CHAPTER 6

Sickness

6.1 INTRODUCTION

‘Early to bed and early to rise makes a man healthy, wealthy and wise’ goes the common saying. This pre-supposes that people wish to be healthy, wealthy and wise, and that is probably a fair assumption. Health is becoming a modern-day obsession. Fit-bits and other activity trackers are worn to ensure one has sufficient exercise. The obsession over healthy eating has a long history. ‘How are you?’ is a standard opening pleasantry in many a conversation. Yet lurking behind this innocuous question is a more profound one. What is it to be well? How are we to understand the notion of health?

These questions are important. Lawyers have attached increasing weight to a ‘right to health’. In elections, health is nearly always recognised as a key theme. Most governments seek to promote health and will have a Department for Health (or some such body). Many employers these days want to be seen to encourage good health among employees. But, what is it, precisely, that these bodies are seeking to achieve? Not surprisingly such questions have produced a burgeoning literature on the definition of health (de Campos 2017; Foster and Herring 2016).

This chapter explores these issues. The academic literature, particularly the medical literature, is typically premised on assumptions about what a good human body is like or what a good life will be. It is assumed that our
normal status is to be free of illness and impairment. The goal of medicine is to return the body to its natural ‘disease-free state’. Callahan (1998) describes well a standard understanding of health:

The goals of medicine encompass the relief of pain and suffering, the promotion of health and the prevention of disease, the forestalling of death and the promoting of a peaceful death, and the cure of disease when possible and the care of those who can not be cured.

By contrast Illich (1974) sees suffering and disease as part of health:

The ability to adapt to a changing environment, to growing up and to ageing, to healing when damaged, to suffering and to the peaceful expectation of death. Health embraces the future as well, and therefore includes anguish and the inner resources to live with that anguish.

In contemporary writing, especially from feminist and disability scholars, there are arguments that we should see impairment and vulnerability as part of the essence of being human (Herring 2016). Under that approach wellness involves being independent and self-sufficient, whereas being interdependent is inevitable and necessary for human flourishing. It is assumed that health is an individual characteristic, whereas our wellness is found in our relationship with others.

### 6.2 Definitions of Health

When the World Health Organisation (WHO) was first established, its founding statement defined health (World Health Organisation 1947) in the following way:

Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.

The WHO continued the work of classifying disease. Its International Classification of Diseases (ICD) seeks to provide standard definitions and a list of conditions which are recognised by the medical profession (World Health Organisation 2011). The original purpose of the ICD was to ‘classify causes of mortality as recorded at the registration of death’. Later,
its scope was extended to include diagnoses in morbidity. The authors of the ICD admit:

Although the ICD is primarily designed for the classification of diseases and injuries with a formal diagnosis, not every problem or reason for coming into contact with health services can be categorized in this way. Consequently, the ICD provides for a wide variety of signs, symptoms, abnormal findings, complaints and social circumstances that may stand in place of a diagnosis on health-related records.

Therefore, there are two categories found in the ICD classification which address these factors directly found in chapter 18 ‘Symptoms, Signs and Abnormal Clinical and Laboratory Findings, Not Elsewhere Classified’ and chapter 21 as ‘Factors Influencing Health Status and Contact with Health Services’ (World Health Organisation 2013).

The WHO is well aware that disease or health does not depend on the diagnosis alone, but also on many factors external to the patient. The WHO International Classification of Functioning, Disability and Health (World Health Organisation 2002) explains:

Two major conceptual models of disability have been proposed. The medical model views disability as a feature of the person, directly caused by disease, trauma or other health condition, which requires medical care provided in the form of individual treatment by professionals. Disability, on this model, calls for medical or other treatment or intervention, to ‘correct’ the problem with the individual.

The social model of disability, on the other hand, sees disability as a socially-created problem and not at all an attribute of an individual. On the social model, disability demands a political response, since the problem is created by an unaccommodating physical environment brought about by attitudes and other features of the social environment. On their own, neither model is adequate, although both are partially valid. Disability is a complex phenomena [sic] that is both a problem at the level of a person’s body, and a complex and primarily social phenomena. […]

The WHO thus integrates the two models, and proposes a biopsychosocial model to describe disabilities. Disabilities are seen as the interactive outcome of health conditions (diseases and disorders) and contextual factors (professional and social background of the subject, local climate, social attitudes, etc.) (World Health Organisation 2002).
Unfortunately, all this still leaves open the question of who decides who is healthy and who is not, and using what criteria. It is important at this point to emphasise the power that can be exercised in determining who is healthy or who is ill, who is disabled and who is able-bodied. We shall impart two anecdotes to illustrate the difficulty of answering the question, ‘What is disease?’

One of us (PC) recalls as a medical student dealing with a patient who had proteinuria. After doing all the tests, up to taking biopsies from his kidney, nothing seemed to be wrong (this was before medical genetics was in widespread use; these days we would have done a genetic screen of this patient). The medical team reassured the patient that he was all right, and that some people might have proteinuria but live to 80, and it is just one of those quirks of Nature. They asked him to come back for tests once a year, and discharged him. Was this patient ill?

One of us (PC) once talked to a medical friend who had recently admitted a child of fourteen who presented with a fainting episode. On admission to hospital, the clinicians diagnosed a transient ischaemic attack (TIA), or a ‘temporary stroke’. A CT scan showed no abnormalities, and an NMR scan shows that in the right frontal lobe, there were some abnormalities in the white matter. A metabolic screen was ordered, and the results showed that the patient had marginally raised sulphites in the urine, and decreased blood levels of arylsulphatase A below the normal range, though not to a level which is normally seen in the disease state. A follow-up genetic screen was performed, and the patient was found to have three mutations in the two alleles of the arylsulfatase A gene which characterise metachromatic leukodystrophy. Two of these mutations were the recognised common pseudodeficiency variants, a pseudodeficiency being thought to be a variant that, although causes a lowering in enzyme activity, does not cause the disease itself. However, the patient was otherwise well; he had none of the ‘classical’ symptoms of metachromatic leukodystrophy, or at least he had not developed any of those symptoms yet. What should we do? The treatment for metachromatic leukodystrophy is a bone marrow transplant, which carries significant mortality and morbidity. Is it worth risking a bone marrow transplant for what seems to be a one-off incidental finding? While watchful waiting was adopted after discussion with the family, they were counselled that early bone marrow transplant had a far better outcome prognostically that one performed further into the disease. The continuing increased medicalisation of the patient continues in what could be an entirely healthy individual. Does he have a disease?
Precision in disease definition is of particular importance in the areas of newborn screening (see Sect. 2.6) and pre-implantation genetics (see Sect. 2.2.4). It is obvious that definitions of disease change over time.

6.3 Case Study 1: Epilepsy

We could find no better illustration of these changes by examining the history of epilepsy. This disease comes about because of abnormal activity in the brain (Goldberg and Coulter 2013). Some of the cases have genetic components (Noebels 2015), but others arise from trauma to the brain (Hunt et al. 2013). Epilepsy certainly is not infectious, and does not necessarily lead to cognitive impairment.

Epilepsy was probably first described by Sumerians. We are certain that between 718 and 612 BC, the Babylonians described it (British Museum tablet BM 47753, see Kinnier Wilson and Reynolds (1990)); they thought that this disease was caused by supernatural entities. Epilepsy was described slightly later in China during the Warring States Period (404–221 BC) (Huang Di Nei Ching; see Lai and Lai (1991) for a short discussion), but it was viewed as a disease, with acupuncture, herbal medicine and massage recommended as possible treatments. Ancient India also viewed epilepsy as a disease with possible treatments (Manyam 1992). ‘The Sacred Disease’, attributed to Hippocrates, also contains a description of epilepsy, but the author rightly claimed that this disease has no supernatural cause, is curable, and even correctly identified the cause of the disease to lie in the brain (Hippocrates ca. 400 B.C.).

Sadly, the Judaeo-Christian tradition propagated the misconception that epilepsy was caused by demons, and also the myth that this disease was contagious (Diamantis et al. 2010). We had to wait until John Thompson Dickson to suggest that decreased ‘vitality’ in certain areas of the cerebral cortex caused epilepsy (Thompson Dickson 1869, 1870a,b). Subsequently, Thompson Dickson (1872a,b) clearly stated that the manifestation of epilepsy was a concatenation of phenomena dependent upon various abnormal states of the surface grey matter of the cerebral lobes […] It will not therefore be difficult to grasp the fact, that if the spot on the surface which becomes the seat of the affection should be a centre presiding over a ganglion controlling muscular movement, convulsion or movement in the muscles so deprived of control will occur; but if, on the other hand, the spot on the surface not be associated with ganglia controlling muscles, muscular manifestations cannot occur. And what is true of the muscular
manifestations is true of all other manifestations of epilepsy, and so definite and perfect are the relations to control of function that they can be brought into algebraic formulae.

At about the same time, Hughlings Jackson published his classic *A Study of Convulsions* (Hughlings Jackson 1870), where he stated: ‘A convolution is but a symptom, and implies only that there is an occasional, an excessive, and a disorderly discharge of nerve tissue on muscles.’ Like Thompson Dickson, he thought that this discharge came from the cortex, when he wrote subsequently: ‘Epilepsy is the name for occasional, sudden, excessive, rapid, and local discharge of grey matter’ (Hughlings Jackson 1873). These ideas are very similar to modern ideas on epileptogenesis, and were subsequently confirmed by Penfield and Jasper (1954).

The next great advance came with efficacious drugs for treating epilepsy, potassium bromide and potassium iodide (Wilks 1861). In 1912, another anti-epileptic drug was discovered, phenobarbital or luminal. This drug was synthesised by Bayer, but was accidentally found to be useful for epilepsy (Hauptmann 1912), and became popular because it had fewer side effects. This was followed in the 1950s by benzodiazepines, many of them synthesised by Leo Sternbach when working for Hoffmann-La Roche (Sternbach 1979). Subsequent research shows that benzodiazepines act on a membrane protein, the γ-aminobutyric acid type A (GABA\textsubscript{A}) receptor (Möhler and Okada 1977; Squires and Braestrup 1977), to exert their therapeutic effect. Nowadays in affluent societies, most people would view epilepsy as a non-transmissible physical illness, not infectious and certainly not caused by demons.

It would be easy for us to stand from where we are and laugh at people who see epilepsy as a curse or something caused by demons; this still happens in some places on the earth. And people in mediaeval Europe or ancient Babylon were probably convinced that they were right to see epilepsy coming from supernatural entities. It is through better scientific understanding that we came to realise the basis of epilepsy. But it took us over 26 centuries to come to where we are. Similarly, homosexuality was viewed as ‘unnatural’, but science discovered it in many animals (Poiani 2010; Sommer and Vasey 2006). These discoveries were referred to in the *amici curiae* brief of the American Psychiatric Association for *Lawrence v. Texas* [2003] 539 US 558, which struck down the sodomy laws in fourteen US states. Could we be holding beliefs about certain diseases or non-diseases which would seem irrational and nonsensical in 26 centuries’ time?
6.4 **Case Study 2: Schizophrenia**

The most likely candidates are probably the psychiatric illnesses, simply because their diagnoses rely mainly on symptoms, and can be subjective. Moreover, little is known about the pathogeneses and disease mechanisms of mental illnesses, simply because we know so little about how the brain functions. Another complicating factor is that there is a very large social dimension to psychiatric illnesses; indeed, some sociologists would go so far as to claim that mental illnesses are merely social constructs (Bowers 1998). However, even with all these other complicating factors, a picture is gradually emerging that there is a biological and an environmental basis to most, if not all, psychiatric illnesses.

Take, for example, schizophrenia, a psychiatric illness characterised by distortions of thought and feeling for a prolonged period of time, in the absence of any known organic causes such as brain tumour. The International Classification of Diseases 10th edition (World Health Organisation 2011) contains detailed diagnostic criteria for mental illnesses, but those for schizophrenia are almost entirely based on symptoms. These diagnostic criteria can be traced to the clinical work of Kraepelin (1893) and Bleuler (1911). Kraepelin first described this illness on pp. 435–445 of the 4th edition of his textbook, naming it ‘dementia praecox’ (Kraepelin 1893). Bleuler (1911) first named it ‘schizophrenia’, to mean there is a separation of function between thinking, memory and affect. Sadly this name has later been borrowed to mean ‘split personality’, which is very different from schizophrenia. Although schizophrenia first made its appearance in the clinical annals in the nineteenth century, researchers suggest that it was also present much earlier, perhaps as early as the fourteenth century in Europe (Heinrichs 2003).

Scientists have attempted, for a long time, to put schizophrenia on a physiological basis, and avoid the somewhat subjective diagnostic criteria in use. Clinicians have known for a long time that schizophrenia has a high heritability of up to 80% (Sullivan *et al.* 2003). A large-scale analysis of over 3300 European schizophrenia patients with over 3500 controls show that there are two genetic components, one involving the major histocompatibility complex, and the other involving thousands of genes, each with a very small effect (International Schizophrenia Consortium 2009). These susceptibility genes appear to cause grey matter loss and neuron pathology (Bennett 2011), probably via neurotransmitter changes (Schizophrenia Working Group of the Psychiatric Genomics Consortium 2014) and an inflammation pathway (Najjar and Pearlman 2015). There
are also brain connectivity changes (Konrad and Winterer 2008) and glial cell changes (Bernstein et al. 2015) in schizophrenia; some of these glial activity changes have been visualised by brain scans (Bloomfield et al. 2016). And the role of environmental factors such as social stress in the pathogenesis is gradually being defined (Mizrahi 2016).

A picture is thus slowly emerging that schizophrenia is linked to defined pathophysologies. Discrete observations are being connected together to form a concrete picture of how genetic and environmental factors combine to produce this disease. Science is reducing the social factors in clinical diagnosis. Indeed, a blood test has been proposed to improve the determination of psychosis risk (Perkins et al. 2015). In the future, we can look forward to more objective diagnostic criteria for even mental illnesses.

### 6.5 Autonomy and Interdependence

In this section we explore two understandings of health: one based on an individualised model of health where the healthy body is seen as one where a person is self-sufficient and has autonomy, and another where a person is vulnerable and depends on others. These are commonly presented as two alternatives, but the there are elements of truth in both models.

#### 6.5.1 Independence and Autonomy as Health

This is the model of health most readers will be familiar with. A well person is one who is able to function independently from others and is able to have a large degree of control over his/her life. In short the traditional understanding of autonomous health is that a person should be ‘author of their life’. Life should be self-determined. As Berlin (1958) puts it:

> I wish my life and decision to depend on myself, not on external forces of whatever kind. I wish to be the instrument of my own, not of other men’s act of will. I wish to be a subject, not an object; to be moved by reasons, by conscious purposes, which are my own, not by causes which affect me, as it were from outside.

Or as Pettit (2001) puts it:

> We want to be the authors of our own stories, to be able to look on our works and say: ‘This bears my signature, this is me.’
Hence illness is typically seen as a time when we become dependent on others to meet our needs and require the services of health care professionals to make us better and return us to our autonomous lives.

This feeds into an understanding of health and the role of medicine which is individualised: the doctor will assess the patient’s body, determine what is wrong, apply the appropriate medication and return that body to full health. And, of course, in many ways that is how medicine works in practice. However, another way of understanding health can emerge.

### 6.5.2 Interdependence and Vulnerability as Health

In this approach vulnerability is an inherent part of being human (Butler 2004; Herring 2013). Fineman (2013) argues:

> Throughout our lives we may be subject to external and internal negative, potentially devastating, events over which we have little control—disease, pandemics, environmental and climate deterioration, terrorism and crime, crumbling infrastructure, failing institutions, recession, corruption, decay, and decline. We are situated beings who live with the ever-present possibility of changing needs and circumstances in our individual and collective lives. We are also accumulative beings and have different qualities and quantities of resources with which to meet these needs of circumstances, both over the course of our lifetime and as measured at the time of crisis or opportunity.

This vulnerability comes from three primary sources. The first is that our bodily fleshy nature makes us vulnerable. We are in our nature corporeal beings. Second, our incapacities to make autonomous decisions make us vulnerable and, third, our emotional state is not, and should not be, stable.

1. The body
   
   We are in our nature corporeal beings. And it is in the nature of human bodies that they are susceptible to sickness, illness and injury. As Fineman (2013) puts it: ‘[W]e are born, live, and die within a fragile materiality that renders all of us constantly susceptible to destructive external forces and internal disintegration.’

   Further, our bodies are ‘profoundly leaky’ (Shildrick 1997). People tend to imagine their bodies as statistic, immutable and a barrier against the world. In fact our bodies are constantly changing, with new material being added to them and old material being discarded.
By the end of each day we have lost a whole host of cells and grown new ones. By our deaths there is little of us that is biologically the same as when we were born (see Sect. 5.7). Further, our bodies are not all human. Inside, they are dependent on a wide range of non-human organisms to survive. Outside, they are constantly interacting with the environment (see Herring and Chau (2014) and Sect. 5.6). Micro-organisms are passed from one person to another. Pollution can have devastating impacts on bodies. It is well known that a broad range of socio-economic factors impact on life expectancy (MacInnes 2013). The truth is our bodies are in a constant flux, are profoundly leaky and deeply dependent on other bodies and the broader environment (Herring and Chau 2007).

2. Autonomy

The ideal person against which the ill or disabled are measured is the autonomous person. We like to think we make our own decisions on issues and act in a rational way. Impairments in rational thought are deemed mental disorders or learning difficulties. But few of us have the capacity to be genuinely autonomous. To be autonomous, a person must not only understand the information about a decision but must be able to use it. Most of us make decisions with an awareness of few of the relevant facts about the decisions we make. Even if we do know the facts, Drobac and Goodenough (2015), in their analysis of the psychology of decision making, list the following requirements for rational use of information:

- parties with stable, well-ordered preferences;
- choices that are fully voluntary and unconstrained;
- relatively equal, and ideally complete, information;
- relatively equal bargaining power and experience;
- sufficient cognitive capacity to evaluate the transaction and to exercise voluntary control over the conflicting factors and emotions involved;
- the absence of monopoly power or other distortions of the market;
- the presence of good faith and absence of fraud in both parties;
- a level of consequence for a mistake that is not disastrous to the party.

The authors, after examining the latest neuroscience and psychology, suggest that few people have these capacities. They are not alone in
their analysis. Levy (2014) refers to a wide range of psychological studies which reveal ‘fallibilities of human reasoning’ (including ‘myopia for the future’, ‘motivated reasoning’ and ‘biases in assessing probabilities exacerbated under cognitive load’). He concludes that ‘human beings are, under a variety of conditions, systematically bad reasoners, and many of their reasoning faults can be expected to affect the kind of judgements that they make when they are called upon to give informed consent’. Kahneman (2011) has listed these cognitive biases and explained how we often fail to reason logically (see Sect. 3.3.3).

3. Emotional instability

We assume that health is tied to a happy state of mind. But happiness is not always commensurate with well-being. There are times when it is right to be sad. Grief may be an unhappy emotion, but it is not an illness; indeed not experiencing grief at the loss of a loved one is more likely to be indicative of a problem. The importance of our emotional state depends upon the support of others and this creates vulnerability. Neale (2012) puts it the following way:

> Even the least vulnerable human being is still fundamentally, and inescapably, vulnerable in the negative sense, since none of us can meet her basic needs and satisfy her core desires without the co-operation of others; and even the most capable adult is vulnerable to hurt and harm, both physical and emotional.

She goes on to explore how striking a balance between positive and negative emotions is part of having dignity:

> Take the example of a bereaved relative at a funeral, or in court during the trial of someone accused of her loved one’s murder. She bears herself with restraint and self-control, and is moderate in her utterances. She may even express forgiveness, call on her community not to retaliate, or request mercy for the perpetrator. All of this impresses us because we assume her to be suffering great pain and distress, and to be conducting herself in this way despite the way she is feeling. In other words, her vulnerability is a necessary and integral part of what we value when we value her dignified conduct. […] Vulnerability is thus an ontological condition of our humanity.
Given our vulnerable nature, we need others to provide us with food and emotional support. We are all profoundly dependent on others for our physical and psychological well-being. In a powerful article Lindemann (2003) contrasts the emphasis on ‘accommodations’ made to assist disabled people with the lack of appreciation of how much accommodation there is for the able-bodied:

Colleagues, professional staff members, and other adults are unconscious of the numerous accommodations that society provides to make their work and lifestyle possible. ATM’s, extended hours in banks, shopping centres and medical offices, EZpass, newspaper kiosks, and elevators are all accommodations that make contemporary working life possible. There are entire industries devoted to accommodating the needs of adult working people. Fast food, office lunch delivery, day time child care, respite care, car washing, personal care attendants, interpreters, house cleaning, and yard and lawn services are all occupations that provide services that make it possible for adults to hold full time jobs.

The able-bodied need the provision of stairs to get to the first floor as much as the wheelchair user needs the lift. Yet it is the provision of the lift for which we pat ourselves on the back for making such excellent provision for the disabled. In fact, we all depend on a wide range of social provisions to live in our society, from sewerage to supermarkets, from banks to buses. Our self-sufficiency is a myth (Herring 2013).

Our health too must be seen as a relational thing. Our well-being depends on the well-being of others around us. Covid-19 has made that abundantly clear. The illness of our family members or of those in our community makes us ill. We are denied our autonomy because of the health of others.

That is why relationships must be at the heart of an understanding of health. There is great wisdom in the National Aboriginal Health Strategy Working Party (Boddington and Raisanen 2009):

Aboriginal health is not just the physical well-being of an individual but is the social, emotional and cultural well-being of the whole community in which each individual is able to achieve their full potential thereby bringing about the total wellbeing of their community. It is a whole-of-life view and includes the cyclical concept of life-death-life.
Rather than seeking to make healthy bodies we may be more effective trying to create health communities and health societies.

6.6 **Legal Significance of the Different Understandings of Health**

The view taken of health as an individual thing or a relational/communitarian thing can have profound effects on the way the law responds to a range of different medical decisions (see Herring (2013) for a description of the legal significance of a vulnerability-centred understanding of the self). Here are some examples:

1. **Mental Capacity**

The standard presentation of the law is that if a person has mental capacity, then their decision must be respected. So, a patient who refuses medical treatment cannot be given it against their will. That is so even if that refusal is seen as one that harms others (*S v. St George’s NHS Trust* [1998] 3 All ER 673). Autonomy has become a key principle within medical law.

This seems very much in line with the independence and autonomy view of health. Our bodies are our own and we can decide what happens to our bodies. However, this presentation is not as straightforward as it appears. That is because it is not true that the law allows us complete authority over what happens to our bodies. Obviously, a patient cannot demand a particular treatment from a doctor (*R (Burke) v. GMC* [2005] EWCA Civ 1003). However much a patient may insist that they can make decisions about their bodies, the doctor is still entitled to refuse treatment. This is, in part, a recognition that we live in a community. The NHS cannot be expected to provide every treatment that every patient wants. But it also requires us to respect the views of others. If doctors in their professional opinion think a treatment is not appropriate, we have no right to demand it of them. So there are relational and communitarian values found in the law, alongside a recognition of the right to refuse medical treatment.

We also find that that traditional assessment of capacity tends to be carried out on a highly individualistic basis. Typically the person is sat down in front of a medical professional and asked a series of
questions. Their answers are used to determine their mental capacity. People are assessed and treated in isolation, and not seen as relational people, in mutually interdependent relationships. The focus is on whether the individual on their own can understand the relevant information, weigh it up and make a decision (Breden and Vollmann 2004; Stoljar 2011).

This reflects a very particular understanding of what it means to have the capacity to make a decision. It is not how most people make decisions. Most think it through with others and rely on their insights, or at least interact with others on the internet. The friends chatting through a topic with a cup of tea might be the archetype of decision making, rather than the philosopher alone in his study (Gilbar 2011). As Ho (2008) argues:

We are socially-embedded beings, such that autonomy often incorporates intrinsically relational or social content, and it is thus impossible to assess patient autonomy without critically evaluating how or whether the interconnected social, political, and health-care structural frameworks often foreclose certain opportunities or pre-determine how individuals approach various health-care situations.

A relational approach would recommend that assessment of capacity should be of an individual located with their network of family, friends and caregivers (Chan 2004). The courts are beginning to recognise this. The Mental Capacity Act 2005, section 1(3) specifically states:

A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.

This may well involve family and friends supporting the decision-maker. Further in Montgomery v. Lanarkshire [2015] UKSC 11, the Supreme Court acknowledged the importance of patients and doctors working together to make decisions about medical treatment. We are beginning to see the acknowledgement that mental capacity and medical decision making is not to be understood simply as an individual thing, but as a relational one.
2. Confidentiality
Traditionally, the law has treated protected information about a person’s body as confidential. It is private and belongs to the individual concerned. However, this understanding of the law is increasingly coming under challenge, particularly in the area of genetics, as shown in the case of ABC v. St George’s [2015] EWHC 1394 (QB), [2017] EWCA Civ 336, [2020] EWHC 455 (QB), as discussed in Sect. 5.9.2.

Some care needs to be taken with this decision. It should be remembered that the claim was in negligence and so the question was not what the doctors ought to have done, but rather whether in not telling the claimant, this act of the doctors fell below the duty of care and therefore generated legal liability. There is nothing in the judgement to suggest it would have been unlawful if the disclosure had taken place (although there is no clear statement that it would have been lawful). What the case highlights is that the notion that information is simply about one body is no longer a helpful concept. The state of our bodies’ health is highly relevant for those around them. In this context there is a strong argument for saying that genetic information is ‘family information’ (Gilbar 2011); it is about a group of people and does not belong to only one person. It is not simply information that belongs to the concerned individual and of relevance only to them. It is relevant to all around them.

It is not that the law is indifferent to the claim that people must be aware that their bodies can impact on others. It is well established (e.g. see R v. Dica [2004] EWCA Crim 1103) that if someone is aware they may be HIV-positive and has sex with another person, passing on the virus without informing them of their status, they can be convicted of the offence of inflicting grievous bodily harm under section 20, Offences Against the Person Act 1861. Indeed, it would appear to follow from this that if a patient diagnosed as being HIV-positive told their doctor that they were going to continue having unprotected sexual relations with their partner without disclosing their HIV status, it would certainly be permissible for a doctor to disclose the status to the partner because that would be needed to prevent a serious crime (something which is a well-established exception to the requirement of confidentiality). This issue is less straightforward in ABC v. St George’s because, by not telling the family of his diagnosis, the man was not performing a crime.
6.7 Conclusion on Understanding Health

Dependency is an inevitable facet of human life (Herring 2013). And because we are dependent we need care. True, there will be times during our lives when our dependency on others is more obvious. In early years and in times of sickness, perhaps particularly towards the end of life, we will need overt care. However, at all times in our life, we need the care of others to meet our practical and emotional needs. Indeed the care we provide for others is an important part of our well-being too. Kittay (1999) wrote of our interdependence:

My point is that this interdependence begins with dependence. It begins with the dependency of an infant, and often ends with the dependency of a very ill or frail person close to dying. The infant may develop into a person who can reciprocate, an individual upon whom another can be dependent and whose continuing needs make her interdependent with others. The frail elderly person [...] may herself have been involved in a series of interdependent relations. But at some point there is a dependency that is not yet or no longer an interdependency. By excluding this dependency from social and political concerns, we have been able to fashion the pretence that we are independent—that the cooperation between persons that some insist is interdependence is simply the mutual (often voluntary) cooperation between essentially independent persons.

In relationships of caring and dependency, our interests become intermingled (Herring 2013). We do not break down into ‘me’ and ‘you’. To harm a caregiver is to harm the person cared-for; to harm the person cared-for is to harm the caregiver. An illness of one person can be an illness for a whole community.

The definition of health, therefore, is a complex issue. We live in our bodies and we live in our society. Health is found in a healthy body and a healthy community. Illness and disease can bring both blessing and curse. Society’s response to certain conditions and provision from them can exacerbate or limit the impact of the condition. What makes health is a complex interplay between our bodies, others’ bodies and the resources offered by a community.