CARING FOR PEOPLE
(YEAR UNKNOWN)

This is the most unusual of all the speeches in this book. The text of the speech is clear and liberal, but neither the date nor the name of the particular conference is given. The speech, however, is important as it sets out some important philosophical beliefs of mine. It becomes clear just how important medical training has been to my views and beliefs.

The title of this address is ‘Caring for People’. You may find it an odd title. You may wonder what relevance it has, or could possibly have, to life at the end of the twentieth century. Well, let me explain.

I am a medical practitioner by basic training, a physician by professional training, a practitioner of the art of medicine at one time, a politician for a period, a doctor by academic training and a teacher today. As an author has written in a recent book: ‘Medicine has lost the plot.’ That is really what this talk is about. How medicine has lost the plot. How too many people get poorer treatment today than they need to get. How more and more people are turning to alternative medicine, to alternatives of any kind. In fact, how they are turning away from orthodox doctoring.

One could well ask why. Why is this happening? Why are people so unhappy? Why are they choosing to use net income, without subsidy or favourable tax treatment, in seeking care for themselves from more expensive alternatives in preference to subsidised care from registered medical practitioners? Why are people so ready to criticise orthodox practitioners when we deliver so much more in the way of diagnosis and treatment than we ever did before?

To answer that, and other, questions one needs to look briefly at the history of medicine and medical science.
In the beginning, many centuries ago, terrible things happened to people. They still happen—but less frequently in the rich countries. First, everyone dies. No-one has solved that problem (although some modern practitioners pretend they have). Droughts, famines and floods occurred. Children suffered and became sick. Injuries and disability occurred. Pain and suffering abounded. Life was short and brutish. Nature was ‘red of tooth and claw’,¹ not benign as some would have us believe.

Even today terrible things happen. Anyone here might well read the account by John Cawte of the death of an innocent child from box jellyfish stings in Arnhem Land and explain to me the justice or degree of divine intervention in that tragedy. Genocide continues to occur in our world today. There is a dreadful drought in Papua New Guinea now. North Korea has famine. The people of Rwanda are still too frightened to return home. Bosnia is still in chaos. And so on. Those permitted to enjoy a placid and serene life are a minority—and a fortunate minority too. Equally, those with access to Western medicine are a minority too; the majority of the world’s people use other forms of care that probably deliver some of the benefits people enjoy here.

So people invented magic and then religion. The first explained events as the result of magical interventions, both malign and beneficial; the second sought to explain otherwise inexplicable things by reference to higher powers with special virtues, special ability to comprehend and special ability to act. Early on there was polytheism, later there was monotheism, and lately there has been monotheism with the divinity divided into three. We have eschewed the worship of idols and images—or have we? Anyhow, later still there emerged science. It seems that what makes science different is that scientific propositions are disprovable—they can be proved wrong. So the test of Einstein’s great theories of relativity had to await a singular cosmological event that tested whether light rays were bent as his theories predicted. So far, those theories have not been disproved—and so they hold sway. But they will continue to be contested.

Thomas Kuhn² has extended the disprovability idea (which, incidentally is associated with the name of Karl Popper)³ and developed a satisfying theory of scientific revolutions. What he has said, simply, is that evidence about a system of belief—called here a paradigm (although that word means an example)—accumulates until some inconsistent observations set people thinking. This is what happened with Newtonian physics in the nineteenth century. A period of instability ensues and eventually there is a ‘revolution’ in which a new

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¹ Tennyson (1849: Canto 56).
² Kuhn (1962).
paradigm appears, to be tested and massaged and added to until it, in turn, is overtaken. So no paradigm is final. Each is a way station along a never-ending road to truth.

Sometimes the flawed paradigms are quite useful—for example, one can rise into the air in an aeroplane and get from Perth to London using Newtonian physics and nothing else. So, even though we know that Einstein rules today, we can still go a long way with Newton.

Using Kuhn’s ideas, one can understand how Galenic\(^4\) medicine and Ptolemaic\(^5\) cosmology were tossed aside—at the right moment and by the genius who appeared at the right time (although the story of the overthrow of Galenic belief involved several geniuses and both examples involved foolish rearguard opposition from the Church).

At this stage we have to consider René Descartes\(^6\) briefly. Among other things, he was the originator of reductionism and of certain dualities that have pushed medicine into an imbalance. Reductionism is the movement to consider small and discrete problems sequentially and to consider them, moreover, separate from any greater whole of which they are a part. It has been a powerful tool that has allowed scientists to isolate problems and to solve many of them.

So the twentieth century has been an age of science. We have understanding of medical science that those living one hundred years ago did not dream of. Let us emphasise that: we are richer intellectually, and more comfortable, as a result of the use of reductionism in science.

But it is the other legacy of René Descartes that has led us astray even more. He proposed a duality of body and soul for philosophical reasons but that duality has dominated medical thinking ever since. It was Descartes who really introduced the concept of the body as a machine to be fixed—a machine that was potentially renewable and immortal.

The result has been that medical scientists have concentrated more and more on the body and less and less on the soul. If we want a pendulum to be centred then we have to say that the pendulum swing today between body and soul is too far in the direction of body and not far enough in the direction of soul.

So what does all this mean?

Where are we today? Why are people unhappy in a world where we can understand more, do more, help more, and intervene more effectively?

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Today, many orthodox practitioners have forgotten that people are their business. Too many concentrate on the detection and treatment of disease, instead of on the care of people. Too many concentrate on medical science when that is only relevant if it helps us to understand the people we see. If about 80 per cent of all illnesses are self-limited then surely our tasks include identifying the other 20 per cent efficiently, reassuring people effectively, and encouraging people to use what modalities of caring they wish for the 80 per cent of self-limited conditions. We should be expert at symptom relief and at the detection and treatment of distress and suffering.

One enlightened practitioner has redefined ‘patients’ as ‘temporarily dependent people’; this alters how one thinks about another human being in need and helps one to become more relevant and more caring towards another person.

Let me tell you a story now. Recently, in a class for advanced students, an experienced counsellor was making her obligatory oral presentation. She chose to recount how her medically qualified father had suffered a stroke that left him aphasic—he could not speak—but able to hear and understand. The specialists attending him had come to the room and spoken to her—not to him. They had set out clearly the diagnosis and the poor prognosis to her in front of her father. At this point, the student wept and continued to weep during the rest of her presentation. At the end, I asked her how much she recalled about the diagnosis, taxonomy and outlook of stroke. ‘Very little,’ she replied. ‘I am not medically qualified.’ Then I asked her what she remembered about the conversation with the specialists. ‘Every word,’ she replied. You will probably agree that no-one should be treated like that. But they are.

Let me tell you another story. It concerns my late mother-in-law, a gracious and beloved woman who was my friend. She was dying in hospital when the specialist visited. He spoke to me about her condition and about the treatment and the prospects. The old lady was polite and she asked my wife what they were saying. Jenny, anxious to settle her mother, said: ‘It’s all right, Mum. They are speaking about you, not to you.’ The specialist blushed and I felt sorry for him. But this was real life—this is what was happening.

The concentration of modern medicine has been on disease. Students are taught about diseases, about the detection of diseases, about the treatment of diseases. They are taught little about the care of people, about the needs of people or about how to deal with people.

The University of Tasmania has acted unusually in making an assessment task the passing on of bad news to a patient or to the relatives of a patient. This should be a basic skill of any practitioner, but it is not taught in most medical schools.
It is instructive to read a novel called *The House of God*\(^\text{7}\) to realise that the same thing was happening in the United States (in Boston actually) 20 years ago; I am assured that things are worse, if anything, now.

Disease is tidy. It is what students want. It confers a kind of mastery over information, which students like. The descriptions of disease are exact—even if classical examples are rare. The textbooks are definite and clear—even if they are sometimes wrong. For example, a textbook published 15 years before I graduated contained a treatment for acute ulcerative colitis that would have killed my patients.

Compared with disease, people are untidy. They often have complicated and unclassifiable problems. Their needs sometimes do not match the training that practitioners have received. They sometimes use wrong words, or describe symptoms in flowery or unusual ways, or use words like ‘system’ or ‘shock’ in ways different from their medically trained interlocutors.

When we teach about people, our students become quite hostile. For them, it is disease they are on about, disease about which they wish to acquire current knowledge. It is not that they have no interest in people; it is just that the examination systems give them no marks for displaying knowledge about people. But worst of all, sometimes the problems that people bring to medical practitioners are ignored as the qualified person looks for disease as he or she has been trained to do. The patient may have little interest in any disease, except as it bears on the problems they have brought to the practitioner. It is this failure to respond to the concerns of the patient that is the cause of so much unhappiness, and resentment, and bitterness.

But it is not the only cause of unhappiness.

Another story, reported by a colleague, is instructive.

Earlier this year I went with a friend, Marion, to see a doctor. She had been experiencing headaches and indications of a growth, possibly a brain tumour, in the centre of her brain. Friends had been called back from overseas, her son thought she might die within the week, and Marion was very frightened. She had x-ray pictures of her brain, MRI images, a radiologist’s report and an appointment to see a neurologist. The pressure in Marion’s head made it difficult for her to think clearly. She was too upset to be able to formulate the questions she needed to ask and wanted help to decide on the best option to follow. So she asked me to come with her to see the neurologist, to support her, and ask any questions on her behalf that she might forget. The neurologist studied the x-ray pictures of her brain, MRI images, and the radiographer’s report and concluded that it was probably a non-malignant growth in the brain, a cyst, or sac of fluid.

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\( ^7 \) Shem (1978).
that could be drained. Only an operation would confirm the diagnosis. Yes, it was serious and the operation needed to be done within days. It would take between five and eight hours but the long-term outlook was very promising and the risks were minimal. If the diagnosis was correct, there would be a full recovery and a return to normal life.

What struck me, as an observer of this interaction between my dear friend and her highly commended medical specialist, was his aloofness. He was cold, almost robotic in his manner. Minimal in both movement and speech. He gave no indication of recognising Marion’s obvious fright and fragility. The message, as I received it, was, ‘This is straightforward. Marion is fortunate that there is a clear diagnosis and we have the surgical procedures that can rectify the problem.’

If it had been Marion’s car, his manner would have been understandable. But this was her brain. For Marion, it was her life. Even the need to protest feels strange, as if he was from another planet and from a species with no understanding of human feeling like Dr Spock from Star Trek.

Yes it was good news, relative to what we knew of brain tumours and their likely fatal consequences, but the manner in which the diagnosis was given and the treatment recommended lacked common human feeling and was disturbing.

There were other complaints, too. He had not communicated some of the major consequences of the operation without being pressed. For example, he had not told Marion that she could expect intense headaches for several days after the operation, until asked. One of his responses to a question was, ‘I have already answered that question.’

Maybe he had and maybe this is just an example of his cold formality. But it was also a discouragement to ask any further questions. Any textbook on communication would have told him that a distressed patient may well need to have information repeated. The message I took was, ‘There is no need to worry, simply turn up for the operation and all will be well.’ It was subtle, hard to identify the many ways in which open communication was restrained, yet the restraint was palpable. I am trained to ask questions both as a researcher and a lawyer, yet I felt inhibited. I imagine most people would simply acquiesce.

Is this an isolated example? A doctor on a bad day with a head cold or having had an argument with his lover? In either circumstance, I could understand, see him as human and excuse his non-caring as an occasional lapse. I suspect not, however. My suspicion is that he treats most of his patients like that.

This is an awful tale. It is a form of abuse of a patient, in my mind. It does not really matter how technically competent the practitioner was, the treatment of the person was dreadful.
So I conceive of my task differently from many of my colleagues. My business is people first, and therefore disease only secondarily and only to the extent that it serves to satisfy the needs of people. Let us be clear. Often it is the disease that brings the person to the practitioner and attention to the disease is what is asked for. In that case, both parties may share a common concern and may be satisfied. But it is not always so. Sometimes people become desperate when no-one listens to their worries but concentrates instead on some disease (or looks for some disease), which is of peripheral interest to them.

My task as a carer involves my asking early on, ‘What does this person want?’ Not, ‘What do I want?’, which is a different question. Sometimes answers can be surprising. Once, I asked a patient what she really wanted and she answered, ‘I want you to help me divorce my husband.’

Mind you, if the practitioner decides to go off on another track that may be quite defensible medically but requires that the practitioner explains to the patient what is being done, why a new course is being undertaken, convincing the patient that the course being followed is reasonable and necessary. Above all, it requires that I ‘hear’ and ‘validate’ the concerns of the patient and that, whatever else I do, there is a response to those concerns that tells the patient that they have been heard, that their concerns are valid, and that I will respond to those.

Too many of our junior colleagues today do not know how to behave in the face of human sadness, of grief, of bad news, of unhappiness. Too many use denial or rejection, too many fail to hear or to validate the concerns of the patient, and too many blame the patient if anything goes awry—in spite of having control of the consultation process.

All I have to do to turn a student to jelly in an exam is to ask him or her to tell the patient some bad news.

Too many of our senior colleagues have a warped view of death and dying. If death is universal—and the mortality rate was 100 per cent last time I looked—then, whatever other expertise practitioners have, they should be particularly expert at handling dying, death, grieving people, separation and loss. Actually, each of us has to be comfortable with his or her own death—a basic requirement for anyone wishing to work in the life and death business.

What actually happens is that too many senior practitioners delegate the tasks of caring for, and speaking to, the dying or their relatives to their most junior team members. Those junior team members are often the least well equipped to deal with the tasks that are thrust upon them. The delegation sometimes says more about the senior colleague than it does about the junior. On ward rounds,
senior specialists sometimes ignore the dying, either not visiting them at all or paying them perfunctory visits in which the dying are not encouraged to say anything distressing or ‘real’.

In their private practices, some senior practitioners make it hard for people to communicate fears and uncertainties, because they are not sensitive to what people wish to communicate or because they have not been taught how to do this task or because they do not wish to allow any personal feelings to intrude upon the consultation.

It is said that the great majority—perhaps 80 per cent—of all communication is non-verbal and people read non-verbal signals well, including infelicitous ones. When the non-verbal signals do not accord with what is said, most people believe the non-verbal cues. We teach that ‘you cannot not communicate’; it is just that what is communicated is sometimes awful and counterproductive.

So my style is to listen to people, to find what they actually want, to respond to those needs whatever else I do; to spend time with the dying and grieving, to encourage people to talk as they wish. Listening is a good medical skill but it consumes time and some practitioners hide behind time limitations as an excuse for talking rather than listening.

Without a good grasp of science, practitioners are dangerous. Without humanity, practitioners are monsters. To miss a treatable disease is a disaster; to be part of a communication failure is a disaster of a different kind.

Let us aim for a style of practice where we care for people like us, where we listen and respond to what people feel and what people say, where we accept people as themselves, and where we see disease as important but subsidiary. If we did all these things, the public would be happier—and so would we. Our work would be more satisfying, our patients would thank us, and our lives would be enriched and fuller. That medicine today has followed its great achievements into significant imbalance is sad but is retrievable. My job is to empower myself and my colleagues to follow that more appropriate and more balanced course, and it is to that task, the care of people, that I will dedicate my teaching and my practice in the years remaining.
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