



JAPAN SOCIETY FOR DYING WITH DIGNITY

# NEWSLETTER

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Membership stands at 125,618 (as of December 6).



# LW Deliberation Process is What's Important

## Ministry of Health, Labour and Welfare Round-table Report Proposal

On October 28, members of the Ministry of Health, Labour and Welfare's "final stage medical treatment round-table" (chaired by Professor Hajime Machino, Sophia University) met for the final time to discuss the report proposal that summarizes what had been deliberated over the past two years. Included in the proposal were ways in which the support situation for patient's choices could be enhanced. With regard to Living Will, the two key points for its proper use are dissemination of the correct knowledge and deliberation-process for its formulation.

### To support "patient's choices" by giving out sufficient information

The round-table evaluates the findings of the Ministry of Health, Labour and Welfare's public opinion polls on final stage medical treatment (2008) and based on the seven sessions, gives advice on its future state. In 2007, a guideline was formed by the Ministry of Health, Labour and Welfare whereby it was basically decided that "proper information and explanation would be given by the medical personnel and the final stage medical treatment implemented would be based on decisions made by the patient himself." The round table was expected to take this concept one step further. There were nineteen committee members, consisting of medical personnel, legal scholars, patients and personnel of related medical organizations and such. Chairman Akihiro Igata of the society was in attendance from the first session and made several statements along the way.

The report proposal summarizes the opinions that were given at the round-table, covering six topics. The main topics are the four as listed below.

1. To correct the information imbalance and enhance the provision of information to the patient-side.
2. To expand the implementation of palliative care
3. To disseminate self-determination through LW, etc. and to enhance its process

4. To support family care, including emotional aspects

### Palliative care is not about "reaching death"

The Ministry of Health, Labour and Welfare guideline is based on the precondition that "proper information is being given." However, members of the round-table felt that at the moment, "the patient and family are being pressed to make decisions without being given enough information or explanation." Findings of the general public polls also reveal that the majority of the general public replied that, "not enough discussion on life-prolonging medical treatment is taking place with the physician." This "information imbalance" is not only about symptoms and treatment methods but also the place of care/treatment and patient life.

It was also pointed out that the wrong image of "palliative care" is taking the lead: palliative care = to reach death. As defined by WHO, palliative care, if necessary, should be provided from the preliminary stage for the purpose of treatment, and the necessity to co-implement "treatment and palliative care" was emphasized.

At the final round-table session to discuss the report proposal, deliberation lingered on topics pertaining to "LW."

When it came to LW legislation, members commented that while "there was a lot of negative feeling among the general public," "The number of people supporting the concept of LW as a means to respect patient's wishes at the final stage is increasing"; thus, the dissemination of the correct knowledge of LW was also seen to be desirable.

### Chairman challenges the LW evaluation

In response, some committee members sought the revision of the report proposal, "What's important is for the self-determined will to be the result of the information provided. The golden rule should not be about documentation or about having a LW." "They should disclose that as many as 60% of the general public were against the LW legislation." Findings of the public opinion polls showed that 56% of the physicians/nurses were in support of LW legislation while among the general public, support was limited to 32%.

Chairman Igata challenged the negative opinions on the LW, “LW embodies the respect for the individual will. Its dissemination is a human rights movement. Don’t tell me that’s not true,” “95-96% of the physicians approve of our society’s LW at the final stage medical treatment setting. Collaboration between patients and physicians exists.” Chairman Igata, on two occasions, sought opinions from other round-table members who remained near silent.

**In what ways is the “report” being reflected in the policies of the Ministry of Health, Labour and Welfare?**

The release of the actual number of legislation opponents was temporarily

## World News

For four days from October 16, the “World Federation of Dying with Dignity” conference was held in Melbourne, Australia, having been held previously in Paris in 2008. A beautiful day, it was hard to imagine that just the previous night, lightening and thunder storm had lashed through the city. The host was Dying with Dignity Victoria. There were eighty plus participants from membership organizations, split between member organizations in Europe, North America and local organizations. I was the only participant from Asia.

**Having participated in the World Federation Melbourne Conference**  
**Soichiro Iwao, vice-chairman**

**Not being able to identify with the practice of assisted suicide activities**

In the morning of October 6, the first day, participating organizations reported on the experiences of having seen someone to the end., etc. Presentation viewpoints, in general, were individual rather than organizational. I was shocked by the pragmatic views on suicide and presentation on the practice of assisted suicide activities like how we could help or what we could have done to help. Somehow, I was unable to identify with their activities which were different from with those of the

postponed partly due to comments made by other round table members. Chair Machino summarized the two differing opinions as follows, “The guideline by the Ministry of Health, Labour and Welfare too is based on the respect for the individual will. So is the LW and we have to make sure that LW doesn’t end up being something in formality only.”

Further adjustments will be made to the report proposal to be presented this spring. It will be reflected in the final stage medical treatment policy by the Ministry of Health, Labour and Welfare.

Japan Society for Dying with Dignity.

At the general meeting in the afternoon, a fiscal report was given in addition to an explanation on the increase in membership dues. Since the Paris conference, two major organizations from Britain and the United States canceled their membership due to differences in activity policies, putting a financial strain on the federation. A vote was taken and motion was approved.

**Open symposium heats up with participation of the general public**

The second day was a full day of open symposium. In the morning, there were presentations on the relationship with law and religion; in the afternoon, there was a report from Oregon (United States) and presentations on palliative care and physician assisted death. There were many local participants from the general public, and the 300-capacity venue was packed. Among the participants were both active euthanasia advocates and opponents, and passionate discussions continued until early evening.

For the local activists, this open symposium proved to be a good occasion to appeal the dying with dignity legislation movement and their activities in the Australian states. I had the chance to talk to some of the activists from Queensland and South Australia states. They told me that they have petitioned the state parliament but

parliament members are disinterested in this kind of legislation, the very reason why it's been shelved for long with no prospect of resolution. I distinctly remember them telling me that the Northern Territory Parliament's resolution to the petition was in itself perceived to be a major happening.

On the 8th, the third day, a presentation was made on "voluntary refusal of intubated nutrition and infusion." Nurses and physicians critical of the current situation commented that, "First and foremost, the individual will should be respected when it comes to the refusal of intubated nutrition and infusion. This is the reason why there should be a clear distinction between euthanasia and suicide." Participants were asked how the voluntary refusal of intubated nutrition and infusion by patients suffering from dementia should be determined, and "utilization of advance declaration" was recommended.

### To be held in Zurich in two years time

For the board member, Ted Goodwin (USA) was chosen as the chairman and Faye Girsh (USA), vice-chairman. It was decided that

## Deepening Discussions and Interest

## PEG (Percutaneous Endoscopic Gastrostomy) Update

### Fears that intubated nutrition that benefits the patient may lead to "life prolongation"

"PEG" is becoming a more common term. It's a procedure that is implemented on the elderly who've lost the ability to eat so that food can be passed directly into the stomach. It is supposed to be an effective nutritional control method, one that is "beneficial to the patient." Yet, if the patient's PEG life is prolonged with no chance for removal of the tube, it can complicate the symptoms, turning into a mere "prolonging" tool. Let me introduce to you what the recent situation of PEG is like now that discussion

the next world conference would be held in Zurich, Switzerland (hosted by the two Swiss organizations) in May 2012. The Tenrei Ohta ceremony was held at the after-party. The award was presented to Alejandro Amenabar, winner of the 2004 Academy Awards, foreign film category (it was accepted by the director of DWD Europe on his behalf)

### In conclusion

The conference prompted me to think deeply about the issue of assisted suicide. In western countries where individual rights are fully respected, a system is in place to assist suicide. This means that under the current law of a particular country, the patient is unable to choose death at the final stage. This is the reason why suicide assistance is such a popular topic, one that has ignited frequent discussions. However, I feel that having suicide as an option at the final stage is fundamentally different from the situation in our country where suicide can end up being treated as a societal problem.

on its pros and cons seems to finally be moving forward.

### "Small mouth" in the stomach, implemented on the elderly

In Kanji characters, the term, "IRO (the word in Japanese for PEG) is written 胃瘻. "瘻 (ro-o)" is a much talked about character, and yet, it's not found in the dictionary. 痔瘻 (jiro-o) is a disease in which a hole is formed in the anus. The same seemingly frightening character, "瘻 (ro-o)" is used for IRO. Are they using this character simply because a hole is formed in the stomach? Here, let's stick to the soft expression of kanji and hiragana characters, 胃(kanji) ろう(hiragana) (it is read IRO and it means PEG).

In the medical setting, the acronym, PEG, is used, taken from the first letters of the three words, percutaneous endoscopic gastrostomy. It refers to an endoscopic procedure to make a "small mouth" in the stomach to pass the nutrition directly in. It is for patients who are unable to take in food orally or else, for those who are prone

to choking on the food during oral intake that can develop into pneumonia. This intestinal mouth is called IRO.

PEG was first developed in the US for children with eating disorders, and it is now being implemented on the elderly. During the past few years, it has seen an explosive spread in Japan. It has eased the sufferings of patients and decreased the burden on caregivers, making long term care/treatment and prolonged living possible. Yet during discussions on the state of final stage medical treatment, problems about PEG are now being raised.

**Number of PEG patients reaches 400,000**

Soichiro Iwao, director of our society, also points this out in his dissertation, “To realize dying with dignity legislation” that was featured in the September 15, 2010 Yomiuri Daily “viewpoint.”

“Let me call your attention to a particular issue about PEG that was raised. That is, PEG can be interpreted as something that’s merely keeping the patient alive. How can we call this true medical treatment if it’s not allowing us to wither and die naturally?”

With more and more elderly being cared/treated, the implementation of PEG is becoming more common in hospitals and medical facilities. From the number of tubes that have been supplied (updated regularly every 4-6 months), as many as 400,000 patients are said to have been fitted with PEG with the number of new placements increasing annually at a rate of 100,000. Amid this situation, the Japan Association of Medical and Care Facilities last September presented their survey findings in a document titled, “30% of the patients in the medical and care wards are PEG patients,” making us acutely aware of this large number.

The organization ran a “patient survey on nutritional intake” targeting member medical and care facilities (850) and heard back from 312 (28,102 patients).

**PEG has been placed in one out of three sickbed patients being treated/cared**

The PEG procedure (including enterostomy) is being carried out in almost all the facilities with nearly 30% of all in-patients having been fitted with it. With the inclusion of nasogastric tubes, it means that 40% or more of the patients are being fed intravenously. Considering that there are

264,000 sickbeds nationwide for patients under treatment/care, the number of “those who are being fed intravenously is estimated to be in the range of 100,000. This is a much larger figure than expected.”

**Situation survey of intubated nutrition  
(Japan Association of Medical  
and Care Facilities)**

	Number of facilities	Number of patients (percentage)
Number of sickbeds for treatment/care	312	28,102
Number of patients fitted with nasogastric tubes	282	3,668 (13.1%)
PEG patients	306	8,082 (28.8%)
Intravenous hyperalimentation patients	213	2,000 (7.1%)
Patients fitted with tracheotomy tubes	213	3,371 (12.0%)

Sickbeds for patient treatment/care are facilities for the elderly who are suffering from chronic illnesses. Their symptoms may be mild and they may not require much treatment but nevertheless, are expected to be hospitalized for long. Many are bedridden. Our society feels that “this is a major topic in final stage medical treatment and includes the state of patient’s self-declared wishes on how he wants to take in nutrition.” The society will continue to work on this by referring to the survey results.

**Impact of the NHK program that's made us aware of the pros and cons**

Another incident that recently raised the awareness of this issue was the showing last July 25 of the ETV Special on NHK Educational Channel. Titled, “You can live without eating - pros and cons of PEG”, it portrayed the anguish of Dr. Yutaka Suzuki (International Medical Welfare University), disseminator of PEG technology in Japan.

The program began by introducing the topic as follows. “The lives of those who are no longer able to eat have been extended enormously due to PEG. It has seen rapid dissemination, endorsed by the very people who want their loved ones to live to the maximum.” Turning to the audience, Dr. Suzuki then asked, “In Japan, many PEG patients are the elderly who are unable to

communicate their will because they are suffering from dementia, cerebral infarction and such. Although we can keep the patient alive by PEG, we don't really know if this is what he wants."

The program proceeds with a focus on Dr. Suzuki who expresses his anguish, "I am responsible for having invited the current situation of supremacy of life-prolongation" and perseveres in his quest to answer "how should we think about PEG." As vice-chairman Iwao pointed out in his dissertation, the program asks, "By simply keeping the patient alive, are we treating him medically?" "In the present situation, we can't die naturally. Is this all right?"

### **"Correct answer" that even physicians are unable to find**

The near-radical move to connect PEG directly to life-prolongation proved provoking and created a huge public stir. On November 28, the program was rebroadcast on NHK. NPO PEG Doctors Network (PDG) that provides information on medical feeding methods, including PEG, invited its web site(<http://www.peg.or.jp>) visitors to share their opinions, "Now that you've seen the program, what do you think?" and many responded, posting comments on the site.

Dr. Suzuki too is a member of PDG and posted a single statement on the HP, "What we need is a discussion that will serve as a passing point to guide PEG to a better PEG." He furthermore says, "The patient benefits medically from PEG if it's used correctly in accordance with the correct application. However, can we really say that life prolongation as a result of PEG brings true happiness when we could have quietly reached the end? There is no correct answer, and both the physicians and families are searching for it."

### **Enough information should also be given to**

### **those who are choosing**

On our LW110, we've been getting more inquiries from families of members asking us about PEG. In addition to questions like, "It was recommended to us by the physician, but what should we do?" they also ask the basic, "Is PEG really a life prolonging procedure?" The counseling has made me more aware of the smallness of the information that is being given to families. Amid this information imbalance with the medical-side, we are seeing a situation in which patients and their families are being pressed to make "decisions" and forced to "consent."

About three years ago, reporter, Satomi Sueda, wrote an article in Nikkei Medical, "Life-prolongation through PEG, is this really good for the patient?" In it, she talked about the findings of the survey that was carried out by a hospital physician in Minakami-Machi, Gunma Prefecture. It targeted 55 PEG patients who had transferred to this hospital due to the availability of PEG procedure. Of this number, 41 patients "were incapable of making their own decisions or communicating" at the time of PEG placement and there was only one patient whose "will was confirmed" at hospital admittance.

This figure suggests that things are being orchestrated at the wishes of the family and the patient's wishes are not known. Family members want to be given sufficient information on PEG; after all, they are the ones making the choice and decision after much pondering. It is not an exaggeration to go so far as to say that the medical facility is responsible to provide this information. I hope that discussions on the pros and cons of PEG will lead us to a better final stage.