



JAPAN SOCIETY FOR DYING WITH DIGNITY

NEWSLETTER

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Membership stands at 123,858 (as of December 5, 2011).



Movements in Legislation

Diet Members Coalition for Dying with Dignity

From September to December, the diet members coalition for dying with dignity (Chairman Teruhiko Mashiko, 91 diet members) worked zealously, holding their board meeting and general meeting. To “speed up the enactment,” they are now compiling the draft proposal for the new legislative bill. It has already been six years since non-partisan diet members began working on the legislation, and the diet members coalition hopes to submit a legislative bill at “this year’s ordinary diet session (period from Jan. to Aug.)”

Draft proposal of a new bill that “respects the patient’s will”

Coalition wants to speed enactment

The diet members coalition has been revitalized under the leadership of Chairman Mashiko. To reignite the activities to promote the dying with dignity legislation enactment that had been at a near standstill, the coalition decided to formulate a draft proposal for the new legislative bill and gather opinions of the Japan Society for Dying with Dignity and Japan Medical Association. In September, it presented this draft proposal to the legal bureau, House of Representatives.

The draft proposal formulation is the stage that precedes the writing of the bill and the proposal serves as a draft for all basic details of the bill. Repeatedly reviewed by the diet members coalition, the latest proposal is titled, “draft proposal of the legislative bill (tentative) concerning the respect for the patient’s will in final stage treatment.” The key points are as follows.

1. Proper respect for the will of the patient who wishes to withhold life-prolonging procedure (targets those who have expressed their will in a LW and such)
2. To withhold life-prolonging procedure if doing so is not refused by the family of the patient who has been given a final stage diagnosis or has been informed as such (when the patient has no family, withholding will be carried out in line

with the Ministry of Health, Labour and Welfare Guideline)

3. To withhold life-prolonging procedure in accordance with this legislation is not accountable to civilian, criminal and administrative conducts.

Society should clearly state “withdrawal,” delete “family’s approval”

At the diet members coalition meeting, our society and the Japan Medical Association both made comments that focused on the contents of “withholding.” According to the diet members coalition, “withholding” simply means the non-commencement of life-prolonging procedure and does not include “withdrawal.” The decision was made, based on the idea that the inclusion of “withdrawal” can provoke numerous arguments and reverse the enactment task back to standstill. “Non-commencement” only was chosen as the first step to legislation as citizens would find it easier to accept.

In response, vice-chairman Iwao and others of the society met with the diet members coalition on September 26 and requested the inclusion of “Persistent Disturbance of Consciousness” that had not been incorporated in the draft proposal. The views of the society were also conveyed. Of the many requests, the society emphasized the following two points.

- * the concept of “withholding” most likely includes “withdrawal” but “withdrawal” should be clearly stated as a different term from “withholding.”
- * “family’s consent,” the requirement for withholding, should be deleted.

Taking this new proposal into account, the diet members coalition held their board meeting in November. From our society, vice-chairmen Iwao, Suzuki and Matsune, and Nagao, the head of the Kansai Chapter, were in attendance. Vice-chairman Iwao stated that, “Non-commencement and withdrawal are both made possible by final stage diagnosis and patient’s will, and the medical results are the same for both.”

In addition, Vice-chairman Suzuki commented that, “Making decisions on

withdrawal have proved to be agonizing in real life medical settings. The exclusion of withdrawal waters down the significance of the legislation.”

The Japan Medical Association too feels that “non-commencement” waters down the significance of the legislation

Having sorted out these arguing points, the latest draft proposal was presented by the legal bureau, House of Representatives at the general meeting of the diet members coalition that was held on December 8. For the contents of “withholding,” “non-commencement + withdrawal of life-prolonging procedure that’s already being implemented” proposal was also included in addition to “non-commencement of new life prolonging-treatment” proposal.

At the general meeting of the diet members coalition, the Japan Medical Association commented that, “There has never been a legal issue over withholding

(non-commencement) in the real life medical setting. The key issue has always been withdrawal, so it’s questionable how much significance the withholding-only legislation will have.” The Japan Medical Association furthermore stated that they would like the coalition to write a legislation that includes the “will of the patient + will of the family + guideline” and to consider the physician’s legal exemption from responsibility.

Vice-chairman Suzuki of the society asserted that the “Ministry of Health, Labour and Welfare Guideline also targets commencement and non-commencement of, changes to and withdrawal of a medical treatment. If the gist of the guideline is to be included in the legislation, withdrawal should naturally be included.”

Thus, it was decided that the diet members coalition would sort out the arguing points and compile a new draft proposal.

In-depth Arguments over Final Stage Medical Treatment Legislation

Study group meets for the second time in Nagoya Think Tank Committee

In its mission to engage in in-depth discussions on final stage medical treatment, the “study group on final stage medical treatment legislation” of the Tokai chapter held their second study session on December 4 in Aichi Medical Association Hall, Nagoya City. There were about fifty participants, including LW accepting physicians from the Tokai region, general physicians, medical profession personnel, lawyers, local diet members and university professors. Voices from real life medical settings were heard, and heated discussions took place to propel the legislation forward.

Physicians, LW accepting physicians, university professors and local diet members also in participation

In consideration from the perspective of real life situation in the medical treatment setting

Called the “think tank committee” by the Tokai branch, the study group was launched in May of last year. Amidst the formulation of the legislative bill, the society is prepared to counter-argue the key discussion points. The theme of the second study session was “key problems of legislation.” In his opening message, chairman Akihiro Igata said, “Within the diet members coalition, there is heightened momentum to realize the legislation. We want to be able to catch this opportunity.”

Chapter Head Hitoko Aoki, the MC, also emphasized the intent of the study group, “Results of the survey undertaken by the Ministry of Health, Labour and Welfare furthermore reveal that more than 80% of physicians respect LW. The Japan Society for Dignity is working to enact the legislation and wishes to collaborate with these physicians. From here, let us transmit the important message so that we can enact the legislation.” Responding to

this callout, physicians made up for more than half of the participants.

During the first half of the study session, vice-chairman Soichiro Iwao gave a keynote lecture on the “present and future of the legislation.” He explained the contents of the new draft proposal for the legislative bill that was recently presented by the diet members coalition, and reported on the society’s opinions and requests concerning the draft proposal.

During the second half, an opinion exchange for key issues took place. In issues concerning self-determination, competence and family involvement, participants narrated what was going on in real life medical setting and shared the experiences that they had with patients’ families.

A physician who works at a hospital that provides geriatric medical treatment reported on the real life situation there, “90% of the elderly who have lost their ability are also not competent.” Another physician talked about a patient who changed his mind after writing an endoscopic gastrostomy (PEG) refusal. The Ministry of Health, Labour and Welfare Guideline that focuses on “presence of family” crossed the physician’s mind and he advised the patient to talk the matter over with his wife.

Sense of danger over

“non-commencement,” the heavy real life presence of “family”

“Respect for self-determination” remains the basics for the legislation. However, how much can a person with low competence be able to decide for himself? How much should the family get involved? Opinions were given by physicians who have had to make these difficult decisions in the real life medical setting.

Participants pointed out the danger that the diet members coalition’s new draft proposal targets “withholding” which only signifies the non-commencement of life-prolonging procedure and does not include “withdrawal.” There were also opinions that “The treatment for a patient who has been diagnosed as being at the incurable/final stage already has the character of life-prolonging treatment. The treatment has already begun, so the term, non-commencement, doesn’t make sense.”

Requests to the society were made, including “We don’t want you to give us empty expectations by arguing the meaning of withholding” and “The society should take action to target withdrawal as well.”