Excerpts from

SIDE EFFECTS

How Our Healthcare Lost its Way

And How We Fix it

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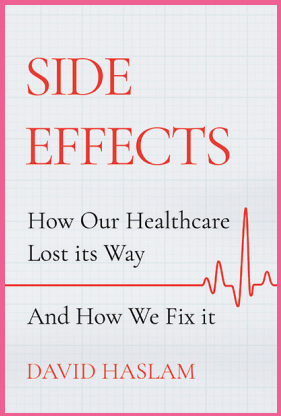
KALEIDOSCOPE
Health and Care

This is a taster of *Side Effects*, by David Haslam.

The full version of the book is available from all good booksellers



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Introduction

Good intentions are fine. We all aspire to do better, to improve, to make a difference.

Indeed, it's incredibly rare for anyone working in health and social care to deliberately want to do harm. Which makes it a puzzle why so many policies, plans, and processes end up making things worse, rather than better.

We all know that medical treatments, designed to help or cure, can have side-effects. The same goes for health care policy. A failure to consider the possible unintended consequences of good intentions has confounded the history of health and care in the UK. And this is complicated by a lack of clarity as to what we really hope to achieve. All too often, stated aspirations fail to be matched by appropriate actions. We are in a mess. Everyone knows we are in a mess.

Side Effects is a book that takes a fresh and challenging look at why health care has lost its way, and how we can fix it. We know we can't go on like this, and yet frank, honest, forthright debate has been all too lacking.

At Kaleidoscope Health and Care our whole approach is also based on being different, being challenging, thoughtful, and supportive, aiming to deliver a future which is kind, connected, and joyful.

If you would like to know more about what else Kaleidoscope does, we would love to hear from you.

In the meantime, we hope you enjoy the book, and get involved in the debate.

Esther Omedi
Part of Kaleidoscope

We've got a problem

I've spent my life working in healthcare. For many years, I was involved in both devising and implementing many aspects of local and national health policy, and I've also experienced it first-hand, as a patient. From every perspective, there is clearly a mismatch between supply and demand. While resources can never be infinite, the demand for healthcare in Britain appears to be inexhaustible. This imbalance is a source of immense tension, and the situation is only getting worse. In this book, I will first assess this extraordinary challenge and then attempt to suggest how we might tackle it.

In the past few years, the NHS has faced a double whammy: first the government's pursuit of austerity reduced its capacity, and

then the immense challenge of Covid-19 tested it to its limits. Even before this, it faced massive and unsustainable pressure. While increased funding is critically important, it cannot be the only solution to every problem.

The coronavirus pandemic has, to an unprecedented degree, devastatingly exposed the challenge that is facing us. For a while, it trumped everything else, and not just in Britain. All around the world, governments recognised the supreme importance of health and healthcare, as well as the key role that the state has to play in protecting its citizens.

The battle with disease – with a single disease that spread easily and posed a particular threat to the eldest and most vulnerable – was in full swing. Humankind had to fight this virus with whatever weapons it could muster, which initially meant prioritising healthcare over the needs of the economy and all the other various priorities that usually jostle for attention. It was extraordinary, but it was necessary. However,

things were far from typical. Funds are not infinite, and they never can be.

In more normal times, when we are not facing a global pandemic, we still find ourselves having to make life-and-death choices. After all, healthcare can be massively expensive. Every year, the cost of care escalates, and the money has to be found to pay for it. Even prior to the pandemic, in 2017, the UK spent £197 billion on healthcare, equating to £2,989 per person.[1] Research scientists continue to develop new drugs and therapies; the potential benefits that they offer to humankind are phenomenal, but the accompanying prices almost inevitably go up and up.

Even before Covid-19, the proportion of national wealth that was spent on healthcare was increasing every year, and every prediction of future trends showed that this challenge was only going to worsen. Although this issue is facing every country on earth, we seem remarkably reluctant to discuss it. Society

might in the short term have debates about whether a particular amount of spending is sufficient, but we rarely consider the longer-term perspective. Burying our heads in the sand and ignoring a deepening problem can never be a sensible long-term policy, however tempting it might be.

However, the increasing cost of care isn't our only challenge. Of the diseases that posed the greatest threat to the average family just a few decades ago, many of them have now been eradicated. Life expectancy has also increased since then, yet people are more anxious about their health than ever, and doctors are as busy as they have ever been. A typical day's work for a British general practitioner 150 years ago would have consisted of a constant stream of patients with pneumonia (which was frequently fatal), diphtheria, cholera and acute rheumatism, in addition to the flood of minor problems that all family doctors would still recognise today.[2] Today's GPs might look at

that workload from a previous age and notice that almost all these illnesses have either been wiped out or are now eminently treatable. They might find themselves wondering what would be left for them to do, but as some challenges have been eliminated, new problems have arisen to take their place. Family doctors today are busier than they have ever been – and this is discounting the impact of the Covid pandemic. So, what is going on? Can we foresee a world where healthcare facilities sit unused while a healthy and happy population has no need for care? Or will the predictions that envisage perpetually rising expectations and demand prove to be accurate? If they do, is this a sustainable model? And what is driving it?

This dilemma is the subject of my book. If we can accept that there will never be enough money to cover every possible eventuality – and it's hard to imagine that there ever could be – how should society make choices? What

is the real value of healthcare, and what is the endgame? Disease and infirmity will never disappear completely, so we need to ask ourselves whether we are using the available funds in the best possible way. When can it be justifiable to spend more money on healthcare, if that means taking money away from other areas of our lives, which might include education or even security?

The problem is a global one, and in the long term, simply increasing healthcare spending is unlikely to be the sole solution. That said, the challenges facing the National Health Service in the UK have been exacerbated by a decade or more of underfunding; I should emphasise that I will most definitely *not* argue in this book that British healthcare currently has enough money. Years of austerity following the global financial crisis of 2008 have had a major impact. Waiting lists had risen to 4.6 million even before Covid attacked, and staffing levels were clearly becoming seriously inadequate.[3]

As the wide-ranging LSE–*Lancet* Commission on the future of the NHS made very clear, the Covid-19 pandemic has reinforced the economic case for investing in health, which is crucial for both fiscal sustainability and societal wellbeing.[4] The commission estimated that in order to implement its funding recommendations, total expenditure on the NHS would need to increase by around £102 billion in real terms, which will represent around 3.1 per cent of the UK's gross domestic product in 2030–31.

These are eye-watering sums, and there is no doubt that the NHS is facing an uphill struggle if it is to catch up once the pandemic is over. But it is equally clear that in the longer term, a more fundamental reconsideration of how we perceive healthcare is required. Indeed, while the population has, in general, never been healthier, we seem to consider ourselves to be more at risk of falling ill than ever – and we are more anxious about our health than at any

time in our history. Despite all the advances we are making in our ability to diagnose and treat illness, the demand on healthcare services continues to rise inexorably.

The key question I will return to throughout this book is a simple one. What is it that we are really trying to achieve through our healthcare system? And if we have a goal in mind, are we going the right way about trying to achieve it?

Today, many aspects of human existence are at risk of being medicalised – another side effect of the hard-won successes of modern medicine. But is this really healthy? Is it logical? And is it beneficial? In the future, it may be that we look back on current events and realise that the pandemic opened our eyes to this challenge. With the vast level of government spending that Covid-19 triggered having threatened the long-term sustainability of health systems, we need to find ways of doing more with less. We have an opportunity to ensure we are focused on doing the right

things, and we should as a priority tackle over-medicalisation and the unnecessary tests, diagnoses and therapies that can potentially cause harm as well as leading to waste – not just of money, but of time and expertise.

How did we get here?

At first glance, it all seems rather curious – because we should be winning.

Year on year, science has made consistent improvements, and medical research is able to answer increasingly complex questions about sickness and health, progress that has had a particular impact on how long we can expect to live. Estimates suggest that in a pre-Enlightenment world, global life expectancy was around 30, largely because of dreadful levels of infant mortality. However, by the early 19th century, people in industrialised countries were starting to live longer. And since 1900, the global life expectancy has more than doubled and is now approaching 70.

It has been calculated that global life expectancy improved as much during the 20th century as it

had done in the preceding 8,000 years. Today, it is higher even in the poorest countries than it was in the developed nations in 1800. Every nation is doing better than the previous best, an astonishing achievement for humanity.

In 1948, the year that the British National Health Service was founded, the UK average life expectancy was 65.9 years for men and 70.3 for women. I was born just after the birth of the NHS. Before this time, I would have been considered lucky to have lived to my current age. By 2016, life expectancy had increased by about 13 years, to 79.5 for men and 83.1 for women. All around the world, the changes have been remarkable. In the Caribbean, life expectancy in 1950 was just 51; by 2015, it had risen to 73. And in the continent of Africa, life expectancy in 1950 was a mere 36; by 2015 it had nearly doubled, to 61.

Despite our long-term global achievements – or in more likelihood as a side effect of them – the cost of healthcare keeps escalating. The global

health economy went from being 8 per cent of the world's GDP to 8.6 per cent between 2000 and 2005. In absolute terms, adjusted for inflation, this represents a 35 per cent growth in health expenditure in just five years.

In most areas of life, improved technology leads to price reductions. Advances in agricultural science, for instance, have caused the cost of food production to fall, meaning that people can be fed more cheaply and efficiently.[5,6,7] It's the same with information technology, so what is it that makes healthcare so different? After all, the diseases that challenged doctors in the distant past have almost all been defeated, and yet they are as busy as they ever have been, if not busier.

How does that make sense? Why aren't costs falling, like they tend to in every other sector? There appears to be three main factors: changing population demographics, inflation and income growth effect, and an increase in the intensity of clinical practice and innovation.

The Office for Budget Responsibility in the UK has concluded that the prime driver of rising healthcare costs is the increase in the intensity of clinical practice. Doctors do more, probably not just because it can be beneficial but because they can.

There is always more that can be done, more that *might* be paid for and more that patients will say 'should' be paid for. In the UK, although Aneurin Bevan recognised the potential impact of this ever-increasing cost, he stated, "Illness is neither an indulgence for which people have to pay, nor an offence for which they should be penalised, but a misfortune, the cost of which should be shared by the community."

Other countries chose to take a different path, but one simple fact remained. However healthcare might be funded, there will never be enough money to pay for everything – so tough decisions have to be made.

Valuing a life

Anyone who is fortunate enough to live in a country with comprehensive state-funded healthcare is unlikely to have any idea what their medicines really cost. Although some drugs can be very cheap – aspirin, for example, has been around since 1899 and costs just a few pence – other drugs are extraordinarily expensive. In the UK, it is often only when people take their pet to the vet and have to pay for its medication, or if they fall ill while on a foreign holiday and receive a bill for emergency treatment, that the true cost of pharmaceuticals really hits them – and it usually comes as something of a shock.

Ignorance may be bliss, but we need to remember that half of the UK population takes at least one prescription drug every day,[8] and the figure is similar in the US.[9] A quarter of people in the UK are on at least three drugs, with millions, particularly the elderly, on at least

five types of medication. These costs really add up. For instance, in one recent year the net ingredient cost of atorvastatin, the most prescribed statin in the UK, was £52,621,269, the cost of levothyroxine sodium (a treatment for an underactive thyroid gland) was £86,942,415, and the cost of omeprazole (a treatment that reduces stomach acid) was £52,767,333. These are quite remarkable numbers.[10] The trouble is that, as we have seen elsewhere, they are so massive that they have little real meaning.

But it's not just these cumulative figures that cause the huge expense, for the cost of individual doses can also be breathtakingly high. In 2019 the US Food and Drug Administration approved Zolgensma, the most expensive treatment in history. It was a treatment for spinal muscular atrophy, a rare disorder caused by a defective gene that weakens a child's muscles so dramatically that they become unable to move and eventually unable to swallow or breathe. In the US, it occurs in about 400 babies each year.

This therapy was priced at $2.125 million per patient by Novartis, who argued that spread across a lifetime, this price was cost-effective. Novartis did not develop Zolgensma themselves but had bought AveXis, the company that did. The *Wall Street Journal* described the acquisition as a 'bet', with the high price necessary for that gamble to be successful.[11]

The simple fact is that as funds are never infinite, difficult funding decisions are inevitable. Different patient groups will always be competing for resources and care, and the measure of 'quality-adjusted life years' (QALYs) at least help make decisions about the use of resources explicit and logical. QALYs are a generic measure of the health of a person in which the benefits, in terms of length of life, are adjusted to reflect the quality of life.

While the use of QALY scores has been criticised because of an implication that some patients will be refused treatment for the sake of others, such choices have always been

made. In a debate in the House of Commons about the role played by the National Institute for Health and Care Excellence (NICE), a politician said, "QALYs, and everything else, mean nothing to people on the street", before going on to demand an approach based on 'fairness'. But how do you define fairness? How do you ensure that you aren't just listening to the loudest voices? When it comes to the cost of treatment, surely it is better to rely on facts than emotion?

Better than cure

It is such an obvious idea that it has become a cliché. The phrase 'prevention is better than cure' has been commonplace since the 17th century, while a version of it has been traced as far back as 1240. Surely an idea that has been around for so long must have some basis in reality? Well, yes and no. The truth is that planning and delivering prevention requires as much critical thinking and analysis as any other aspect of medicine – it should not be given automatic blanket approval.

Prevention is about helping people to stay healthy, happy and independent for as long as possible. It means stopping problems before they arise rather than treating people when they become ill. It feels entirely logical to believe that if we could manage people's health more effectively, the ever-increasing

pressure on our healthcare systems would ease. A 2017 review of the cost-effectiveness of public health measures showed that 'for every £1 invested in public health, £14 will subsequently be returned to the wider health and social care economy'.[12] The benefits of preventative medicine have rarely been more obvious than during the coronavirus pandemic; the vaccination programme has exemplified the benefits of preventing disease rather than waiting to treat it.

There is little doubt that if you want to improve the health of a nation, you will achieve better results if you invest in housing and education, along with addressing the various other social factors that dramatically impact on health.

At the same time, no nation could ever abandon the provision of health services and focus on these social inequalities – even if the results achieved were much better. Sickness and disease will always happen to individuals; however effective prevention might be and

however logical it might be to focus on the social determinants of health, governments simply cannot ignore healthcare provision. It might theoretically be possible to greatly increase overall levels of health through massively increasing spending on the social determinants of health, but citizens will continue to become ill with cancer, heart disease, mental health problems and an endless number of other conditions.

While no government or healthcare system could ever say, 'We've spent everything on prevention – there's nothing left for treatment,' the problem is that the opposite does sometimes happen – when times are tough, the prevention budget is generally cut. I can understand why today's crises get the lion's share of funding, but it is also breathtakingly short-sighted – another case where healthcare decision-making results from short-term budgeting rather than long-term planning.

Of course, prevention can only go so far. There is no escaping the fact that we will all eventually die, so it has to focus on improving quality of life and not just on longevity. Focusing on prevention and the social determinants of health is the right thing to do, but it will not necessarily reduce costs. In fact, it might be the modern-day equivalent of the naïve fallacy that was popular soon after the birth of the UK's National Health Service: the idea that better care would lead to a healthier population and lower costs.

Hearts and minds

Which is more important, depression or cancer? This probably sounds like a completely absurd question – a bit like asking whether apples are superior to carrots, or whether Tuesday is better than wi-fi. But there is little doubt that many people – policy makers and politicians in particular – have indirectly answered this question with their actions, even if they didn't intend to. And their response has a profound effect on how our healthcare system operates.

For the past few years in England, when a family physician suspects that one of their patients might have cancer, the NHS prioritises their care to the extent that all referrals should be seen by a specialist within two weeks. Time matters, and so the system leaps into action to ensure effective care is offered as quickly as possible.

By contrast, let us remember the report that found that eight out of ten NHS trust finance directors in England agreed that funding pressures had led to longer waiting times for people in need of mental health treatment.[13] And even after patients had been able to access mental health services, cost-cutting had led to shorter courses of treatment and less contact with services. It's quite a contrast with the way the system approaches cancer.

The challenge facing every health system is that you can only spend money once. If your priorities are focused on physical health, there will not be enough money left to give mental health problems the attention they require. In addition, current research indicates that the correlation between mental and physical health is stronger than we previously believed. Our focus on the physical will likely prove to be short-sighted.

Overall, there can be little doubt that the rigid divisions between physical and mental health

are increasingly seen as arbitrary, and the focus on the physical at the expense of mental health issues may eventually be regarded as illogical and prejudicial. We can only hope that the long-term allocation of healthcare budgets reflects this change in attitude, but this is unlikely to happen without public pressure. When waiting times for mental health services create the same angry headlines as excessive waits for heart disease or cancer treatments, we may see action.

Age and ageing

I'm a problem – or at least that's what journalists and politicians keep telling me. As a headline in the *Daily Mail* in May 2013 tactfully put it, 'Elderly population pushing NHS to brink of collapse, says Minister'.

Over the past year or so, the claim that the ever-increasing costs and challenges facing our healthcare system are primarily the result of our 'ageing population' has become more common. I've lost track of the number of academic papers I've read and lectures I've listened to that have claimed that oldies like me are the problem. Countless news broadcasts and newspaper articles mention the phrase as if it explains everything – bizarrely, our 'ageing population' has been depicted as a thoroughly undesirable development, a source of expense and problems rather than an astonishing

achievement and a remarkable potential resource. And in a book about the escalating costs of healthcare, it is not a topic that I can ignore.

Those of us who retain our health into later life have a great deal to look forward to. The neuroscientist Daniel Levitin has examined World Health Organization data from 60 countries and has shown that while happiness declines in our thirties, it picks up again when we reach the age of 54, peaking at the age of 82.[14] In an interview he said, "You realise you've gotten through all these things that were stressing you out. If you make it to 82, you know you've managed [and] you're OK." Indeed, he attributes happiness in old age to people readjusting the 'too-high expectations' of their youth to 'realise that life is pretty good'.

The way we live can clearly have a profound effect on our health. As they become older, many people begin to question their priorities. Age often brings multiple health problems and

a multiplicity of different appointments and tests, which can become immensely time-consuming. If you add preventative check-ups and medications to these, you end up with a healthcare system that is designed to add more years to our life, but sometimes ends up taking away the life from the years. In her book *Natural Causes: Life, Death and the Illusion of Control*, the American writer Barbara Ehrenreich described how, in her mid-70s, she gradually gave up on many medical measures, such as cancer screenings, annual check-ups and cervical smears.[15] As she wrote, "Most of my educated middle-class friends had begun to double down on the health-related efforts at the onset of middle age, if not earlier. They undertook exercise or yoga regimens: they filled their calendars with upcoming medical tests and exams."

Instead, Ehrenreich came to realise that she was 'old enough to die'. If she was acutely ill, she would get it sorted, but she wouldn't

agonise about each and every risk factor and how to avoid it. She made choices around diet and activity because she enjoyed them, not because she wanted to do things that would extend her life.

Each of us will react to this idea differently, but I think Ehrenreich makes a valid point. After all, old age is very much a phase of life rather than a disease. It isn't there to be defeated or endured. It is there for living – not just for merely existing. As we get older, the medicalisation of our every waking activity feels like a curious priority. However hard we try, we can't beat the Grim Reaper; scrambling for new things that might prolong our life is no way to live. There's much more to life – and to ageing – than that.

And in the end...

It may well be apocryphal, but there's a great story of a poster being displayed in a maternity unit to remind staff that, "The first two days of life are the most hazardous." Someone had written on it, "And the last two aren't too good, either."

Birth and death are the only two certainties in every life, and yet contemporary Western culture has a tendency to forget that the second of these things is an inevitability that needs to be planned for. Dying should not be seen as failure, as what happens when medical care and treatment fails. When we are determining the needs of any healthcare system, end-of-life care should be treated as an important priority rather than being dismissed as an optional extra. There is nothing optional about dying, yet its arrival is sometimes treated as a surprise, as a failure.

As an event that faces us all, it should be an important aspect of healthcare budgeting rather than a mere afterthought.

To understand contemporary attitudes to death, we can compare the funding of services that are offered at the start of life with those that are used at the end. As the chief executive of the UK charity Marie Curie, which provides care and support to people with terminal illness, said in a newspaper interview, "Just imagine if the quality of your local maternity services depended on how much money had been raised by cake sales and sponsorship of marathon runners. We would regard this as an entirely intolerable state of affairs." Then why, he asked, do we accept this funding model for the care that we receive at the end of our lives?[16]

A colossal £500 million is spent each year on cancer research, while a derisory £5.49 million goes towards researching end-of-life care. We need research into cancer treatments, of

course – science must advance, but not at the cost of delivering care to those who need it. It's not as if we have made a conscious decision to spend a fortune on a number of barely effective drugs that are offered, sometimes inappropriately, at the end of life, while failing to deliver the investment in community and primary care that keeps being promised, but never appears. Is this really how our society would like its funds to be prioritised?

Our changing demography means that the situation is only going to get worse. Today there are 1.6 million people aged over 85, and this is expected to double over the next 25 years. This wonderful achievement for humankind will mean that many more of us will have multiple health problems in our final days, and it is clear that our current healthcare systems are not geared up to cope. We should ignore the problem at our peril.

A way forward

With demand for care increasing, costs escalating, populations growing and expectations rising, and all while economies are facing a desperate struggle to source sufficient funding, what possible solutions might there be? After all, there do *have* to be solutions. If this challenge isn't tackled, we will end up either with increasing waiting times, reductions in the quality of care or with the most expensive care being restricted to those who are able to pay – not a recipe for a cohesive, happy and functioning society.

There is no doubt that the Covid-19 pandemic has had – and will continue to have – a profound impact on healthcare systems around the world.

However, this global catastrophe may also provide a natural pivot point – an opportunity to rethink, and maybe to start anew. We simply

cannot carry on as we were before – and while some people think the long-term answer is to continue the massive healthcare spending that was needed in the early days of the pandemic, this is simply unsustainable and ignores the urgent requirements of other aspects of public life.

So what is the solution? In democracies, the budgetary approach of governments tends to be based on what is most likely to be acceptable to the electorate. It is difficult to deliver quality, affordability and access simultaneously, at least without significant changes to the way services are delivered. This is not just an issue for politicians – it is an issue for the whole of society, whether we are patients, clinicians, academics, industrialists or citizens. It is key that any change must be based on evidence. The decision-making process should be as transparent as possible, and it must involve service users as well as clinicians and managers.

Some of the challenges I've described include a lack of clarity as to the ultimate aspirations of care, an excessive focus on single conditions at a time when many of us have multiple long-term conditions, and the outdated hospital-led paradigm for healthcare. We've looked at waste, overtreatment and overdiagnosis, increasing expectations of healthcare and the puzzling situation whereby populations that have never been healthier are nevertheless increasingly concerned about health issues. We've noted that medical solutions may be used for non-medical issues, the ever-increasing costs of pharmaceuticals, underinvestment in public health measures and the challenge posed when very expensive therapies for small numbers of patients are prioritised over comfort and care for much larger numbers of patients. That's quite a list.

Solutions

No single solution will address all these issues, but a great deal could be done to address some of them. This might begin with an acceptance that for all its successes, healthcare has lost its way and needs to refocus. It will also require a greater clarity around the ultimate aim of medical care. Throughout history, there has been a constant and futile fight with mortality. Just as every generation looks back with astonishment at the weapons that its predecessors chose to use in this fight, future generations will look at us in just the same way.

If healthcare systems are to flourish, there must be a far greater emphasis on self-care, and on care from family, friends and the community. A patient with diabetes spends around 0.02 per cent of their year in contact with the NHS, which probably equates to four 30-minute consultations. That leaves 99.98 per cent of their time having to deal with the

reality of living with diabetes.[17] So far, the NHS has been poor at supporting many aspects of self-care. Greater access to support through information technology will assist this partnership, as the uptake of digital consulting during the Covid-19 pandemic showed. The absurd demarcation between healthcare and social care must also be addressed. The suffering caused by Alzheimer's disease is just as challenging as the suffering caused by cancer, but at the time of writing only one of these conditions receives healthcare funding in England. How can this be moral, ethical or kind?

In the full version of this book, I wrote about the pharmaceutical industry researching a medication to treat loneliness. While this example of a medical solution for a non-medical problem may be extreme, it perfectly demonstrates the porous boundaries of healthcare. The then British prime minister Boris Johnson's statement that general practitioners

would be able to *prescribe* cycling as an aid to fitness and weight loss is a classic example of the gradual medicalisation of everyday life.[18]

By focusing on non-medical solutions, the benefits can not only be greater but dramatically cheaper – as well as more humane. Take the example of the small Somerset town of Frome.

Back in 2013, Dr Helen Kingston, a local GP concerned about the number of patients who were unhappy with the medicalisation of their lives, launched a project called Compassionate Frome.[19] Frome Medical Practice combined a compassionate programme of community development with routine medical care. They recognised that the impact of social connectedness can be greater than giving up smoking, reducing excessive drinking, reducing obesity and any other preventative interventions. In particular, they became aware of the role played by primary and community services in identifying those

people who are in need of support at moments of crisis. Care coordination teams systematically enabled these people to be offered the help they needed.

Remarkably, when isolated people with health problems were supported by community groups and volunteers, the number of emergency admissions to hospital decreased spectacularly. The number of admissions per 1,000 population in Frome fell from 25 to 21, at a time when for Somerset as a whole it increased from 27.8 to 35.7.[20]

But as the focus of this book has been the affordability of healthcare, we should also take note of the savings. The cost of unplanned hospital admissions in Frome fell from £5.7 million in 2013–2014 to £4.5 million in 2016–2017, a reduction of 20.8 per cent.

The idea behind the project is straightforward and humane. It aims to reduce isolation and loneliness in what is frequently a disconnected

society, while significantly reducing healthcare costs. Kindness, compassion and community gets better results than focusing only on the medical model.

If it doesn't work, don't do it

American surgeon Atul Gawande has written about the remarkable variability in healthcare costs between comparable populations in the US.[21] His conclusion was stark: the primary cause of extreme costs was the overuse of medicine. Many procedures were being done unnecessarily, and only the doctors' bank accounts were benefiting.

This phenomenon exists all around the world. It is not necessarily driven by greed, but it often occurs when doctors don't realise that a procedure is less valuable than they think. In my own early days in medicine, I used some treatments with the best of intentions – treatments that have since been shown to be entirely useless, or even dangerous.

As a result, a number of organisations around the world have attempted to develop lists of healthcare procedures that are of little or no value to the patient. One study in the Netherlands examined 193 clinical guidelines and found a total of 1,366 lower-value services.[22] The majority (77 per cent) of them referred to care that should not be offered at all, whereas 23 per cent recommended aspects of care that should not be offered routinely.

In the UK, NICE has also made a significant number of similar recommendations.[23, 24] A review of them by the Academy of Medical Royal Colleges stated that doctors have an ethical duty to prevent waste in the NHS; the savings of nearly £2 billion could be used more effectively elsewhere.[25] Can you think of any logical reason why any doctor should continue to use therapies that have been proven to have no value? Neither can I, which brings us to the next solution.

Tackling waste

A 2019 report concluded that about $1 of every $4 spent on healthcare in the United States may be wasted due to a combination of avoidable administrative hassles, failures in coordination and delivery of services, use of unnecessary treatments and fraud.[26] The total annual cost of waste in the US healthcare system has been estimated at between $760 billion and $935 billion.

In England, a report on waste in non-specialist acute hospitals in the NHS showed about £5 billion of unwanted variation in costs.[27] The report made 15 recommendations designed to tackle this problem and help trusts match the best. As an example, the average price paid for a hip prosthesis varied between £788 and £1,590, with the hospitals that bought the most tending not to pay the lowest price. Other initiatives that could be replicated in every healthcare system include 'Getting it Right First Time', a programme designed to tackle

variations in the way services are delivered across the NHS and to share best practice.[28]

Tackling waste also means tackling duplication, which wastes time for patients and clinicians, as well as resources. On a simple level, the absurd situation whereby a patient sometimes needs one appointment for a consultation, another for a blood test, another for an X-ray and another to get the results takes up a remarkable amount of time and resources. A Spanish study in 2019 that looked at the impact of re-engineering outpatient processes using a patient-centred approach showed that productivity increased by 34 per cent, satisfaction improved and complaints fell.[29]

Waste isn't a problem that's restricted to the UK. For instance, the United States typically spends approximately twice as much as any other high-income country on medical care, yet its utilisation rates are largely similar. Prices of labour, administrative costs and goods, including pharmaceuticals, appear to be the

major drivers of the difference in overall cost. As patients, physicians, policymakers and legislators debate the future of the US healthcare system, such data are needed to inform policy decisions. Talking about cost-effectiveness should never be dismissed as demanding rationing – it is simply being rational.

Excessively expensive therapies

Should the price of therapies be set by the value they bring or by the maximum the market can bear? Organisations such as NICE in the UK are well positioned to make decisions about cost-effectiveness. No one, apart from the exceedingly wealthy, chooses to spend money without asking, 'Is this worth the price I'm being asked to pay?' – and there is no reason why healthcare products should be any different.

Organisations such as NICE focus on key criteria including the use of evidence, patient involvement, clinical expertise and transparency in order to make decisions about

cost-effectiveness. Keeping such decisions independent of politicians remains critical for public trust. One radical solution would involve the state taking control of the pharmaceutical industry. This suggestion, which is flagged up occasionally by commentators, is too complex and political an issue for this book, but it might well be possible for the state to govern much of the drug innovation process. This would help to control a system that is currently not working to the overall benefit of society.

In the meantime, there is clearly a place for greater transparency around drug pricing. While scrutiny might decrease pricing power, a public debate and the development of trust in the industry might in the longer term produce a more sustainable business model. It is inappropriate for an industry that is literally a matter of life and death to so many people to be so shrouded in secrecy.

The boundaries of funded healthcare

In the UK, ever since the NHS was founded in 1948, there has been a gradual dilution of the universal offer of free care of everything for everyone. Most patients over the age of 16 and under 60, for example, contribute to the cost of their prescription drugs.

If providing everything for everyone is becoming challenging, society needs to debate whether there are aspects of care that should no longer be part of the all-inclusive offer. One logical and effective model that would facilitate such a discussion is a citizens' assembly. The people who would be chosen to take part would be reflective of the wider population, both in terms of demographics and attitudes. Such assemblies have been used around the world, with particular success in Ireland – where they debated and made recommendations that changed the abortion law – and in Canada. Wherever they are used, participants are asked to make trade-offs and

arrive at workable recommendations. The citizens' council of NICE, which was set up in the early days of the organisation, provided a public perspective on moral and ethical issues when producing guidance and decisions.

Determining the boundaries of care requires political courage, and they will need to be kept up-to-date following new research and discoveries. But without some form of decision-making process, new areas of provision will continue to be driven by the pharmaceutical industry, whose motivation might be determined more by their own self-interest.

Every country's healthcare system will need to address this challenge. Even systems that are funded through insurance rather than taxation will require clarity of purpose – after all, funds are never infinite, however they are generated. If this seems too difficult, the alternative is to leave such decisions to be dictated by commercial pressures. Should

the healthcare system treat everything that pharma or healthcare tech companies develop treatments for, or should there be some form of prioritisation? Of course, if there turns out to be sufficient funding to provide everything for everyone, I will be delighted to have been proven wrong – and more than a little astonished.

There is one additional challenge that requires debate. In systems that provide universal health coverage for all citizens, should there be any obligations on the individual? For instance, some people believe that an obese citizen who doesn't exercise, drinks alcohol to excess or has an appetite for recreational drugs should not be entitled to state-funded healthcare. Equally, there are others who argue strongly that such an individual may well be responding to a disadvantaged upbringing and may be more deserving than most. Such debates are challenging and complex, but they should not be ignored.

Choosing wisely

When people are faced with a healthcare challenge, non-medical approaches can often be superior – as illustrated by the use of community activity to improve quality of life in Frome, while reducing healthcare costs. 'Choosing Wisely' is a major international campaign that engages physicians and patients in conversations about unnecessary tests, treatments and procedures. It was created to challenge the idea that doing more is better, promoting the idea that 'just because we can, doesn't always mean we should'.

The recognition that doctors and other clinicians often carry out work that is neither necessary nor beneficial is intriguing. Many doctors argue that their treatment choices are to some extent determined by their patients' expectations rather than what is necessary. When doctors are patients themselves, the treatments they choose are frequently different from those they typically offer to

patients. In a study in the *Archives of Internal Medicine,* a group of doctors received a survey that either asked them to assume they were the patient suffering from bowel cancer or that asked them about the advice they gave to others.[30] Of the physicians who answered for themselves, 38 per cent chose a treatment that carried a higher risk of death but fewer side effects; only a quarter said they would recommend that treatment to their patients.

We have an intriguing scenario where doctors seem to second-guess what their patients want, often without good evidence. This has profound implications, and a King's Fund report asked whether we're wasting money on care that patients don't in fact want.[31]

Finding out patients' genuine wishes can benefit them hugely. Furthermore, as an unintended consequence of the preference of fully informed patients to choose fewer treatments, the NHS would likely save billions of pounds. Vast numbers of prescriptions,

investigations and operations may have been carried out because doctors assumed they were what their patients wanted. To make the situation even more complex, patients will have been grateful for care that they probably didn't need; while they might think 'the doctor wouldn't recommend it if it wasn't necessary', the doctors might be choosing a treatment 'because that's what my patient wanted'. This state of confusion would not be out of place in *Alice in Wonderland*.

Ensuring that patients understand the risks and the benefits of a given course of action can make an immense difference to the quality, quantity and cost of healthcare. It would help immensely if clinical trials focused on the issues that are of most interest to patients rather than prioritising the interest of researchers. However, I am encouraged by developments such as the Personalised Care Institute, which has been set up to equip health and care professionals with the knowledge, skills and confidence to involve

patients in decisions about their care. As I described earlier, evidence shows that this leads to better health outcomes and increased patient and clinician satisfaction; it is both a major practical change to the NHS and a key part of the NHS Long Term Plan. If we can integrate healthcare services around the individual, it will be a major step forward.

Curing and caring

For a long time, it seemed that medical advances were potentially unlimited, that we could take on and defeat one condition after another. After all, medical science had successfully eradicated smallpox and was making good progress in tackling many of the other major infectious diseases. It seemed to many people that developments such as genomics, stem-cell technology, personalised medicines and early prevention would result in us all living long and healthy lives, followed by rapid deterioration and death at an advanced age – an aspiration that seems as far away as

ever. Every small medical advance has massive economic and human cost, and ill health appears to have infinite reinforcements.

We are all going to die. While it is wonderful that medical science is able to spend unimaginable sums researching and treating disease, we seem to have forgotten that death is not the worst thing that can happen to the elderly. Disability, loneliness, isolation, frailty, poverty and fear can make their last months – if not years – something dreadful, and yet we spend nowhere near as much time or money trying to address these issues.

Our healthcare systems must have a culture of care rather than a near total focus on cure, including more support to allow the elderly to live independently in their own homes. Some of us may die earlier, but we will live more fulfilled lives and will hopefully have better deaths. We are currently using a 20th century model of hospital-based service delivery to meet 21st century needs.

Caring for patients is clearly a fundamental role of any healthcare organisation. Sadly, over the past decades, many aspects of healthcare delivery have been industrialised, with clinicians learning to 'process' patients while focusing on efficiency. In his challenging and inspirational book *Why We Revolt,* Victor Montori encouraged healthcare organisations to turn away from this industrialised focus towards a greater focus on caring and kindness, looking at the world through the eyes of the individual patient.

Aspirations

There can be little doubt that healthcare is on the cusp of great change. Astonishing advances in personalised therapies, genomics, big data and artificial intelligence will have an impact, but this won't come for free.

We need to be clear what the focus of healthcare should be. While the benefits of scientific and technical research are huge, we

should not ignore the importance of care. We must put as much effort into the war on frailty and loneliness as we do into the war on cancer. We need to ensure that we have a workforce that can offer continuity of care whenever it is appropriate – after all, it is associated with reduced mortality, greater patient satisfaction, better health promotion, increased adherence to medication and less hospital usage.[32]

Over the past decades, the UK has invested billions of pounds in new drugs. While some have been immensely worthwhile, others have added little of value. At precisely the same time, underinvestment in the healthcare workforce has had a massive impact on the ability of citizens to be able to build up a trusting relationship with a clinician. Continuity of care is increasingly rare, and yet we know that it offers true and major benefits. A trusting relationship with a clinician has been proven to improve patient experience and outcomes, while also reducing mortality. It is one of the most effective

interventions we know for multi-morbidity. It reduces emergency department attendance, hospital admissions and overall healthcare costs.

As patients have to navigate the complexity of modern healthcare, the vast amount of information available online and the increasing advances in technology, many will need a trusted interpreter to help them find the best solutions that work for them. This partnership approach to healthcare, with clinicians focusing on individuals, will be increasingly important.[33] Clinicians will work in partnership with technology rather than being replaced or feeling threatened by it.

And these benefits can work both ways. Having an ongoing relationship with patients is much more satisfying for clinicians; it boosts morale and reduces the likelihood that doctors and nurses will leave healthcare or retire early. If a drug this effective, and with so many benefits, was denied to the public, there would be an outcry.

It's all very puzzling. This gradual diminution of the doctor–patient relationship is an unintended side effect of a raft of different policies. A generation ago, most people would talk of 'my doctor'. Today, at a time when a trusting relationship with an expert clinician has never been more important, it has never been more endangered.

We need to tackle waste, duplication of effort, poor end-of-life care and a deterioration in doctor–patient relationships. We need to focus on prevention. The inverse care law must be not only understood, but tackled. The profit motive cannot be the only thing that is allowed to drive pharmaceutical companies. There are good people out there, after all, and they can make a huge difference.

Most of all, we must remember that healthcare is a human business. Kindness, humanity and caring really matter – and they don't need to cost anything.

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