Excerpts from

Japan Society for Dying with Dignity Newsletter
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General Meeting of the Diet Members Coalition for Dying with Dignity

Name Change with intent to obtain support from broader spectrum of society

With the new name, "Diet Members Coalition for honoring patients' end of life decisions," Diet members will deliberate on the draft bill which honors patients' end of life decisions: Focus on one bill rather than two as previously proposed to reinforce strategical efforts to push submission into legislature.

The Diet Members Coalition (Chairman Teruhiko Mashiko, 187 members) held a general meeting on May 27 to decide on the following matters:

- New name for the coalition
- Adopt only one bill which allows withholding and withdrawing life prolonging measures, and drop the two-bill proposal as previously suggested

Although the effort by the Diet members to legalize the living will started over ten years ago, the bill has not yet gone into legislature for deliberation, and this was the first meeting held by the federation in almost a year.

During his introduction, Chairman Mashiko (Democratic Party, Upper House) spoke of the increase in the number of members among the Coalition and the attention this issue has gained among the Diet members. He said this meeting should drive our efforts to cross over the threshold in legislature. Secretary General Shunichi Yamaguchi (Liberal Democratic Party, Lower House) stated that he was very confident about the bill being passed by majority once it gets into legislature for deliberation.

With the Coalition adopting the new name, the emphasis shifted from the legalization of the living will to priority placed on honoring individual's right to make his/her own end of life decisions. Chairman Mashiko explained that the reason for the name change was to make clear to the general public the purpose of the Coalition and what it's trying to accomplish. In the past, people have typically rejected the idea altogether when the term "dying with dignity" was associated with withholding and withdrawing life prolonging measures.

The current movement by the Diet members to legalize the living will began with the efforts of Japan Society for Dying with Dignity (JSDD) back in 2003. The term "dying with dignity" proposed by JSDD, was received positively by the general public for the most part; however, occasional misunderstandings of the term and confusion with positive euthanasia have led to unnecessary conflicts with opposition groups. Consequently, the Diet Members Coalition paid more attention to the need for a name change during last year's board meeting, and the new name now mirrors the title of the proposed bill.

This has enabled the Diet Members Coalition to take some symbolic steps forward. The bill is now entitled "honoring the patient's end of life decisions." Previously, two bills were developed; one legalizing only withholding any life prolonging life measures, and the other legalizing both withholding and withdrawing any life prolonging measures. JSDD claimed that it was meaningless to omit the withdrawal of existing life prolonging measures. Currently, each of the seven political parties which belongs to the Diet Members Coalition is following proper internal procedures to reach its own final party decision.

"JSDD will modify the existing template of the living will to align with the new draft bill"
President Iwao explained in the Diet Members Meeting

JSDD President Soichiro Iwao announced after attending the general meeting of the Diet Members Coalition that JSDD will start reviewing and modifying the current living will to be used as the standardized template once the bill is passed. The bill states that a patient's decision must be in writing or in a form specified by the Ministry of Labor, Health and Welfare (Clause #7). What the form will look like is still undetermined, but the format of a written statement with the patient's decision (the current living will issued by JSDD) has been widely recognized and well received by the Japanese society throughout JSDD's 40 year history.

Last year, JSDD founded the Living Will Revising Committee involving a wide range of professionals who are involved with caring for terminally ill patients in order to improve the existing format of the living will by aligning it more with the proposed bill. Last spring, a constructive report was published pointing out what should be our emphasis for the near future: 1) dealing with the lower mental capacity of an increasingly large population of the elderly; and 2) building a higher level of trust and practicality for the living will.

President Iwao explained that all the efforts made by JSDD will be a positive contribution one way or another to the living will format which will eventually be developed and specified by the Ministry of Labor, Health and Welfare.

New draft bill major clauses and key points

"The Bill to honor patient's self-determination for end of life medical treatments" presented by the Diet members consists of thirteen clauses. Once all parties consolidate their opinions, they will develop the final bill to be submitted to legislature.

Major clauses	**Main points**
Clause #1 (Principle) Currently, physicians' immunity is not protected by law to withdraw or withhold any life prolonging measures. Consequently, some patients are forced to receive medical treatments against their wishes. Legalizing the physician's immunity will fully guarantee execution of the patient's end of life decisions.	**Patient's decision will be honored and executed with physician's immunity** Often, physicians are hesitant to withdraw life prolonging measures because of possible litigation. Given immunity, they will be relieved from any civil, criminal and administrative liabilities, and patients' decisions can be executed without fear or hesitation.

Clause #5 (Definitions of legal terms) Terminal stage = medical condition in which the patient is diagnosed as incurable, and death is imminent even if treated with any means available, including artificial hydration and nutrition. Life Prolonging Measure = medical measure which is not a treatment or palliative care, taken with the sole purpose of prolonging one's life.	**Life Prolonging Measures include artificial hydration and nutrition.** The term, terminal stage is commonly understood as a condition in which cure is unforeseeable, and progression toward death is unavoidable. artificial hydration and nutrition is clearly stated as part of life prolonging measures, which is the significant point of this clause.
Clause #6 (Criteria for diagnosis of terminal stage) Two or more physicians with professional knowledge and experience capable of making proper medical decisions must individually make the same diagnosis. In case of oral cancer, one or more physicians and one dentist must make the same diagnosis.	**Patients residing in remote, rural areas who have little access to physicians and in-home terminal care** Patients living in remote areas will have difficulty meeting this requirement. Under current conditions, prior coordination between physicians and district medical association must be arranged.
Clauses #2, 7, 8 (Criteria for expression of patient's decision) Patients 15 years of age or older can express their decision regarding withdrawal of life prolonging measures in free writing or on a form specified by the Ministry of Labor, Health and Welfare. The patient's decision must be of his/her own free will under no duress or coercion, and the decision can be retracted by the patient at any time. Patients over 15 years of age are also eligible for organ transplants.	**Written statement of patient's decision of his/her own will under no duress required** The patient's decision must be expressed clearly and concisely in all points. Since the format of expression will be standardized, the current living will issued by JSDD will also need revision to align with the new bill.
Clauses 7, 9 (Withdrawal and immunity) Physicians have immunity from any legal liabilities (civil, criminal and administrative) for execution of patient's written statement to reject all life prolonging measures.	**Possibility of executing withdrawal of life prolonging measures even if lawful procedures are not met** Clause #13 stipulates that this act does not prohibit the withdrawal of life prolonging measures when stipulations of this act are not met. It leaves room for physicians' professional discretion.

Memo: Diet Members Coalition for Legalizing the Living Will

A Diet members Coalition is a group of Diet members seeking the same political goals and promoting the same political policies regarding certain topics, regardless of party alliance. There are about 500 Coalitions, including groups who share same hobbies which operate only with membership fees.

The objective of their activities is mainly centered around enactment of legislation and policy proposals on political and social issues. The Coalition for Legalizing the Living Will is one of them, established in April 2005 with the efforts by JSDD. As stated, it is a non-partisan coalition group, which has been the core body of movement aiming at legislating the topic of terminal medical care for over 10 years.

The Diet Member Coalition for Legalizing the Living Will has prepared a draft bill based on the outline that JSDD submitted, after conducting hearings with numerous health care, religion, and patient groups as well as all government sectors that are involved. It continues its legalization process while seeking and gaining wider public acceptance
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= Activity Report 2014 =

Over 900 cases of telephone counseling hotline

40% of cases regarding medical treatments; increasing number of cases regarding anxiety of solitary, elderly living conditions

The purpose of our "Telephone Counseling Hotline" is to listen to any questions, confusion or fear the members may have regarding medical treatments, and supply the members with all necessary information to help them make the right decisions. Data from 2014 medical consultations was recently compiled.

There was a total of 434 cases, which was close to previous year's number, but some cases consisted of multiple categories. When we based the total number by category of cases, we had 965 cases, more than previous year's 886 cases. There was a noticeable difference in the complexity of the cases this year, and the average consultation call was 30-50 minutes.

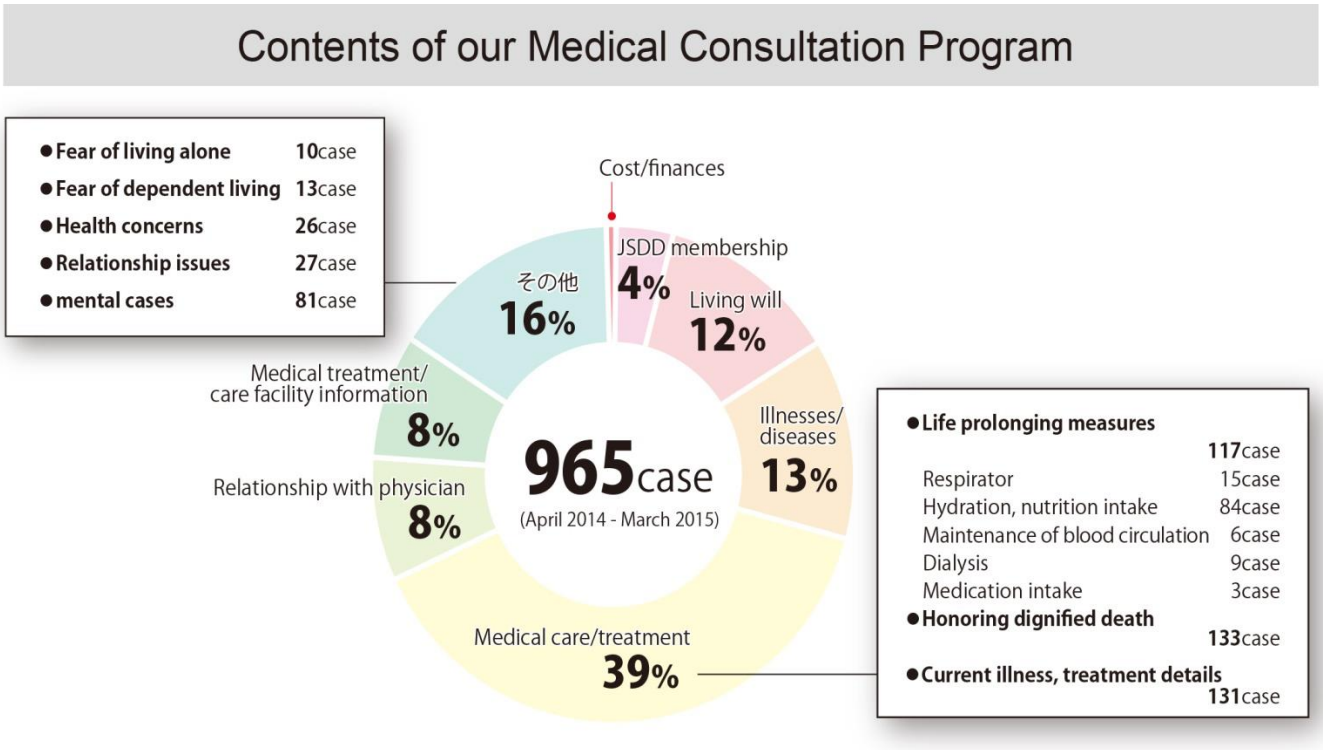
The contents of the consultations were categorized as follows (see figure on next page):

Medical care/treatments----------381 cases (39%)
Diseases/illnesses----------121 cases (13%)
Living will----------114 cases (12%)
Other ----------157 cases (16%)

Categories with major increases from last year were 6 points for "Other" and 3 points (8%) for "Relationship with physician." The category, "Other," was made up of 50% "Anxiety of solitary and aging living conditions/general health concerns/relationship concerns" and the other 50% regarding "Mental illnesses." What we can see from this trend is that we live in a predominantly elderly society now, and that people are having less and less family bonds and friends with whom they can discuss intimately about their anxiety and fear.

Advised to include a third party between family and physician for better communication

Main complaints regarding relationships with their primary physicians were that they didn't know where or how to begin their conversations, and their relationships became worse when trying to discuss specific medical care or treatments. Issues with the topic of diseases/illnesses were typically caused by a lack of communication with their physicians.



Medical treatment or Life prolonging measure? How about stomach feeding?

The largest category "medical care/treatment" was further broken into the following three subjects almost evenly:
Life prolonging measures----------117 cases
Respect for dignified death----------133 cases
Specific medical treatments----------131 cases

The topic of "Life prolonging measures" was mainly inquiries about hydration and nutrition intake including stomach tube feeding, nasal feeding and central vein feeding with a total of 84 cases. Every year, the top question is whether it is right or wrong to immediately switch to stomach tube feeding once the patient can no longer eat orally. There were also many calls from family members placed under a lot of pressure, asking for our

help in making decisions when physicians suggest stomach tube feeding and want family's consent or when they are asked to arrange for in-home terminal care because they want to discharge patients who refuse stomach tube feeding.

The category of "Respect for dignified death" was mostly complaints about physicians not understanding it or honoring it. Often, the issues lie in misunderstandings of how the patient wants his/her end of life to be, and whether the existing measures are considered treatment that can improve the condition or merely life prolonging.

Physicians often reject family's request to remove a respirator from a patient who has been in a long term unconscious state, because they claim that the patient is still under medical treatment, not a life prolonging measure. They say that it would be useless or meaningless in this case to be a JSDD member or have a living will. However, based on our analysis of data from this year and previous year, we see a gradual trend of medical providers listening more to the voices of patients and their families. This trend is very optimistic; however, the reality still lies in which patients and family members are not prepared to make any clear responses or decisions when the physicians ask a number of questions to try to support their decisions.

Here is an example of a consultation call:
The consultant responding to a call regarding stomach tube feeding tries to get as much information as possible about the patient's condition by asking specifically what the physician had said about the purpose of the medical treatment and his/her prognosis in order to best assist the caller and provide satisfactory responses. Unfortunately, physicians do not provide their patients with full and understandable explanations in most cases, leaving them with confusion.

Once clearing up any confusion, our consultant provides the caller with accurate information on stomach tube feeding to include its advantages and disadvantages. Finally, this is where the real problem solving begins. The decision of accepting or rejecting stomach tube feeding for the patient is left to the family. Do they have sufficient information to make a proper decision? We need to stop and listen to the physician's explanation and diagnosis once again to ensure that we are all on the same sheet of music.

Assist patients and their families seeking sufficient information by providing them what they need through consultation

People seek our consultation program because they were not able to gain enough explanation from their physicians. In many cases, they don't understand the explanations given by their physicians, but hesitate to ask them for clarification because the physicians seem so busy, resulting in more confusion. In such cases, having a third party to be the communication conduit between the physician and the patient's family can help.

In a hospital, the third party can be another nurse in the ward or a social worker in the patients' consultation room to help

provide more accurate and relevant information for the family. It can be another family member or a family friend, not necessarily a health care provider in some cases. From our experience, people who seek our consultation feel trapped because they have no one else with whom to discuss and share their problems.

The main role of our medical consultation program is to remove any confusion our members or their families have and resolve their problems by providing them with information they need.