Excerpts from

Japan Society for Dying with Dignity Newsletter
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New Year's Message

With the World Con as a catalyst, we seek to move decisively toward the legalization of death with dignity.

Dear Members,

I would like to respectfully extend my New Year's greetings to you all, and sincerely celebrate with you the arrival of the fresh and auspicious New Year of Reiwa 8.

Last year's NHK morning drama series *Anpan* portrayed the lives of Mr. and Mrs. Takashi Yanase, the creators of *Anpanman*, and conveyed a powerful message about the meaning of "justice" and the importance of "living." The opening line of the original draft of the lyrics to the anime's theme song, *Anpanman no March*, reads: *"Yes, it's a joy—the joy of living, even if life were to come to an end."*

Having once stood on the brink of death from starvation during the war, Mr. Yanase expressed through the spirit of Anpanman both the joy of being alive and the inherent fragility of human beings who must one day die. The philosophy of death with dignity—namely, "deciding for oneself how to live in the final stage of one's life"—is about living authentically until the very end. It is, I have come to reaffirm, precisely the same as the Anpanman spirit of "living one's life fully and brilliantly."

We have continued our efforts to bring our members' "end-of-life wishes" to society and to see them realized. As in previous years, we devoted ourselves to promoting awareness of the *Living Will*, an advance directive for end-of-life care, emphasizing through online seminars and public outreach the importance of clearly expressing one's wishes in advance. We also strengthened our consultation system for members, enhancing support that stays close to their concerns and questions regarding end-of-life issues. In the coming year as well, we aim to make further progress in discussions surrounding end-of-life care, medical treatment, and death with dignity.

"Death with Dignity"
—The Spirit of Anpanman

"Death with dignity" is not merely the refusal of life-prolonging treatment; it is the Anpanman spirit of "living true to oneself until the very end." We will continue to reinforce collaboration with medical and long-term care professionals, as well as

community-based awareness activities, so that our members' wishes are respected—whether at home, in care facilities, or in hospitals—and that they may face the end of life with peace of mind.

In November of this year, the *World Federation of Right to Die Societies (WFRtDS) Tokyo Conference 2026*, hosted by the Japan Society for Dying with Dignity, will be held in Tokyo. At the conference, discussions will extend beyond death with dignity to include the realities in Europe and North America, where medical aid in dying (physician-assisted dying) has become increasingly common. We also plan to examine the situations in South Korea and Taiwan, where laws on death with dignity have already been enacted. By learning from global developments, we hope to apply these insights to future efforts toward legislation in Japan.

Our long-cherished goal is to establish a legal framework for death with dignity. Legalization is an essential foundation for a social system that protects individuals' wishes from excessive life-prolonging treatment and enables the provision of truly necessary medical care and support. To make our members' desire to "remain themselves until the very end" a shared understanding throughout society, we will pursue legislative advocacy with renewed determination. As Chairperson, I am fully committed to making this a year in which the philosophy of death with dignity takes deeper root in society and a major step is taken toward its legalization.

In closing, I sincerely wish all our members continued good health and happiness, and offer these words as my New Year's greeting.

Celebrating Our 200th Issue

"Death with Dignity" as Spoken by Distinguished Figures Part 2

Since the founding of the Association in 1976, our newsletter has been published four times a year. With this issue, we proudly mark both our 50th anniversary and the publication of our 200th issue.
To commemorate this milestone, over the course of two consecutive issues—the previous one and the present—we have carefully selected interviews in which distinguished figures spoke about "death with dignity," choosing those that many readers expressed a desire to read once again. We present here edited excerpts of those conversations.
In this second installment, we feature novelist Setsuko Shinoda, who speak poignantly on themes such as:
"Is there such a thing as the 'right time to die'?"

Setsuko Shinoda,
Novelist

(Excerpt from Newsletter No. 178, July 2020)

Is there such a thing as the 'right time to die'?

—In your book *Cancer Came from Behind Caregiving!* published last year, you wrote about your mother, now 96, living in a dementia ward of a psychiatric hospital. Has the caregiving environment changed due to COVID-19?

Shinoda: Visits are currently prohibited. Since February 23, I haven't been able to see her at all. As the COVID alert level rose, at first I could still go as far as the entrance to the dementia ward to drop off laundry, but now I can only reach the hospital's outpatient reception area.

—Has there been any change in your mother's condition since then?

Shinoda: She still has an appetite and eats properly, but her intestinal function has declined, making digestion and absorption difficult, so she's losing weight. At 96, I imagine that the ward's policy is not to pursue aggressive internal medical treatment. Going forward, this may well relate to issues of death with dignity.

—It sounds like there were many difficulties before she entered the current dementia ward.

Shinoda: Three years ago, in November, my mother was hospitalized with suspected intestinal obstruction, which led to her admission to a long-term care health facility. But those facilities don't allow extended stays. After about a year, we were asked to leave, so I had to look for another place. Before I even had time to worry, I visited around 14 different facilities in between work commitments.

—You're an only child, aren't you? Handling everything on your own must have been hard.

Shinoda: That couldn't really be helped… Two months later, we managed to place her in a group home. From my perspective it seemed clean and home-like, but for my mother, it

wasn't ideal. She worked as a nurse until she was 60, didn't socialize much in the neighborhood, and didn't particularly enjoy lively group interactions. In a group home, although residents have private rooms at night, during the day they spend time together in a small living area. As her dementia progressed, problematic behaviors increased, and she was eventually transferred to the current dementia ward.

—When did her dementia symptoms begin?

Shinoda: Around age 70. When she was 73 and I was 42, my husband and I moved to a place about a three-minute walk from her home, thinking ahead. I knew I would be the only one she could rely on. That was in 1997.

He Was Crying Out in Pain

—Your father passed away some time ago. What was his final period like?

Shinoda: He died in 2014 at the age of 90. On January 3 that year, he was struck by a car and hit his head. He was taken to a university hospital with a skull fracture and acute subdural hematoma. He didn't complain of pain, but the doctor said that if the bleeding solidified into clots, neurological damage was inevitable—a cerebral infarction.

—What was he like when you visited him?

Shinoda: He was conscious, but while talking he would gradually drift into a drowsy state. Eventually he could no longer eat by mouth and was put on nasal tube feeding. He later developed severe enteritis as well. Thanks to the capabilities of the university hospital, he was kept alive, and after three months he was transferred to a regional core hospital. There, the doctor said, "We can't continue nasal feeding indefinitely, so we'll place a gastrostomy tube."

I had heard that a feeding tube can prolong life in patients with little chance of recovery, but often causes greater suffering, so I considered refusing.

—That must have been a very difficult decision.

Shinoda: Exactly. Standing in front of someone whose life is sustained entirely by tubes, it's not an atmosphere in which you can easily say, "Please stop and let him fade away." After that, he repeatedly developed aspiration pneumonia—vomiting the stomach contents, which then entered his lungs. Around June, his condition was deemed stabilized, and he was transferred to a hospital with a long-term care ward. There, the policy was "no aggressive treatment." The amount of nutrition via the feeding tube was reduced, IV fluids were added, but eventually even IV access became difficult.

He was bedridden, and when nurses repositioned him, he cried out loudly in pain. His body had stiffened. It was truly heartbreaking. Feeding tubes, vomiting, aspiration pneumonia, IVs—after enduring all that, he finally died when he vomited and the contents obstructed his airway. It was seven months after the accident.

—Witnessing your father's final days, has it shaped your own thoughts about death?

Shinoda: What I think now is that somewhere between one's 80s and 90s, there may be a "best time to die." When my father was brought to the hospital after the accident, still without pain, the doctor told us, "Tonight is the critical moment." If he had died then, he would have been spared all the suffering that followed.

Later, when he became drowsy, there might have been the option not to initiate tube feeding—allowing him to pass peacefully in his sleep. Instead, his final months were filled with repeated suffering: forced feeding, vomiting, aspiration. His screams during repositioning still echo in my ears. I now think those months must have been like torture. He could have had a peaceful death, yet instead was kept alive for seven months while enduring immense suffering. I strongly felt, *"This is not how a human being should die."*

The Natural Cycle of Life and Death Has Been Distorted

—In *Cancer Came from Behind Caregiving!*, you wrote that humans, like all living creatures, live, reach the end of their lifespan, die, and are replaced by the next generation, yet this obvious truth has been forgotten, distorting the natural cycle of life and death. You also wrote that skyrocketing medical costs may stem from modern Japanese society's refusal to accept the reality that life has an end, and from the way end-of-life care is practiced accordingly. Some might see this as a bold assertion.

Shinoda: I think it's simply stating the obvious (laughs). Of course, if politicians, bureaucrats, or medical professionals said it, it might cause problems. But we're novelists—independent professionals. If we don't say it, then who will? I feel that speaking such truths is part of our role, almost a kind of obligation.

Ms. Shinoda's mother passed away in 2022 at the age of 98.

"If we independent professionals don't speak out, then who will?"

Setsuko Shinoda

Born in Tokyo in 1955. Novelist. After graduating from Tokyo Gakugei University, she worked for the Hachioji City Office in welfare, education, and public health departments, and was involved in establishing a municipal library. She left public service in 1990 to pursue writing.

Her novel *Summer Calamity* (1995) was nominated for the Naoki Prize, which she won in 1997 for *Women's Jihad*. Other major awards include the Minister of Education, Culture, Sports, Science and Technology's Art Encouragement Prize (2011) and the Yoshikawa Eiji Prize for Literature (2019). She received the Medal with Purple Ribbon in 2020. Her many works include *The Eldest Daughters*, *Gosaintan*, and *Virtual Rituals*.

Announcement

World Federation of Right to Die Societies (WFRtDS)
Tokyo Conference
To Be Held in November!

Theme
MY LIFE, MY CHOICE

Dates: November 25 (Wednesday) – November 28 (Saturday), 2026
Venue: Toshi Center Hotel
(2-4-1 Hirakawa-cho, Chiyoda-ku, Tokyo)

The World Federation of Right to Die Societies (WFRtDS) was established following the first international conference held in Tokyo in August 1976, and subsequent conferences in the United States and the United Kingdom. It is now an international organization comprising 63 member societies from 30 countries.
The Federation was founded with the following five objectives:

1. That the choice of how one dies should be entrusted to the individual.
2. That Living Wills (advance directives expressing one's wishes) should be respected as a fundamental human right.
3. To work toward the legalization of Living Wills.
4. To establish an international liaison center for the exchange of information.
5. To hold international conferences on a regular basis.

Perspectives on how one should face death vary widely from country to country, shaped by each nation's history, culture, and social environment. While there is shared agreement on striving for a "good death based on self-determination," it is natural that the paths toward that goal and the systems supporting it differ. The Federation respects this diversity, supports each country in developing the most appropriate framework for its own society, and promotes the sharing of information among members.

Fourth Conference in Japan, the First in 22 Years

As time has passed since the Federation's establishment, many developed countries have increasingly focused on the legalization of euthanasia. While the Japan Society for Dying with Dignity has consistently upheld its original mission of promoting the legalization of Living Wills and does not support euthanasia, we believe that open and honest discussion about how we face death is also necessary in Japan.
Such discussions should not exclude the topic of euthanasia. Rather, we believe it is essential to engage in frank learning and in-depth dialogue without taboo. The 2026 international conference is intended to provide precisely such a forum.

The international conference is held biennially. This will be the fourth conference hosted in Japan, following the first Tokyo conference, Kyoto (9th), and Tokyo again (15th). Recent conferences were held in Canada in 2022 and Ireland in 2024. Experts from around the world will participate, delivering lectures on the legal frameworks surrounding death with dignity and euthanasia in their respective countries, as well as the latest developments concerning issues at the end of life.
At the 26th Tokyo Conference, we are honored to welcome Mr. Kunio Yanagita, a distinguished nonfiction writer, who is scheduled to deliver the keynote address.

This year marks the 50th anniversary of the Japan Society for Dying with Dignity. Through this international conference, held in this milestone year, we aim to once again strongly advocate for the legalization of Living Wills in Japan.
Further details regarding the Tokyo Conference 2026 will be announced progressively in our newsletter and on the Association's website.
We sincerely look forward to welcoming you to the conference.

What Will the Final Stage Be Like?

Report on the Findings of a Study on Signs of Dying

Mitsutaka Yakabe, MD; Sumito Ogawa, MD
Department of Geriatric Medicine, The University of Tokyo Hospital

Much remains unknown about the characteristics of patients in the final stage of life and the signs that precede death. To address this gap, we conducted a questionnaire survey in August 2021 with the cooperation of the Japan Society for Dying with Dignity. Physicians who serve as cooperating doctors for living wills were asked to provide information on patients they had previously cared for at the end of life, and the collected data were subsequently analyzed.
The study included 437 individuals who died between 2017 and 2021, ranging in age from 21 to 106 years (mean age: 79 years). The place of death was the patient's home in 64.5% of cases, hospitals in 21.7%, and nursing homes in 6.9%. Overall, 52.7% of patients received analgesic treatment, and 64.8% received palliative care aimed at alleviating physical and psychological distress in a comprehensive manner. While more than 80% of patients aged 64 years or younger received such care, the proportion was only about 20–30% among those aged 90 years or older.
Only 41.3% of patients had a "living will" (a document in which individuals state their wishes regarding life-prolonging treatment and care). The rate was 51.7% among those aged 64 years or younger, compared with just 27.9% among those aged 90 years or older, indicating a marked age-related difference. Approximately half of those who died at home had a living will, whereas the proportion was about 30% among those who died in hospitals or nursing homes.

Half a Day Before Death: "Tremors of the Limbs"

Commonly observed signs preceding death included prolonged sleep, difficulty eating, and reduced conversation about one week before death; decreased responsiveness, shortness of breath, and coldness of the hands and feet about two days before death; and tremors of the hands and feet about half a day before death.
These findings suggest that patient characteristics may differ depending on age at death and place of death. Causes of death differ between younger patients and those aged 90 years or older, and it is possible that patients dying from dementia or senescence experience less suffering.
In Japan's super-aging society, it is anticipated that many patients will spend their final days at home or in nursing homes. Establishing systems that ensure appropriate pain management and palliative care in these settings is therefore an urgent priority. In addition, promoting awareness of advance care planning (ACP) is considered essential in order to encourage older adults to express their wishes regarding life-prolonging treatment and care while they remain healthy and retain decision-making capacity.
The results of this study, titled *"Clinical Course in the Final Stage of Life and Signs of Dying,"* are currently under submission to an English-language academic journal and are being revised in preparation for publication.

From the telephone and email medical consultations

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End-of-Life Planning Consultations for Those Living Alone or as a Couple

This is a page where we introduce specific consultation cases and answers given over the phone or by email. A nurse will answer the questions, but sometimes, we will ask for the help of an advisor doctor.

According to information from the Healthy Longevity Network, of the 14,878 households consisting of older adults, 49.5% are "single-person households aged 65 or over," while 46.6% are "couple-only households aged 65 or over." The number of households made up solely of older adults continues to increase year by year. Against this backdrop, there has been a growing number of consultations regarding vague but deep-seated concerns among people living alone or as couples in later life. In this article, we present several consultations that we invite readers to consider by imagining themselves in similar situations.

【Case 1】

A 78-year-old woman living alone has been diagnosed with stage III colon cancer. She has no close relatives she can rely on, and her anxiety about physical decline and what will happen after her death is increasing. After her death, whom should she consult about cremation and the interment of her remains?

【Response】

We recommend contacting a local Community General Support Center and consulting with professionals such as lawyers, judicial scriveners, or administrative scriveners. They can provide detailed information about the voluntary guardianship system and voluntary contracts for post-death administrative arrangements. With regard to cremation and burial, if preparations are not made in advance, there is a possibility that one's wishes may not be respected. For this reason, taking steps beforehand is extremely important.

【Case 2】

A married couple, both aged 75, live together. They have no children, and even if something were to happen, their friends are of the same generation and cannot be relied upon. At present, they are living in good health, but if both were to be hospitalized around the same time, where should they turn for advice?

【Response】

In preparation for such a situation, it is important to make arrangements in the following areas:

1. support during hospitalization,
2. personal guarantorship,
3. management of the home, and
4. life after discharge.

First, it is advisable to prepare a list of emergency contacts so that hospitals can easily reach relevant parties in the event of an emergency. Another option is to consult a welfare office or a Community General Support Center and ask them to help you think through support during hospitalization and assistance with daily life after discharge. For matters related to personal guarantorship and home management, please consult a trusted professional.

The Moment You Feel Anxiety Is the First Step

The cases presented here are only a small sample. In the future, the concerns faced by people living alone or as couples in later life are likely to continue to grow. In order to achieve a better end of life, it is not enough merely to clarify one's wishes regarding medical care and long-term care; it is also essential to steadily undertake preparations such as organizing one's assets and drafting a will. Rather than thinking "this is too troublesome," let us proceed step by step, one item at a time. Accumulating these preparatory efforts can help reduce psychological burdens and may also provide an opportunity to reassess relationships with those who matter most.

When you first feel anxious, let that moment become the first step toward "better end-of-life planning." From time to time, it can be helpful to attend study sessions or seminars on the adult guardianship system, or to make use of consultation desks provided by municipal governments, in order to obtain valuable information.

An Article by Professor Yanagida That Deeply Moved Me
Kazuaki Onozato, 66, Tokyo

The interview article with Professor Kunio Yanagida, an excerpt of which appeared in Newsletter No. 199, was truly deeply moving. After my mother passed away, my father lived alone in rural Tochigi, where he had once been evacuated during the war. As the eldest son, I felt that I should not allow my father to continue living alone indefinitely. Yet I was unable to return to the countryside, and I also could not bring him to Tokyo to live with me. As a result, I let time pass by without taking action.
Eventually, my father came to require nursing care. At first, I supported him through long-distance home care, but a few years later his primary care physician recommended that he move into a care facility. During the COVID-19 pandemic, my father passed away peacefully, alone, within that facility.
I regret what I did—deeply and repeatedly. Each time I remember my father, I come to understand more clearly how much he loved me, and with that realization, my regret grows even stronger. And now, I feel very strongly that my father lives on within me.
I believe I have discovered what Professor Yanagida refers to as "the life of the spirit." At the same time, I have begun to think seriously—and to act—about how I should live the rest of my life, how I can make my children happier, and how I might one day join my father after death.
I now believe that facing death with sincerity leads to living sincerely, and that living sincerely and dying sincerely leads to a life without regret. The articles in the newsletter include many valuable pieces that are truly helpful in thinking about how to live. I sincerely hope that as many people as possible—young people included—will have the opportunity to read them.

So That My Grandchildren Will Not Be Confused
Kazue Sakai, 89, Hyogo Prefecture

About sixty years ago, my husband was hospitalized due to overwork and passed away five months later. Our only son, who was two years old at the time, also died suddenly at the age of 49. At that time, I was in my late seventies.
Losing my beloved son, whom I had relied on so deeply, plunged me into complete darkness. I lived separately from my two grandchildren, but nine years ago, when I was about to turn 80, I joined the Japan Society for Dying with Dignity so that I could declare in front of my grandchildren, "If I am taken away by ambulance, I do not want life-prolonging treatment."

Since then, I have lived alone, giving thanks each day for the life I have been allowed to continue living. My 90th birthday is just around the corner. Recently, I purchased a *Living Will Notebook* and wrote down my wishes so that my grandchildren will not be at a loss in the future.

Translation: Open AI. (2026). Chat GPT(January 7 version). https://chat.openai.com