

# DYING IN AMERICA

Jan-Paul Malocsay

Keisuke Kinoshita's classic 1950s film "The Ballad of Narayama" (Narayamabushi-ko) tells the story of a village so poor that oldfolks no longer able to earn their keep are by custom left on a mountaintop to die. As so often in Japanese cinema, the film invites participation in the protagonist's moral dilemma. This son must carry his mother up the mountain and leave her there. *Giri* demands it, his duty to community survival. *Ninjo* is deeply, helplessly, tragically opposed, for a reason as profoundly human as the bond between mother and child.

No doubt like many a Japanese viewer of that film—or the later version by Shohei Imamura—I felt the power of its story return with a fearful vengeance when my turn came to carry my own old mother up the mountain of her dying.

I don't mean to over-dramatize my own performance of the duty involved in helping a parent on that final difficult journey. My thought is that the central metaphor of "The Ballad of Narayama" speaks to a state of affairs now deeply troubling East and West. Japanese concerns are addressed in feature-length films by Hisako Matsui on families caring for sufferers of Alzheimer's disease: "Yuki" (1998) and "Oriume" (2001). More recently, Naomi Kawaze's "Mogari no Mori" has won a prize at the Cannes International Film Festival.

The phrase "healthcare crisis" is in constant use in American media now and "end of life care" is just one of many issues competing for attention. Ironically, the crisis is rooted in material prosperity and longer life. We like to

think that ordinary oldfolks no longer face the old-fashioned alternatives: work till you drop; or dwindle in the state of idleness lamented in the traditional song "Ole rockin' chair's got me."

The old rocking chair is a wheelchair now, for reasons good and bad. The good has to do with livelier expectations for the latter end of life. After my mother died, my eighty-year-old friend Sue wrote: "Don't be afraid to make big changes." Translation: "You've done your duty. Now get on with your life. Make a new life. Don't be a stick in the mud."

## A Fortunate Minority

Sue offers good advice I hope to follow. It comes from a lady who represents a fortunate minority—those who have had the wisdom, discipline, and foresight to manage their lives and resources well. In Sue's case, family support came early in life. Her parents believed in education. She herself became a highly successful teacher of music. She never married, but has always had friends who lend one another family-style support. She too has been a supportive friend to friends now gone. (Is there a Japanese equivalent of our Yankee individualist notion that friends are the family we choose for ourselves?)

Recently Sue and a woman friend her age both sold their houses in the North and moved South to join a retirement community in Florida. They share a small house in a community of 680 residents. Most are former professionals like themselves, people with broad experience and wide-ranging interests.

The structure of such a community is a subject in itself and difficult for biological families to arrange. Its end-of-life arrangements seem close to ideal. Help with “assisted living” keeps residents in their homes for as long as possible. When nursing home care becomes necessary, they move to the community’s own facility, still close to those who have become their neighbors and friends in what may be described as their choice of extended family. That aspect of continuity is increasingly important—and difficult for biological families to arrange—in a country where children are apt to live and work far from their aging parents.

The cost of such arrangements are necessarily high. The hefty monthly fee would be guaranteed by a deposit that might well represent the largest, most important investment Sue has ever made. The community’s investment in its residents would be based on complex calculations. For example, it must make a difference that this community is designed for highly motivated types of individuals. Would their preference for active over passive lifestyle lead to longer life, no matter what afflictions of old age they suffer? Would their expectations of dying be high as well—and witnessed by supportive friends with a vested community interest in the highest possible standard of care?

It doesn’t really matter that Sue is a single woman. The arrangements she has made would seem pretty wonderful to any older American. The longer we live on average, the higher our expectations of the latter end of life. The value Americans put on independence rises accordingly. Trouble is, with longer life comes the possibility of slower dying, and dying, willynilly, makes dependents of us all.

### More In The Mainstream?

Alzheimer’s disease is a major concern of those who think about slow dying. One in eight

Americans over 65 now has that disease. Add another twenty years of life and that number rises sharply, to half the population over 85.

My mother had Alzheimer’s resulting in a complex form of dementia whose treatment began with the usual experimentation and ended in a familiar paradox: drugs effective against her worst symptoms reduced her to a vegetative state. I am writing about her because she died, one might say, in the mainstream, dependent on a system of healthcare whose complex deficiencies I found shocking and disturbing. I’m not alone in this. Being in charge of someone dying is in one sense an isolating experience, it is so time-consuming and exhausting. At the same time it makes you feel part of a very large crowd. Suddenly, it seems, everyone you meet has a story to share. Most clearly mean well, though the message in general is: “It never gets better; it only gets worse.” Some actually say that.

Now that it’s over, I know that my mother’s dying torment was mercifully brief for an Alzheimer’s victim—half a year, not the year after year so many other caregivers told of witnessing and suffering through themselves. And yes, caregiver suffering is a significant part of a rather grim picture. Thirty percent of Americans now are involved in some kind of eldercare, even as traditional family care itself grows increasingly dependent on our system of so-called managed healthcare.

That word managed has an interesting resonance in the world we live in now. Thinking how to explain it to readers in a country as strong on management as Japan, I find myself wondering how and when we Americans started thinking of ourselves as living with a choice of worlds this side of the grave. How is this different from the Buddhist concept of the “fleeting world” of impermanence? Could the aspect of choice distinguish the two, *mujo* being a matter of accepting destiny, choice a matter of

taking control?

Certainly freedom of choice is one of America's most cherished values, closely allied to individual liberty and the self-reliant, competitive spirit we think of as defining our national character. You'd think our national economy would characterize itself as a productive society but no, the model is consumptive. We call it The Consumer Society because that sounds better. (I doubt that generations younger than mine are aware that consumption was the old-fashioned word for tuberculosis.) The consumer society lives and breathes free choice. This is supposed to mean that consumers, not producers, are in charge. The notion is that a nation of such consumers will pick and choose freely in a marketplace where cost is regulated by supply and demand and issues of quality are settled by sales. According to this worldview, the more choices the better, no matter how bewildering, how oppressive (to some of us) the sense of overplus and glut.

I suspect that Japan's consumer society has much in common with the American one. I just hope that the Japanese version does a better job of living up to the promises implicit in a term with a resonance as reassuring as "managed healthcare." This I know: lots of Americans share my conviction that families still need to be vigilant and very much involved in seeing to the welfare of loved ones declining and dying in the mainstream of our healthcare system.

### **Last Wishes**

My mother wanted what so many elderly Americans do: to go on living at home till she died, preferably in her sleep, "no fuss no muss no bother." That time-honored phrase is meant to convey a cheerful disdain of unwanted complications. Here of course it seeks to disguise the fear and dread that comes of knowing that dying puts a burden on the living,

slow dying especially. It must be the same with oldfolks in Japan, that tendency to say outright, "I don't want to be a burden."

That's why the central metaphor of "The Ballad of Narayama" has such power. The mother's anguish is the son's as well. Dying and dependency in the end seem equally dreadful. Even when the person dying is entirely confident of the caregiver's good intentions, the whole scenario has the look and feel of a terrible betrayal. At least that's how it seems to me now—now that I understand why old people say they fear dependency more than death itself. (Leave it to American funnyman Woody Allen to quip: "I'm not afraid of dying. I just don't want to be there when it happens.")

Some oldfolks are lucky that way. My paternal grandparents were practical middle-class people. They assumed that he would die first, as men so often do. She would join other widows in a rest home maintained by the P.E.O., a society dedicated to the improvement of women. She had belonged to the local chapter all her married life—over fifty years when suddenly she died. He lived on alone in their musty old house whose repairs kept him occupied. He welcomed my visits but told me repeatedly that life without his Mary was not worth living and that he sometimes "worked the differential calculus" to keep from weeping. A letter from him reached me in England a week after he died. He walked out to mail it, went back home, laid down for a nap, and never woke up. In his clear firm hand he quoted Latin verses from his student days still in living memory that day he died at 85 in 1969. His death in retrospect seems enviable. His mind and body were intact. He mourned at home, where memory lives in a familiar world. He took care of himself till his time ran out. No system of healthcare intervened. He was spared so much. . .

My poor mother didn't get her wish. Here I must pause to clarify my perspective on what

follows. It must be said that my mother contributed to the sadness and torment of her decline by being who she was. As the eldest of her eleven surviving children—born before World War II, the others all after—I always felt I knew her best and pitied her most whose woman's woes might have furnished a script for Kenji Mizoguchi.

Still, her children did right by her. Most were scattered far and wide, but without the moral and material support of my siblings, I could never have done what needing doing in her later years. We are a jokey bunch so the situation was summed up accordingly: "We send her the ammo; you stand in the line of fire."

Our chief concern was to make it possible for her to live in her own home. Beginning in the 1980s I came for extended working visits increasingly important as she began to fail. She was grateful for our help, but resolutely independent too. In 2003, I could see that she needed fulltime help. She put up fierce resistance to my coming back to live in the tiny study I had built in the garden many years before. Another stock American phrase comes to mind: "She made my life a living hell." It took some doing to keep *giri* firmly in mind, the only way I knew to cope. On several occasions I had to remind her of a promise made many years before: "I will never desert you, but I reserve the right to tell you plainly what I think."

For my part, I felt obliged to remember that old saying, "the apple doesn't fall very far from the tree." I have no child or spouse to speak plainly to me. All the more reason to keep *giri* firmly in mind in another sense: the duty every elderly person owes family and society to remain as fully engaged as possible, exercising mind and emotions as much as any part of the aging body. Being 67 and my mother's son imparts an extra measure of caution: vigorous exercise of the self-critical faculty seems absolutely vital. And there let the matter rest, on principle—the

one the ancient Romans put so well: *De mortuis nil nisi bonum*. (Say nothing of the dead unless it be good.)

As for the living, I want to beware of being—or seeming to be—ungrateful and unfair where our healthcare system is concerned. Its glaring defects are apt to obscure the hard work and earnest good intentions of many individuals hired to care for the dying. Still, some part of me wishes that I could name even one particular angel of mercy working in that system—a person whose compassion cut through the fog of routine, regulations, and suffering as highly resistant to the human touch as Alzheimer's. But there was no such person. There was only another other part of me that kept saying: "This is your mother; the compassionate touch has to come from you."

My dutiful state of mind in that regard got a fearful jolt one day. A well-meaning lady, thinking to console me, repeated something my mother said in a rare lucid interval in the nursing home. According to her, my mother said: "My father was never there for me. My son is the father I never had."

I wasn't a bit consoled. I was shocked. I had always known that her dad was, to put it politely, inadequate. I had always assumed that my mother's peculiar ferocity was rooted in the loss of her mother at thirteen, just when a girl might have a special need for maternal guidance and reassurance. Given that, could she have avoided marrying so early and unwisely? I knew all about that aspect of her difficult life. I thought I knew her perfectly well, yet his other dimension of her pain took me by surprise.

I was overcome with an odd mixture of pity, grief and shame at a very bad time—just minutes before the doctor took me aside to say that my mother might well die that day. She was lying unconscious, dying of pneumonia, a condition commonly referred to back in ole rockin' chair days as "the old person's friend."

I shared that old-fashioned sense of the situation, of death as “blessed release” as people then would say. (Blessed in that style of venerable phrase is pronounced as two syllables.) But pneumonia did not befriend her after all. She lived to suffer another six weeks, asking me over and over and over again: “Is this a nightmare? Tell me this is a nightmare.” She had nothing else to say in her last weeks of life and no wonder, given the horrors of continued healthcare whose aspect of “managed” moved her back and forth between hospital and nursing home as required by formulas based on a factor as uncaring as cost.

### A Film Not For Showing

I can’t go on. The whole story would make tedious, gruesome reading. My own documentary film version might be too hard-hitting for showing in Japan. I’ll never make a film, but the script for that one keeps writing itself into my nightmares. (I’ve been prone to nightmares since I was small.) When I heard that Kawase’s prize at Cannes this year was for a film on Alzheimer’s I thought aha, are the grim realities of care outside the family more of an issue now? Will Kawase’s view be less reticent, less hopeful than Matsui’s? Can the Japanese genius for understatement make art of so much sordid circumstance?

My mother’s ashes were handed to me in a plain white cardboard box symbolic of her wishes: no funeral, no family gathering, no memorial, just simple cremation. She had her complex reasons why. The box was surprisingly heavy. When she was mad we compared her to a banty hen. She was the best of good housekeeping moms, just not somehow affectionate, and so we conspired against her, early and late. Her elderly threats were turned to jokes. When she railed against gravestones we held a contest to write her epitaph. The winner: “Tragically Obnoxious.”

Her last delight in life was riding in the car. We had just come home when she suffered the stroke that took her away in an ambulance, never to return. Her house was the center of her universe. Without it, she was truly, cruelly lost. In its place, Alzheimer’s built a paranoid fantasy of having been kidnapped.

### A Final Resting Place

The box rides forty miles in the passenger seat. This is my wish, not hers. This quiet small valley watered by a spring-fed stream suits my notion of earthly paradise. The cool clear water ripples over pebbles with a whispering sound and pools deep silences where springtime floods rage against banks of stubborn rock. Yet water wins all battles over time. Beaches of streamworn fragments change shape and location constantly. The rocks themselves are rich in shells from vanished seas—vivid impressions of life’s defenses succeeding and failing long before humans sought meaning in the passingness of things.

I sat with the box sitting next to me for the longest while, numb with grief, not for her loss but for her life. I had thought I was ready, but it seemed I was not. A month had passed, time to think about Sue’s advice: “Don’t be afraid to make big changes.”

A Japanese friend had sent me incense money but a solemn fragrance in the air took precedence. It mingled odors true to life—cool springwater, sun-warmed rocks, sycamore leaves, the bitter tang of summer ripening into fall.

A fossil shell worth keeping caught my eye, fit memento for such a day.

I spilled her ashes awkwardly. I found I had nothing to say. Nonplussed, dry-eyed, I felt convicted in a court of love. Can *giri* do its work without support from *ninjo*? Is that where ritual comes in, to make up for that common human deficit?

I came back to the house that centered her life for over fifty years. I set to work and washed its windows. That would have pleased her while she lived, though only she could do it right.

### Looking To The Future

A year has passed. Her house is now my house, but I feel no sense of ownership, even though years of my life have gone to keeping it intact, years of strength I have outlived, a fact that worries me, and with good reason. Yet even if I had the strength, it wouldn't be wise to invest it here. She may be gone, but while she lived the house was her refuge and her strength, her creation and assertion of a stubborn will to live on her own terms. She was very American that way, self-reliant to a fault. I say to a fault because I admire old-fashioned American self-reliance, even as I identify strongly with its Japanese opposite, the value put on community, on the need to define and discipline your individuality in terms of the common good.

One thing I never did for my mother was paint her house inside. She always did that herself, and frequently, lifelong. She was painting into her seventies. And when arthritis put a stop to that, I was never allowed to take her place. She was an expert seamstress too, so curtains, clothes and all were homemade. Her taste in home décor was defiantly eccentric. It was sometimes happily fanciful too, as when she gave a hole in the wall a play-clay mouse peering out of a nosegay of plastic flowers.

No one who knew my mother could ever think of her house as anyone's but her own. Knowing her life as I do, I struggle to think of her house as the happier part of a story so sad. Some part of that whole story starts telling itself to me every time I walk in the door.

That's why I think of her house as needing a complete stranger, someone to give it new meaning, new life.

I've had a year to think about these things,

living in my study in the garden as much as possible. I have always slept out here, Japanese style, on the floor. I can see her house from here, a short way down the garden path. The garden and this tiny room feel like mine because they were made to serve a need as basic as surviving, let's say, the dutiful years I saw stretching ahead a quarter of a century ago. It wasn't practical then, and wouldn't be now, to add kitchen and bathroom to this small space. Its chief attraction is this picture window view into the heart of a garden I won't be able to recreate anywhere else for my own old age. But that's all right too, because Sue is right: I mustn't be afraid to make big changes.

END

### ENDNOTE

J-P Malocsay is a working gardener and freelance writer now searching for a simple, affordable house and garden suitable for his own last stage of independent life. He feels deeply indebted to Professor Keiko McDonald of the University of Pittsburgh for many years of exposure to the wisdom and fascination of Japanese cinema and culture.