

Building Community-Based Care Systems for Elderly Persons with Memory Loss—A Case Study

by Keiko Yamanashi
Social Development Research Group
yamanasi@nli-research.co.jp

Introduction

We have entered an era in which dementia will affect one in four persons aged 85 and above, and one in two persons aged 95 and above. But unlike the past, senile dementia is no longer viewed with disdain as an abnormality. In fact, radical changes have occurred in the perception of dementia, as well as in care methods and modes. Programs have been initiated that empower people to continue living a normal, dignified life in a familiar environment for as long as possible. This has become possible due to three shifts in the paradigm of care—first, the focus of care has shifted from caregiver to care recipient; second, the site of care has shifted from facility to home; and third, the goal of care has shifted from looking after people to supporting them to live.

1. Dementia Care Focuses on “Sphere of Daily Living”

At present, 3.87 million persons are certified for care or assistance under the Long-Term Care Insurance (LTCI) system. Of these, approximately 40% show symptoms of dementia (level II or above on the senile dementia scale of autonomous activities of daily living).¹ Senile dementia is projected to keep growing and affect 3.85 million persons by 2040, making the disorder a top priority for long-term care (Figure 1).

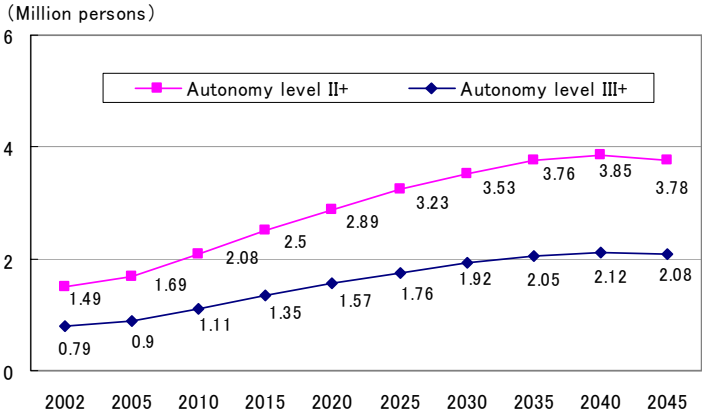
One issue being considered for the fiscal 2006 revision of the Long-term Care Insurance (LTCI) system is a system for 24-hour, 365-day home care, including small-scale, multi-function services.² Ahead of this debate, a report on the future direction of long-term care policies called *Long-Term Care in 2015* (by the Study Group on Long-Term Care, an advisory group to the director of the Health and Welfare Bureau for the Elderly) lays out specific measures to establish a care system that respects people’s dignity by 2015, when all baby boomers will have reached the age of 65. Regarding senile dementia care, the report emphasizes the need for a structure of

¹ Formulated by the Ministry of Health, Labor and Welfare, the scale of autonomous activities of daily living enables people to quickly and objectively assesses the condition of elderly persons diagnosed with dementia by a physician.

² Small-scale, multi-function services support a person’s sphere of daily living by providing an integrated menu of services, such as day care, overnight stay, emergency and night-time visit, and residence. They are currently not designated by LTCI, which recognizes only single-function services.

services to support people in living within their “sphere of daily living.” It calls for community-based systems for early discovery and consultation with specialists, dissemination of knowledge and understanding of dementia among all local residents, and community-wide networks for support and collaboration. The report thus promotes the view that dementia care in the future is inconceivable without the active involvement of local residents and resources.

Figure 1 Number of Persons with Senile Dementia



Notes: Calculated from *Persons Certified for Long-term Care or Assistance and Afflicted with Senile Dementia*, and *Population Projections for Japan: 2001-2050, January 2002* (does not take into account policy factors such as advances in long-term care and medical treatment).
 Source: Ministry of Health, Labor and Welfare, Long-Term Care Study Group, *Long-term Care in 2015*.

The point at issue is how best to prepare communities in caring for persons with senile dementia. To genuinely accommodate their sphere of daily living, collaboration will be essential among local residents and resources. Below we present a case study of one town’s pioneering initiative in senile dementia care.

2. Case Study—Honbetsu, Hokkaido

The town of Honbetsu, located in the northeastern part of the Tokachi District of Hokkaido, has a population of approximately 10,000, of whom 25.9% are at least age 65 (as of 2002). In 2000, the town launched an innovative program to build a community-based care system for elderly persons with dementia under the slogan, “Honbetsu: where people with memory loss can always take a stroll.” The goal was to empower all residents to live to an old age in the community with peace of mind. Based on issues raised by care managers and family caregivers, programs were initiated in seven areas (Figure 2).

Figure 2 Community-Based Care Program for Elderly Persons with Dementia

Measures (2002~2003)	
1. Educational program	<ul style="list-style-type: none"> ▪ Promote understanding of dementia in community ▪ Conduct theatrical performances about LTC, lectures on welfare ▪ Train employees involved in care ▪ Conduct educational activities alongside dementia prevention classes ▪ Conduct educational activities alongside healthcare programs
2. Support for patients and families	<ul style="list-style-type: none"> ▪ Conduct dementia prevention classes ▪ Operate office for consultations regarding memory loss ▪ Enhance care management ▪ Enhance dementia prevention within LTC prevention program, enhance early care for dementia
3. Early detection, diagnosis, and care	<ul style="list-style-type: none"> ▪ Enhance early detection and follow-up system ▪ Enhance collaboration between primary care physician and specialist ▪ Enhance collaboration among participating organizations
4. Support for family caregivers	<ul style="list-style-type: none"> ▪ Have care manager analyze situation of patients and their family ▪ Organize small study classes ▪ Enhance family caregiver's support association
5. Community-based care system for senile dementia	<ul style="list-style-type: none"> ▪ Pursue goal of "Honbetsu: where people with memory loss can always take a stroll"—examine present status, strive for improvement ▪ Construct Memory Loss Community Network in model district of Council on Social Welfare program, with their collaboration
6. Services infrastructure	<ul style="list-style-type: none"> ▪ Establish services to support activities of daily living ▪ Examine role of facilities in supporting activities of daily living within community
7. Patient's rights, family's role	<ul style="list-style-type: none"> ▪ Clarify and protect rights of persons with senile dementia ▪ Examine rights and roles of family ▪ Construct system to protect rights of persons with senile dementia

Source: Compiled by NLI Research Institute

1. Educational Program to Enhance Knowledge and Understanding of Dementia

From the start, the town placed a strong emphasis on spreading knowledge and understanding of dementia. By means of theatrical productions, welfare lectures, health classes, and pamphlets, the town strives to prevent dementia and eliminate prejudice toward dementia.

The theatrical productions are original works with a different theme each year. Familiar topics and real-life examples are staged to draw laughs from the audience, while physicians offer explanations during the performance. The productions convey the need for community support and importance of participation by residents, and suggest ways to participate.

The educational program acknowledges the difficulty families have in mustering the courage to tell others about a family member suffering from dementia. Feeling that other residents know or understand little about dementia, families tend to fear prejudice and discrimination. The family's desire to hide dementia, however, makes the patient more reclusive, and aggravates dementia symptoms. Honbetsu's educational program, which responds to needs expressed by families, is a key element of the community-based care system.

2. Enhanced System for Early Discovery, Diagnosis, and Follow-up Care

Dementia symptoms can be curbed if correctly discovered at an early stage and appropriately dealt with. As soon as dementia is suspected, people are encouraged to consult a special window staffed by employees of the Home Care Support Center and Health Management Center. Depending on the circumstances of their case, they may be referred to services for long-term care prevention, prevention of dementia symptoms, or support for the family; or if necessary, to early diagnosis and treatment at a collaborating medical institution, and use of LTC services. In addition, effective tools have been introduced for early diagnosis—a check sheet for early onset of dementia, and brain fitness checklist—which are designed to detect dementia based on conditions of daily living activities without hurting the pride of the person concerned.

Surprisingly, the consultation window is used by non-family members as well. According to available data, the first person to detect signs of dementia is most often the affected person's long-time friend, followed by the daughter-in-law, and son. According to the town's advisor, Dr. Kazumi Takano of the Hiroshima Prefectural College of Health Sciences, from the start of the community-based system, "There was debate that the program might violate privacy. But we decided the solution was to let the whole town know about the system and reach a consensus: by having the first person to notice symptoms take responsibility in reporting the case, preemptive action can be taken to fight dementia." This stance—that care problems concern not only the immediate family but are the responsibility of every person in the community—is regarded as the cornerstone of the community-based care system.

3. Program to Support Family Caregivers

The family caregivers' support association—a program designated by the MHLW's Future-Oriented Research Project—seeks to reduce the burden on family caregivers. It is staffed by trained and registered volunteers who help fill in gaps in existing services by, for instance, accompanying people on a stroll, conversing with them, or monitoring patients at home when family caregivers are away.

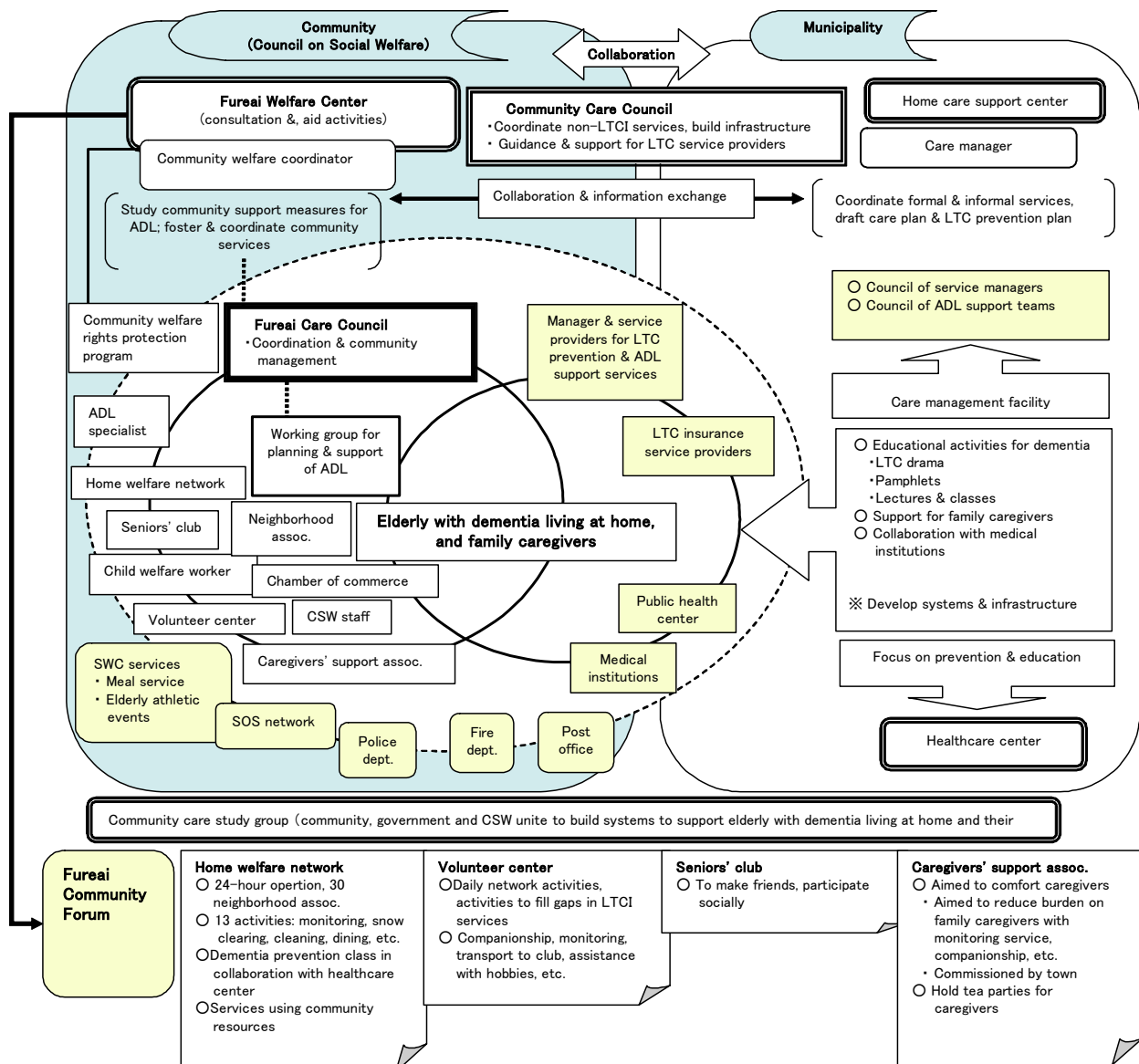
The service is affordable and accessible, with a nominal fee of 100 yen for two hours, and 200 yen for each additional hour. Users and their families are highly satisfied with the service because it is (1) available for long periods, (2) available when LTC service providers take the day off, and (3) takes into consideration the lifestyles and interests of individuals.

Moreover, the service has produced a surprising and unexpected result—it not only serves the intended function as a respite service, but has actually helped improve dementia symptoms. This unexpected bonus effect will be addressed in future studies.

4. Memory Loss Community Network

For persons with senile dementia to continue living in the community, the understanding and support of neighbors is essential. The Memory Loss Community Network was constructed in response to needs cited by family caregivers and care managers: (1) support in monitoring elderly at home when the family is away, (2) venues for community interaction within walking distance, (3) opportunities to share hobby activities with others, and (4) visits to reclusive elderly persons (Figure 3).

Figure 3 Memory Loss Community Network



Source: Report on the Program to Promote Community Care for Senile Dementia in Honbetsu (2003).

The Memory Loss Community Network is operated by the Welfare Center located within the Council on Social Welfare. Local residents provide support by participating in the home welfare

network, volunteer center, family caregivers' support association, and seniors' club. Community welfare coordinators (social workers) from the Welfare Center and care managers collaborate to provide a comprehensive range of services including public services and community support activities.

5. Freedom to Stroll

Five years after being initiated by the public administration and Home Care Support Center, the community-based support program continues to grow, with local residents playing the lead role.

The slogan—"Honbetsu: where people with memory loss can always take a stroll"—expresses the town's basic stance to boldly face the issue of senile dementia. Senile dementia is cast in a new light by redefining roaming behavior as strolling with an alternative objective. In this way, the slogan shifts the concept of care from one that sees roaming as a problem behavior, to one that values the freedom to stroll while taking precautions to protect people from danger.

Taking a Stroll in Honbetsu

When people with senile dementia take a stroll, it may look like they are just roaming around aimlessly. But if you went up to them and asked, they would all give you a sound reason. "If I don't go help, the business will fall apart," says a 95-year-old man, still in the prime of his career. "I was invited to Hanako's birthday party," an 85-year-old woman explains youthfully.

So you see, they do have good reasons. No one is roaming around aimlessly. When they stepped outside, they just temporarily forgot where they were going or why, and instead remembered a new reason. That's why we call it a memory lapse stroll. So let's all watch over them and let them enjoy the stroll.

Dr. Kazumi Takano, advisor to Honbetsu

3. Expectations for Close Care

1. Status of Dementia Care

In facility-based care, where approximately 80% of residents show symptoms of dementia, old and new care methods coexist amid an ongoing transformation in dementia care.

In the past, care focused primarily on the caregiver's convenience. Roaming, for instance, was regarded as a problem behavior to be controlled with long corridors leading nowhere, physical restraints, and isolation-type care. However, in recent years, attitudes toward persons with senile dementia have changed radically. The focus of care is shifting to the patient—care now addresses how elderly persons feel when they roam and what the causes are, with an emphasis on personal

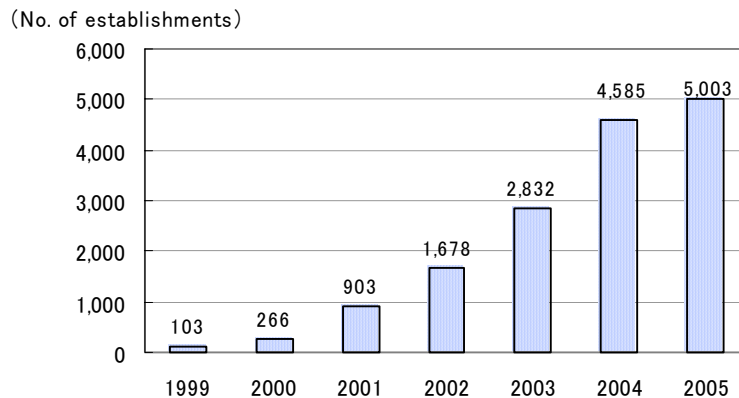
dignity and possibilities for life.

Gone are the once common standardized methods such as making patients wear diapers rather than use the restroom, and making them sit in wheelchairs or tying them down to prevent roaming. Motivated by a strong desire to improve the quality of care, care practitioners have developed new types of services that are small-scale, individualized, and high quality. These include group homes, small-scale multi-function services, and facilities that are subdivided into small units.

As for home-based LTCI services, while home visits and day care have become well established, family caregivers still suffer a heavy physical and mental burden due to communication difficulties and roaming behavior by physically healthy (mobile) elderly persons. In many cases, this burden is difficult to alleviate using existing care services.

One solution is to use group homes for persons with senile dementia (Figure 4). These homes have grown rapidly in recent years and are expected to play a major role. Designated as category 3 residences under LTCI, they are intended for persons with senile dementia who prefer neither facility-based nor home-based care. Aimed at normalization, they practice user-oriented care characterized by a small-scale, home-like environment with close care.

Figure 4 Number of Group Homes for Elderly with Dementia



Note: As of March of each year. For 1999, shows number of establishments receiving state subsidies; from 2000, shows number of establishments listed on WAM-NET.

2. Effectiveness of Care and Characteristics of Dementia

Close care is designed to accommodate the characteristics of dementia. Below we describe basic dementia symptoms and assess the effectiveness of available care.

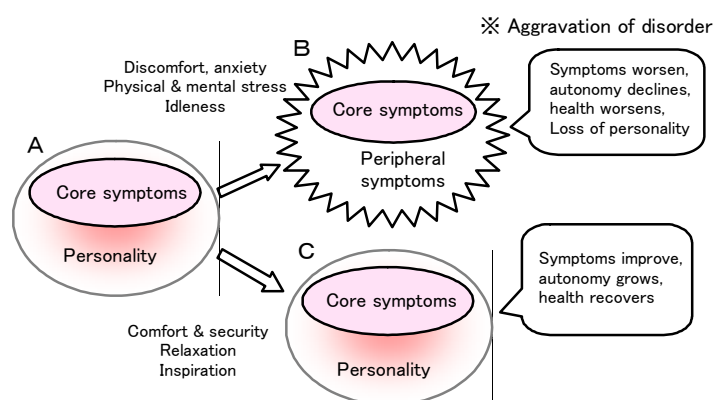
Dementia can be classified into three types: vascular dementia, Alzheimer's type, and other causes. While they differ in characteristics and progression, no fundamental treatment exists for any type. Thus an appropriate form of care is more important than medical treatment in halting

the progress of symptoms.

Dementia symptoms consist of core symptoms and peripheral symptoms. Core symptoms refer to the loss of cognitive functions such as memory loss, disorientation, and learning disability. For example, a person may become unaware of the time or place, or forget the faces of family members.

On the other hand, peripheral symptoms, which include roaming, paranoia, and delusion (symptoms leading to so-called problem behavior), are secondary symptoms aggravated by inappropriate treatment or a change in environment. These symptoms reflect the aggravated psychological state of a person when he or she cannot adequately express stress, anxiety, or discomfort. The new types of dementia care, which emphasize close care, companionship, and respect, are effective in dealing with these symptoms (Figure 5).

Figure 5 Aggravation of Peripheral Symptoms



Source: Compiled by Ms. Kumiko Nagata, chief of research, Tokyo Center for Research and Training in Senile Dementia Care

Moreover, senile dementia decreases a person's ability to adapt to changes in the environment. For example, when a person suffers memory loss, living in an unfamiliar place and being surrounded by strangers can aggravate the sense of anxiety, confusion, loneliness and frustration, thereby sapping what little capability is left. This points to the importance of creating a small, home-like living environment where people can make new friends and acquaintances.

We note here that even though people's memory and cognitive functions become impaired, they still retain their emotional character. They know when they are being treated as unintelligent and incompetent, and repeated instances of shame and humiliation only serve to hurt their pride and confidence. Thus care must be founded on respect for their personality and dignity.

Close care does not refer merely to physical proximity. The method involves building a close relationship, being able to discern what type of support is needed, and enhancing their

capabilities, roles, and enjoyment. It means growing close emotionally to them without severing existing relationships and community ties.

4. Community Living—The Ultimate Form of Care

After considering the characteristics of dementia, we conclude that the best form of care is one that enables persons to continue living in a familiar community setting.

To support this aim, we need to build extensive networks that involve the whole community—including residents, shops, and even newspaper and postal delivery persons—and fill in the gaps in LTCI services with new services such as patient monitoring support and new opportunities for community interaction. Moreover, we must create a community in which people can live with peace of mind, and enjoy the support and understanding of others in the community.

In the town of Honbetsu, Hokkaido, programs have been implemented to ensure that the dignity of elderly people is respected, residents support each other, and the sense of security and warmth is fostered—all so that people can continue living in a familiar community setting. For town residents, the resulting change in awareness has not only generated support for persons with senile dementia and their families, but boosted the overall level of health management to prevent long-term care and dementia.

The most desirable result would be to prevent dementia altogether. Vascular dementia, which causes half of all dementia cases, could be prevented by controlling high blood pressure, diabetes, and high cholesterol with proper health management. Enabling elderly persons to remain healthy for as long as possible is a worthy goal for the aging society, and the educational programs toward this end serve as an effective preventive measure for other residents as well.

Moreover, another positive result occurs from effective LTC prevention measures, greater support for family caregivers by community residents, and more places for elderly persons to visit—residents can rely less on LTCI services. As a result, the town or municipality acting as LTCI insurer also stands to gain by containing benefit costs.

With care now focusing on the sphere of daily living, it is time for municipalities to fashion a unique “municipal insurance framework” that maximizes the value of the long-term care insurance concept. They have the opportunity to create comprehensive and unique community-based care systems that incorporate the community’s characteristics and needs of residents, and that contribute to enhanced collaboration and smooth operation among the municipality, medical and welfare institutions, residents, and local resources. Honbetsu is proof that this is possible.