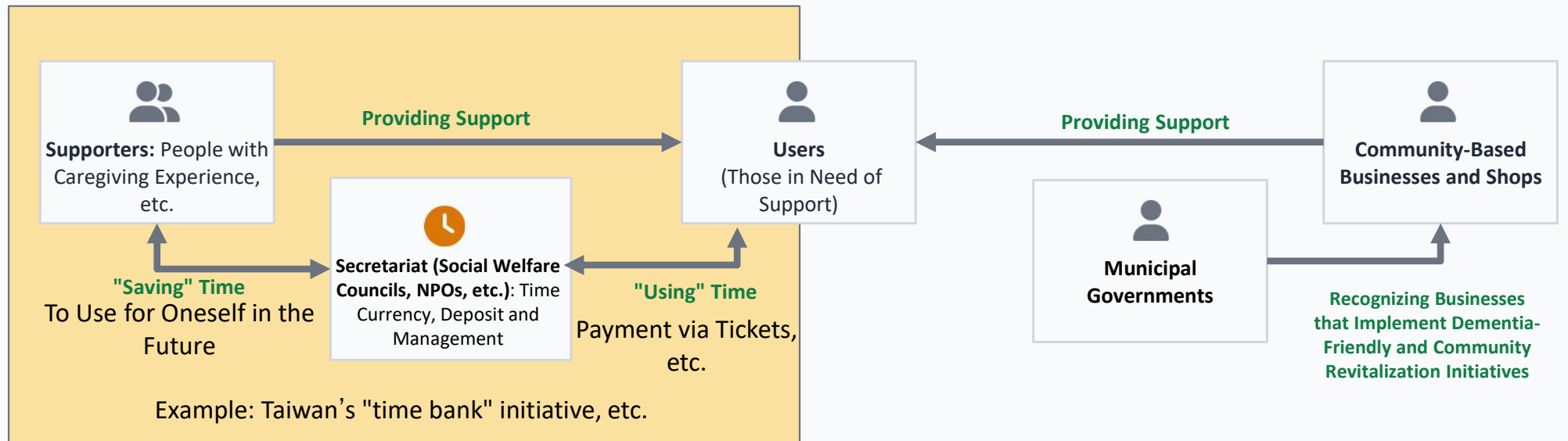
Implementation Timeline: 3–5 Years

Implementation Timeline: 5+ Years

Purpose and Overview of the Measure

Restructure community-based mutual aid initiatives from a model dependent solely on goodwill into a sustainable system. By developing a reciprocal framework in which the experience and time of supporting others is reciprocated as support for oneself in the future, reduce the psychological resistance to receiving support and create a community in which both supporters and recipients can participate with peace of mind. At the same time, leverage private-sector vitality and digital technology to build a mechanism for mutual support.

Mechanism



Specific Use Cases	Light Assistance	Transportation and Outings	Social Interaction and Monitoring
	<ul style="list-style-type: none"> Changing Light Bulbs, Taking Out Garbage Weeding the Garden 	<ul style="list-style-type: none"> Accompanying for Shopping Accompanying to Medical Appointments Accompanying for Walks 	<ul style="list-style-type: none"> Monitoring and Welfare Checks Providing Community Spaces

Expected Outcomes
<ul style="list-style-type: none"> Community revitalization: Regeneration of weakened neighborhood ties and fostering a culture of mutual aid Purpose and role creation: Promoting social participation by enabling those with past caregiving experience or those available to help at a given time to become "supporters" Reducing psychological burden: Aiming to lower the psychological resistance to receiving support through a "mutual benefit" framework

Recommendation 7: Mutual Aid System for the Future:

Building a Support Scheme for Sustaining and Expanding Community-Based Mutual Aid

Implementation Timeline: 1–2 Years

Implementation Timeline: 3–5 Years

Implementation Timeline: 5+ Years

Points Requiring Further Consideration

- **Sustainable operational structures and funding**

The greatest challenge is who will handle secretariat functions such as managing time currency and matching supporters with recipients, and with what structure. Social welfare councils and NPOs are envisioned as potential operators, but securing funding for operational costs and building personnel structures are essential. Since the aim is a system that does not depend on goodwill, a design in which the operation of the system itself depends on goodwill would be contradictory.

- **Ensuring the quality and safety of support**

Mutual support by residents differs in nature from services provided by professionals. Since there are situations in which some knowledge and skills in responding to people with dementia are required, mechanisms for basic training of supporters and response to accidents and incidents during support (insurance, liability, etc.) need to be established. This can be coordinated with volunteer development at Dementia Cafes in Recommendation 3.

- **Clarifying the relationship with existing community activities and volunteer systems**

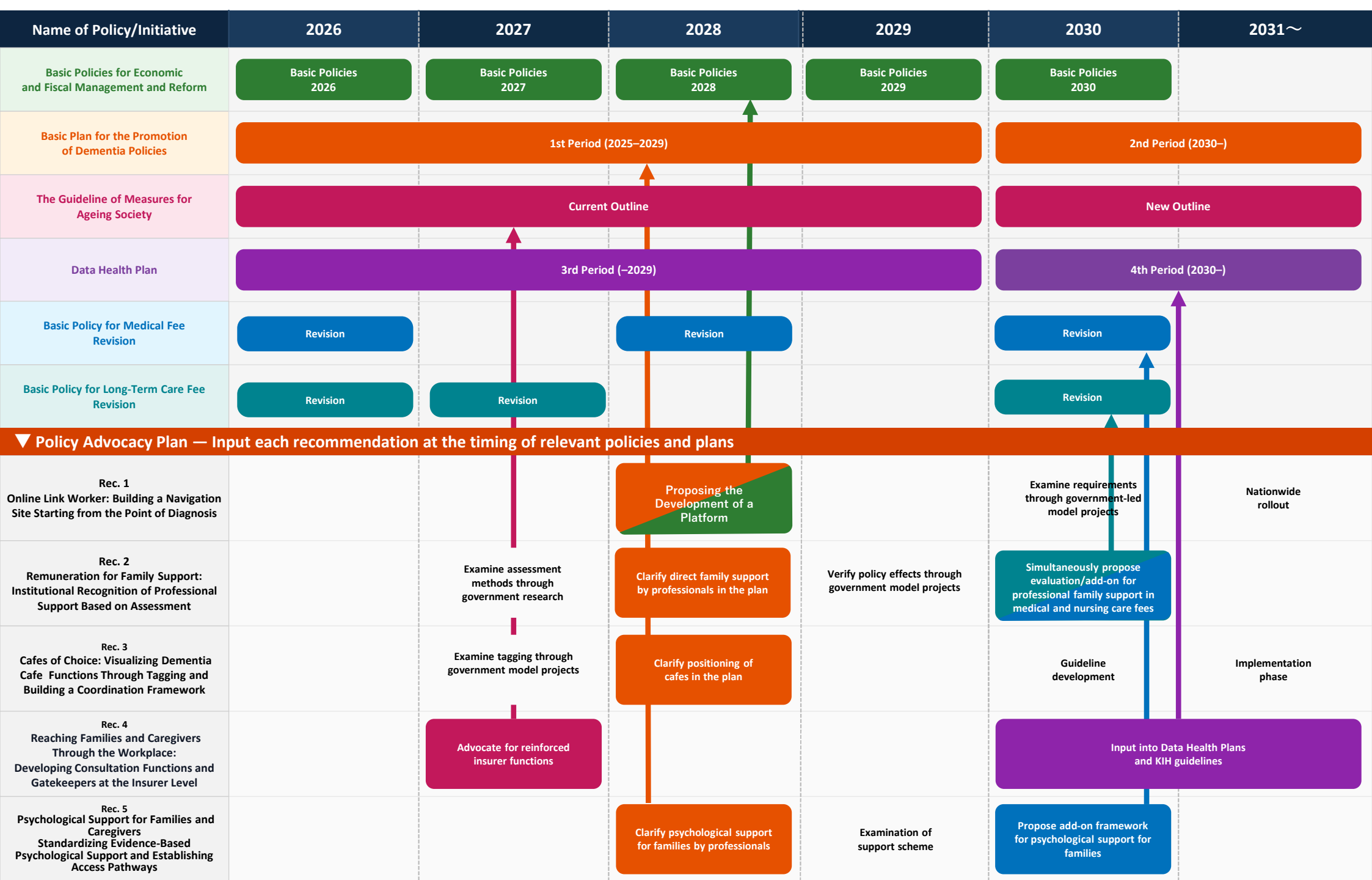
Various mutual aid initiatives already exist in communities, such as the Long-term Care Prevention Volunteer Point Program, Dementia Supporter activities, and monitoring activities by Welfare Volunteers. To ensure that a new system does not overlap or compete with these, the differentiation from and coordination with existing activities need to be organized.

- **Securing and motivating "supporters"**

While participation of former caregivers as "supporters" can contribute to social return of experience and the creation of purpose, for those who have just finished caregiving, it may also pose a psychological burden. In addition to offering choices regarding timing and manner of participation, a design that makes the reciprocity of future returns tangible is important for motivating participation.

- **Diversifying models to match local characteristics**

Relationships among residents, available transportation, and social resources differ significantly between urban and rural areas. Rather than a one-size-fits-all model, flexible designs offering multiple schemes that municipalities can select and combine according to local conditions are needed.



[Legend] Upper rows: Schedule of existing policies/plans (reference lines);

Below the red band: Advocacy actions for each recommendation (timing for policy input); Color coding: Policies/measures targeted for input

April 2026

Health and Global Policy Institute: Guidelines on Grants and Contributions

As an independent, non-profit and non-partisan private think tank, HGPI complies with the following guidelines relating to the receipt of grants and contributions.

1. Approval of Mission

The mission of HGPI is to achieve citizen-centered health policy by bringing stakeholders together as an independent think-tank. The activities of the Institute are supported by organizations and individuals who are in agreement with this mission.

2. Political Neutrality

HGPI is a private, non-profit corporation independent of the government. Moreover, we receive no support from any political party or other organization whose primary purpose is political activity of any nature.

3. Independence of Project Planning and Implementation

HGPI makes independent decisions on the course and content of its projects after gathering the opinions of a broad diversity of interested parties. The opinions of benefactors are solicited, but the Institute exercises independent judgment in determining whether any such opinions are reflected in its activities.

4. Diverse Sources of Funding

In order to secure its independence and neutrality, HGPI will seek to procure the funding necessary for its operation from a broad diversity of foundations, corporations, individuals, and other such sources. Moreover, as a general rule, funding for specific divisions and activities of the Institute will also be sought from multiple sources.

5. Exclusion of Promotional Activity

HGPI will not partake in any activity of which the primary objective is to promote or raise the image or awareness of the products, services or other such like of its benefactors.

6. Written Agreement

Submission of this document will be taken to represent the benefactor's written agreement with HGPI's compliance with the above guidelines.

April 2026

Supporting Organizations (in Japanese syllabary order)

Eisai Co., Ltd.

Otsuka Pharmaceutical Co., Ltd.

Eli Lilly Japan K.K.

Novo Nordisk Pharma Ltd.

Acknowledgement

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