



Excerpts from



**Japan Society for Dying with Dignity Newsletter
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**5th Japan Living Will Study Workshop held in celebration of 40th
Anniversary of Japan Society for Dying with Dignity (JSDD)
-Topic: Planning terminal care at home or nursing home-**

In celebration of our 40th anniversary, the 5th Japan Living Will Study Workshop was held at the National Graduate Institute for Policy Studies in Roppongi, Tokyo on June 18th with 300 participants. The topic of this workshop was “Where and how to spend the last chapter of your life.”



The first session was the speech by a special guest, a successful film actor, Masaomi Kondo, who is also a member of JSDD. Our Vice President, Dr. Kazuhiro Nagao interviewed him. Mr. Kondo talked about an episode from his recent NHK TV series, and also shared some of his personal experiences when confronted with his grandfather’s death. At the age of 53, this was when he decided to join JSDD and stay home for the last days of his grandfather’s life. His speech was so vivid and inspiring as if it was a live stage performance by a professional actor, and his jokes brought laughter to the audience.

The second session was the actual workshop chaired by Vice President, Dr. Yutaka Suzuki, and two other physicians who specialize in taking care of terminal patients at their homes and nursing homes.



Dr. Kazuo Io, Chief of Tachikawa In-Home Care Clinic, talked about his experiences in providing palliative care to over 200 terminally ill patients annually in their homes in Tachikawa, Tokyo. Many of his terminal ill patients are diagnosed with cancer. His speech title was “How to live the end of your life with no regrets.”

Family members are the leading players in palliative care

He preached to the audience, “The hospital is not a place to die. It is a place to provide medical treatment. What I’m pursuing is to provide peaceful in-home terminal care.” He continued, “We (doctors) are not the leading player in this process. The patient’s family is. To support the patient 24/7 seamlessly is what in-home medical care is all about. To make this happen, there must be three solid commitments; one from the patient, one from his/her family, and one from the doctor.”



Mariko Saito, a JSDD member whose husband died of cancer under Dr. Io’s care, took the stage and talked about her experience.



Another speaker was Dr. Masayuki Miyagishima, Director of a clinic associated with a nursing home in Hachioji, Tokyo, reported how his clinic provides peaceful and secure end of life environment for its patients.

Become part of the patient’s life story

This clinic tries to understand the life history of each patient from a healthy stage, through declining health, and helps them through the dying process. Dr. Miyagishima told the audience that the percentage of

its residents who are dying in hospitals has decreased to less than 30%. With more experience, increased awareness and confidence of care givers in dealing with terminal patients have led to a much more satisfying environment.

During the discussion session, Mr. Kondo and Dr. Nagao exchanged their opinions about certain decisions they must make when the patient enters the dying process, such as calling for an ambulance, what to do when the patient can no longer eat, or administering an IV.

2nd Visiting Lecturer Conference

How to respond to audience's questions –Training to gain skills required to promote the living will



Visiting lectures are a major campaign pillar to enlighten and propagate the significance of the living will. A total of 19 lecturers, who are directors of each regional chapters, gathered together on June 19th at the JSDD headquarters.

The visiting lecture program was designed to target the non-member audience to educate and inform them of what kinds of services JSDD provides and the concept of the living will. It is not a symposium or a forum intended for large audiences. The benefit of this type of program

is that it gives the lecturers the opportunity to answer each question thoroughly so that people can understand them more clearly.

As such, selected lecturers must have the ability to speak adequately and convincingly, and have enough experience themselves to be able to share them with their audiences. One of the frequently asked question is, “What are the benefits of becoming a member of JSDD?” Their answers typically include:

- The living will serves as a clear expression of his or her wish
- It gives them an opportunity to talk to their families about their wishes
- It can be considered their last gift to their families

They also explain that JSDD provides free phone consultation service, quarterly newsletters, and invitations to symposiums/forums with various topics.

Last Year's Visiting Lectures captivated over 6,000 participants

The lecturers encountered some difficult questions to answer accurately and convincingly, for example:

- Can JSDD membership guarantee me death with dignity?
- Is my living will still valid if I am diagnosed with dementia?
- What happens when the ambulance takes me to the ER?
- Why is the living will not legalized yet?

There were many intense discussions and exchange of opinions in search of finding satisfying answers to these questions. The visiting lectures are held nationwide, and last year's participants totaled over 6,000.

Let's invite a visiting lecturer!

What is a visiting lecture?

JSDD's regional chapter directors are the lecturers. They will come to your requested location to explain the concept of the living will and answer any questions people may have. It's a mini workshop which takes only about an hour and a half. It is open to anyone regardless of JSDD membership status who is interested in deepening their understanding of the topic.

Location: It can be a public or private room where meetings can be held; however, the cost to rent the space will be your expense.

Looking for any possible groups interested in receiving this service. In the last year, we have held 130 lectures nationwide and 6,000 people have participated. You can contact any chapter office of JSDD. Thank you.

Dying at home –disparity of rates based on locality

Three times more in large cities; five times more in mid-size municipalities

This data is a barometer of how strong in-home terminal care is in your community



Most of us want to die in the comfort of our own home. In July, Ministry of Health, Labor and Welfare published a report with statistical data from a survey of 1,741 municipalities by city, ward, town and village. This was the first time such a study has been conducted, and what it showed was that there is a huge disparity in the numbers among the localities.

Below is the list of top locations where people have died based on 2014 demographical data:

Hospital	-----75.2%
Home	-----12.8%
Nursing Home	-----5.8%
Clinic / Assisted Living Home	-----Minimal

The full report "Data regarding in-home terminal care by locality" is available on the Ministry of Health, Labor and Welfare website. The report contains the number of clinics that provide and support in-home terminal care as well as number of visiting nurse stations.

The following chart shows the percentages of in-home death in cities with population over 200,000 (126 cities):

City (Prefecture)	% In-Home Death
Yokosuka City (Kanagawa Prefecture)	22.9%
Katsushika Ward (Tokyo)	21.7%
Ichikawa City (Chiba Prefecture)	21.5%
Shinjuku Ward (Tokyo)	21.4%
Sumida Ward (Tokyo)	20.0%
Edogawa Ward (Tokyo)	19.9%
Toshima Ward (Tokyo)	19.2%
Koto Ward (Tokyo)	18.7%
Funabashi City (Chiba Prefecture)	18.7%
Fukushima City (Fukushima Prefecture)	18.5%
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Saga City (Saga Prefecture)	9.3%
Akita City (Akita Prefecture)	9.2%
Isezaki City (Gunma Prefecture)	9.1%
Hirakata City (Osaka)	9.0%
Matsue City (Shimane Prefecture)	8.8%
Kita kyushu City (Fukuoka Prefecture)	8.7%
Sasebo City (Nagasaki Prefecture)	8.5%
Toyama City (Toyama Prefecture)	8.5%
Asahikawa City (Hokkaido)	8.5%
Kagoshima City (Kagoshima Prefecture)	8.0%

The next chart is the percentages of in-home death of medium-sized municipal communities with population between 50000 and 200,000 (428 cities):

City (Prefecture)	% In-Home Death
Toyooka City (Hyogo Prefecture)	25.6%
Chuo Ward (Tokyo)	21.5%
Urayasu City (Chiba Prefecture)	20.5%
Ikoma City (Nara Prefecture)	20.1%
Oamishirazato City (Chiba Prefecture)	19.9%
Tachikawa City (Tokyo)	19.6%
Tosu City (Saga Prefecture)	19.5%
Date City (Fukushima Prefecture)	19.4%
Handa City (Aichi Prefecture)	19.3%
Kitakami City (Iwate Prefecture)	19.2%
Tenri City (Nara Prefecture)	19.2%
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Hioki City (Kagoshima Prefecture)	6.9%
Yukuhashi City (Fukuoka Prefecture)	6.9%
Imari City (Saga Prefecture)	6.9%
Goshogawara City (Aomori Prefecture)	6.7%
Komatsu City (Ishikawa Prefecture)	6.7%
Usa City (Oita Prefecture)	6.7%
Yuri honjo City (Akita Prefecture)	6.5%
Numata City (Gunma Prefecture)	6.4%
Takeo City (Saga Prefecture)	5.7%
Gamagori City (Aichi Prefecture)	5.5%

Reflecting degrees of effort by municipalities

As much as 30% of total municipalities surveyed had no terminal patient care services such as in-home care support clinics and visiting nurse stations which provide 24/7 full time care.

By analyzing these charts, we drew the following conclusion:

- Top 9 cities in terminal patient care were located in Tokyo, Chiba and Kanagawa prefectures.
- In the medium-sized municipal category, 5 out of 9 lowest ranking cities were in Kyushu Island.
- Municipalities with large numbers of hospitals relative to their populations and municipalities with shortage of in-home care service showed low percentage of death at home.

Such a noticeable disparity of in-home death rate among municipalities maybe contributed by the shortage of manpower to engage in in-home terminal care system and the differences in the level of public awareness in terms of comprehensive care system, especially end-of-life care.

The data of in-home death (see definition in the footnote below) rates shown in the above charts does not equate to the actual level of in-home terminal care, but it is certainly a measure of how much effort is placed in in-home terminal care by the municipalities.

Special circumstances found in Tokyo

If you look at the data from large cities, you will notice that all wards of Tokyo show 6 to 9 points above the national average. This is definitely a reflection of their strong efforts to establish and improve their in-home terminal care system, but there are particular circumstances inherent in Tokyo.

Yokosuka City, ranked #1, has 10% nursing home death (not in-home death), If we combine it with in-home death, then the rate jumps to one person out of 3.

In Tokyo (23 wards) on the other hand, nursing home death is 5% in all wards. If we combine it with in-home death, the rate is over 20%. The difference between Tokyo and Yokosuka is apparent, when comparing hospital death in Yokosuka is 60% as opposed to 73% in Tokyo. The

market value of real estate can be a contributing factor, which is much higher in Tokyo than anywhere else, discouraging more nursing homes to be established.

Another contributing factor of higher in-home death rates in Tokyo or any large city may be the high number of solitary deaths, according to Mainichi Shimbun (Newspaper). The 2014 statistical data for solitary death in Tokyo shows 28% of all natural deaths was in solitude.

The highest in-home death rate nationwide was 54.8%, Kamitsu-shima Village in Tokyo, followed by 50.0% for Yoroncho in Kagoshima Prefecture. Both are small islands, isolated from the mainland; however, there also a small village with 0% in-home death rate.

Note: “In-home death” indicates a case of death confirmed by a doctor at a home. This includes death in the patient’s own home, group home and assisted living home. The term strictly refers to the place of death, thus, cases in which in-home care patients were sent to a hospital are excluded.

Multi-vocational cooperation, not just lip service

Yokosuka City, ranked #1 in-home death rate in large cities

Result of 5 year effort to encourage people to spend end of life at home

Yokosuka City, Kanagawa Prefecture, was ranked #1 for in-home death rate among cities with population of over 200,000. Our staff went to the city, located on Miura Peninsula, to visit Ms. Rieko Kawana, Director of City Community Medical Support Promotion Division, to find out how it became the top city.

Natural ground for “Yato”



There are about 50 residential communities built on hills facing the Tokyo Bay, known as yato.” It used to be almost impossible to drive in and out of these areas because the roads were basically stair cases. For a long time, it was customary for doctors to visit patients’ residences for both urgent and regular medical care.

In 2011, a promotional movement extended this “visiting doctor” idea to in-home terminal care. A survey conducted showed 60% of their citizens wished to have their end of life care at home. A

conference was held, as the official communal care promotional body.

Medical Association and hospitals are focused

The power of the private sector accelerated this effort and related activities. Among the participants of the conference was the city’s medical association, which built an in-home medical care station called “Seagull Plaza.” “Team Kinugasa” of Kinugasa Hospital, which also runs a

hospice, also joined the conference. Team Kinugasa has five independently operational professional teams, each consisting of a physician, a nurse specializing in care support, a medical social worker and an office administrator. They play an integral role in streamlining and promoting in-home medical care. The conference was filled with main players of medical profession.



Photo-“The partnership of multiple vocations to Yokosuka citizens with in-home medical care is our treasure,” says Ms. Rieko Kawana, Director of Yokosuka Community Medical Support Promotion Division.

Manners and courtesy for a “joint” structure

No matter how close, there are always walls among different vocational groups when working together. To break through the walls, Yokosuka formed a study workshop consisting of many different professional workers. Medical professionals, care givers, officer administrators, and nutritionists, altogether 175 workers met and brainstormed.

The workshop compiled all points from the brainstorming session and published a booklet in 2014 called “Etiquette for In-home Medical Care Cooperation and Promotion,” which explains in detail etiquette and manners required for sharing sensitive information to care managers and physicians, with whom many patients find difficult to communicate.

In dire need of physicians to engage in in-home medical care

Veteran physicians with in-home medical care experience provided mentorship and instructions to other clinical physicians. To train the hospital doctors to understand in-home medical care, seminars were held by experienced in-home care doctors, sometimes held at their hospitals when time was extremely limited.

Out of the 316 clinics, only 66 provide in-home medical care, an increase of 12 clinics in the last two years. Information regarding the city’s in-home care program is shown on its website. Terminal in-home care is now provided by 14 clinics.

Access to JSDD Living Will

Another main issue was the local residents’ lack of awareness. In 2013, Yokosuka City published a guidebook called “Let’s stay home until the end,” which included various real life episodes and easily interpreted explanations. About 30,000 copies were distributed and read by its residents. Although this book introduces JSDD’s living will, the city plans to develop its own format of the living will.

Yokosuka City Data

Population	410,000	Nursing Home	10.0%
Elderly Population	30%	Hospital	60.4%
Number of Annual Death	4,592	Clinic	2.8%
Death Locations:		Assisted Living Institution	1.7%
Home	22.9%	Other	2.2%

A Memorial Address for Honorary Chairman, Dr. Akihiro Igata for taking the lead in the successful JSDD membership drive, who was still passionately involved in various activities until the day he died

By Dr. Soichiro Iwao, JSDD President



Our honorary chairman, Dr. Akihiro Igata, passed away on August 12th. He was 87 years old. I was told that his students from Kagoshima University were planning to have a celebration party for his upcoming 88th birthday. It is difficult to accept his departure.

He served as the 5th JSDD president from 2002 to 2012. During his tenure, the membership rate increased drastically from 100,000 to 120,000. His leadership demonstrated his firm conviction of avoiding confrontation and finding more common factors.

While he was the chairman of Nagoya University School of Arts and Sciences, he actively involved himself in various JSDD projects even after he had retired from JSDD presidency. I am told that he appeared healthy when he attended the Forensic and Ethical Medicine Study Workshop held by Tokai Chapter in late July. The following day he emailed me, “I am rigorously pursuing the perfect living will format which no Diet members will be able to find any reason to turn down.

Photo – Born in 1928 in Hamamatsu City, Shizuoka Prefecture. Dr. Igata received his MD from Tokyo University School of Medicine in Neurology. His assignments include: Professor at Kagoshima University School of Medicine, Chairman of Kagoshima University Hospital, Chairman of National Center for Geriatrics and Gerontology, President of JSDD (2002 - 2012).

Dr. Igata was heavily involved in pursuit of resolving the cause of SMON (subacute myelo-optico-neuropathy), setting the medical criteria of Minamata disease, defining the criteria for brain death, and reforming the system of health care insurance.

Looking back on his career path, I became aware of his relentless spirit to explore the unknown world. His involvement in the dying with dignity movement while he was involved in the geriatric healthcare must have been a part of his challenge to shape our future medical science and medical care.

Since my assignment at the Ministry of Health and Welfare, I am deeply indebted to him in so many ways, including my involvement with JSDD.

He lived alone in Toyoake City, Aichi Prefecture after he lost his wife 17 years ago. According to his eldest son, he started having difficulty breathing and called the emergency number himself on the evening of August 12th. The city has an emergency service specifically for people living alone to automatically speed dial a neighbor and a relative when calling 119 (emergency). He went into cardiopulmonary arrest while he was still in transit to the emergency room, and his death was confirmed upon his arrival at the hospital.

He taught me the importance of dignified death and that it is a physician's obligation. His guidance is what brought me to work for this movement. I dearly embrace what he left for us and wish to move forward towards further growth and development of JSDD. My sincere condolences for his family.

Frontline Local Chapter Activities in 2016

1. Study Workshop of Tokai Chapter

Discussion among professionals in medicine, law, forensic and medical ethics

JSDD has a forum where doctors and lawyers get together periodically to discuss issues surrounding medicine, ethics and law. Three years ago, Tokai Chapter (headed by Tsukasa Kobayashi) started a "Forensic and Ethics on Terminal Medical Care Workshop." It is coming up on its 30th meeting, going through a number of heated discussions.

According to the founder, Ms. Hitoko Aoki, former president of Tokai Chapter, it was necessary to establish a legal system in which both doctors and lawyers jointly accept the wishes of terminally ill patients.

Mr. Kunio Aoyama, an attorney and former Nagoya High Court Judge, and also the Director of Tokai Chapter, was one of many professionals who used to feel that there was no place for doctors and lawyers to discuss their different aspects in order to work together towards the same goal. He had agreed with Ms. Aoki and voluntarily accepted her offer to become the Chairman of the Study Workshop.

With its members consisting of about 20 doctors and lawyers, the workshop has become beyond a single Chapter activity. Mr. Takuo Kanagawa, a forensic medicine scholar, former president of Hokuriku Chapter and a young lawyer specialized in death with dignity laws, (non-JSDD member) also joined the workshop.

The meeting was held at Aoki Memorial Hall located at Ms. Aoki's private residence, where the group meets eight to nine times a year, having discussions over two hours typically. The topics are diverse and since recently include overseas reports and analysis.

Live reports from Europe, Americas and Asia

For example, the 26th session was about a model case on mental capacity support in southern Australia, and the 27th meeting analyzed the Advance Directive in the United States. Live reports on the Death with Dignity Act in Taiwan and Korea were discussed at the 28th session.

There are too many topics that need to be discussed, says Ms. Aoki. Mr. Aoyama of Tokai Chapter says he wants to study end-of-life related laws and ethics with a broad perspective.

2. The 3rd Hokuriku Chapter Living Will Study Workshop In pursuit of honoring the patient's wish

Hokuriku Chapter (headed by President Yoichi Shinto) held its 3rd living will study workshop on June 11th at Kanazawa City Culture Hall in Kanazawa City with 40 attendees.

Mr. Takuo Kanagawa (former President) and Mr. Toshio Yamazaki (Director) chaired the workshop, and four panel speakers were invited to share their thoughts on terminal medical care and honoring patients' wishes.

Dr. Kitamura, Director of Ishikawa Prefecture Takamatsu Hospital, explained the difficulty of confirming dementia patients' wishes. Dr. Masaki Kita, Director and anesthesiologist of Kanazawa Prefecture Hospital, proposed that an ideal solution to this problem is to require all patients in his hospital to submit their living wills if they already have them, and urge others to prepare them with their families.

Next, Mr. Toshimitsu Moriguchi, Deputy Nurse of Internal Medicine Department at the same hospital, expressed his opinion from a nurse's perspective how much easier to handle situations when patients have already prepared their living wills and know what their wishes are. Ms. Kazuyo Nakajima, Professor of Ishikawa Prefecture Nursing School stated that it is difficult to teach the concept of dying with dignity to young students, but it is so important to disseminate the importance of the living will to society, especially to nurses and doctors. Mr. Tadakuni Fujii, Director of Hokuriku Chapter representing patients, said that he has a living will but is not confident that it will be honored and followed. He expressed his strong wish that one day, patients can feel confident and assured about the execution of their living wills.

Lastly, the audience joined the discussion regarding tube feeding and artificial dialysis. Mr. Shinto, the newly elected Chapter President, adjourned the meeting with his closing remarks.

Photo-Panel speakers listening to opinions from the audience

3. The 2nd Kansai Chapter Living Will Study Workshop Face to face with community led to success



2nd Kansai Living Will Study Workshop held on June 11th in Toyoakecho, Osaka welcomed 435 people with the topic, “Caring for terminally ill dementia patients,” and was cosponsored by the town’s Caregiving Family Association and Social Welfare Council.

Dr. Kazuhiro Nagao, President of Kansai Chapter Vice President of JSDD, was the guest speaker. He explained thoroughly the definitions of dementia and “end of life” or “terminally ill.” The key points of his speech were as follows:

- Providing comfortable environment for both patients and caregiving families
- “End of life” with least pain and suffering without extended dying process
- We are all in charge of our own “end of life”
- Even dementia patients can determine their wishes

His speech was followed by the four panelists. Dr. Mawatari, owner of a clinic expressed a doctor’s anguish over terminal care. Ms. Etsuko Komiya, president of an organization called Free Station, explained some of the reasons why death with dignity is not easily carried out, and asserted that one must have a life with dignity first.

Mr. Kidera, president of the town’s Caregiving Family Association, shared his own experiences with dementia patient and their difficulty expressing end of life choices. Ms. Taeko Maruo, president of an NPO, talked about the importance of eating.

During the Q&A session, a question was raised about specific challenges for family caregivers. The discussions that followed deepened the audience’s understanding of the topic.

Kansai Chapter expressed its anticipation that this forum will spark a trigger for improving in-home terminal care in town, and that having this type of forum hand in hand with other community groups brings effective results which they would like to continue in the future.