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HEALTH CARE: WHY SHOULD WE BE CONCERNED ABOUT VALUES AND ETHICS?

Learning Outcomes

By the end of this chapter, you should be able to:

- Identify and discuss a range of health care situations in which consideration of values and ethics is important;
- Critically appraise the worth of the view that a concern with values and ethics is an essential requirement for all those involved in health care;
- Begin a personal account and justification of the importance of values and ethics to your own practice, or study.

Introduction

I am beginning this book with a claim. My claim is that everyone involved in health care should have a fundamental concern with issues of values and ethics. Whatever your occupation, regardless of the activity you are engaged in, the nature and practice of health care demands this concern. From the midwife running an antenatal class through to the nurse caring for a terminally ill patient, from the health promotion specialist planning a smoking prevention programme for young people through to the occupational therapist assessing an elderly person's ability to cope in their own home, this concern is essential. Indeed, I would want to extend my claim further. I would want to say that unless we actually have this fundamental concern with ethics and values as part of our health care-related thinking and practice, we can't properly see ourselves as engaged in health care at all.

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Q. At the very beginning of this book, do you agree with the first part of my claim – that everyone involved in health care, regardless of their occupation, or the activity they are involved in, should have a concern with values and ethics? Do you agree with the second part – that unless we have this concern, we are not properly engaged in health care at all? Whether you agree with me or not, *why* do you hold the view that you have? Make a written note of your responses to these questions and refer to it as you work your way through the rest of this chapter, and other parts of the book, to see if your initial position, and your justification for it, might be changing.

This claim – that we should each have a concern with values and ethics in all of our activities, and that unless we do so we are not properly engaged in health care at all – is a large one to be making. It's possible that you may completely disagree with one or both parts of it. One response I posed to the question above might have been: I just get on with my job as best as I can so why do I need to think about values and ethics? Perhaps more likely, you may agree that some aspects of health care involve difficult questions of ethics (whether and when we should deliberately end life, for example), but that most day-to-day practice requires nothing more than honesty and good intentions. So even if you accept the first part of the claim, you might be very doubtful about the second part. Surely, doing your best is good enough, at least for most of the time?

In some ways, this is a realistic and reasonable response. Those involved in health care practice, whatever their occupation, are busy people. They are often trying to deal with others who are in very difficult circumstances. They are frequently doing so with limited resources. We might well view the seemingly esoteric concerns of ethics as being of little relevance in these kinds of situations (Seedhouse, 1998). Surely, the rubric of 'doing your best' is the one that counts the most here?

I want to argue, though, that while this kind of response is understandable, it is not sufficient. It is not sufficient for two reasons. First, *what exactly* do we mean by 'doing your best'? What counts as 'best'? Who decides what this is? One answer to this last question is to say that it is up to individual practitioners. But if that is so, we are leaving an awful lot up to these individuals. Are we *really* happy to suggest to the individual midwife or nurse, the health promotion specialist or the occupational therapist, that how they decide to conduct their practice, and what counts as '*best* practice' is entirely down to them? This seems to be both unfair to patients or clients, and an unacceptable weight on health care professionals themselves.

The second reason why the response of 'doing your best' is not sufficient is because even if health care practitioners were able (or wanted to) establish what exactly this meant by themselves, there would be a potentially infinite variety of situations in which they would have to apply this rule. (This is accepting in the first place the idea that 'doing your best' is enough of a rule to provide a guide to your action.) What does 'doing your best' mean for the midwife working with an antenatal class? What does it mean for the occupational therapist undertaking

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a home assessment for an elderly person? The difficulty now is that not only do we potentially have practitioners who might be ambivalent about their capacity to apply a rule, but we also face a range of situations in which that rule might be applied.

It is all beginning to look a little like peeling the skin off an onion. We think about one question, then another appears, and then another. Posing rigorous and appropriate questions is, of course, an important part of academic work (Bonnett, 2001). The kinds of questions that I've just raised are in response to views some might express about the lack of, or limits to, the use in thinking about values and ethics in health care. But simply asking questions is not enough here. There is a need for me to *justify* my initial claim that everyone involved in health care, regardless of what they are doing, should have a concern with values and ethics and that unless this is present, we can't consider someone to be properly engaged in health care at all. Part of this justification must involve thinking carefully about the nature of values, and of ethics. This is a task that I will undertake a little later. At the moment, I want to concentrate on the idea that questions of values and ethics emerge in all aspects and contexts of health care.

To do this, I'm going to examine three separate 'case studies'. The studies are quite different from each other. They have been deliberately chosen to be different because my intention is to demonstrate that values and ethics permeate the entire field of health care. If I can show that ethics and value-related difficulties emerge in contrasting parts of the field, my claim that all health care workers engaged in any kind of activity or intervention should be concerned with them will be supported. It will then be possible to move on to more detailed discussion about the nature of values and ethics, and how they connect with practice and policy in health care. It will also be *easier* to do so because doubts about the worth of a project looking at values and ethics – 'What has all this got to do with *me*?' – will have been addressed.

Thinking About...

As you read through the following case studies, consider carefully whether they bear any similarity to aspects of your own experience. If they do, identify that experience, how you think and feel about it now, and if possible how you thought and felt about it at the time that it happened. If you cannot find any similarity in any of the studies, consider why you believe that to be the case.

CASE STUDY: LIVING AND DYING

Let's start by thinking about the kind of case where many people (possibly) might see ethics and values-based discussion as being important, and as playing an essential part in deciding what to do (or at least in deciding how we feel about and react to what is done).

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In August 2005, retired GP Michael Irwin travelled with 74 year-old widow May Murphy from Glasgow to Zurich in Switzerland. Mrs Murphy, who was terminally ill, intended to kill herself with the support of the Zurich-based organisation Dignitas, which helps terminally ill people end their lives (Dyer, 2006). In the apartment used by the organisation, Mrs Murphy took a lethal dose of barbiturates. Dr Irwin was present in the room with Mrs Murphy and her younger son Alan when she swallowed the barbiturate solution:

He [Dr Irwin] recalls her saying, 'I want to die, my body has gone' ... 'She could hardly move her arms. She had to use both hands in order to hold this little glass,' he said. (Dyer, 2006)

Assisted suicide is against the law in the United Kingdom, so Mrs Murphy and Dr Irwin had travelled to Switzerland, where the practice is legal. But some months after his return to England, Surrey police interviewed him under caution about his role in Mrs Murphy's death. In January 2006, the Crown Prosecution Service was actively considering a possible prosecution of the doctor after he had admitted helping a number of people to receive support from Dignitas.

The issue of assisted suicide is deeply contentious and controversial. A bill to permit it under certain circumstances, introduced into the House of Lords by Lord Joffe, was blocked in May 2006 by a majority of his peers. The bill, based on practice in the state of Oregon in the USA, would have given doctors the right to preside over the administration of lethal drugs to a patient. The patient would be able to request such drugs if his death within six months was certain, and if he was mentally competent and suffering unbearable pain (Woodward, 2006). In the debate that preceded the Lords' rejection, Lord Joffe said:

As a caring society we cannot sit back and complacently accept that terminally ill patients suffering unbearably should just continue to suffer for the good of society as a whole. We must find a solution to the unbearable suffering of patients whose needs cannot be met by palliative care.

Taking a different kind of view, his fellow peer, the fertility expert Lord Winston, argued:

My mother is 93. She slips in and out of a pre-dementia situation. During a lucid period some months ago, she said to me, 'I have finally reached the end.' She then became very confused and aggressive and didn't know where she was. Only last week she finds that she is enjoying life again. We cannot predict how people may feel about the future and to take that view is ultimately the most presumptuous thing we can do.

The conflicting views expressed by these members of the House of Lords are mirrored in larger society. The British Medical Association (BMA), the doctors' organisation for the UK, has traditionally been opposed to physician-assisted suicide, arguing that it would worsen doctor-patient relationships (Meikle, 2004). In June 2005, however, it dropped this position, although still

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rejecting the idea of euthanasia. (While not entirely clear, the distinction between assisted suicide and euthanasia seems to lie in the notion that the former involves doctors *giving patients the means* to kill themselves whereas the latter involves the physician directly administering the fatal dose of a drug (Harding, 2005).) Perhaps the end of the BMA's explicit opposition rests to some extent in its acknowledgement of the direction of social opinion. According to a poll by YouGov for the Dignity in Dying group, 76% of respondents from the general population said they were in favour of assisted suicide provided safeguards were in place (Woodward, 2006). Among doctors themselves, in another poll conducted for the Voluntary Euthanasia Society, 45% thought that helping patients to die when they were suffering unbearably was acceptable. In the same poll, 45% also thought that they had colleagues who had supported assisted suicide, while 27% had been asked for help by patients who wanted to die (Meikle, 2004.)

Q. In the polls above, 76% of general population respondents thought that, with certain conditions, assisted suicide should be legal. The number of doctors who responded in this way was 45%. Assuming polling conditions were the same in each poll, which is unknown, why do you think a lesser number of doctors agreed with assisted suicide?

I began this case study by suggesting that it was one in which many people would clearly see the relevance of values and ethics. Health care professionals, perhaps most likely (but not necessarily always) doctors, may have to face the choice of allowing a fellow human to continue suffering unbearably or supporting a patient's decision to end their life. Thinking about this choice, it almost immediately extends beyond the law, for the legal position is relatively clear: neither doctors nor anyone else can help people end their own lives. (This is the position applying in the UK.) So we begin to enter the territory of values. Should we preserve life at all costs? Are there certain circumstances in which life can properly be said to be worth so little that the best possible course would be for it to be ended? Who should make these kinds of decisions? If it is patients themselves, can we trust their judgements? (An opposing view might be how dare we *not* trust their judgement?) If it is to be doctors, what are our grounds for believing that they are trustworthy enough to decide reasonably between life and death on our behalf? This is especially important given our recent history of shocking exposures of medical neglect, and even deliberate evil done under the cover of medicine – the most terribly dramatic example of this perhaps being the case of mass-murdering GP Harold Shipman (Smith, 2002, 2003).

Thinking about the questions that I have just posed, my guess is that we would each of us hold different views, and we would hold those different views for separate reasons. We cannot resolve or agree on them simply by considering the law, or technical or other kinds of fact. We possess the views that we do because we hold certain kinds of **beliefs** and **values** – about the nature

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of life and death, about personal choice, about well-being and suffering, about what it is to be a health care professional. Within this complex of beliefs and values are some that we would probably quite easily want to describe as being related to **ethics**.

But while it is likely that most of us will see the place of values and ethics in considering the case of Dr Irwin, there may be some who still wonder about it, at least in terms of personal relevance: ‘What has all this got to do with me? I am a health care professional (a nurse, say) but my job is such that I never have, and am never likely, to enter a situation where a patient is asking me to help them die. And if I did, then I would simply go to a higher authority and tell them about what has happened. They would decide what to do. Even if the question were ever in my hands, it would very quickly be out of them.’

In some ways this sounds like a plausible response to the issue of assisted suicide. It is plausible because I would agree that for many health care professionals, the issue has never been and is never likely to become a reality. Paradoxically, the highly dramatic nature of this case study, which has given it such strong resonance in terms of values and ethics, means that we may be unlikely to encounter it in our practice, or if we do, it will be so fundamental and so overwhelming that in all likelihood our instinctive (and very possibly right) reaction will be to seek help.

Q: ‘There’s no need to think about this. It’ll never happen to me and even if it did, the responsibility would be someone else’s.’ What problems do you think there might be with this sort of response to the case of assisted suicide?

It seems to me that there are two difficulties with this kind of response. The first relates to our **individual responsibilities** as health care professionals. If we are conscientious and thoughtful practitioners, would we really be happy about completely abdicating responsibility if we were ever to meet this kind of ‘life and death’ situation? I would agree that it is quite reasonable for us to seek the help of others. Indeed, we may well have a professional obligation to do so (notwithstanding our legal obligation to act in certain kinds of ways). But to pass it over without thought to someone else seems to be denying our sense of professional integrity in a very important way. Part of being a health care professional is surely taking responsibility for thinking carefully about the kinds of situations the patient or client you have ‘professed’ to serve is facing (Koehn, 1994). I would want to extend this idea and suggest that we need to think carefully not only about the *actual* situations our patients or clients are in, but also about *potential* circumstances that we might encounter. Part of being a thoughtful health care worker is allowing and developing empathy for our patients and clients, and an imagination for the difficulties they face – even the kinds of highly dramatic difficulties I have discussed.

The second reason relates to what I will call the **public responsibilities** involved in being a health care worker, and especially occupying a professional role. In a highly important sense, dramatic questions of life and death are

problems *for us all*, whether or not we are health care professionals. I described earlier the YouGov poll in which a large majority of respondents from the general population gave qualified support for the idea of assisted suicide. I would want to argue that this kind of expression of public opinion is of great importance in shaping the views and decisions of those charged with making public policy and enacting the laws that govern our actions. Even though the Joffe bill was blocked, the politicians concerned would have been keenly aware of public opinion, in much the same way that I have already suggested the BMA probably was when it decided to drop its opposition to assisted suicide. The relationship between public opinion and public policy or legislation is a complex one and mediated by many different factors (Cribb, 2005). However, there is no doubt that one way or another, policy makers and legislators in our liberal-democratic society have to listen to the people, for it is the people who provide them with power. Our position as citizens in a democracy allows us to form opinions on matters of life and death and it would seem to be neglectful of our democratic responsibilities if we did not.

But health care professionals have a particular responsibility to shape and influence public policy in relation to matters of health care, including the kinds of 'life and death' issues I have been discussing. This responsibility stems from the power they possess by virtue of their professional training, and the relatively large degrees of autonomy that society allows them (Ham, 2004). Such power means that the views, beliefs and actions of health care professionals hold particular importance in our society. If we as professionals form particular beliefs and have certain views about the nature of life and death, and about living and dying, they will probably be taken very seriously by our fellow citizens.

For these reasons of both individual and public responsibility, it seems very hard to suggest that health care professionals should take little or no interest in the case of Dr Irwin and Mrs Murphy. The fact that they should be interested lies in both their individual and their public interests as health care professionals. These interests, it is clear, extend beyond the factual and descriptive. They lie in the nature of the beliefs we have and the values we hold. The interests are **ethical** ones.

Case Study: Better Living?

I suggested before that the kind of 'life and death' example provided by the Dr Irwin and Mrs Murphy case was *perhaps* the sort of circumstance in which people most easily consider that ethics has a part to play in deciding what to do or how to think. But if I am to justify my assertion that ethics and values should be of concern to everyone in health care, then I need to show that their consideration is relevant in cases where the dilemma *seems to be* not so acute. Indeed, a key theme I am trying to develop in this book is that values and ethics are relevant to all (or at least very nearly all) aspects of health care. It is the idea of the worth of thinking about values and ethics in 'ordinary' health care (which in fact is 'extraordinary in its ordinariness') that I am mainly intending to try to explore.

Towards the end of 2006, *The Observer* newspaper carried a story with the headline, 'NHS must pay for fat children to get surgery' (Revill, 2006b). The National

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Institute for Health and Clinical Excellence (NICE) was recommending that, as a case of last resort, severely overweight teenagers should be offered bariatric surgery ('stomach stapling') as a treatment for their obesity.

Currently, most patients who might be eligible cannot be given surgery as most primary care trusts, which hold treatment budgets, refuse to pay for the £8000 operation. Between 50 and 200 teenagers a year could get treatment. (Revill, 2006b: 1)

Q. Do you think the National Health Service (NHS) should pay for obese children and teenagers to have this kind of expensive treatment?

This headline and story appeared on the first page of the newspaper. It's possible that we might start off by responding to it in at least two different ways. On the one hand, we may think that of course the NHS should be paying for this sort of treatment in cases where everything else has failed. We know that obesity leads to a string of health problems for teenagers, problems that will worsen in adult life. These include type 2 diabetes and psychological problems in adolescence itself, and coronary heart disease (CHD), stroke and cancers in adulthood (NHS Centre for Reviews and Dissemination, 2002). Surely, if we can prevent these kinds of problems by offering surgery when all else has failed, this can only be for the good? After all, even simply on the economic terms that seem to be of most concern to the story-writer, the cost of widespread morbidity and early mortality consequent on unchecked obesity will be much greater than the cost of this treatment.

On the other hand, though, we might wonder exactly why the NHS should be paying for this expensive treatment for teenagers who, we may feel, have only themselves to blame. After all, the reasons for obesity are quite clear, aren't they? Obese children eat too much, especially the 'wrong' kinds of food – high in fat, salt and sugar and with little actual nutritional value (NHS Centre for Reviews and Dissemination, 2002). They spend all their time slumped in front of televisions and computers. If only they would change their own behaviour, we would be rid of the problem; so why should we pay when they don't? My guess is that for most health care professionals, if they respond to the story in either of these two ways, it will most likely be the first. Perhaps above anything else, the vast majority of those working in health care are motivated by a desire to do good, to contribute to efforts aimed at producing more health (leaving aside what that might mean for the moment) and at the alleviation of suffering and disease. They will want to prevent the suffering of these teenagers with very real problems and if bariatric surgery is the method of last resort in doing so, then the cost should be borne by the National Health Service. Health care workers may well be reluctant to enter into the process of 'blaming the victim', which seems to play a prominent part in the second sort of response to the story.

Yet closer thought and analysis reveals a much greater complexity than either of these two kinds of initial response allow. Rising levels of childhood

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obesity are a major concern to planners and policy makers in the United Kingdom (UK) (Department of Health, 2004), as they are in other developed countries. Research demonstrates that the causes of obesity are not simple to isolate (NHS Centre for Reviews and Dissemination, 2002). Over the last 60 years or so, the way in which lives are lived, at least in the developed world, has changed beyond all recognition. We live and work in very different ways from our grandparents or great-grandparents. With regard to diet and food particularly, when, where, how and even why we eat are different now from the situation in, say, the earlier part of the twentieth century. Many people have a much wider variety of food choices available to them and more money to spend on their groceries bill. But work and other pressures of modern life mean that many of us have less time to shop and cook sensibly. Takeaway and so-called junk food have become commonplace (Campbell, 2006; Sweny, 2007). Many people no longer sit down in families and eat together. Fashion, and concern for body image, play a big part for a large number of people in determining how, what and why they eat. In the same edition of the newspaper as the headline story I am discussing, Clarissa Farr, Headmistress of St Paul's Girls' School, condemned the fashion industry's 'deplorable' obsession with ultra-thin sizes:

'It is grossly irresponsible that this kind of thinking is encouraged as something desirable,' Farr said. ... Society's obsession with thinness [she added] was 'a form of fundamentalism, a form of extremism. ... This is about pressure to conform'. (Asthana, 2006)

And of course such pressure to conform, along with beliefs that you are failing to do so, can lead to individuals having very problematic relationships with food. So we might very reasonably be led to the view that treating obesity as a narrow problem of individual lifestyle, amenable to highly specific medical or surgical treatment (ideas inherent within one or other of the positions we initially reviewed) is not enough. Towards the end of the story, its writer quotes public health expert Dr Geoff Rayner from City University in London:

'We are medicalising something that is actually to do with how we live as a society. People become overweight because of their environment – because we take a car rather than walk – because we spend hours in front of the TV and because we are saturated by the junk food industry. If you take a purely medical approach to this, you start to normalise what is a deeply abnormal state.' (Revell, 2006b)

It seems to me that Rayner's quote exemplifies the difficulties involved in tackling the problem of childhood obesity, and why our responses to it are centrally related to questions of values and ethics. If we are concerned about this problem, or involved with it in some way at the level of policy or professional practice, we are likely to be motivated at least in part by a desire to help people towards what we might broadly call 'better living'. We want people to live longer and more fully, free as far as possible from physical and psychological pain. We want these things and hold them as values partly because they seem to match up with our conceptions of what is meant by 'good human living'.

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But while such broad values may be widely shared (and we might be very suspicious of someone who *doesn't* hold them), their exact nature, along with how we go about achieving them, is much more subject to debate. In this case, is 'better living' not being obese? Or is it not being worried by a society that places a premium on certain ways of appearing and behaving? Is our own 'better living' something that we as individuals are essentially responsible for? Or is it something that we share as a responsibility with all the other members of our highly complicated society? Different answers to these questions will lead us towards separate understandings of the nature of the value of 'better living'. For example, if I think that 'better living' involves me doing my best to stay in good physical shape, I will understand it primarily as a value related to **individual responsibility**. If, on the other hand, I understand it as being dependent on collective pressure and effort, I will conceive it as a value that is **socially mediated**.

Q•Do you think the value of 'better living' is down to the responsibility of the individual? Or does society hold a responsibility for the value of 'better living' of its members? Or is the responsibility shared in some way?

How I understand the nature of the value of 'better living', and where responsibility for it lies, will lead me to beliefs about what I should do or what attempts I should support to bring about more of the value. If I think of it as a value connected to individual responsibility, I might well support efforts strongly to persuade people towards lives filled with more nutritional food and greater levels of exercise. If I consider it a value that is largely socially mediated, then my concern will be for work that aims to alter social structures that influence (positively or negatively) the value and its production or diminution. For example, I might consider it a good thing to ban advertising of 'junk food', especially to vulnerable consumers such as young people (Campbell, 2006). These issues of what to do to produce more of a desired value are, as I will discuss in Chapter 4, issues of ethics.

So from discussion about a case that perhaps superficially appeared to be fairly clear-cut, we have begun to uncover a range of potential values and a variety of ethical issues. These are likely to frame and influence our actions in the area of teenage obesity, or our decisions about which actions to support. Moreover, I want to continue with my claim, made earlier in relation to the example of Dr Irwin and Mrs Murphy, that the actions and support of *health care professionals* have special ethical importance, simply because of their being professionals. And while I began this particular example with the idea that it appeared to represent a case and a dilemma that was less 'acute' than the 'life and death' situation Mrs Murphy and Dr Irwin found themselves in, this certainly doesn't mean that it's any less important. For what could be more essential to a health care professional than thinking about ways to encourage 'better living', and about the debates over values and ethics that are intimately connected to its promotion?

Case Study: Better Lives?

Joe is 11 years old, autistic and severely developmentally delayed. He lives with his parents in Hertfordshire. His latest obsession is to drive with his father in the family car, listening to cassettes of Albinoni, Vivaldi, the Jam and Abba:

Joe's obsessions possess him utterly. When I tell him we'll take another drive at five o'clock (five hours away), he pulls up a chair in front of the kitchen clock, sits down to stare at the passing minutes and waits, and points, and asks constantly for reassurance that the moment will come. ... Given the alternatives that day, there is no realisable purpose or pleasure capable of supplanting the car, or even interrupting his long – sometimes very long – anticipation of its meandering bliss. By comparison, Jeremy Clarkson is an Amish. (Blastland, 2006: 33)

Michael Blastland is Joe's father. In an essay published in the *New Statesman* magazine in April 2006, he reflects on the nature of Joe's life, and the extent to which it squares up with an understanding of what it is to be human, and to live a human life:

You can run through the philosopher's common measures of what it means to be one of us and find either that Joe fails them outright, or that his inclusion is in doubt. Humanity has deep structured language, it is said; Joe does not. Human beings have complex morality; Joe demonstrates time and again, sometimes brutally, a frail grasp of moral norms and instincts, mostly because he lacks an adequate appreciation of how his behaviour affects others. We have rich self-consciousness; Joe has little if any concern for how others see him and scant reflection, I suspect, on his own thoughts. It is also said that people are, above all, social creatures whose relationships are uniquely subtle and sophisticated. Joe, according to the dominant theories of autism, might be unaware that other people have any kind of mental life, might be blind to the existence of others' minds, and thus incapable of understanding their behaviour or making sense of social situations. (Blastland, 2006: 33)

Thinking About...

Joe has little or no sense of self, or of relationships with others. Consider the effect this might have on our understanding of him as a fellow human being.

Does this mean that Joe can't be said to be human? This question is at the centre of the debate that Michael Blastland has with himself, both in this essay and in a book on which the essay is based (Blastland, 2007). As Joe's father, Blastland's deliberations are framed completely by the love that he has for his son. Indeed, it is this love, and the closeness to Joe it gives him, that provides him with at least part of the answer to the question. Joe is loved and in the love between father and son, meaning for the life emerges. Love gives the life potential. More widely, we all recognise this potential (or at least we all ought to, argues Blastland): 'We define Joe not only by what he can understand or could have hoped for, but what you and I can understand or could have hoped for.' (Blastland, 2006: 35).

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This might all sound a bit vague and mystical, but the reality is that a life like Joe's challenges us to ask important questions. In the first place, we need to ask whether we agree with what Michael Blastland seems to be asserting; does the meaning of Joe's life depend on the meaning given it by others? Is it right (or even possible) to talk about life's meaning being wholly ascribed not by the individual whose life it is, but by other people? It is certainly true that *some* of life's meaning is given to me not by myself but by others and how they see me (as kind or as funny, for example), the relationships I have with them, and so on. But I also gather meaning through what might be called my 'inner life' of thoughts and feelings and emotions. What if I was suddenly stripped of all those things? At the very least, I would want to say that if this happened to me, my life would be much less rich. I might even want to say that this wasn't my life at all. The truth is probably that the meaning of my life depends on a mix of the meaning I give to it and that which others ascribe to it. So what if, as in Joe's case, the former is absent?

This leads us to the second question. If I can imagine that for me the absence of my own 'inner life' would make my life much less rich at the very least, it's possible that others might also take this view. So does this mean that such a life (the kind of life Joe has) is *less* valuable than other lives because the inner dimension is missing? One possible way of responding to this question is with a further one; if we had the choice, would we want more or less of the kinds of lives that Joe represents to be created? Many might take the view that we should do what we can to avoid the creation of lives that, as they see it, would be blighted by disability or dysfunction. And it would certainly seem perverse to suggest that we actually wanted *more* severely autistic babies to be born into the world. If this seems like entry into potentially dangerous territory, that is because it is. There is danger for two reasons. First, if we say that we have no desire to see more severe autism in the world, it is not that much of a further step to suggesting that we actually want *less*. This certainly implies a wish or a willingness to alter the patterns of lives being born. And this wish or willingness is something that, at least in theory, could be enacted. It appears to be the case, from research, that autism has a basis in genetics (Wheelwright and Baron-Cohen, 2001). If this is so, then we could conceive of this genetic basis being altered or modified through the immense capabilities we have to hand as a result of advances in reproductive and genetic technology (Cohen, 2006). Wanting (and possibly having the power) to create less of certain kinds of lives (and by implication more of other kinds) should stop and make us think about the desirability of these sorts of wishes and projects.

This leads us to the second reason why the territory is dangerous. If we believe that there might be worth in trying to create less of certain kinds of lives, where do we draw the line? We know that in more or less complex ways, changes in the sequence of genes cause a range of diseases and disabilities, including cystic fibrosis, epilepsy, Down syndrome and Huntington's disease (Cohen, 2006). Should we aim to eliminate this whole range of disorders with genetic components? Should we be aiming for the creation of non-disordered, 'normal' human beings? But what do we mean by 'normal'? Isn't part of being human having to cope with a world in which disability and disease is present? Isn't it a human duty to love and care for those who are born to us, even if (as in Michael Blastland's case), that new person is profoundly disabled?

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We do not have to search very far into the past to recognise that history is filled with examples of people and nations that believed ‘normality’ was constituted by a certain kind of being. For the Nazi regime, being Jewish (or homosexual, or gypsy) was not normal and so Europe saw the extermination of six million people as these ‘abnormalities’ were dealt with (Burleigh, 2001). It is this really quite recent past that is part of what lies at the heart of concerns about the new genetics and the potential it has for allowing us to create so-called designer babies (Glover, 2006).

If talk of Nazi eugenics and ‘designer babies’ seems far from the case of Joe and his obsession with car rides, there is a need to be reminded of how easily we got to this position. If Joe’s life has meaning only because it means something to others, and this is not the case with the majority of people, then we could argue that his life is *different* from others. If it is different, we could potentially take the view that it holds less **value**. Holding less value, we might assert that we should try to avoid such lives being created. But if we agree with this assertion, we might also agree that we should do our best to avoid the creation of a whole range of lives that are different, that don’t conform to our conceptions of ‘normality’.

Thinking About...

On page XX, I asked whether you agreed (or otherwise) with my claims that everyone involved in health care should have a concern with values and ethics, and that unless this is present we are not properly engaged in health care at all. Reflect on whether your consideration of these three case studies has altered your initial position in any way.

Conclusion: The Challenge of Values and Ethics

The case of Joe should make us do very much more than just worry about the implications of ‘high-tech’ genetic engineering projects. It should make us reflect, as health care students or workers, about the value we place on certain kinds of lives. This also applies to the other two case studies within the chapter, concerning assisted suicide and the end of life, and childhood obesity. In all of the cases, individuals (or groups or populations) confront us with strong values related to their lives, their behaviour and their circumstances. Dr Irwin and Mrs Murphy are asking us to see the value of physical life as diminished through painful suffering. Actors in the case of childhood and teenage obesity are demanding that we see lives affected by the problem as both valuable and vulnerable. They also pose the question of who has responsibility for seeking ‘better living’ for those faced with the consequences of obesity. Joe’s father is asking that we share his conception that a life without seeming regard for others is valuable because we make it so.

The people in these case studies are not simply presenting us with their own values. I want to argue that they are also requiring us (either explicitly or implicitly)

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to be clear about our own values. They want to know whether we share their values, or whether our own are different and, if so, how and why. In turn, they want to know what action we will take to reinforce their values, or to promote our own (or those of the policy makers and managers controlling our work). They want to know these things for a very simple reason. It is this:

If health care is about creating better lives (or at least making the conditions of living and dying more tolerable), then there is a need to know what motivates us in our work, and why we take the decisions and act in the ways that we do.

The case studies that I've presented here could be replicated and extended many times over, but they all lead us towards a pressing requirement to respond to this demand. By virtue of what health care is, and what it aims to do, this demand faces us in every health care-related situation. If we are serious about our work, and respectful of the patients or clients with whom we are involved, we have a duty to respond. It would be showing disrespect not to try to do so. This is the basis for my assertion that that everyone involved in health care should have a fundamental concern with issues of values and ethics. **We need to examine the values that underpin our actions, and the ethics of those actions themselves, because they are responses to the task of creating better (or more tolerable) lives – and these lives are valued, one way or another, by those whose lives they are.** The task now is to clarify how this challenge can be met.

Chapter Summary

In this chapter, I have:

- Used a number of case studies to exemplify the view that questions of values and ethics permeate all aspects of health care, from prevention to acute treatment;
- Developed and defended the view that, as a consequence, values and ethics are central to the study and practice of health care;
- Encouraged you to think about the essential importance of exploring your own values and ethical positions as a fundamental response to the 'valuable lives' of the patients or clients with whom you actually or will potentially work.

Further Reading

Dworkin, R (1995). *Life's Dominion: An Argument about Abortion and Euthanasia*. London: HarperCollins. This is a beautifully written and argued book setting out positions in relation to these issues of 'life and death' ethics.

Seedhouse, D (1998). *Ethics: The Heart of Health Care* (Second Edition). Chichester: Wiley. By way of contrast, much of Seedhouse's focus in this book is on the 'everyday' ethics of health care.