



Excerpts  
From



**Japan Society for Dying with Dignity Newsletter**  
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As of March 10, 2014, JSDD has 124,351 members.

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**Movement in Legislation**

**A Growing Chance for Legalization of the Living Will bill**

Since February, the Diet has been active with the movement of legalizing the Living Will. The project team formed by the Liberal Democratic Party and the Diet Members Coalition for Dying with Dignity (DMCDD) held respective meetings for further discussions. It was disclosed that both meetings aimed at the submission of the living will bill to legislature during this session (deadline of June 22). With many other important bills which must be passed immediately, the probability of the living will being the priority of discussion is low; however, acceptance of the bill which had been under scrutiny for the past 10 years to move forward would be a huge step for JSDD.

Upon forming the project team on February 5, the Liberal Democratic Party (the ruling party in Japan) invited the President of JSDD, Dr. Soichiro Iwao, and Vice President of Japan Medical Association, Dr Kenji Matsubara to its hearing for the team’s first conference.

The hearing began with Dr. Matsubara (VP of Japan Medical Association) explained the arguments against the statutory movement of the living will by presenting previous medical malpractice cases against physicians and expressed his concern for criminal prosecutions of physicians once it became a law. He stated this logic as follows: “When doing something may lead to being prosecuted, many physicians may feel that it’s better to do nothing. Since physicians are fulfilling their professional moral and ethical obligation, as long as it is agreed that they are immune from criminal prosecution, legalization is not necessary.”

In response, Dr. Iwao presented the results from a recent study conducted by the Ministry of Health, Labor and Welfare on national awareness regarding terminal stage of life, in which 70% of respondents were in support of Advance Healthcare Directive (Living Will), yet only 3% actually had it in writing. He emphasized the likelihood of many patients being forced to accept life prolonging measures against their will just because they do not possess written documents expressing their will regarding their own end of life medical care.

Furthermore, Dr. Iwao stated that currently, most hospitals ask the patients whether they would accept life prolonging measures as part of their admissions process. He stated, “The main issue here is that physicians are constantly put in a difficult position to make professional decisions of removing already administered life prolonging measures, unless statutory immunity for physicians is in place.”

### **Japan Medical Association Dr. Matsubara argues against statutory immunity**

Reports suggest that on February 20, legislative general meeting was held to discuss the two draft bills regarding the living will by both political parties.

The Liberal Democratic Party (the ruling party) formed the project team as mentioned earlier, and published an updated report. The Democratic Party also published a report stating that their next cabinet will make the final decision on the bills.

On the same day, heated discussions continued between Japan Medical Association and JSDD. The first speaker, Takashi Hanyuda, a young member of the House of Councilors argued that Japan Medical Association and other medical organizations have already established medical guidelines for terminal patients, which are much more detailed than the proposed bill. He claimed that there is no need for a new law if these medical guidelines are endorsed by the Judiciary branch.

Dr. Iwao countered the argument that patients’ self-determination is the basis of this law, and that the only way to discuss this issue at national level is by passing this bill legislatively.

### **Current Diet in session at high energy level**

During the project team conference held on February 19, Professor Kiyoshi Kitamura, Medical Education International Research Center at Tokyo University School of Medicine and Mr. Yoshihiro Mizuno, attorney at law of Aichi Bar Association, both proponents of the living will legalization, stated their stands respectively.

Mr. Mizuno, while in support of the living will legalization, pointed out two main issues:

1) It is a fundamental problem that a physician’s decision is regarded as illegal and he/she can be criminally prosecuted when the patient’s wish is not honored.

2) Unless the definitions of “incurable illness” and “terminal stage” are clarified, making proper judgment is difficult.

Professor Kitamura emphasized the necessity of educating medical students the importance of properly taking care of dying patients. He explained that students do not have the opportunities to face dying patients during their rotations in the current curriculum.

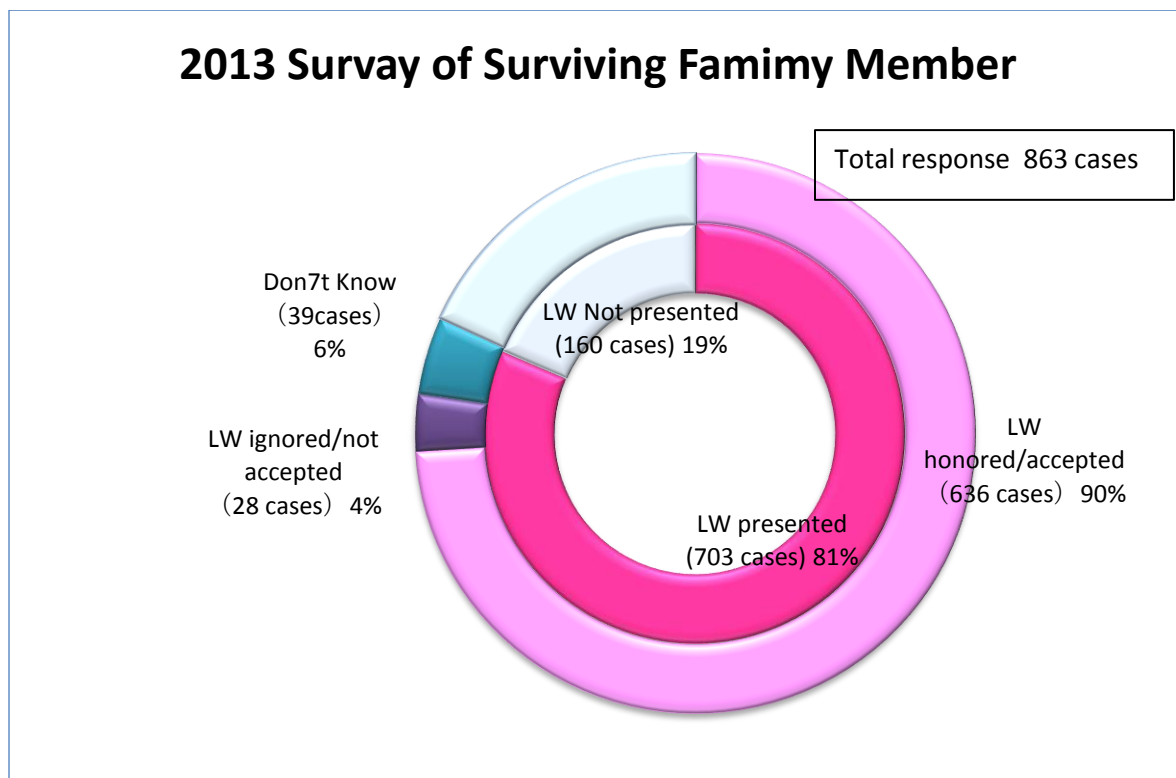
After the conference, Mr. Shunichi Yamaguchi, who presided the conference, answered some questions from journalists by summarizing that a clause will be added to protect disabled persons and that the definition of “terminal stage” must be clarified before pushing this bill in May or June at the latest.

Mr. Mashiko, the leader of DMCDD, also responded to a journalist during the conference held on the 20<sup>th</sup> that his basic target is to present the bill during this Diet session.

### **2013 Survey of Surviving Family Members**

#### **Terminal medical care: 90% of Living Wills were honored**

Results of the 2013 survey revealed that 90% of living wills were honored, although not all cases were simple. In some cases, it worked smoothly as if it was a free pass. For some, it was only accepted after family members provided consent. We must pay attention to the 4% of cases in which patients’ living wills were not honored. This highlights the necessity of legal endorsement in order to resolve this issue. We deeply appreciate the surviving family members for their cooperation with the survey in midst of their mourning.



A total of 863 responded out of 1,358 surveys mailed (64%), of which 703 people either presented their patients' living wills or verbally expressed the patients' wills. As to how the healthcare providers responded to the living wills, 418 respondents (59%) answered that they were "fully honored;" 218 responded that they were "somewhat honored" (31%); a total of 636 (90%) with honored living wills. Responses of "Completely ignored" and "Somewhat ignored" were 4%, and "don't know" responses were 6%.

The percentage of honored living wills was 90% in 2011, 92% in 2012, with the average of 90% in the last three years.

Below are some of the comments we received from families and doctors, which we hope will assist us in determining the most effective method of submitting the living will.



### **Living Wills were honored**

- **Relief for the doctor:** The doctor told us that administering life prolonging measures at that point would only cause more pain and burden on the patient. That's when we showed him the living will. He seemed so relieved that he didn't have to cause any more burden on the patient (Saga Prefecture).
- **JSDD Membership card was the key:** With the membership card, my mother's attending doctor and all the nurses were well aware of her wishes. They never mentioned administering of a feeding tube when she started having problems swallowing food. If she did not possess her membership card, and we only verbally told medical team of her wishes, things would not have gone this smoothly. We realized the importance of the membership card (Hokkaido).
- **Heart breaking reality:** My mother just passed away, and I saw the reality of medical care that I wished I hadn't seen. She was admitted to a rehabilitation hospital, but the patients were all administered feeding tubes, prescribed pain killers and sleeping pills regardless of whether they actually needed them. Is that to save time and jobs? It was such a disheartening phenomenon (Fukuoka Prefecture).
- **My Aunt's dignified death:** My aunt was told that she had only one more month to live, as they explained to her the results of her CT scan. I wanted her to live for a little bit longer, but she presented them with her living will and told them explicitly, "I do not want any life prolonging measures but please give me medication to deal with the pain. I do not want to feel any pain." In my opinion, my aunt had a dignified death (Osaka Prefecture).
- **ALS patient received best care:** My husband, who was of old age and with ALS, had very supportive and caring doctor and nurses, who told him "We'll do our best to care for you in accordance with your wishes." He died at home because his wish was to die in a natural way. We had all the services available to include doctor's checkup visits, nurse's visit care, in-home bathing service and visiting care helper service. They all took such good care of him, and we are all very grateful. He was a JSDD member, and we had no unnecessary stress (Aichi Prefecture).
- **Presenting the JSDD Membership card and switching to palliative care:** I saw some patients who were tube fed at my wife's nursing home. I was shocked and speechless to see that they were unconscious and bed ridden. My wife and I had become JSDD members 20 years ago. When my wife entered her terminal stage, we were asked about life prolonging measures.

We had no reservations about providing them with her JSDD membership card. They switched her medical care from treatments she was undergoing to palliative care. We decorated her room with flowers and played her favorite music. She was able to die peacefully and comfortably (Kanagawa Prefecture).

- Collaboration among many different professionals: As soon as I showed the medical staff of my mother's nursing home her JSDD membership card, they formed a special team for her consisting of doctors, nurses, care helpers, and myself. We had an open communication which directed her final terminal care planning. We all worked as a team to determine and care for my mother to have a smooth and comfortable death (Saitama Prefecture).
- Talking with JSDD consultants gave us a peace of mind: There were no doctors at hospitals for acute patients who gave us any detailed explanations, but rehabilitation center staffs welcomed and gladly accepted my mother's living will. The problem we had was that my sister had a hard time accepting the living will. When we called JSDD, a consultant listened to us very carefully and gave us a peace of mind (Kanagawa Prefecture).

### **Living Wills were submitted, but not honored**

- Why did you call the ambulance for this patient?: My husband's pulse was dropped to 38 and he was in pain, so I called the ambulance. At the hospital, the doctor asked me if we want to administer a pacemaker, so I told him that my husband is a JSDD member. He then asked me, "Then why did you bring him in an ambulance? I'll have to ask you to leave because I have to attend to my job as a doctor." I had no choice but to comply with the doctor since my husband was suffering from excruciating pain. They immediately inserted a tube in his neck and moved him to ICU. All of this happened in a blink of an eye. He eventually suffered from pneumonia and died a month later (Hyogo Prefecture).
- We should've talked more: We were told that stomach feeding may give my father a chance for recovery, so I agreed to it. However, he suffered from reflux of food and repeated cases of pneumonia. He became weaker as more tubes were inserted and never recovered. I regret not talking to him more about details when he became a JSDD member in 1999 (Yamagata Prefecture).
- I couldn't refuse it: When I showed my 95 year old mother's doctor her JSDD membership card, he responded, "I have to do what I have to do." None of my family members knew anything about life prolonging measures, so we had no idea how to refuse them. My impression was that the living will did not work out well (Aichi Prefecture).
- Too busy to talk: Our doctor at the hospital seemed to have the knowledge of the living will, but his attitude was that he had no time to discuss the pros and cons of the living will. He said, "If you're not satisfied, please go to another hospital or take him home and care for him there to spend his terminal stage." I was not confident that I could take care of him at home, so I gave up on the whole idea (Ishikawa Prefecture).



### **Living Wills were not submitted**

- I just wanted her to live longer: My mother told me that she had joined JSDD several years ago and did not want any medical treatments when she died. When the time came, I just wanted her to live longer, so I asked the doctor to do everything possible to save her life. I

didn't submit her JSDD card. I knew what I did was against her wishes, but I just couldn't understand her wishes (Hokkaido).

- Making the right decision: My father had an acute cardio pulmonary failure and was taken to a hospital. The doctor told us that even with life prolonging measures, he would be bed ridden permanently. I didn't think that was what he wanted, so I told the doctor not to administer them. Later, I found his JSDD membership card and realized that I had made the right decision (Saitama Prefecture).
- A peace of mind: Although we did not submit his JSDD card, my husband's membership gave us a peace of mind and helped us making the right decisions and preparations. We are grateful that my husband was a JSDD member (Tokyo).
- Our whole family was at a loss: When My wife suffered from cerebral infarction, my entire family including myself was at a loss. We all asked the doctor to do his best for my wife's recovery. She had a living will, but I couldn't show it at that time because I just wanted her to live even one day longer as a husband (Kagawa Prefecture)



### Letters from Doctors

- Family members need to know: Since the patient normally can't express his own will, it's necessary for family members to be fully knowledgeable about the content of the patient's living will (Tottori Prefecture).
- Looking forward to legalization: I've been following the legalization movement of the living will very closely. I expect full legal immunity for doctors and medical institutions unless obvious malicious intentions are proven. I am a strong opponent of administering meaningless, rather harmful life prolonging measures (Kumamoto Prefecture).
- Graceful decision: Since I live in a rural area, when elderly patients are nearing death, they are sent home at their own will. They make their beds in the middle of their houses just like their ancestors did for generations, and doctors are called after death. We shouldn't ignore our tradition of elderly's graceful and honorable decisions carried on for generations (Chiba Prefecture).

### 2013 Surviving Family Survey Results

Response rate	Responded	863	64%
	Did not respond	495	36%
	Total	1358	100%
Gender of deceased	Male	484	56%
	Female	379	44%
	Total	863	100%
Age of deceased	Under 60	8	1%
	60s	47	5%
	70s	210	24%
	80s	410	48%
	Over 90	188	22%
	Total	863	100%

Place of death	Hospital	540	63%
	Home	167	20%
	Hospice	38	4%
	Nursing home	107	12%
	Other	11	1%
	Total	863	100%
Living will submission	Submitted	703	81%
	Did not submit	160	19%
	Total	863	100%
Living will submission location (multiple answers)	Primary care doctors	108	
	Home visiting doctor	110	
	Hospital attending doctor	549	
	Nursing home doctor	113	
	Nurse	185	
	Nursing home worker	104	
	Paramedic	22	
	Other	8	
Living will submission time (multiple answers)	All the time	312	
	After being diagnosed with a serious illness	299	
	At terminal stage	136	
	After being in vegetative state	14	
Response to living will submission	Fully honored / accepted	418	59%
	Somewhat honored / accepted	218	31%
	Totally ignored / not honored / declined	7	1%
	Somewhat ignored / not honored / declined	21	3%
	Don't know	39	6%
	Total	703	100%
Discussions regarding life prolonging measures	Satisfied	549	85%
	Not satisfied	19	3%
	Neither	79	12%
	Total	647	100%

## **Living Will Issues to be Resolved**

### **– Analysis of the Surviving Family Survey**

1.4% → 2% → 3% → 4%

The above percentages depict the number of ignored/declined living wills according to the surveys conducted since 2010. 4% or only 28 people from last year were declined their living wills.

However, the average number of deaths per year in Japan is roughly 1.25 million. 4% of 1.25 million amounts to 50,000 people. Of course, not everyone possesses a living will, but the survey also showed over 70% of the people were in support of the living will, in which case this number is not far off.

Why is it so difficult to carry out a simple wish, “I want to decide how I die peacefully and comfortably.”?

As mentioned in one of the letters above, some doctors immediately respond to a living will with, “If you’re not satisfied, please go to another hospital.” Recently, JSDD received the following survey response: My mother fell down at home and was sent to an emergency room in an ambulance. She was automatically administered a life prolonging measure. When I submitted her living will to the doctor, he rejected it because it would put him in jail under the current law.

This response doesn’t elaborate if his mother was in her terminal stage, but the son was so torn about the outcome that he wishes that the bill guaranteeing immunity for doctors will soon pass in legislature.

There are many doctors who demonstrate true understanding of dignified death. In one case, a doctor told the family members that further attempts to prolong the patient’s life would only be a burden to the patient. In another case, it was the doctor who told the patient’s family that it’s important to respect and honor the patient’s will.

It seems that poor recognition of the living will and the fear of prosecution contribute to doctors’ inability to terminate life prolonging measures.

There was a case in the 2010 survey: a patient’s family members asked the doctor to terminate the patient’s life prolonging measures, but the doctor refused to listen. They remembered that the patient had a living will, so they found it and presented it to the doctor. The doctor realized the patient was fully prepared, and was ready to discuss the matter seriously with the family. In a way, the living will for dignified death played the same role as a passport for entering another country. Once the living will acquires legal status, doctors who don’t see it as a legal document today would likely change their minds and accept it.

### **Importance of discussing the living will among family members**

Communication challenge is not limited to the medical care providers. One of the cases in the 2012 survey reported as follows:

When my mother’s doctor told us that even if the surgery was successful, it was likely that she might end up in persistent vegetative state, I submitted her living will and told him to refrain from any life sustaining measures. My sister and uncle were upset at me and called me inhumane. In the end, her mother ended up paralyzed and suffered for a year and a half before she died.

Cases such as this one is not uncommon in which the patients’ wishes were not honored because of insufficient communication among family members. In the most recent survey, there was more than one case of families being told by their doctors that they still had to do everything they



can despite having a living will. In some cases, families couldn't object because of their lack of understanding regarding life prolonging measures. In another case, the patient's living will was not honored because of insufficient preparation on the healthcare provider side.

University hospitals and acute care hospitals typically push the patients out once all possible medical treatments have been provided. We have a shortage of palliative care hospitals and doctors or hospitals and doctors who can provide palliative care in our society. The process of shifting the course of care from active medical treatment to palliative care is often vague. However, as we improve our end of life medical care system, more living wills will be honored. The legalization of the living will most likely improve the system and facilitate the process of dignified death.

## **Self Determination at Terminal Stage ~ Dementia**

### **Discussion from medical and legal perspectives Tokai Chapter 4<sup>th</sup> "Think Tank" Conference**

A study group on the legalization of terminal stage patient medical care, sponsored by Tokai Chapter (greater Nagoya region) held its conference ("Think-Tank" Society) on March 2 in Nagoya; its theme was self-determination from dementia patients' view. The "Think Tank" Society was Founded in 2010 as an armament to ignite the legalization movement of the living will. This was its 4<sup>th</sup> conference. There were lively discussions (see photo below) about how to read, perceive, interpret and understand the minds of dementia patients both from medical and legal perspectives

### **Collaboration with local medical association brought in many doctors**



Cosponsored by Aichi Prefectural Medical Association, the conference brought in altogether 60 people, including 28 doctors from Nagoya City Medical Association, 4 Diet members from Tokai districts, lawyers, scholars and other healthcare professionals.

Dr. Soichi Iwao, President of JSDD and Dr. Mitsuaki Tanaki, Chairman of Aichi Medical Association made the introduction, followed by two key speeches: Medical perspective by Dr. Hitoshi Yamamura (Director of Tokai Chapter and Senior advisor for Gifu Hospital) and judicial

perspective by Mr. Kunio Aoyama (Director of Nagoya Chapter and former Judge for Nagoya High Court).

Dr. Yamamura presented the audience with two cases of dementia patients. He stated, “As the number of citizens over 65 years of age reach 25% of the total national population, my question to you is, how do we, as medical professionals, deal with the situation of decreased mental capacity, quality of life, and complications with other illnesses?”

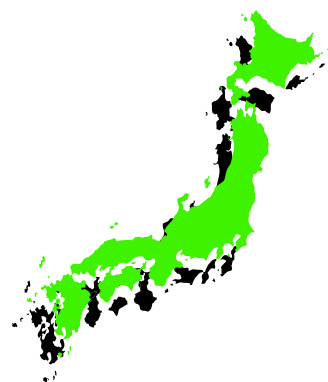
Mr. Aoyama addressed the following point: Medical treatment is a very personal matter, an inalienable nature of that individual; therefore, the right to choose is not automatically transferred to family members even when the patient loses his or her mental capacity. Currently, medical decisions are made by family members, but when no agreement is reached among the members, the medical setting becomes chaotic. This is especially the case when the patient has a terminal illness or is in terminal condition; judicial preparation must be taken into consideration.

After the two key speeches, Ms. Hitoko Aoki, Head of Nagoya Chapter took the chair to mediate the discussions among all attendees, focusing on keeping the discussions around the following four questions:

- Is it necessary to obtain consent from dementia patients?
- Is the patient’s living will valid if it was prepared while in good health?
- How are informed consents obtained?
- How are patients diagnosed in terms of mental capacity?

One from the audience made a statement, “It might be necessary to obtain informed consent from the patient, but what’s really important is to determine the level of mental capacity and then decide whether the patient has the ability to make his or her own decisions.” The point of discussion became the difficulty in determining a patient’s level of mental capacity. Another responded, “There are currently no standard criteria in the medical community. Experienced family practitioners can better determine the level of dementia and mental capacity than doctors employed by hospitals. It is the doctor’s responsibility to decide whether the patient is capable of giving consent or not.” With regards to informed consent, many agreed that it should not be a one-time event. In other words, continuous communication, long term examination and observation, and tenacious approach is necessary for dementia patients.

## **Terminal Stage Medical Care Prefecture Residents Awareness Survey**



Recently, some local (prefectural) governments have begun a survey regarding what type of medical care their residents would like to receive at the end of their lives. In the next 10 years, the population of senior citizens over the age of 75 will rapidly increase. Subsequently, the number of death will increase as well. The current medical system evolved around hospitals will not be the solution for meeting the needs of elderly and dying people to receive compassionate medical treatment and care. The government is on its way to shifting this system toward more localization, which is based on community involvement and existing in-home care system. The

survey based research will be the first step for the local governments to analyze and determine the type and details of the system needed in each region.

**OKAYAMA PREFECTURE** announced the results of its survey last August titled, “Residents Satisfaction Study,” in which 1405 responded. Below are some of the results regarding the living will and the advance medical directive:

I know what a living will is-----13%  
I’ve heard of it, but I don’t know what it is-----13%  
I don’t know-----71%

The following questions were asked after an explanation of the living will was provided:

I support the living will-----62%  
I support it, but the document isn’t necessary-----19%  
I don’t support it-----2%

**CHIBA PREFECTURE** conducted an internet survey of its residents. Results from about 10,000 respondents are as follows:

I would not want to receive any life prolonging measures----86%  
I have prepared a documentation for this-----5%  
(Senior citizens over the age of 70: 8%)

Do you want to prepare a document for this?  
I don’t know-----Over 50%

These results indicate a lack of knowledge regarding the living will.

Responses from medical care professionals in the same survey were as follows:

Living will is necessary-----77%  
Support promotional efforts for the living will for patients and families-----73%

Overall, this survey revealed that many people do not know much about the living will or what it is used for.

**KANAGAWA PREFECTURE** developed a Prefectural Grand Medical Design in 2012, which establishes its basic goals for promotion of medical policies over the next 10 years. The Design’s first clause spells out that the vision of the medical policy is to facilitate the process of choosing and refusing specific medical treatments and life prolonging measures in emergency situations. This was based on the awareness survey (1,500 respondents) conducted in a previous year with the following results:

I would not want to receive any life prolonging measures-----77%  
It is a good idea to have a living will-----87%

The Design states that the declaration (living will) document must reflect the patient's will and preference regarding life prolonging measures and executed in accordance with judicial arrangement regulated by the federal government.

## **LOCAL GOVERNMENTS CAN NO LONGER IGNORE ISSUES SURROUNDING END OF LIFE CHOICES**

The Annual death rate is expected to increase 1.3 times, to 1,540,000 by 2015. Currently, 80% of deaths occur in hospitals, but to increase the number of hospital to meet the demand of "death beds" would be difficult and unrealistic.

At the national level, Japan is aiming to shorten hospital stays in general, build more rehabilitation hospitals, and increase the number of home visiting doctors, nurses and caregivers to maximize the total in-home medical care system.

In order to deal with the various medical needs in different regions, local governments have recently been granted authorization to make certain changes on their own, such as shifting emphasis from acquiring any more technologically advanced medical beds to building more rehabilitation hospitals, and developing more training programs for in-home medical care. Once the in-home medical care system is in place, the next step is to incorporate peaceful and comfortable final departure of elderly patients. Local governments will find more roles and responsibilities in the near future.