



Excerpts from



**Japan Society for Dying with Dignity Newsletter
No. 166, July 1, 2017**

Main Contents:

- Phone consultation data compiled from FY2016 ----- 1
- 2017 Fiscal Year Business Plan and Budget Plan Finalized ----- 3
- A prospective system for LW Supporting Physicians -----5

PHONE CONSULTATION RESULTS FROM FY2016

Over 1,000 cases in two consecutive years reveal patients’ desire and hesitation to talk to their doctors

- “I’m so afraid that if I request for the termination of a life prolonging measure, the hospital may kick me out.”
- “I don’t know how to approach the doctors about discussing the termination or non-commencement of life prolonging measures.”
- “I’d like to talk with the doctor about whether the current condition is considered terminal stage and whether a life prolonging measure has already been administered, but I don’t know how to approach him.”

In order to assist with members’ problems and concerns such as these via phone, JSDD is equipped with a consulting staff of registered nurses to provide necessary information and support. Here are the results from fiscal year 2016:

The total number of telephone consultations was 472, almost the same number as the previous year which was highest to date. Some calls consisted of multiple cases; therefore, the total number of cases based on itemized content was 1,139. This was also similar to the number from the previous year. Over 1,000 cases were handled for two consecutive years. An average call time has been getting longer. One consultant commented, “Many calls would take 30 to 40 minutes, and the content of each case has become more complicated.”

An imminent decision was sought in a tube feeding case

The cases were categorized as follows based on content:

Medical treatment: 364 cases (32%)

Illness: 175 cases (15%)

Living Will: 161 cases (14%)

Unsatisfying relationship with primary care physician: 138 cases (12%)

The breakdown of *Medical Treatment* was as follows:

Diagnosis, Treatment Details: 156 cases

Honoring Death with Dignity: 130 cases

Life Prolonging Measures: 68 cases

The breakdown of *Life Prolonging Measures* was as follows:

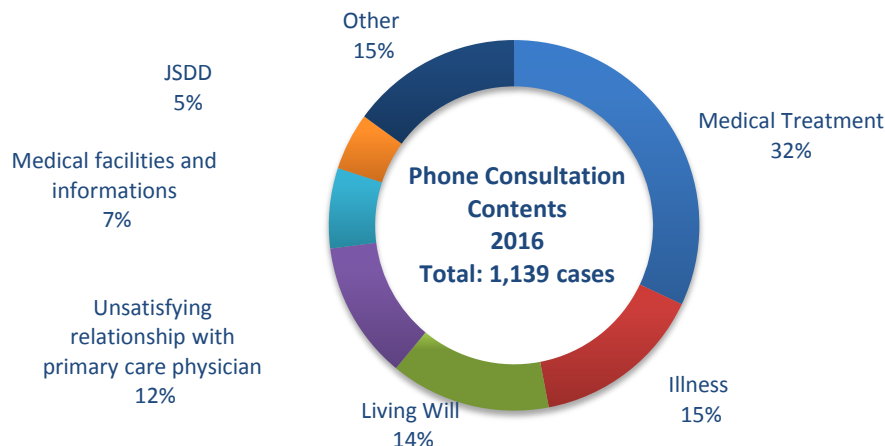
Tube feeding, nose feeding and central IV feeding: 46 cases

These results highlight family members' concerns and anxieties over having to make such important and immediate medical decisions.

Consultation contents are itemized separately as "Medical Treatment," "Illness" and "Unsatisfying relationship with primary care physician," but they are closely interconnected and are the core topic of telephone consultations.

One consultant states, "Unless you have a deep understanding of the illness and a full acceptance, you would not be able to confirm the diagnosis, progress and prognosis. Furthermore, you would not be able to judge whether or not the current condition is considered terminal stage or whether the treatment considered a life prolonging measure. Over the phone, I can almost visualize their anxiety when they describe how much they want to discuss with their doctors what they should be doing to make their loved one's end of life dignifying and all those important matters families need to figure out."

JSDD will make a commitment to continue providing the callers with all necessary information by listening to each call politely and carefully and helping them sort out their confusion in the best way possible. We sincerely look forward to your call.



2017 FISCAL YEAR BUSINESS PLAN AND BUDGET PLAN FINALIZED

Let's expand LW promotion and develop young leaders in local chapters

Japan Society for Dying with Dignity, now a general incorporated foundation, has finalized its 2017 fiscal year business plan and budget plan at the Board of Directors meeting on March 25. The 2016 fiscal year financial statements will be reviewed by the council on June 24.

At the board of directors meeting, JSDD President, Dr. Iwao, expressed his goal of broadening the scope of our current LW promotional activities by working closely with various regional medical organizations.

Membership Status

End of year 2016 enrollment number was recorded as 112,397 members. The net loss of membership was approximately 4,000 for the year. Though we had new enrollment of approximately 5,300, we lost 9,300 due to death, and others for not paying membership fees for three consecutive years, etc. The main reasons for the membership decrease of roughly 5,000 were the failure of payment for three consecutive years and losing contact. This drop rate is rapidly catching up with the new enrollment rate. The problem is related to the increase of aging members, with the average member age of 78, and JSDD must resolve this issue imminently.

2017 Business Plan

- 1) More emphasis on the Living Will Promotion Campaign
- 2) Further research and development
- 3) Maximized efforts to convert JSDD into a public benefit corporation

These are the three fundamental points of our 2017 policy.

As for the locally rooted LW promotional activities, the nine regional chapters (including prefectural and local communal organizations) plan to hold more forums, seminars and visiting lectures, a total of 280 upcoming events. We will hereby like to introduce two event models as an aid to support the local chapters.

One is "Study Group for Legalizing End of Life Medical Care," commonly known as the "Think Tank Association" established by Tokai Chapter in cooperation with a local medical association, who has offered the place and opportunity for LW supporting physicians to participate and freely exchange information. Through these events, they will serve as role models to increase the enrollment of LW supporting physicians.

We welcomed 250 new LW supporting physicians in the last year, with a total of 1,600 current registrants. This upcoming year, our target is a total of 1,900 registered.

The other event program we plan to introduce is the Kyushu Chapter's training program to nurture future junior leaders who can continue our efforts in progressive local activities. The

first event is scheduled to take place in July in Saga Prefecture, to be followed by other local chapters.

As to the JSDD Living Will format, a revision will be issued shortly after the 2015 committee report had previously identified the issues to be considered. Online membership enrollment is also under way, which will be available in 2018.

Converting JSDD's status to a public-benefit corporation

JSDD is currently a general incorporated foundation. The government Cabinet Office rejected our request on December 9, 2016 to convert to a public-benefit corporation.

The reason for the rejection was that the government recognized the level of public impact on this matter, and was not comfortable to make this change without legal foundation for end of life medical care. In other words, government approval to change JSDD to a public-benefit corporation will have other implication and give the wrong perception to the public; therefore, it will only approve its status change once the living will is legalized. Unsatisfied with this decision, JSDD filed an administrative lawsuit for annulment while deliberating the recognition of a public-benefit corporation, and resubmitted the application on May 1.

The 2017 Fiscal Year Budget Plan

As JSDD's financial status has been rather stable, income from new membership enrollment was estimated to be ¥143,480,000 (¥3,710,000 less than the 2016 expenditure) and operating income to be ¥152,290,000. The operating expense of ¥170,950,000 is estimated, which is the same as the 2016 expense reflecting the reduced cost of newsletters due to the decreasing number of members. The bottom line shows a deficit of ¥18,660,000, which is still within our expected range.

The 2016 Fiscal Year Financial Statements Draft

The budget plan started with a deficit of ¥30,000,000, but we were able to reduce it to ¥18,000,000. Our efforts of reconsidering costly projects and not refilling vacant positions in the headquarters staff contributed to this outcome.

ACTIVITIES UPDATE COLUMN

“Prepare your Living Will”– interview of an agreement for collaboration between Japan Medical Association and JSDD

On March 26, Yomiuri Newspaper published a full page article entitled, “The Role of the Living Will,” covering interviews with Chairman of Japan Medical Association, Dr. Yoshitake Yokokura and President of JSDD, Dr. Iwao. This was the first time Japan Medical Association made such a strong statement expressing its commitment.



Japan Medical Association consists of 167,000 total physicians, most of whom work in clinical settings. Chairman, Dr. Yokokura often expressed in mass media the importance of making a living will with emphasis on the patient’s dignity and quality of life when faced with end of life.

Japan Medical association holds Bioethical Committee Meetings to discuss end of life medical care for elderly patients, and Dr. Iwao is one of the committee members.

Details of the interview were introduced by “JMA Medical News” in its May 20th issue and disseminated to all clinical physicians and other medical facilities throughout the country. Major activities conducted by JSDD were introduced, encouraging the readers to develop their Living Wills so they can have a peaceful end of life.

Dr. Iwao expressed JSDD’s eagerness to support this Living Will campaign by Japan Medical Association, calling out to every citizen who doesn’t have one yet.

THE PROSPECT OF DEVELOPING A SYSTEM FOR LW SUPPORTING PHYSICIANS

JSDD aggressively seeks a common point of contact

“The Think Tank Association” established by Tokai Chapter shows an increased number of physician participation, many of whom are registered LW supporting physicians. The common point of contact will aid in their mutual understanding, leading to a system which satisfies JSDD members’ needs.

The Think Tank Association has attracted the attention of JSDD inside and out. Established by Tokai Chapter, Aichi Prefecture Medical Association, and Nagoya City Medical Association, this study group for end of life medical care was established in 2010.

The 7th session of the meeting was held on February 19 at the Nagoya Prefecture Medical Association Grand Hall in Nagoya City, with the theme, “Terminal Medical Care and Palliative Care for Cancer.” Members of both Medical Associations, LW supporting physicians, nurses and attorneys, altogether 60 people attended, of which 25 attendants were physicians.

The lectures, reports and exchange of opinions were conducted at the high level equivalent to the educational courses designated by Japan Medical Association.

There is a reason why so much attention is directed to this Think Tank Association. The strong bond formed between the local medical associations and JSDD, despite the tendency to grow separately in terms of end of life medical care, has something to do with it.

Also every joint meeting brought more and more participants to become registered LW supporting physicians (a total of 132 LW supporting physicians among four prefectures, Shizuoka, Aichi, Mie and Gifu).

“I want to know more about the living will concept to keep up with constant changes in medical care”



**By Hideki Nomura, M.D.
Aichi Clinic Nonami (Nagoya)**

Dr. Hideki Nomura of Nagoya City attended the 7th session of the Think Tank Association meeting. He had already attended three or four of these meetings before. “I believe that JSDD is one of the organizations that is very serious about the LW. I attend these meetings to find out what the general public thinks about end of life issues and the LW, and also the trend in public opinion and government policies on this matter.”

His clinic is located in the residential district, north of Nagoya. Many of his patients are in-home patients; therefore, he has to visit them often and does not wear the typical white coat. He wears his own gown. In the entrance hall, seasonal plants are potted nicely in line.

He started his career as a hospital physician, and later worked in nursing facilities specializing in geriatrics. In April last year, he opened his current clinic which is heavily involved in local community health care such as in-home patients care and end of life care.

In 2010, he registered himself as a LW supporting physician for JSDD. He said he joined because as a physician, satisfying patients’ medical wishes as much as possible would be quite natural.

His clinic has three physicians to include internal medicine, pediatrics and visiting medical care. He has about 130 registered in-home medical care patients and takes care of about 30 terminal patients annually. He says, “I think I take care of more terminal patients than the average local clinic.”

“I don’t just provide terminal care. The patients and I search for the best medical care for their end of life together.”

We know that the way we think of medical care is changing, including how much of it we seek. Dr. Nomura says, “I’m trying to attend not only the think tank meetings, but any medical related study meetings out there.” No matter how much experience he gains, he maintains a humble attitude and an open mind to learn and understand new ideas.

Based on his medical experiences, he has one request to JSDD:

“I concur that the LW is a practical tool in time of life ending, but in my opinion, the trend of in-home care needs to emphasize the step prior to that, which is the concept of Advanced Care Planning, the process of patient and doctor together searching for the best treatment for the patient.” He says the next challenge is to seamlessly connect this process to the LW.

The next Think Tank meeting’s theme will be “Geriatrics” to connect to the local community

The number of LW supporting doctors reaches 1600 nationwide; however, these physicians are merely names on a list in JSDD newsletters and websites used only upon request by members.

There is a movement to further develop this system by offering opportunities for the Think Tank Association members and other doctors to get together and deepen their relationships and exchange opinions.

Tsukasa Kobayashi, the president of Tokai Chapter says, “We are seeing more doctors participating in the Think Tank Association, and we know many doctors share the same ideas as Dr. Nomura. If we take a more aggressive approach to contacting other physicians, we should be able to get more to register as LW supporting physicians.”

Our plan is to send a list of questions to potential LW supporting physicians by asking for 1) information on their methods, and 2) capabilities and limitations of terminal medical care. Their responses will give us an insight as to the future of JSDD and developing a comprehensive LW supporting physicians’ registry system.

The theme of the 8th Think Tank Association meeting will be “Geriatrics.” Japan is reaching the peak of a predominantly elderly society and a large death rate. Under these circumstances, it would be ideal to make the Think Tank Association into an all physicians’ assembly, inviting the Nurse Association, Hospice Association as participants. Many ideas are being tested to develop a great system of LW supporting doctors.