

# Euthanasia

## THE DILEMMA OF CHOICE

The debate surrounding an individual's right to choose how and when they die is poised to intensify as a group of bipartisan lawmakers prepare to submit a draft bill on the controversial subject this spring

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Euthanasia is an emotionally charged issue for people on both sides of the debate. Proponents of euthanasia argue that a person suffering from terminal illness should be given the freedom to choose how and when they die. Such discourse is given weight by the Japanese term for the practice — *anrakushi*, which literally means “peaceful death.”

On the other hand, opponents generally argue that euthanasia is nothing short of murder, and the use of palliative care can often give a terminally ill person a more comfortable, dignified death. In some cases, they say, a desire to die prematurely is merely rooted in depression.

The government has enacted no specific legislation on euthanasia and the Supreme Court has only ruled on the matter once

without providing any specific guidance. Instead, the basic framework of Japan's euthanasia policy to date has been laid out in two local court cases, one in Nagoya in 1962, and another after an incident at Tokai University in 1995. The judgments in these cases established a legal framework and a set of conditions within which euthanasia could be legal. In both cases, however, the defendants were found guilty of violating these conditions when hastening the deaths of their patients.

And yet there is still an unwillingness to discuss euthanasia openly, something a group of bipartisan lawmakers wishes to change by submitting a bill on death with dignity, or *songenshi*, to the Diet this spring. The draft would exempt doctors from criminal and civil responsibility for halting life-prolonging treatment if a patient is over 15 years old and has given consent in writing. Two doctors also need to agree the patient has absolutely no chance of recovering.

Continued on Page 14





## TimeOut | Feature

Continued from Page 13

Comprising more than 140 lawmakers from across the political spectrum, the bipartisan group has been discussing the issue for almost 10 years. Prime Minister Shinzo Abe has even lent the group his support, saying in a budget meeting last year that legislation on dying with dignity deserved consideration.

With support from both sides of the political divide, it would seem unlikely the bill will be defeated in the Diet. What's more, even opponents of the proposed bill agree that lawmakers should respect a person's right to die as they wish.

But the gulf between the two sides of the debate couldn't be any wider.

Masatoshi Oda was diagnosed with progressive muscular dystrophy as a child, and became a firm believer in dying with dignity as his condition deteriorated. He didn't like the idea of being hooked up to a ventilator, and said that if he ever found himself in such a situation, he would prefer to accept death and leave this world in peace.

Oda didn't want to live if he had to depend on someone being with him around the clock for the rest of his life. He was not suicidal, but rather didn't wish to burden his family with his failing health. Once hooked up to a ventilator, Oda would need assistance to do even the most menial tasks.

In 1997, Oda's lungs collapsed and he went into respiratory failure. He was just 29 years old.

Doctors told Oda's family that he would die unless oxygen was artificially pumped into his body. Despite being aware of Oda's wishes, his mother instructed the hospital to do everything it could to save her son.

"When I regained consciousness, the first thing I saw was a huge machine sitting beside my bed," Oda recalls. He very quickly realized that he had been hooked up to the one thing he feared the most. "I wasn't angry or anything," he says. "It just took a while for me to accept that I had been hooked up to a ventilator."

Had a law on dying with dignity existed back in 1997, Oda would have died. Now, however, the 45-year-old is relieved the doctors performed the tracheotomy and kept him alive.

Had such legislation existed, he would never have had a chance to enjoy a glass of red wine and prosciutto after a day's hard work, nor would he have been able to watch some of his favorite Hollywood movies in theaters. He is now proud to rank "The Avengers" among his favorite films.

Most importantly, however, he would not have been able to be at his mother's side when she passed away a few years later.

"Back in 1997, doctors told me after performing the tracheotomy that I might never speak again," Oda recalls. "But here I am speaking to you now. They also said I might have trouble eating solid food, but three months after the operation I was secretly eating instant noodles in hospital."

Oda heads Ko-net, a group of about 60 people who rely on ventilators. While acknowledging that life on a ventilator is certainly not a walk in the park, Oda now realizes he misunderstood what it would be like.

And although he does have to rely on people to complete many daily tasks, he feels that his life is as good as it was before the operation.

For example, even if he misses the last train home after belting out too many Godaigo tunes at karaoke, it isn't the end

of the world. He simply goes into a 24-hour manga cafe and asks for permission to recharge the batteries on his ventilator until the train services restart the following morning.

As far as he's concerned, life is worth living.

"I am not against anyone who wishes to die with dignity, but codifying such rights in legislation isn't the answer," he says.

Creating legislation on euthanasia may help clarify the overall process but death shouldn't be turned into a process, let alone a simple one, he says.

"I am living proof that there shouldn't be a law on dying with dignity," he says.

The Japan Society for Dying with Dignity has approximately 125,000 registered members across the country. All members carry identification cards that say they refuse to receive any life-saving treatments once they enter the terminal phase of their illness.

In April last year, the group released a survey of relatives of terminally ill people who passed away in 2012. The survey asked family members whether doctors had in fact agreed to respect the patients' will in terms of their desired medical treatment.

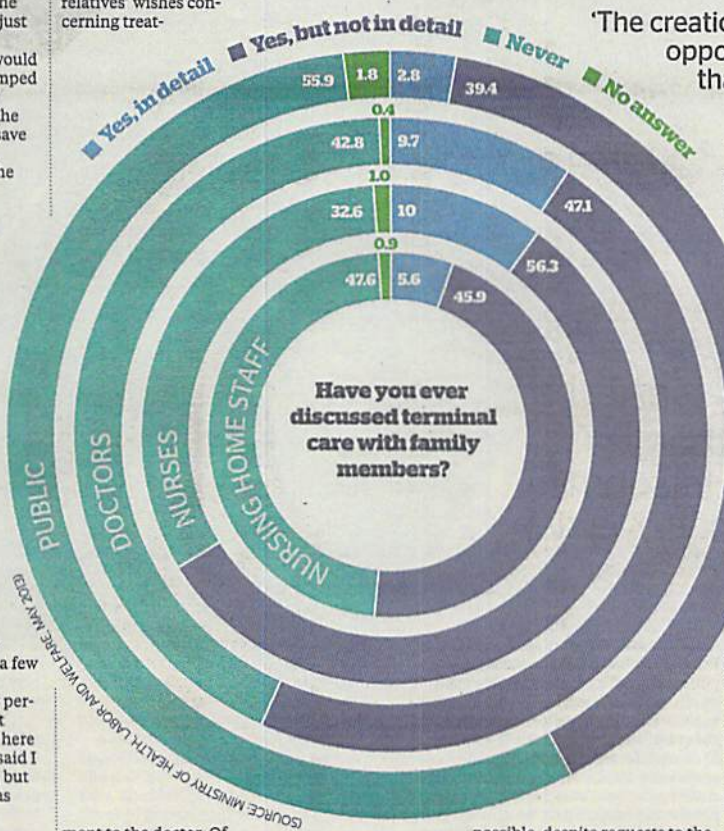
Of the 845 replies the organization received, 696 said they were able to present a Japan Society for Dying with Dignity membership card or convey their sick relatives' wishes concerning treat-



Soichiro Iwao JUN HONGO

'The creation of a law gives all of us an opportunity to discuss a subject that is difficult but necessary.'

Japan Society for Dying with Dignity  
President Soichiro Iwao



will help doctors do their jobs without fearing subsequent prosecution.

In 2006, a doctor at Imizu City Hospital in Toyama Prefecture was investigated for murder after the hospital revealed that he had disconnected ventilators from seven patients and caused their deaths over a five-year period of time.

The doctor claimed he had obtained consent from the families of all terminally ill patients, but some suggested that appropriate procedures were not followed. The doctor wasn't charged with murder, but the case drew attention to the gray area that exists between medical malpractice and the act of following a dying patient's last wishes.

The courts have adopted a different approach on active euthanasia, viewing such actions as akin to mercy killing rather than the act of letting a patient die without treatment.

In 2009, the Supreme Court upheld an 18-month suspended prison term to a former doctor at a hospital in Kawasaki who injected a muscle relaxant into a terminally ill patient in a bid to hasten their death. The family of the victim claimed they neither requested nor consented to such treatment. The doctor vehemently denied any intent to commit murder, and later published a book titled "Watashi ga Shitakoto ha Satsujin Desuka?" ("Was It Murder that I Committed?") in 2010. In handing down their ruling, the judges failed to create any additional guidelines covering situations in which euthanasia may be recognized.

All the while, the government has sidestepped making any determinations on the subject. In 2007, the Ministry of Health, Labor and Welfare issued a guideline on medical treatment of the terminally ill, but did not lay out clear rules on how or when a doctor can avoid being held legally responsible for respecting a patient's wish to die.

ment to the doctor. Of those, 639 said the doctors agreed to follow the patients' requests.

A total of 18 people, or 3 percent, however, said that doctors chose to act on their own accord and place the dying patient on life support.

Some of those cases involved family members who found themselves unable to go through with their sick relative's wishes. A few cases involved families who were divided over whether or not to pull the plug. Other cases saw doctors giving terminally ill patients the best treatment

possible, despite requests to the contrary by disbelieving relatives.

Japan Society for Dying with Dignity President Soichiro Iwao believes that legislation should be in place to govern such situations, otherwise further ad hoc results will occur. "Everyone should have the right to decide how they want to end their life," Iwao says.

Iwao has tried to explain his views to opponents of dying with dignity "but it always feels like our discussion is taking place on different wavelengths."

If anything, setting the rules straight





Masatoshi Oda YOSHIKI MIURA



Hiromi Ebihara YOSHIKI MIURA

The controversy surrounding the issue is not only limited to Japan. India and Mexico have passed legislation that recognizes passive euthanasia, while Belgium, Luxembourg and the Netherlands have gone so far as to recognize active euthanasia. What's more, Belgium became the first country in the world to abolish all age restrictions on the right to die in a parliamentary vote on Thursday, extending the right to die to terminally ill children.

Nevertheless, the practice still generates plenty of robust opposition. Just last month, for example, a Fort Worth hospital in Texas that kept a woman who was 23 weeks pregnant on life support for two months complied with a court order and removed her from the machines. Doctors had initially refused to honor the family's request to disconnect her, claiming that the law prevented them from doing so until they could perform a cesarean delivery.

Iwao, who also serves as a board member of the World Federation of Right to Die Societies, says there needs to be standard guidelines codified in law to eliminate the confusion in Japan. There is no excuse for failing to establish better guidelines, he says, stressing that the law should ultimately back an individual's right to decide how they want to end their life.

Back when Iwao was the chief of the health ministry's health policy bureau, he didn't see the need to codify guidelines on dying with dignity in legislation. His views changed, however, after he read some surveys on dying with dignity as he was preparing to give a speech at a conference on the issue.

"There was a survey that said more than 80 percent of people wish to spend the last days of their lives at home" instead of on a hospital bed, he says. In reality, however, this seldom happens in Japan. Instead, he says, terminally ill patients are kept alive with ventilators and gastroenterology surgeries.

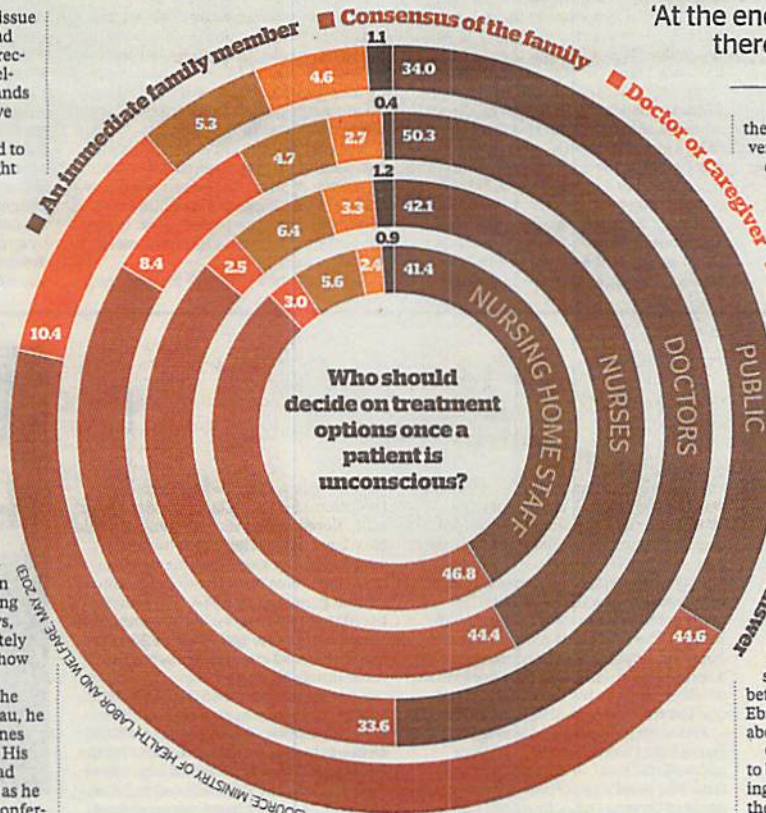
"People who choose that path have every right to do so, but those who do not wish to do so should have an equally respected right to die with dignity," he says. "Despite our rapidly aging society,

we've avoided discussing the topic of how to end one's life. The creation of a law gives all of us an opportunity to discuss a subject that is difficult but necessary."

Thirteen years ago, Ko-net member Hiromi Ebihara put a ventilator tube in her mouth for the first time and slowly inhaled. She could feel the oxygen rush into her lungs as her heart pumped oxygen-infused red blood cells through her body to her fingertips. In a few seconds, her mind became clear.

'At the end of the day, I don't think there is any dignity in dying.'

Ko-net member Hiromi Ebihara



these days she relies on a wheelchair and ventilator, she has defied common medical knowledge and is now 36 years old. Ko-net members often refer to such cases when highlighting flaws in the proposed legislation, saying doctors often can't tell when a patient becomes terminally ill. Ebihara, like Oda, is not opposed to terminally ill patients making a decision to end their life. However, she is against the creation of a law that "would make death a decision that is reached after consultation with a flow chart."

"Creating a law would also put more pressure on vulnerable people," she says, noting that it is already tough for seriously ill patients to fight for their lives even though they often have little chance of survival. Any decision to give up in a battle for life should be respected, but laws shouldn't control this process, she says.

"There just needs to be trust, understanding and plenty of communication between the family, doctors and yourself," Ebihara says. "There is no need for a law about dying with dignity."

On Jan. 26, Ebihara took a state exam to become a certified social worker, having spent the past two years studying for the test. If her calculations are correct, she believes she scored well above the passing grade. The results arrive in mid-March.

"I think I passed," she says, looking forward to what the future holds. Having experienced more medical lows than highs in her lifetime, Ebihara has her own take on death.

"At the end of the day, I don't think there is any dignity in dying," she says. "Rather, it is about living with dignity and, if you can do that, one will likely find themselves right where they want to be at the end."

"I was back to being myself again," Ebihara says, recalling those first few moments on a ventilator.

Ebihara was diagnosed with spinal muscular atrophy as an infant, and over the next two decades her muscles had weakened to the point that they couldn't support her own body weight. She could only inhale about 10 percent of oxygen that a normal adult is able to because her rib cage had suppressed her lungs.

She was put on a ventilator. Doctors initially said Ebihara wouldn't live beyond her third birthday. Although