



Excerpts
From
Japan Society for Dying with Dignity Newsletter
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As of December 10, 2012, JSDD has 125,160 members.



Self Determination

In Commemoration of Presidential Succession and Movement towards Legalizing the Living Will

A grand party was held on November 10, 2012 in Chiyoda Ward, Tokyo, commemorating the succession of JSDD presidency and publicizing the movement to legalize the Living Will. Among the attendees were members of the Diet, medical associations, government officials, the media, and groups associated with JSDD, a total of approximately 150 people.

Mr. Teruhiko Mashiko, who leads the Diet Member Coalition for Dying with Dignity (DMCDD), gave a speech encouraging everyone to work together to pass the law which exemplifies and prioritizes patient's self determination. He was followed by other congratulatory speeches by Mr. Masaharu Nakagawa, a member of the House of Councilors, Mr. Norihisa Hara, Director of Medical Policy, Department of the Ministry of Health, Labor and Welfare, and Mr. Kuninori Takagi, President of International University of Health and Welfare.

Mr. Akihiro Igata, the Honorary Chairman who recently handed over the JSDD presidency to Dr. Iwao, was presented with a bouquet of flowers by Ms. Hitoko Aoki, Vice President and leader of Tokai Chapter to display everyone's appreciation for his contribution to JSDD during his ten year presidency.

New Mission and Direction for JSDD

Committee Reaching a Final Conclusion

A committee (consisting of all 25 board members) which has been studying and discussing the future prospect of JSDD is close to completing its final report. The committee plans to make three main points:

- 1) Mission and administrative functions after the Living Will is legalized
- 2) Financial prospect
- 3) Membership increase and activity level increase by local chapters

Resulting from many deep discussions, the committee has made a great progress envisioning the organization's future. The final report is scheduled to be released early this year, but the committee wants to share some main points of the report at this time.

Impending Tasks

- We must recover from the financial deficit incurred from reducing the membership fee for members 80 years and older (enacted in 2007). It will be inevitable to change the current fee system, considering a large number of members are reaching the age of 80. The committee voted unanimously to go back to charging a flat membership fee regardless of age for new members. Fees for current members remain the same. We hope to implement the new membership fee system starting 2014 after being introduced in the general members meeting in June.
- Corporate assets owned by JSDD are basic corporate funds which should be spent for strategic purposes and for supporting local chapters. However, the distribution ratio must carefully be scrutinized in the future. In view of our current fiscal standing, the revised fee system will not lead to an immediate positive overturn. In the meantime, we'll be obliged to use another fund for closing the deficit.
- The current administration must be innovated, and the function of the headquarters must focus on three elements: membership management, general affairs, and public relations planning. Public relations are not limited to publishing newsletters and maintaining website, but also focusing on research activities. Although distribution of our corporate assets will determine the extent of research activities, a constructive suggestion was made to form an academically based organization specializing in the study of dignified death.
- There is a need for the nine chapters to increase their respective basic local activities, and the headquarters to expand broadcasting the concept of dignified death throughout Japan. Both

headquarters and local chapters must boost their activities simultaneously and work as a team. Many expressed the opinion that it may be imminent for all local chapters to review the number and age groups of their staffs and reorganize them before allocating more energy and resources into local activities.

Post-Legalization Tasks

- What legal role JSDD plays with regards to the Living Will depends on how the law is written. Nonetheless, JSDD is expected to remain as the primary resource for registry of Living Wills and providing assistance for those in need.
- The core mission of JSDD will remain the registry of Living Wills. In order to stay in existence, we will need to undergo some organizational changes. We wish to gain the status of a Public Benefit Organization which will make us eligible for tax benefits.
- We must look into the validity of the current Living Will issued by JSDD; whether it meets the requirements imposed by the Ministry of Justice and the Ministry of Health, Labor and Welfare. For example, the current Living Will does not include an expiration date and appointment of a medical power of attorney. While we expedite the submission of the bills to legislature, these issues must be resolved simultaneously.

Movement in Legislation

Diet member Coalition for Dying with Dignity (DMCDD)

Teruhiko Mashiko of DMCDD led a general meeting on November 13, 2012, just prior to the dissolution of the House of Representatives. Mr. Mashiko stated that due to a lack of time allotted for a special session of the Diet, “we regret that our two bills were not presented in this session, but every effort will be made to present them during the upcoming session starting in January 2013.”

Post-Election: Two Bills Prepared for Submission to Legislature

If passed, the bill will be named “Terminal Stage Patient’s Self Determination Act.” The first bill (non-commencement of life prolonging measures) and the second bill (non-commencement + withdrawal of preexisting life prolonging measures) were announced in March and June 2012 respectively. The only difference between the two bills is the inclusion of the patient’s right to remove any pre-administered life prolonging measures. During the DMCDD general meeting in September 2012, the idea of submitting two separate bills instead of only one was recommended for further discussions within each political party. In the midst of this process, an election for the House of Representatives was held. Of 134 DMCDD members, 86 are House of Representatives. Currently, all activities are on hold until reorganization of the new House is complete.

Terminal Stage Patient's Self Determination Act:

Main Points

Excerpts from the First bill and the Second bill prepared by DMCDD

Basic Principles: Conduct of terminal care and making the decision whether to utilize life prolonging measures must be based on mutual trust among the patient, his/her physicians and family, and other healthcare providers (Article 2).

Physician's Responsibilities: Regarding non-commencement and/or withdrawal of life prolonging measures (Second bill), the physician must explain the consequences of withholding life prolonging measures to the patient and his/her family and ensure that they fully understand them (Article 4).

Definitions:

Terminal Stage = a period of time which begins when a patient is diagnosed as being an incurable and nearing death, even after all appropriate and available medical treatments have been administered.

Life Prolonging measures = medical treatment given to a patient solely for the purpose of prolonging life without offering any benefits to relieve suffering, restore bodily functions, or enhancing quality of life (Article 5).

Terminal Stage Determination: Two or more qualified physicians with appropriate knowledge and experience must independently reach the same diagnosis (Article 6).

Written Expression of Self Determination: Anyone over the age of fifteen can have a Living Will (or a written document in accordance with an ordinance set by the Ministry of Health, Labor and Welfare), stating one's wishes to refuse any life prolonging measures if diagnosed as being in terminal stage and allowing physicians to withhold or withdraw any life prolonging measures accordingly (Article 7).

Retraction of Living Will: A person can retract or change the content of his or her Living Will at any time (Article 8).

Exemption from Legal Liability: A physician treating a patient in accordance with Article 7 of this bill shall be exempt from criminal, civil and administrative liability (Article 9).

Special Consideration: Special emphasis will be made to ensure that dignity of disabled persons needing life prolonging measures will not be impaired (Article 13).

Review and Revision: This bill will be reviewed three years after enactment as a goal, and revisions will be made as necessary depending on the effects of the bill and any social or environmental changes regarding terminally ill patients (as a rider).

Third Think-Tank Society Session Held in Nagoya

**Pushing a Statute on Terminal Care in Collaboration with
Aichi Medical Association**

JSDD's Tokai Chapter, co-sponsoring with Aichi Prefecture Medical Association, participated the third Think-Tank Society conference held on November 25, 2012 at Aichi Prefecture Medical Building in Nagoya. Among other participants were approximately 50 local physicians who strongly voiced their opinions in the discussion.

A Joint Study Conference with Aichi Prefecture Medical Association **Field Healthcare Providers' Opinions Vary**

Founded in 2010, this study group's main theme this year was on the two bills being submitted to legislature. Dr. Mitate Yamamoto, Vice President of Aichi Medical Association and Ms. Hitoko Aoki, president of Nagoya Chapter presided the meeting and mediated the discussions.

The guest speaker was Dr. Masafumi Kuzuya, Professor at Nagoya University School of Medicine, discussing mainly on the hydration and nutrition aspect of life prolonging measures. He commented that the recent popularity of tube feeding developed to replace I.V. nutrition is slowly diminishing due to many criticisms and negative media attention.

JSDD's President, Dr. Soichiro Iwao gave a slide presentation of the current status of the Living Will legalization process, emphasizing that it is the patient's self determination which will be guaranteed under the law, without which the Living Will cannot be legalized.

Exchange of opinions developed quickly and intensely as the meeting progressed. The proposed second bill only applies to patients with written documents, such as the Living Will. A physician working in a nursing home expressed his opinion that this law seems so far from reality of nursing home medical settings because typically, terminal stage patients have no written documents of self determination, and tube feeding is decided after discussing with the patient's family members.

Concerns over Legalization of Living Will: **Self Determination Guaranteed by Law** **In the USA: Over 40% of Citizens Possess a Living Will**

JSDD President, Dr. Iwao informed the group, "After 30-40 years since the living will was legalized in the USA, 41% of its citizens now possess living wills. Once legalized, more people will have it in Japan; we must make this happen."

Both bills state that two physicians, one of whom being the primary physician, must unanimously diagnose a patient terminally ill. A question was raised as to the roles and responsibilities of the second physician who is not the patient's primary, which brought up another point that the physician diagnosing a patient to be terminal ill would have very different roles and responsibilities from a physician actually providing terminal care for the patient.

Regarding the second physician, a local medical association proposed an idea of each local medical association selecting a physician who is an expert on terminal care to be the second doctor for all terminal patients in the region. Dr. Iwao responded with a reference to guidelines from the Ministry of Health, Labor and Welfare, which specifically uses the term "medical team" when referring to pronouncing a patient terminally ill, to keep any one physician from making such a crucial decision. This is the reason both bills require more than two physicians to independently diagnose a patient as terminally ill.