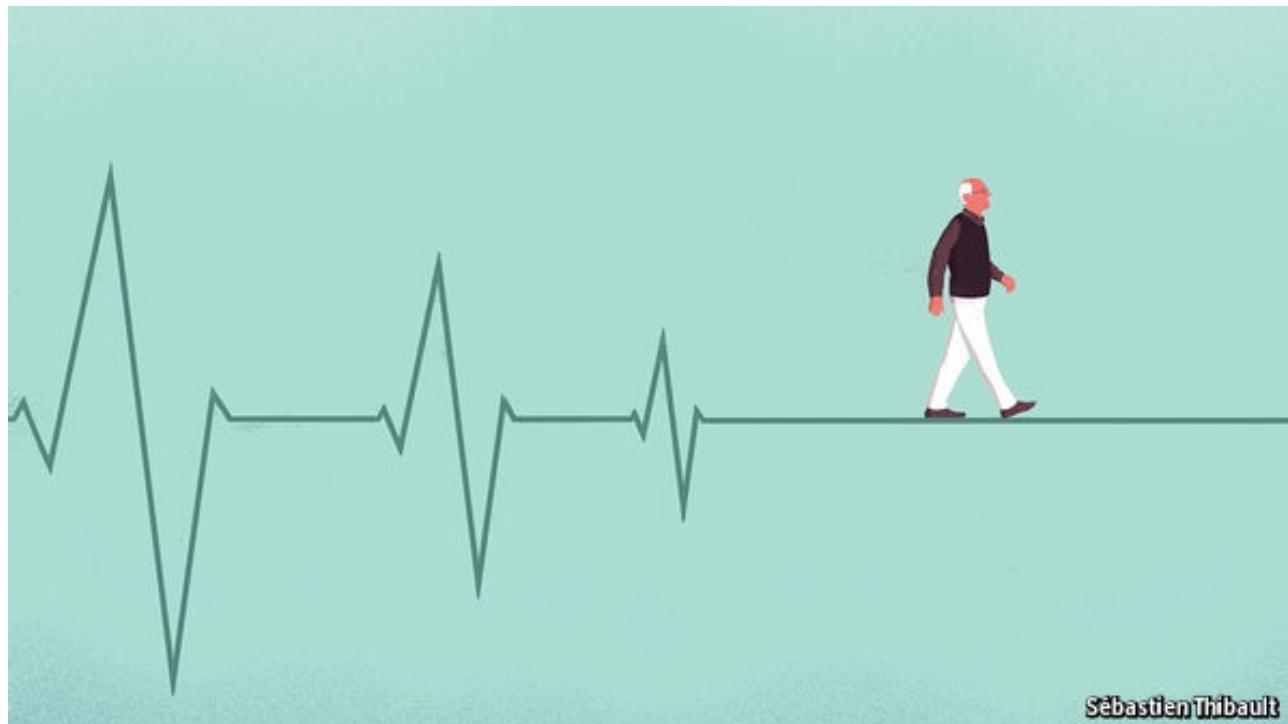


End-of-life care

A better way to care for the dying

How the medical profession is starting to move beyond fighting death to easing it



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A STROLL from Todoroki station, at the kink of a path lined with cherry trees, lies a small wooden temple. A baby Buddha sits on the sill. The residents of the Tokyo suburb ask the infant for *pin pin korori*. It is a wish for two things. The first is a long, spry life. The second is a quick and painless death.

Just part of this wish is likely to be granted. The paradox of modern medicine is that people are living longer, and yet doing so with more disease. Death is rarely either

quick or painless. Often it is traumatic. As the end nears, people tend to have goals that matter more than eking out every last second. But too few are asked what matters most to them. In the rich world most people die in a hospital or nursing home, often after pointless, aggressive treatment. Many die alone, confused and in pain.

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The distress is largely unnecessary.

Fortunately medicine is beginning to take a more thoughtful approach to people with terminal illness. Reformers are overhauling how end-of-life care is delivered and improving communication between doctors and patients. The changes mean that patients will experience less pain and suffering. And they will have more control over their lives,

right up until the end.

Many aspects of death changed during the 20th century. One was when it happens. The average lifespan increased by more over the past four generations than over the previous 8,000. In 1900 global life expectancy at birth was about 32 years, little more than at the dawn of agriculture. It is now 71.8 years. In large part that is a result of lower infant and child mortality; a century ago about a third of children died before their fifth birthday. But it is also because adults live longer. Today a 50-year-old Englishman can expect to live for another 33 years, 13 more than in 1900.

The chance of an adult dying was once largely unrelated to age; infections were indiscriminate. Michel de Montaigne, a French essayist who died in 1592, wrote that death in old age was “rare, singular and extraordinary”. Now, says Katherine Sleeman of King’s College London, death mostly comes by stealth. She estimates that in Britain only a fifth of deaths are sudden, for example in a car crash. Another fifth follow a swift decline, as with some cancer patients, who stay fairly active until their final few weeks. But three-fifths come after years of relapse and

recovery. They involve a “slow, progressive deterioration of function”, Dr Sleeman says.

People in rich countries can spend eight to ten years seriously ill at the end of life. Chronic illness is rising in poorer countries, too. In 2015 it accounted for more than three-quarters of premature mortality in China, according to the Global Burden of Disease, a survey. In 1990 the share was just a half. The World Health Organisation (WHO) predicts that rates of cancer and heart disease in Sub-Saharan Africa will more than double by 2030.

A side-effect of progress, however, has been what Atul Gawande, a surgeon and author, calls “the experiment of making mortality a medical experience”. A century ago most deaths were at home. Now, according to a survey of 45 rich countries by the WHO, fewer than a third are. Death also used to be egalitarian, says Haider Warraich of Duke University Medical Centre and the author of “Modern Death”. Income did not much affect when or where people died. Today poor people in rich countries are more likely than their better-off compatriots to die in hospital.

No dying fall

Many deaths are preceded by a surge of treatment, often pointless. A survey of doctors in Japan found that 90% expected that patients with tubes inserted into their windpipes would never recover. Yet a fifth of patients who die in the country’s hospitals have been intubated. An eighth of Americans with terminal cancer receive chemotherapy in their final fortnight, despite it offering no benefit at such a late stage. Nearly a third of elderly Americans undergo surgery during their final year; 8% do so in their last week.

The way health care is funded encourages over-treatment. Hospitals are paid for doing things to people, not for preventing pain. And not only patients, but those who love them, suffer. Many people who may need intubation or artificial ventilation are not in a condition to indicate consent. An American study found that in about half of cases involving decisions about the withdrawal of treatment there is conflict between family and doctors. A third of relatives of patients in

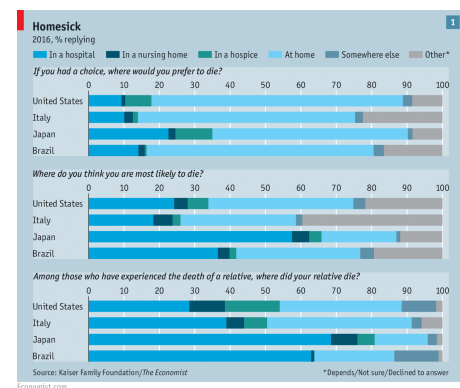
intensive-care units (ICUs) report symptoms of post-traumatic stress disorder.

Many people will want to “rage, rage against the dying of the light”, as the poet Dylan Thomas put it. Others will have particular events they want to attend: a grandchild’s graduation, say. But the medical crescendo often occurs by default, not as a result of personal choice based on a clearly understood prognosis.

The huge gap between what people want from end-of-life care and what they are likely to get is visible in a survey conducted by *The Economist* in partnership with the Kaiser Family Foundation, an American health-care think-tank. Representative samples of people in four large countries with differing demographics, religious traditions and levels of development (America, Brazil, Italy and Japan) were asked a set of questions about dying and end-of-life care. Most had lost close friends or family in the previous five years.

In all four countries the majority of people said they hoped to die at home (see chart 1). But fewer said they expected to do so—and even fewer said that their deceased loved ones had. Apart from in Brazil, only small shares said that extending life as long as possible was more important than dying without pain, discomfort and stress (see [article](http://www.economist.com/news/international/21721374-international-survey-finds-living-long-possible-not-peoples-main) (<http://www.economist.com/news/international/21721374-international-survey-finds-living-long-possible-not-peoples-main>)). Other research suggests that wish, too, is increasingly unlikely to be granted. One study found that between 1998 and 2010 the shares of Americans experiencing confusion, depression and pain in their final year all increased.

What healthy people think they will want when they are mortally ill may well change when that moment comes. “Life becomes mighty precious when there is not a lot left,” says Diane Meier, a geriatrician at Mount Sinai Hospital in New York. It is common, for example, to hate the idea of a feeding tube but grudgingly accept one when the alternative is death.



Words I never thought to speak

Yet the gap between what people hope for and what they get cannot be explained away so easily. Dying people's wishes are often unknown or ignored. Among those involved in making decisions about a loved one's end-of-life care, more than a third in Italy, Japan and Brazil said they did not know what their friend or family member wanted. Either they never asked, or only thought to do so too late. A Japanese woman who cared for her mother, an Alzheimer's patient, says she regrets that "once the door closed there was no way of knowing what she wanted."

And sometimes, even when relatives know a loved one's wishes, they cannot make sure they are granted. Between 12% and 24% of those who had lost someone close to them said that the patient's wishes had not been carried out. Between 25% and 38% said that friends or family had experienced needless pain. Across the whole survey most people rated the quality of end-of-life care as "fair" or "poor".

End-of-life care can resemble a "conspiracy of silence", says Robert Fine of Baylor Scott & White Health, a Texan health-care provider. In our survey majorities in all four countries said that death is a subject which is generally avoided. An obvious reason is that death is feared. "In every calm and reasonable person there is a hidden second person scared witless about death," says the narrator of a Philip Roth novel. One school of psychology—"terror management theory"—holds that fear of death is the source of everything distinctively human, from phobias to religion.

But death was once what Philippe Ariès, a French historian, called a "public ceremony", where friends and family gathered. Now, changing family structures mean the elderly and dying are more isolated from younger people, who are therefore less likely to witness death up close, or to find a suitable moment to talk about its approach. Just 10% of Europeans aged over 80 live with their families; half live alone. By 2020, 40% of Americans are expected to die alone in nursing homes.

In Japan, where survey respondents were most likely to say that not being a financial burden was a primary consideration, daughters are abandoning their traditional caring role. That has given rise to institutions such as the House of

Hope, a hospice in east Tokyo that looks after people who are too poor for hospital care and too alone to die at home. A decade ago Hisako Yanagida, 88, lost her husband, with whom she had sung in a traditional Japanese troupe. Now her sight is going but she can still make out the faded pictures of the two of them on her wall. She tries not to think about death: “There is no point.”

But the chief responsibility for the failures of end-of-life care lies with medicine. The relationship between doctors and seriously ill patients is one of “mutual suspicion”, says Naoki Ikegami of St Luke’s International University, in Tokyo. A decade ago it was common for Japanese doctors to withhold cancer diagnoses. Today they are more honest, but still insensitive. One Japanese woman recalls her oncologist saying that if her chemotherapy made her bald, it would not be a big deal.

And doctors commonly overestimate how long the terminally ill will live, making it more likely that they will duck frank conversations, or recommend drastic treatments that have little chance of success. One international review of prognoses of patients who die within two months suggests that seriously ill people live on average little more than half as long as their doctors suggested they would. Another study found that, for patients who died within four weeks of receiving a prognosis, doctors had predicted the date to within a week in just a quarter of cases. Mostly, they had erred on the side of optimism.

Doctors often neglect palliative care, which involves giving opioids for pain, treating breathlessness and counselling patients. (The name comes from the Latin *palliare*, as in “to cloak” pain.) A typical question is “What is important to you now?” It does not seek to cure. As a result, “it is seen as what you do when you give up on a patient,” sighs Dr Ikegami. It receives just 0.2% of the funding for cancer research in Britain and 1% in America.

Breaking the taboo

What studies there have been show the cost of this neglect. Since 2009 several randomised controlled trials have looked at what happens when patients with

advanced cancer are given palliative care alongside standard treatment, such as chemotherapy. In each, the group receiving palliative care had lower rates of depression; and in all but one study, patients in that group were less likely to report pain.

Remarkably, in three trials the patients receiving palliative care lived longer, even though the quantity of conventional treatment they opted to receive was lower. (The other two trials showed no difference.) In one study their median survival was a year, compared with nine months for the group receiving only ordinary treatment. A review in 2016 of cases where palliative care was used instead of standard treatment found that even when it was the only care given, it did not seem to shorten life.



The reason for the results is unclear, and the research has mostly been on cancer patients. Those receiving palliative care spend less time in hospital, so may contract fewer infections. But some researchers think that the explanation is psychological: that through counselling they reduce depression, which is linked to earlier death. “A conversation can be more powerful than technology,” says Dr Sleeman.

At St Luke’s hospital in Tokyo, Yuki Asano supports the argument. Ever the executive, the 76-year-old slides his business card across the tray of his bed. The former boss of a brewery company (and 7th *dan* in *kendo*, a Japanese martial art) is riddled with cancer. He stopped chemotherapy last year. The care at one of Japan’s few dedicated palliative centres has helped him feel ready for death. “I achieved everything I wanted in life,” he says. “Now I am waiting for the awards ceremony.”

But few of the 56m or so people who die each year receive good end-of-life care. A report published in 2015 by the Economist Intelligence Unit, our sister company, assessed the “quality of death” in 80 countries. Only Austria and America, the EIU found, had the capacity to ensure that at least half the patients for whom palliative

care was suitable received it.

Many countries promise public access to palliative care but do not pay for it. Spain has passed two laws to ensure palliative care is available but in reality, just a quarter of patients can get it. Though the hospice movement, dedicated to providing high-quality care to dying patients, started in Britain in the 1960s, only about a fifth of the country's hospitals provide access to palliative care every day of the week.

The way health-care providers are funded often sidelines palliative care. In Japan hospital doctors receive no payment from insurers for talking to patients about end-of-life options. In America hospitals suck up a big share of spending, even though the seriously ill are often better treated elsewhere. Nine in ten emergency visits are because of escalations in symptoms, such as breathlessness; most of these patients could be treated better, faster and more cheaply at home. Medicare, the public-health scheme for the elderly, does not generally cover spells in nursing homes.

Slowly, however, countries are reforming. In 2014 the WHO recommended integrating palliative care with health systems. Some developing countries, including Ecuador, Mongolia and Sri Lanka, are beginning to do so. In America some insurers are realising that what would be better for patients would be better for them, too. In 2015 Medicare announced that it would pay for conversations about end-of-life care between doctors and patients.

"Talking almost always helps and yet we don't talk," says Susan Block of Harvard Medical School. To improve end-of-life care, she says, "every doctor needs to be an expert in communicating." American oncologists, for example, need to have an average of 35 conversations per month about end-of-life care. In a study of patients with congestive heart failure, doctors rarely followed up after a patient expressed a fear of death. Nearly three-quarters of nephrologists were never taught how to tell patients they are dying. A common cause of burnout among doctors is an inability to talk with patients about death.

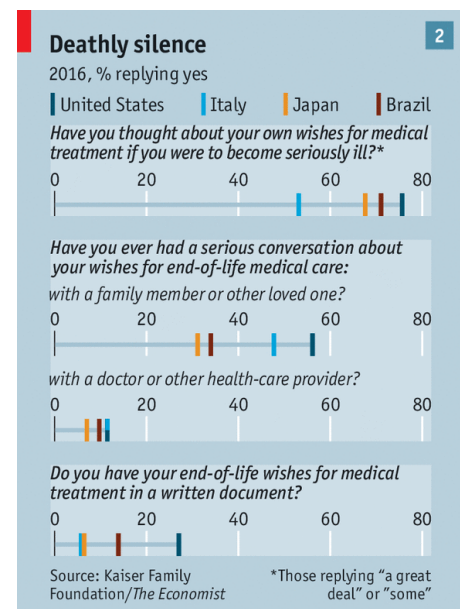
To fill this gap Ariadne Labs, a research group founded by Dr Gawande, has

launched the “Serious Illness Conversation Guide”. It is a straightforward checklist of the topics doctors should be sure to talk about with their terminally ill patients. They should start by asking what patients understand about their conditions, check how much each wants to know, offer an honest prognosis, and ask about their goals and the trade-offs each is willing to make.

Early results from a trial of the guide at the Dana-Farber Cancer Institute in Boston suggest it led to doctors having more and earlier conversations. Patients reported less anxiety. Tension between doctors and families was eased. The scheme is being expanded; in February Baylor Scott & White became the first big provider to use it for all its staff. England’s National Health Service is trying it out in Clatterbridge, near Liverpool. Japan is retraining its oncologists in how to talk about death.

In America advance directives and living wills, documents that spell out the treatment people want if they become incapacitated, have become more popular over the past few decades. In our survey 51% of Americans over 65 had written down their end-of-life wishes. Yet such documents cannot cover all the possibilities that may arise as the end nears. Doctors worry that patients may have changed their minds. In one study just 43% of people who had written living wills wanted the same treatment course two years later.

Living wills are rare outside America (see chart 2). But there is a broader cultural shift. More than 4,400 “death cafés”, where people eat cake and talk about mortality, have sprung up. They discuss books such as “When Breath Becomes Air”, by the late Paul Kalanithi, a neurosurgeon, and the documentary “Extremis”, which is set in an intensive-care unit and offers a more honest account of hospital care than in popular TV shows. In Japan “ending notebooks” are now available, to record messages and instructions for relatives.



Economist.com

Here at the end of all things

In 2010 Ellen Goodman, an American author, founded the Conversation Project, which started with people gathering to share stories of the “good deaths” and “bad deaths” experienced by their loved ones. It publishes guides like those from Ariadne Labs, but for use by people without medical training. Laurie Kay from Boston, who is 70, recently told her husband and daughter that what mattered to her was dignity. She wants to look good: her nails should be painted. Her views may change, she says, but “having opened the conversation now we can reopen it later.”

Experiences of death are being shared online. Dying Matters is a popular forum. In 2013 Scott Simon, a journalist, tweeted from his mother’s bedside as she died (“Heart rate dropping. Heart dropping”, read one tweet). Kate Granger, an English geriatrician who died of cancer last year, planned to tweet during her final days using the tag #deathbedlive. She did not quite manage it, but a tweet she prepared was sent posthumously: “TY all for being part of my life. Pls look after my amazing hubby @PointonChris (Ps - Don’t let him spend all his money on a Range Rover) xx”.

Bringing death “within the pale of conversation” is needed to overhaul end-of-life care, argues Dr Warraich. Yet the “death positive” movement is not an excuse for medicine to remain stuck in its ways. Death will remain terrifying for many people. Unless the way health care is organised changes, most people will continue to suffer unnecessarily at the end.

Correction (April 30th): A previous version of this piece said that Laurie Kay is in her 80s. She is in fact only 70. Apologies.

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