End-of-life care

How to have a better death

Death is inevitable. A bad death is not

IN 1662 a London haberdasher with an eye for numbers published the first quantitative account of death. John Graunt tallied causes such as “the King’s Evil”, a tubercular disease believed to be cured by the monarch’s touch. Others seem uncanny, even poetic. In 1632, 15 Londoners “made away themselves”, 11 died of “grief” and a pair fell to “lethargy”.

Graunt’s book is a glimpse of the suddenness and terror of death before modern medicine. It came early, too: until the 20th century the average human lived about as long as a chimpanzee. Today science and economic growth mean that no land mammal lives longer. Yet an unintended consequence has been to turn dying into a medical experience.

How, when and where death happens has changed over the past century. As late as 1990 half of deaths worldwide were caused by chronic diseases; in 2015 the share was two-thirds. Most deaths in rich countries follow years of uneven deterioration. Roughly two-thirds happen in a hospital or nursing home. They often come after a crescendo of desperate treatment. Nearly a third of Americans who die after 65 will have spent time in an intensive-care unit in their final three months of life. Almost a fifth undergo surgery in their last month.

Such zealous intervention can be agonising for all concerned (see article). Cancer patients who die in hospital typically experience more pain, stress and depression than similar patients who die in a hospice or at home. Their families are more likely to argue with doctors and each other, to suffer from post-traumatic stress disorder and to feel prolonged grief.

What matters

Most important, these medicalised deaths do not seem to be what people want. Polls, including one carried out in four large countries by the Kaiser Family Foundation, an American think-tank, and The Economist, find that most people in good health hope that, when the time comes, they will die at home. And few, when asked about their hopes for their final days, say that their priority is to live as long as possible. Rather, they want to die free from pain, at peace, and surrounded by loved ones for whom they are not a burden.

Some deaths are unavoidably miserable. Not everyone will be in a condition to toast death’s imminence with champagne, as Anton Chekhov did. What people say they will want while they are well may change as the end nears (one reason why doctors are sceptical about the instructions set out in “living wills”). Dying at home is less appealing if all the medical kit is at the hospital. A treatment that is unbearable in the imagination can seem like the lesser of two evils when the alternative is death. Some patients will want to fight until all hope is lost.
But too often patients receive drastic treatment in spite of their dying wishes—by default, when doctors do “everything possible”, as they have been trained to, without talking through people’s preferences or ensuring that the prognosis is clearly understood. Just a third of American patients with terminal cancer are asked about their goals at the end of life, for example whether they wish to attend a special event, such as a grandchild’s wedding, even if that means leaving hospital and risking an earlier death. In many other countries, the share is even lower. Most oncologists, who see a lot of dying patients, say that they have never been taught how to talk to them.

This newspaper has called for the legalisation of doctor-assisted dying, so that mentally fit, terminally ill patients can be helped to end their lives if that is their wish. But the right to die is just one part of better care at the end of life. The evidence suggests that most people want this option, but that few would, in the end, choose to exercise it. To give people the death they say they want, medicine should take some simple steps.

More palliative care is needed. This neglected branch of medicine deals with the relief of pain and other symptoms, such as breathlessness, as well as counselling for the terminally ill. Until recently it was often dismissed as barely medicine at all: mere tea and sympathy when all hope has gone. Even in Britain, where the hospice movement began, access to palliative care is patchy. Recent studies have shown how wrongheaded that is. Providing it earlier in the course of advanced cancer alongside the usual treatments turns out not only to reduce suffering, but to prolong life, too.

Most doctors enter medicine to help people delay death, not to talk about its inevitability. But talk they must. A good start would be the wider use of the “Serious Illness Conversation Guide” drawn up by Atul Gawande, a surgeon and author. It is a short questionnaire designed to find out what terminally ill patients know about their condition and to understand what their goals are as the end nears. Early research suggests it encourages more, earlier conversations and reduces suffering.

These changes should be part of a broad shift in the way health-care systems deal with serious illness. Much care for the chronically ill needs to move out of hospitals altogether. That would mean some health-care funding being diverted to social support. The financial incentives for doctors and hospitals need to change, too. They are typically paid by insurers and governments to do things to patients, not to try to prevent disease or to make patients comfortable. Medicare, America’s public health scheme for the over-65s, has recently started paying doctors for in-depth conversations with terminally ill patients; other national health-care systems, and insurers, should follow. Cost is not an obstacle, since informed, engaged patients will be less likely to want pointless procedures. Fewer doctors may be sued, as poor communication is a common theme in malpractice claims.

One last thing before I go

Most people feel dread when they contemplate their mortality. As death has been hidden away in hospitals and nursing homes, it has become less familiar and harder to talk about. Politicians are scared to bring up end-of-life care in case they are accused of setting up “death panels”. But honest and open conversations with the dying should be as much a part of modern medicine as prescribing drugs or fixing broken bones. A better death means a better life, right until the end.

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*

Print edition | International
Apr 29th 2017 | TOKYO

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.

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). 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.
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.

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 cafes”, 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.

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.

Last wishes

What people most want in their final months

*Our survey of what matters most at life’s end*

Print edition | International
Apr 29th 2017/SÃO PAULO

<table>
<thead>
<tr>
<th>Thinking about your own death, how important is:</th>
<th>United States</th>
<th>Italy</th>
<th>Japan</th>
<th>Brazil</th>
</tr>
</thead>
<tbody>
<tr>
<td>family not burdened financially</td>
<td>0</td>
<td>10</td>
<td>20</td>
<td>30</td>
</tr>
<tr>
<td>being comfortable/without pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>being at peace spiritually</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>family not burdened by decisions</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>having loved ones around you</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>having your wishes for care followed</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>living as long as possible</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: Kaiser Family Foundation/The Economist

Economist.com
AFTER his stroke Maria’s father could no longer speak. But with his daughter reciting the words next to him, he could still pray. His final days brought a lot of pain but Maria believes that at the end, as he clasped her hand, he was at peace. When she thinks about her own priorities for her death, “being at peace spiritually” is top of the list.

It is a sentiment shared by fellow Brazilians, according to a survey conducted jointly by The Economist and the Kaiser Family Foundation, an American non-profit focused on health. Fully 88% thought that being at peace spiritually at the end was “extremely” or “very important” (see chart). In America and Japan not burdening families with the costs of care was the highest-ranked priority, cited as extremely important by 54% and 59% respectively. (The Japanese may be worrying about the cost of funerals, which can easily reach ¥3m, or $27,000.) A third of Italians emphasised having loved ones around them. Brazil was the only country where more people said they would put extending life ahead of reducing pain and stress than the other way around.

Religion accounts for some of these differences. There are more Catholics in Brazil than any other country. Many have presumably been influenced by their church’s long insistence that life should be extended whenever possible, even by heroic measures. In court battles in America and elsewhere, when families have sought to have feeding tubes removed from relatives who are in a persistent vegetative state, the church has often been opposed (though it now condemns only active measures to hasten death, rather than patients’ decisions to reject treatment, or death that is hastened by pain relief). Eighty-three per cent of Brazilians said that religion played a “major role” in their thinking about end-of-life care, against 50% of people in America and 46% in Italy.

In Japan, just 13% said that religion played a major role in their thinking. In other surveys most Japanese report that they are atheists or have no formal religious affiliation. But the idea of “spiritual peace” is nonetheless important in Japan—it is ranked second for what matters close to death.

The relative weights people place on extending life, and easing death, are also shaped by the quality of care available, and perceptions of what they will personally receive. Ninety per cent of Brazilians rated their health-care system as “fair/poor”, compared with 54-61% in the other three countries. Though their constitution guarantees comprehensive, free health care for all, it falls far short of that ideal. Even before a crippling recession that has already lasted three years, care was often precarious. More recently, cash-strapped hospitals in big cities, including Rio de Janeiro, have seen patients die in corridors.

In America, Italy and Japan people with degrees were most likely to say that too much emphasis is placed on extending life towards its end, as opposed to alleviating suffering. Better-educated people were also more likely to say patients and families should play a bigger role in decisions about end-of-life care.

Almost half of black Americans, and nearly as many Latinos, said that health care placed too little emphasis on preventing death, compared with just 28% of white Americans. Other research has found that minorities are more likely to die in hospital than white Americans. Richer Americans are more likely to die at home or in a hospice than those on lower incomes. All of which suggests a bitter irony: those who most need hospital care may receive it only when it is too late.