

## Justice KT Desai Memorial Lecture 2017

### Law of medicine and the individual: current issues

#### What does patient autonomy mean for the courts?

by

The Rt Hon Lady Justice Arden DBE<sup>1</sup>

*Every human being of adult years and sound mind has the right to determine what shall be done with his own body...*

Cardozo CJ in *Schloendorff v Society of New York Hospital* 211 NY 125, 129, 105 N.E. 92 (NY 1914)

### 1. PREAMBLE

1. I am greatly honoured to be asked to speak to you in honour of Chief Justice Desai. I have heard many say that he was respected and loved, and that he was well-organised and produced his judgments expeditiously. I have also read that his judgments were always very precise and reflected his erudition.<sup>2</sup> It is difficult to think of qualities that are more important in a judge.
2. I am also honoured to be invited as your guest speaker tonight, given that I am a judge in another system, albeit one which has a very close association with your own. In consultation with Justice Manohar, I have chosen to speak about medicine and the law. This is an area that touches on all our lives. I have had to make difficult choices

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<sup>1</sup> Member of the Court of Appeal of England and Wales. In the usual way, if any question of law discussed in this article comes before me in my judicial capacity, I shall consider the matter afresh.

<sup>2</sup> See *The Bombay High Court – A Chronicle of Judges and Lawyers (1947-2013)* by Mr Arinash J Rana, Senior Advocate of the Bombay High Court.

as to the areas to include because there is a bewildering range of topics in this field which could form the basis of a stimulating discussion.

## **2. INTRODUCTION**

3. I am going to discuss patient autonomy, so I need to explain to you what I mean by this term. The idea behind patient autonomy is neatly summarised by the quotation from Cardozo CJ in 1914 that I have put at the top of this article. The idea is not new, but the role the concept plays in the law has changed and that has had a ripple effect, as I see it, and has given rise to new questions.
4. The first proposition I want to advance in this lecture is, in very broad terms, that the common law (as we in England and Wales know it) has recently made a significant swing. It has swung from a tolerance of paternalism (the idea that “doctor knows best”) to the promotion of individualism. I want to show you how that development has taken place in English law.
5. Then I want to pose the question: what are the implications of this development? Has the law yet fully captured the nature of the doctor/patient relationship? Is the law’s acceptance of patient autonomy our final destination in this field, or is patient autonomy in fact merely a more complex idea which means that the current state of the law is just a staging post from which we will have to refine our ideas?

### **A. CONTEXT FOR CHANGE – SPEED OF DEVELOPMENT IN MODERN MEDICINE**

6. Why is patient autonomy becoming increasingly important today?
7. Medicine these days is an inspiring subject, and it is much in the news. In October 2017 the world read about the remarkable operation in Delhi in which doctors

separated two-year-old twin boys who were conjoined at the tops of their heads. It has also read about the discovery by scientists at Harvard that they could manipulate the order of atoms in DNA. This discovery might enable scientists to rewrite the human genetic code and could eventually treat diseases, such as cystic fibrosis, which are caused by a single error in the human genetic code. There are many other wonderful discoveries, such as the gene-editing tool, Crispr-Cas9, which can be used to scour the billions of letters of genetic code, find their defective genetic target and break the DNA to effectively disable it. Much valuable work is being done by scientists in the UK. Some of the emerging possibilities raise huge ethical problems for doctors and society. Today, where we ask whether it would be ethical to use new technologies, tomorrow people may ask whether it would be ethical *not* to use them if it were, for instance, to help produce children who would avoid some painful congenital disease or condition. The world is moving very fast in the field of medical science.

8. The breakthroughs in medicine in recent years would have been unthinkable to the previous generation. Of course, medicine does not work in every case and we must all suffer sadness and disappointment from time to time and remember that the science is imperfect.
9. As medical science expands it is bound to intrude more into people's lives, especially when science can now treat cases that we would have thought in the past only nature could cure. So, advances in science are bringing increasingly difficult cases before the courts. It is little wonder that correspondingly there is a move towards greater patient autonomy regarding the treatment a patient receives.
10. My first example of advances in modern science leading to greater involvement of the law is about the treatment of a person at what the doctors felt was the end of his life.

The problem for the judges was in defining the test to apply and in analysing the nature of the step proposed to be taken. This case concerns modern medical science: the doctors were able to keep a patient alive though they considered that he had absolutely no quality of life.

11. The case is *Airedale NHS Trust v Bland*.<sup>3</sup> Young Anthony Bland was a victim of the disaster at the overcrowded football stadium at Hillsborough, UK, in 1989, when 96 people died and 766 suffered injuries. It is said to have been the worst disaster in British sporting history. Anthony Bland had been in a persistent vegetative state (“PVS”) for three years following the accident. PVS means that the brain stem is alive but the patient has no cognitive function. There was no question of euthanasia but the hospital and his family wanted to know whether it would be lawful to withhold artificial feeding and antibiotic drugs because he had no hope of recovery. As Butler-Sloss LJ pointed out in her judgment in the Court of Appeal, the issue was what would be in the patient’s best interests, not whether nutrition could be withheld. Both the Court of Appeal and the House of Lords concluded that artificial feeding and other support could lawfully be stopped where a patient was in PVS with no hope of recovery, provided that responsible and competent practitioners were of the view that it would be in the patient's best interests not to prolong his life because to continue the treatment was futile and would not confer any benefit on him. That was so even though it was known that he would die as a result. As Hoffmann LJ put it in the Court of Appeal, to continue this treatment was as much a choice as stopping it. Moreover, it would not be a criminal act to discontinue life support by withdrawing artificial feeding or other support because there was no duty to continue life in those

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<sup>3</sup> [1993] AC 789 (House of Lords); [1994] 1 FCR 485 (Court of Appeal).

circumstances. As Hoffmann LJ again put it, there was a conflict of moral principles and the law had to show that it had full respect for life but did not pursue the principle of sanctity of life when life was devoid of any real content.

12. My second example is *Re A (Children) (Conjoined Twins: Surgical Separation)*.<sup>4</sup> This case concerned a pair of twin baby girls who were joined at the hip but one was dependent on the other for her blood supply. Through the wonders of modern medical science the doctors had a way of separating them but only one could survive. If no action was taken, both would die. Their parents, who were Roman Catholic, refused to agree to an operation because it would result in the death of one of the twins. The hospital considered that the separation should take place and applied to the court for a declaration that it could lawfully carry out the surgery. The Court of Appeal agreed with the hospital. The Court of Appeal recognised that the separation would not be in the best interests of the twin who would die, but the Court had to strike a balance and do what was best for each by considering the worthwhileness of the proposed treatment, having regard to the actual condition of each twin and the advantages and disadvantages which flowed from the performance or non-performance of that treatment. Permitting the operation to go ahead was the least bad option. The one would die not because of the surgery but because her own body could not sustain her life. This case involved many difficult questions about the choice to be made.

#### **B. SOCIAL TREND TOWARDS QUESTIONING CLINICAL JUDGMENT**

13. This summer, there was a great deal of publicity in the United Kingdom about a baby called Charlie Gard. Charlie was 11 months old. He was on a life support machine

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<sup>4</sup> [2001] Fam. 147.

and terminally ill. He suffered from an extremely rare genetic condition known as encephalomyopathic mitochondrial DNA depletion syndrome. Sadly he had brain damage. His parents wanted him to have some experimental treatment known as nucleoside. This was only available in the USA. The parents raised over £1.3m (12m lakhs in rupees) to enable him to travel there. The wishes of the parents of a sick child are of course of great importance in decisions as to the child's treatment but in this instance the doctors at Great Ormond Street Hospital in London who were treating Charlie disagreed with the parents' views. They did not think it was in his best interests to have this treatment. In their view, it was in his best interests that his life-support should be withdrawn: the doctors did not consider that any treatment could reverse this the brain damage he had suffered. So the matter had to go to the court. There was no doubt about the dedication of the baby's parents. Unfortunately, however, there was a worrying breakdown of trust between the parents and the doctors. There was the obvious question who should make this decision for this unfortunate child – the parents or the doctors?

14. In the end it was the court which had to decide. The issue was solely this: was it in the child's best interests to have any further treatment? The case went first to the High Court, then to the Court of Appeal, then to the Supreme Court and finally to the European Court of Human Rights ("the Strasbourg Court").<sup>5</sup> The case attracted a huge amount of media interest. In addition, the Pope and the President of the United States intervened to offer their support to the parents. The judge in the High Court found on the evidence that it was not in the child's best interests to have further treatment and

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<sup>5</sup> *Gard v United Kingdom (Admissibility)* (39793/17), [2017] 2 F.L.R. 773. The decision of the Strasbourg Court contains a convenient summary of the other decisions.

none of the other courts considered that it should interfere with his decision. The parents then found what they thought was important new evidence and returned to the judge in the High Court, but he ruled that the evidence did not change matters. He made an order that permitted the doctors to allow Charlie to die.

15. There were resources for the treatment of the child in this case, but difficult issues about resources could arise in other cases where treatment is unaffordable in a public health system. The main issue was how far the parents had the right to choose the treatment for their beloved baby son.

## **2. MY “SWINGOMETER”**

16. I am of course going to describe the situation in rather broad terms for the purpose of this lecture. I am going to ask you to make a mental picture of a pendulum. In years gone by, on the night after a general election in the UK, when results were being announced by each Parliamentary constituency, the BBC used to use a swingometer to demonstrate the swing first one way and then another. I am going to ask you to picture the same sort of pendulum in your mind’s eye. My proposition is that, in the law of medicine, the pendulum has swung decisively from paternalism at one end to autonomy at the other. I am using the idea of a swingometer to trace this development of the law.

### **A. THE OLD REGIME: CLINICAL NEGLIGENCE - THE STANDARD OF CARE GENERALLY**

#### **DEPENDS ON MEDICAL OPINION**

17. I am going to call the starting point of the pendulum “the old regime” but, as you will see, it is still the regime which applies in clinical negligence cases today.

18. The leading case in the UK is *Bolam v Friern Hospital Management Committee*.<sup>6</sup> Mr Bolam suffered injury as a result of electro-convulsive treatment which he had agreed to undergo. He sued the hospital and the case was heard by a judge and jury. The hospital had failed to warn Mr Bolam that he could suffer injury during the treatment. When it came to the allegation of failure to warn, the judge told the jury that the material considerations were, first, whether the hospital, in not warning Mr Bolam about the risks involved in the treatment, had fallen below a standard of practice recognized as proper by a competent body of professional opinion and, second, if good medical practice did require warning, whether Mr Bolam, if warned, would have refused to undergo the treatment. Moreover, the judge held that Mr Bolam had to show to the satisfaction of the court that, had he been warned, he would not have taken the treatment.<sup>7</sup>

19. The judge instructed the jury:

it is not essential for you to decide which of two practices is the better practice, as long as you accept that what the defendants did was in accordance with a practice accepted by responsible persons.

20. In other words, a doctor is not liable in negligence unless no competent doctor would do what he did.

21. The standard of care laid down in this case has generally been approved by higher courts. The decision implies that, when it comes to warning a patient about the possible risks involved in any course of treatment, it is for the doctors to decide what he or she needs to know. It was probably the prevailing view at the time that the medical profession should be in principle be trusted to make the best decision in the

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<sup>6</sup> [1957] 1 WLR 582.

<sup>7</sup> At pages 582-3.



patient's interests. So the general rule is, therefore, that doctors are not liable in negligence if their actions are in accordance with a body of professional body of opinion, even if not all doctors would have agreed with that opinion.

22. The rigour of the rule was modified in a case called *Bolitho v City and Hackney Health Authority*<sup>8</sup> in 1998, so that the body of opinion supporting the doctor's actions must be a reasonable and responsible body of opinion. A body of opinion that would not withstand logical analysis would not suffice. That is hardly a surprising qualification. With that exception, the low standard set by *Bolam* continues to apply generally in relation to clinical negligence. The policy behind it would appear to be to avoid discouraging the practice of medicine, or the development of new treatments, and generally to encourage the development of medical science. That policy is not seriously doubted even today.

**B. PATERNALISM AND PRACTITIONER-PROTECTING APPROACH IN THE LAW ABOUT  
DISCLOSING RISKS**

23. For a long time, the low standard in *Bolam* was applied to the question of what information the doctor should have given to the patient, when he gave his consent to treatment, about the risks of proposed treatment. Doctors were, therefore, the gatekeepers to information about material side effects. So, for example, in *Sidaway v Board of Governors of the Bethlem Royal Hospital and the Maudsley Hospital*,<sup>9</sup> a patient underwent surgery for persistent neck pain. This operation carried a 1-2% risk that there might be damage to the spinal cord. The doctors failed to inform the patient of this risk. She did suffer this damage as a result of the operation, and was left

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<sup>8</sup> [1998] AC 232.

<sup>9</sup> [1985] AC 871.

severely disabled. Both the trial judge and Court of Appeal held that the surgeon had followed a practice accepted as proper by a responsible body of medical opinion at that time. They consequently found the surgeon not liable in negligence.

24. The House of Lords agreed. The members of the House of Lords expressed different reasons for their conclusions. Part of the reasoning was that the doctor was the judge of what information should be provided to the patient. It is enough for me to cite a passage from one speech, that of Lord Diplock. He considered whether it would be desirable for the law to move to an “informed consent” view, which arose from American and Canadian jurisprudence, but he concluded that that would not fit within the English law of negligence, and that the courts should not put themselves in the “surgeon’s shoes”.<sup>10</sup>

**C. MID-POINT OF THE PENDULUM’S SWING: GREATER FOCUS ON THE IMPORTANCE OF  
DISCLOSURE**

25. The English courts interpreted this decision narrowly, reflecting an awareness of the increasing importance which was in fact being attached to personal autonomy. The narrow approach is reflected in the decision of the House of Lords in *Chester v Afshar*.<sup>11</sup> There, a neurosurgeon advised a patient to undergo spinal surgery, which carried a risk of causing *cauda equina* syndrome. The neurosurgeon did not warn the patient of this risk. The patient reluctantly had the operation and the risk occurred. The judge found that, had the warning been made, Ms Chester would not have undergone the surgery at the time she did, but he did not find she would never have undergone the surgery, nor that there was any way of minimising the risk. The judge

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<sup>10</sup> Page 984 -5.

<sup>11</sup> [2005] 1 AC 134.

nonetheless awarded damages, holding that there was a sufficient causal link between the failure to warn and the damage which the patient suffered, and that that link was not broken by the fact that the patient would have had the operation at some time anyway. The Court of Appeal dismissed the appeal.

26. The House of Lords also dismissed the appeal, though on different grounds. The House's reasoning brings out some important points which bear on the paternalism/autonomy debate. For example, Lord Bingham noted that the rationale behind the duty to warn is to enable adult patients of sound mind to make their own decisions as to what is done with their bodies.<sup>12</sup> Lord Hope stated that all of the *Sidaway* speeches recognised the fundamental importance of the right to decide, and that the function of the law is to protect the patient's right to choose.<sup>13</sup> Lord Walker noted that personal autonomy had become more important in the 20 years since *Sidaway* was decided.<sup>14</sup>
27. The remainder of the decision concerned the question of causation. By a majority, the House of Lords upheld that the award of damages, despite the judge's finding that the patient would have sought alternative treatments, and found that there were none, and would then have gone on ultimately to have the operation when the risk of *cauda equina* would have been exactly the same. The majority's reasoning on causation on that point remains controversial. The majority concluded that it was within the scope of the doctor's duty to warn Ms Chester of the risks, and that the law's function was to protect her right to choose. They considered that the law would have failed to

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<sup>12</sup> At [5].

<sup>13</sup> At [54] to [ 56].

<sup>14</sup> At [92].

discharge its function if there was no remedy when the doctor did not meet his obligations.<sup>15</sup> Though the risk was not created by the failure to warn,<sup>16</sup> as a matter of legal policy, justice required the law of causation to be modified.<sup>17</sup> The heart of the duty to warn was the patient's right to make an informed decision, a decision for which they may take many different matters into account.<sup>18</sup> As already explained, the judge had found the patient would have sought more information, but he had not found that she would certainly not have had the operation at some time. The majority of the House of Lords considered that to hold, as the ordinary laws of causation would require, that the patient had no remedy because of these findings, would not protect those patients who agonise over their decisions. As an extension of the law on causation, therefore, the majority held the injury could be regarded as having been caused by the breach of duty.<sup>19</sup>

28. The minority disagreed with this approach and held that there was no reason for departing from the usual consequences of causation. The risk of the syndrome occurring would be the same whenever Mrs Chester had the operation, and so it would not matter when she had the operation and, therefore, she failed to show any loss caused by the non-disclosure. Be that as it may, for present purposes, the significance of this case is the emphasis it placed on patient autonomy.

**D. ARRIVAL OF AN INFORMATIONAL RIGHT FOR PATIENTS WHICH IS NOT DEPENDENT ON  
MEDICAL JUDGMENT**

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<sup>15</sup> see [55] to [56], per Lord Hope.

<sup>16</sup> See [81].

<sup>17</sup> [85].

<sup>18</sup> [86].

<sup>19</sup> [87].

29. Then came the important decision of the Supreme Court in *Montgomery v Lanarkshire Health Board*<sup>20</sup> in 2015. This completes the swing of the pendulum. It was an appeal from the Scottish courts. There the claimant had suffered injuries during his birth. He had been a large baby, and his mother was of small stature. His mother had not been advised of the risk of birth injury, which could be avoided if she had a caesarean section, because the doctor did not think that a caesarean operation was generally in the best interest of mothers and he was of the view that the risk of the baby suffering serious injury was small. The evidence was that had his mother been informed of the risks she would have asked for a caesarean section.
30. The UK Supreme Court decided that it was no longer open to the doctor to say that it was in the best interests of the patient not to disclose the risks of some treatment. Nor was it open to the profession to say that that was the generally accepted practice. The patient was to be treated as a fully autonomous being and had the right to know the downsides of any treatment that was offered.
31. The leading judgment was the joint judgment of Lord Kerr and Lord Reed, with which Lord Neuberger, Lady Hale, Lord Clarke, Lord Wilson and Lord Hodge agreed. Lady Hale gave a concurring judgment.
32. In this article I can only pick out some of the points which the judgments made. Lord Kerr and Lord Reed noted that, since *Sidaway*, there had been a dramatic shift away from paternalism in medical care. Patients were “now widely regarded as persons holding rights, rather than as the passive recipients of the care of the medical

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<sup>20</sup> [2015] AC 1430.

profession.”<sup>21</sup> Healthcare services were becoming more patient-oriented. This change was encapsulated in the medical profession’s own literature, such as the General Medical Council’s *Good Medical Practice* guide, which instructed doctors to “[r]espect patients’ right to reach decisions with you about their treatment and care.”

33. The move away from paternalism was stimulated by the enactment of the Human Rights Act 1998. Since that Act, the courts had increasingly recognised that the law reflects fundamental values, one of which was value of self-determination and autonomy. More information was available on the internet and patients tended to look at that information. All the changes pointed away from the view that the patient was entirely dependent on information provided by the patient’s doctor. They pointed, instead, to a legal approach whereby patients were treated as adults capable of understanding that medical treatment was an uncertain process, and as persons who accepted responsibility for the risks that affected their own lives.<sup>22</sup>
34. Lord Kerr and Lord Reed considered that there was a distinction between the doctor’s role in considering investigatory or treatment options, and his role in discussing with the patient any recommended treatment and alternatives. The former is an exercise of professional skill and judgment, and so negligence there is to be judged by reference to the expertise of members of the medical profession (i.e., the *Bolam* test). The latter, however, is not. The patient is entitled to decide which risks to health he or she is willing to run, and that may sometimes depend on non-medical considerations, or on value judgments which the patient herself must make. The question of treatment is not a purely medical one, and so the *Bolam* test is not apposite. Lord Kerr and Lord Reed

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<sup>21</sup> [75].

<sup>22</sup> [74]-[81].

further noted that, if *Bolam* were to be applied to the question whether a doctor should inform patients of the risks they run, it would be likely to sanction behaviour, not on whether there was a difference in medical practice, but on the basis of the differences in various doctors' attitudes to their patients.<sup>23</sup>

35. Lord Kerr and Lord Reed, therefore, held that *Sidaway*, insofar as it applied *Bolam* to the issue of whether a doctor should inform a patient of the risks they face, was unsatisfactory. Instead, they restated the position thus:

87 An adult person of sound mind is entitled to decide which, if any, of the available forms of treatment to undergo, and her consent must be obtained before treatment interfering with her bodily integrity is undertaken. The doctor is therefore under a duty to take reasonable care to ensure that the patient is aware of any material risks involved in any recommended treatment, and of any reasonable alternative or variant treatments. The test of materiality is whether, in the circumstances of the particular case, a reasonable person in the patient's position would be likely to attach significance to the risk, or the doctor is or should reasonably be aware that the particular patient would be likely to attach significance to it.

36. Lord Kerr and Lord Reed refined the issue of "materiality" somewhat by stating that whether a risk is material could not be determined by simple percentages. A risk's significance had to be assessed more holistically, by reference to the particular patient in issue. So, for example, that assessment would include thinking about the effect of on the patient's life if the risk materialised, and the alternatives available.<sup>24</sup> Under this assessment, for example, the risk of a very slight mobility loss or delay in one's little finger may not be as important to a lawyer as it would be to a concert pianist.

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<sup>23</sup> [82]-[84].

<sup>24</sup> [89].

37. Lord Kerr and Lord Reed also held that a doctor's disclosure had to be intelligible. The patient should be put into a position where he or she can make an informed decision. Bombarding the patient with technical information would not suffice, nor would simply demanding the patient's signature on a consent form.<sup>25</sup> The Supreme Court realistically recorded that "Few patients do not feel intimidated or inhibited to some degree."<sup>26</sup> Lords Kerr and Reed held that a patient could make it clear that they did not wish to consider any information: that would mean that a doctor could not be in breach of duty for not providing that information.
38. Having concluded that the doctor could not restrict disclosure of material risks about proposed treatment, Lord Kerr and Lord Reed recognised two exceptions. These were: (1) where the doctor "reasonably considers that its disclosure would be seriously detrimental to the patient's health", and (2) in circumstances of necessity, "as for example where the patient requires treatment urgently but is unconscious or otherwise unable to make a decision."<sup>27</sup> It is clear that Lord Kerr and Lord Reed expected the first exception to be available only in rare circumstances.
39. Applying the new rule to the facts of *Montgomery*, the Supreme Court concluded the doctor should have advised Mrs Montgomery on the risks to her unborn child of difficulties in childbirth, and should have discussed the alternative of a caesarean section. The lower courts had focused on a consequential risk that the baby might suffer a grave injury, which was relatively small. However, the risk in question was substantial (9-10%), and its occurrence could result in not only injury to the baby, but

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<sup>25</sup> [90].

<sup>26</sup> [58].

<sup>27</sup> [88].



emergency procedures that would be traumatic for the mother. An elective caesarean section, by contrast, presented much smaller risks. Though the doctor withheld the information because she did not think a caesarean would be in Mrs Montgomery's best interests, this was not what the "therapeutic exception" was intended to cover.<sup>28</sup>

### 3. IMPLICATIONS OF *MONTGOMERY* FOR THE ROLE OF THE COURTS

40. *Montgomery* is for me a landmark decision because of its focus on the patient and the patient's right to know. It represents a paradigm shift in the role of the doctor. The same will apply to the clinicians. The doctor or clinician is no longer wholly in control of the treatment options. The patient herself must be fully involved in those choices. This is an important point of principle because patient autonomy is an aspect of individual liberty. The patient should be in a position to make decisions about his or her body, and to give her fully informed consent to any intrusions into it. (There is a parallel here between patient autonomy and privacy. The patient is entitled to protection by the law for his or her private space.)
41. This paradigm shift has considerable implications for the role of the courts. As I have said, the conclusion that all material risks must be disclosed is an important point of principle, but the decision has to be worked out in practice. The courts cannot lay down a principle of this kind with the specificity needed to bring clarity and certainty to the practical problems which doctors meet on a day-to-day basis. This lack of clarity and certainty has to be solved not by the courts stepping in but by a professional body.

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<sup>28</sup> [94].

42. In November 2016, the Royal College of Surgeons in London issued a guide to good practice on explaining the risks of treatment: *Consent: Supported Decision-Making*. This valuable document contains a number of key principles, which I will quote because it summarises some of the important points that I have sought to make. First, “The discussion has to be tailored to the individual patient. This requires time to get to know the patient well enough to understand their views and values.” Second, “All reasonable treatment options, along with their implications, should be explained to the patient.” Third, “Material risks for each option should be discussed with the patient. The test of materiality is twofold: whether, in the circumstances of the particular case, a reasonable person in the patient’s position would be likely to attach significance to the risk, or the doctor is or should reasonably be aware that the particular patient would likely attach significance to it.”
43. It seems to me that this is an area which is best regulated in this way. There is a message here about the way in which the law can most efficiently operate in the field of medical care. So my first point is that the courts should not, as it were, go it alone but treat the problem of the doctor/patient relationship as requiring a multi-layered solution, that is, a solution that involves the medical profession, their regulatory bodies and in appropriate cases, the legislature.

#### **4. THE ROLE OF TRUST AND NEED FOR DIALOGUE**

44. We should not, however, allow our support for the principle of patient autonomy to obscure the practical difficulties of making the correct amount of disclosure and of doing so in an accessible way. As Lord Kerr and Lord Reed recognised, the law does not want doctors to spend all their time explaining risks to patients. Moreover, many patients will not want the detail, or will find it unnecessarily frightening or be

confused by it. They may be so ill that they cannot really exercise a judgment about it. They may principally want to know how competent the doctor is. They may want some statistics about how many cases the doctor has dealt with successfully, and in how many cases the treatment has failed or gone wrong. But statistics may be unhelpful because, of course, some of the best and most experienced doctors will treat the most serious cases and, therefore, may have a larger percentage of cases where treatment does not achieve a successful outcome. The patient has to rely on the doctor's evaluation of the risk and benefits.

45. Patient autonomy, now elevated to an important principle in this context, is a dynamic concept, but I query whether it should be seen, or was intended to be seen, as the sole organising principle of the doctor/patient relationship. One must not forget the significant role in practice of trust. I mentioned the issue of trust in the case of Charlie Gard, and observed how it seems to have broken down. If that happens, it may have unfortunate results for the patient. It is surely common knowledge that a patient may simply want the doctor's opinion on what is best for him, and may trust the doctor's judgment on this matter. The question of trust between doctor and patient is separate from the concept of autonomy. The doctor's duty of disclosure and the patient's autonomy are two key parts of the relationship between doctor and patient, but there are also other factors, particularly trust, in that relationship which are over and beyond the discussion in *Montgomery*. The choice is not in practice always a binary choice between paternalism and autonomy. The relationship is often more of a two-way process. The dialogue between patient and doctor, which is an essential part of their relationship, does not stop with the provision by the doctor of information about material risks.

## **5. ALLOCATING FINITE RESOURCES**

46. The concept of autonomy also brings difficulties in practice, as I have already indicated, when it comes to the allocation of resources. Patient autonomy may mean that the patient learns about some other form of treatment which is costly. The patient may ask for that treatment. The patient may not always be able to have that treatment. Take the case of the childless couple who desperately want to have their own children. They may have a great deal of fertility treatment but it may fail. They ask for the treatment to be repeated. There is a small chance that, if the treatment is repeated yet more times, it may work. The mere fact that they know about this possibility does not mean that they will necessarily be entitled to demand this treatment. Doctors, particularly in the public health system in the UK, must also consider the needs of other patients, and whether there are resources to give all the healthcare that people would like to have. These are hard decisions, and historically the law has given considerable discretion to doctors in this difficult field.
47. Another implication of the move to patient autonomy is the spotlight that it necessarily throws on patient consent. That itself brings a number of problems which I am going to deal with in the next section of this article in view of the breadth of the topic.

## **6. FURTHER IMPLICATIONS OF PATIENT CONSENT**

### **A. AUTONOMY MEANS AN ADULT PATIENT CAN REFUSE TREATMENT**

48. Let me remind what Cardozo CJ said: “Every human being of adult years and sound mind has the right to determine what shall be done with his own body...”<sup>29</sup>
49. As we have seen, the disclosure of risks is particularly important in the context of consent to treatment. The principle here is one of informed consent. The consent of a patient is essential for all treatment and investigations unless the individual does not have capacity. It is, therefore, open to a patient to refuse treatment, even where that course would be potentially harmful and even if the consequences might be fatal. A pregnant woman has the right to refuse treatment even if this would lead to the death of her unborn child. It is well-known, for instance, that Jehovah’s Witnesses will refuse blood products. The novelist Ian McKewan wrote about this situation in his 2014 novel, *The Children Act*. The story is about a fictional family judge, Judge Maye. At one point, she is asked to make an order overriding the decision of a young boy, just three months short of his eighteenth birthday, when he would obtain his majority, to refuse blood products to treat his leukaemia. He was a Jehovah’s Witness. Judge Maye goes to see the boy. She returns and makes the order because she considers that the child has refused his consent under pressure from his parents.
50. But the story unfolds. After his eighteenth birthday, when he obtained his majority, he is again ill with leukaemia. He again needs a blood transfusion. This time there is no question of overriding his lack of consent. He refuses a blood transfusion with the result that he dies. This novel vividly illustrates the type of case which from time to

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<sup>29</sup> *Schloendorff v Society of New York Hospital* 211 NY 125, 129, 105 N.E. 92 (NY 1914).

time comes before the family courts in England and Wales when patients refuse consent to life-saving treatment.<sup>30</sup>

## **B. COURTS CAN NOW TAKE HEALTHCARE DECISIONS FOR THOSE WHO LOSE CAPACITY**

51. The Mental Capacity Act 2005 gave new powers to the courts to decide whether treatment was in the best interests of a patient who no longer has capacity to decide for himself or herself. There is a recent case which shows how this legislation has been applied. The case is *Aintree University Hospitals NHS Foundation Trust v James*,<sup>31</sup> on which I sat in the Court of Appeal but which subsequently went to the Supreme Court.
52. Mr James was critically ill in intensive care in hospital. Everyone agreed that he had lost capacity to make decisions about his medical treatment. Therefore the clinicians had to take decisions about his healthcare in his best interests. The family of Mr James wanted the hospital to give him certain potentially invasive treatments if this was necessary to sustain life, but the clinicians did not consider that this was in his best interests. So that the matter was brought before the court.
53. The judge did not accede to the clinicians' wishes. By the time, however, that the case came to us in the Court of Appeal, the prospect of any improvement in Mr James' condition had seriously diminished. We unanimously held that it was in Mr James' best interests not to have the invasive treatment in question. In the meantime Mr James had sadly died. The case went to the Supreme Court. The Supreme Court dismissed the appeal.

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<sup>30</sup> The tragic story is in fact based on events that occurred in real life: see *Re G (Education: Religious Upbringing)* [2012] EWCA Civ 1233, [2013] 1 F.L.R. 677, [81].

<sup>31</sup> [2014] AC 591.

54. The Supreme Court held that, since there had to be consent to any invasive treatment, the relevant question was whether the treatment should be given, not whether it should be withheld. That meant the court had to decide whether the treatment was in Mr James' best interests. The court did not have to ask what decision Mr James would have made for himself. However Mr James' likes and dislikes had to be taken into account. In fact he had fought strongly and successfully against cancer some years previously. The court had to consider his interests in a holistic way. It was unhelpful and unnecessary to ask whether he would return to good health. The court had to ask whether Mr James would return to a life which he could regard as worthwhile. It was not for others to say that a life he would regard as worthwhile was not worth living.
55. These are difficult decisions. The court is having to make decisions which may mean that a patient is denied treatment. Because of the need to respect the patient's autonomy, the court has to consider the matter from the point of the patient in the light of his or her circumstances.
56. The Mental Capacity Act 2005 has put the court into the position not just of regulating events after they have happened (as is the position in a negligence action), but of making decisions on clinical matters, including matters in the final stages of life.

### **C. THE LIMITS TO CONSENT: ASSISTED DYING**

57. As I have already said, the right to make an autonomous decision does not mean that patients are always entitled to have the treatment they want. There are those who have retained capacity to make decisions about their healthcare but who want to end their lives. For this discussion, they are people who have made that decision because

of some serious illness or affliction, but cannot end their lives themselves because of some physical infirmity. An example would be where the person in question is in an advanced stage of motor neurone disease.

58. In the past, there was no question in the UK of these persons coming to court and asking to be provided with the necessary medication. Until the Suicide Act 1961, it was a criminal offence in England and Wales to commit suicide. That offence has been abolished but it is still a criminal offence to assist a person to commit suicide (I will call this “the assisted suicide ban”). The issue of assisting dying has arisen because the argument is that there must be a right to choose to die as part at least of one’s right to private life, which is guaranteed by the European Convention on Human Rights (the Convention).<sup>32</sup> Human rights have, therefore, added a new dimension to the problems in this field.
59. So, under English law, as a result of the assisted suicide ban, if a patient needs help to commit suicide, for example through the administration of some drug, the patient does not have complete autonomy. As we shall see, the jurisprudence on assisted dying shows that there may be a public interest in the sanctity of life which overrides the patient’s rights to autonomy, unless, that is, the restriction placed on his autonomy in this regard (by the assisted suicide ban) has to be set aside because it violates the Convention.
60. There have been a series of major challenges to the assisted suicide ban. In the first case, a Mrs Pretty sought to argue that the ban violated her rights under (among other

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<sup>32</sup> The UK was a party to the European Convention on Human Rights from its entry into force in 1950. Indeed British lawyers contributed to its drafting. However, the Convention had not been incorporated into domestic law until the Human Rights Act 1998, which meant that, until that Act came into effect on 2 October 2000, the domestic courts could not give effect to rights guaranteed by the Convention. The position on that has now changed.



Articles) Articles 2, 3<sup>33</sup> and 8 of the Convention. She wanted her husband to help her to end her life when her illness (motor neurone disease) progressed to such a state that she no longer wished to live because of her suffering. By then, she would no longer be able to commit suicide without his assistance. Her claim was rejected by the House of Lords<sup>34</sup> and subsequently (save with respect to Article 8) by the Strasbourg Court.<sup>35</sup> The Strasbourg Court held that the right to die was not protected by Article 2, which protected the very opposite, namely the right to life. As to Article 8, the Strasbourg Court held that the assisted suicide ban was within the margin of appreciation (that is, discretion for the national authorities), and that it was justified, provided that there was some means of reviewing individual cases. It also held that Article 8 was engaged but not violated on the facts of the case. Mrs Pretty, therefore, failed in her attempt to obtain an undertaking from the Director of Public Prosecutions, in advance of her husband committing an offence that he would not be prosecuted under the assisted suicide ban if he helped her to commit suicide in the final stages of her illness.

61. This led to the second case, brought by a Mrs Purdy, who also had a terminal illness which would ultimately incapacitate her from terminating her own life. She successfully challenged the absence of a published policy of the Director of Public Prosecutions on deciding whether to prosecute under section 2 of the Suicide Act 1961. Her case also went to the House of Lords, who granted her an order that the

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<sup>33</sup> Article 3 of the Convention provides: “No one shall be subjected to torture or to inhuman or degrading treatment or punishment.”

<sup>34</sup> *R(o/a Pretty) v Director of Public Prosecutions (Secretary of State for the Home Department intervening)* [2001] UKHL 61, [2002] 1 AC 800.

<sup>35</sup> *Pretty v UK* (App no 2346/02) [2002] ECHR 2346/02.

Director of Public Prosecutions should produce guidelines as to when people would be prosecuted for having assisted a person take his own life.<sup>36</sup>

62. The third case, which I wish to examine in more detail, is *R (Nicklinson) v Ministry of Justice*.<sup>37</sup> Mr Nicklinson had been an active person but in his early fifties suffered a heart attack which left him with “locked-in” syndrome: able to move only his head and his eyes, and unable to communicate except laboriously through blinks of the eye and a computer. Mr Nicklinson found his life unbearable and wished to end it but would need assistance to do so. In the Supreme Court, it was explained that a doctor would be able to provide a computer that could be operated by the patient with a blink of an eye to trigger a lethal injection, and the case proceeded on the basis that this method would be used. Many of the justices saw an important difference between this method of ending life and that where another person gives the lethal injection. As Lord Neuberger put it:

[94] To my mind, the difference between administering the fatal drug to a person and setting up a machine so that the person can administer the drug to himself is not merely a legal distinction. Founded as it is on personal autonomy, I consider that the distinction also sounds in morality. Indeed, authorising a third party to switch off a person's life support machine, as in *Airedale NHS Trust v Bland* [1993] 1 All ER 821 or *Re B (adult: refusal of medical treatment)* [2002] 2 All ER 449 seems to me, at least arguably, to be, in some respects, a more drastic interference in that person's life and a more extreme moral step, than authorising a third party to set up a lethal drug delivery system so that a person can, but only if he wishes, activate the system to administer a lethal drug.

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<sup>36</sup> *R(o/a Purdy) v Director of Public Prosecutions* [2009] UKHL 45, [2010] 1 AC 345.

<sup>37</sup> [2014] UKSC 38; [2015] AC 657. This was heard with the appeal in *R (o/a AM) v Director of Public Prosecutions* [2014] UKSC 38, where the principal issue turned on whether the court could give directions to the Director of Public Prosecutions to exercise of his prosecutorial discretion, but the issues on that appeal are outside the scope of this paper. The appellants subsequently made applications to the Strasbourg Court, but these were ruled inadmissible (Apps no 2478/15 and 1787/15).

63. Mr Nicklinson sought to challenge the assisted suicide ban by relying on his Convention right to respect for his private life under Article 8. He lost in the High Court and in the Court of Appeal, and then decided to refuse all nourishment. He sadly died before the appeal to the Supreme Court took place, but the Supreme Court allowed the appeal to proceed. At the time of the hearing before the Supreme Court, an Assisted Dying Bill had been introduced in the House of Lords by Lord Falconer, though this would only have permitted physician-assisted suicide for persons with terminal illness and a prognosis of six months or less.<sup>38</sup>
64. It is a measure of the importance attached to this case that nine Supreme Court justices were empanelled to hear it. They concluded that the jurisprudence of the Strasbourg Court permitted a state to have an absolute ban on assisted suicide (as in section 2 of the Suicide Act 1961), provided that it was properly justifiable to protect the vulnerable, but that they still had to consider whether English law complied with the Convention. This was a potential case of what the Supreme Court of Canada, in a case I shall refer to below, memorably called “overbreadth”.<sup>39</sup>
65. On this issue, the members of the Supreme Court took different views. The judgments are comprehensive and cover the issues in depth. Space does not permit me to summarise the judgments in any detail, still less can I offer critical comment, as the issues may yet come back to the courts.<sup>40</sup> Lord Neuberger, with whom Lord Mance and Lord Wilson agreed (in addition to giving their own judgments), held that no declaration of incompatibility should be made when Parliament was about to

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<sup>38</sup> For the outcome of this Bill, see paragraph 71 below.

<sup>39</sup> For the meaning of this term, see paragraph 74 below.

<sup>40</sup> Because Parliament has not yet produced a definitive answer to them.

consider the matter. So they did not provide an answer to the question whether there was a violation of Mr Nicklinson's rights. They indicated that a declaration of incompatibility might be made if the matter was not resolved by Parliament. Lord Neuberger foresaw the possibility that persons with locked-in syndrome might be vulnerable and need protection too.<sup>41</sup>

66. Lord Sumption, with whom Lord Clarke, Lord Reed and Lord Hughes agreed, held that this was a classic case where the issue should be left to Parliament, though they (the judges) might intervene if Parliament chose not to debate the issue.<sup>42</sup> Lord Sumption gave three main reasons for this:

...The first is that, as I have suggested, the issue involves a choice between two fundamental but mutually inconsistent moral values, upon which there is at present no consensus in our society. Such choices are inherently legislative in nature. The decision cannot fail to be strongly influenced by the decision makers' personal opinions about the moral case for assisted suicide. This is entirely appropriate if the decision makers are those who represent the community at large. It is not appropriate for professional judges. The imposition of their personal opinions on matters of this kind would lack all constitutional legitimacy.

[231] Secondly, Parliament has made the relevant choice. It passed the Suicide Act in 1961, and as recently as 2009 amended s 2 without altering the principle. In recent years there have been a number of Bills to decriminalise assistance to suicide, at least in part, but none has been passed into law.... As Lord Bingham observed in *R (on the application of the Countryside Alliance) v A-G* [2007] UKHL 52 at [45], [2008] 2 All ER 95 at [45], '[t]he democratic process is liable to be subverted if, on a question of moral and political judgment, opponents of the Act achieve through the courts what they could not achieve in Parliament'. Cf *AXA General Insurance Ltd v Lord Advocate (Scotland)* [2011] UKSC 46 at [49], [2012] 1 AC 868 at [49] (Lord Hope).

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<sup>41</sup> Paragraph 85.

<sup>42</sup> Though Lord Clarke ([293]) stated that he would expect the courts to intervene if Parliament failed altogether to address the matter, and Lord Sumption accepted that that might be a different case ([233]).

[232] Third, the parliamentary process is a better way of resolving issues involving controversial and complex questions of fact arising out of moral and social dilemmas. The legislature has access to a fuller range of expert judgment and experience than forensic litigation can possibly provide. It is better able to take account of the interests of groups not represented or not sufficiently represented before the court in resolving what is surely a classic 'polycentric problem'. But, perhaps critically in a case like this where firm factual conclusions are elusive, Parliament can legitimately act on an instinctive judgment about what the facts are likely to be in a case where the evidence is inconclusive or slight: see *R (on the application of Sinclair Collis Ltd) v Secretary of State for Health* [2012] QB 394, especially at [239] (Lord Neuberger), and *Bank Mellat v HM Treasury* [2013] UKSC 39 at [93]–[94], [2013] 4 All ER 533 at [93]–[94] (Lord Reed). Indeed, it can do so in a case where the truth is inherently unknowable, as Lord Bingham thought it was in *R (on the application of the Countryside Alliance) v A-G* [2008] 2 All ER 95 at [42].

67. The majority made it clear that the decriminalisation of suicide did not mean that there was a Convention right to an assisted suicide: the issue was whether the state had violated article 8 by interfering with respect for a person's private life. As Lord Mance said:

[159] It would be wrong in my view to deduce from this that the Strasbourg jurisprudence accepts that those capable of freely reaching a decision to end their lives, but physically incapable of bringing that about by themselves, have a prima facie right to obtain voluntary assistance, which is now the issue in this case, to achieve their wish. Article 8(1) is, on the authority of *Pretty v UK* (2002) 12 BHRC 149, engaged in this area. But it does not by itself create a right. A right only exists (at least in any coherent sense) if and when it is concluded under art 8(2) that there is no justification for a ban or restriction.<sup>43</sup>

68. The minority view was that of Lady Hale DP, now the President of the UK Supreme Court, and Lord Kerr. They considered that the Supreme Court should make a declaration immediately. Lady Hale approached the matter through the rule that a person who is adult and mentally competent may decide to end medical treatment.<sup>44</sup>

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<sup>43</sup> See also per Lord Sumption at [216] and per Lord Hughes at [264].

<sup>44</sup> Paragraphs [302] to [303].

She attached particular weight to a person having autonomy over their own body.<sup>45</sup>

While she accepted that it did not follow that a person with locked-in syndrome has a right to demand help from another person, in her view, for the state to criminalise the actions of a person in these circumstances goes beyond the minimum interference which the law should authorise.<sup>46</sup>

69. The declaration of incompatibility which she would have made would have declared that the assisted suicide ban was incompatible with the Convention if a person has made a free and fully informed decision to end his life and is competent to make that decision but requires help to do so.<sup>47</sup> She considered that a legislative scheme could be put in place providing for judges to make decisions. She took the view that these decisions would be no more difficult than the decisions which courts are now required to make in any event as to whether the continuation of medical treatment is in the best interests of a person who no longer has capacity to make decisions on his own behalf: see, for example, *Aintree*. As Lady Hale, with whom Lord Kerr on this point agreed (in addition to delivering his own judgment), put it:

[314] It would not be beyond the wit of a legal system to devise a process for identifying those people, those few people, who should be allowed help to end their own lives. There would be four essential requirements. They would firstly have to have the capacity to make the decision for themselves. They would secondly have to have reached the decision freely without undue influence from any quarter. They would thirdly have had to reach it with full knowledge of their situation, the options available to them, and the consequences of their decision: that is not the same, as Dame Elizabeth pointed out in *Re B (adult: refusal of medical treatment)* [2002] 2 All ER 449, as having first-hand experience of those options. And they would fourthly have to be unable, because of physical incapacity or frailty, to put that decision into effect without some help from others. I do not pretend that such

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<sup>45</sup> Paragraph [311].

<sup>46</sup> Paragraphs [313] to [314].

<sup>47</sup> Paragraph [321].

cases would always be easy to decide, but the nature of the judgments involved would be no more difficult than those regularly required in the Court of Protection or the Family Division when cases such as *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [2014] 1 All ER 573 or *Re B (adult: refusal of medical treatment)* [2002] 2 All ER 449 come before them.

70. Lady Hale was a very distinguished Law Commissioner for many years and has much experience with translating complex law reform into legislation that produces criteria which are manageable by the courts and can work. Lady Hale did not consider that there was evidence that to permit assisted suicide in these circumstances would impose pressure on the vulnerable and the elderly.<sup>48</sup>
71. In the UK, after the Supreme Court of the United Kingdom decided *Nicklinson*, Parliament debated the Assisted Dying Bill, which had already been presented, but the Bill did not complete its stages in the House of Lords before Parliament was dissolved for the 2015 election. In addition, the House of Commons rejected the Bill by 330 votes to 118.

## **7. DECISION OF THE SUPREME COURT OF CANADA LEADS TO LEGISLATION ON ASSISTED DYING IN CANADA**

72. In fact, Canada has very recently adopted legislation on assisted dying in the wake of a decision of its Supreme Court, as I shall now explain. In February 2015, the Supreme Court of Canada gave its momentous decision in *Carter v Canada*,<sup>49</sup> in which it unanimously held that two provisions of the Canadian Criminal Code unjustifiably infringed the right to life in section 7 of the Canadian Charter of Rights

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<sup>48</sup> Paragraph 316.

<sup>49</sup> 2015 SCC 5.

and Freedoms (“the Canadian Charter”).<sup>50</sup> The first provision was section 241(b) of the Canadian Criminal Code, which is similar to the English assisted suicide ban, and the second was section 14, which invalidates a person’s consent to having death inflicted on him. Unlike the position in the UK, the Supreme Court of Canada did not have to go through a two-stage approach of considering what the Strasbourg Court had held, and then, if the question fell within the state’s margin of appreciation, the nature of the right for the purposes of English law. The Supreme Court of Canada had to consider, and consider only,<sup>51</sup> the position under the Canadian Charter.

73. *Carter* is also not on all fours with *Nicklinson* because the trial judge had in that case made extensive findings of fact as to whether, for instance, ‘a permissive scheme with properly designed and administered safeguards was capable of protecting vulnerable people’. The Supreme Court of Canada rejected an application for further evidence on the way in which the issue was operating in Belgium.
74. The judgment of the Supreme Court of Canada requires comprehensive study, which is outside the scope of this article. A major point was its conclusion on what was called “overbreadth”. That meant that the prohibition was designed to protect the vulnerable but it went further than was necessary to achieve this aim.<sup>52</sup> Accordingly, the Supreme Court of Canada ruled that:

[127] The appropriate remedy is therefore a declaration that s. 241 (b) and s. 14 of the *Criminal Code* are void insofar as they prohibit physician-assisted death for a competent adult person who (1) clearly consents to the termination of life; and (2) has a grievous and irremediable medical condition (including

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<sup>50</sup> This provides: “Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice.”

<sup>51</sup> Canada is not party to any relevant regional human rights instrument, unlike the UK which is a party to the Convention.

<sup>52</sup> See judgment, [85] – [86].



an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition. “Irremediable,” it should be added, does not require the patient to undertake treatments that are not acceptable to the individual. The scope of this declaration is intended to respond to the factual circumstances in this case. We make no pronouncement on other situations where physician-assisted dying may be sought.

75. The Supreme Court of Canada then suspended the declaration for 12 months. That period was to enable Parliament to devise an appropriate statutory scheme. Subject to that delay, the declaration no doubt gave the appellant all that he could have hoped for. The Supreme Court of Canada left matters to Parliament but only after deciding that Charter rights had been infringed. The Supreme Court of Canada has the last word on that topic so it perhaps not surprising that legislation was ultimately passed to facilitate assisted dying in certain limited circumstances.
76. The essence of the new Canadian legislation is that physicians, and in some cases nurse practitioners, may provide an assisted death for adult patients who do not lack capacity and who suffer from a grievous and irremediable condition as defined in the legislation. Death must be reasonably foreseeable in a timescale that is not too remote. Patients must make a voluntary request for such assistance. And they must have been informed of the means available to alleviate their condition and give their likely informed consent. There must be a certificate from at least two independent physicians confirming that the conditions are met. There is a fifteen day “cooling off period” in which the patient can change his mind. The preamble states that the government of Canada reaffirms its commitment to palliative care. The legislation does not, at least at this stage, extend to minors or persons who are mentally ill.<sup>53</sup>

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<sup>53</sup> See *An Act to amend the Criminal Code and to make amendments to other Acts (medical assistance in dying) 2016*.

## 8. FURTHER CHALLENGES IN THE UK

77. Since the UK Parliament rejected the Bill, which it was due to consider at the time of the Supreme Court's decision in *Nicklinson*, more cases have been brought before the courts. On 5 October 2017, the Divisional Court of the High Court of Justice, Queen's Bench Division heard and rejected the application of a sufferer of motor neurone disease, a Mr Conway.<sup>54</sup> His case was different from that of Mr Nicklinson because he sought only an adjustment to section 2 of the Suicide Act 1961 to permit others to provide him with assistance to enable him to commit suicide at an appropriate time in the future. There was evidence that, since he would increasingly require mechanical assistance with his breathing, he could refuse to have this treatment and he would then receive palliative care when he died as a result of that refusal. The Divisional Court rejected his application even though Parliament had not adopted the legislation that it was about to consider when *Nicklinson* was decided. The position remained that it was not permitted constitutionally for the courts to take this route. The courts, the Divisional Court held, following *Nicklinson*, had to leave the matter to Parliament.
78. That conclusion does not mean the court has no function. The court may be required to explain the position in greater detail than it would have done before. So, too, in *Nicklinson* the Supreme Court seems to have spelt out the issues with great clarity and depth in order to assist the debate that was likely to happen in Parliament and no doubt elsewhere. That suggests that there is in some circumstances a special role for the Supreme Court and a special type of judgment required. A measure of Parliamentary debate has now taken place. It did not lead to any change in the law,

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<sup>54</sup> *R(o/a Conway) v Secretary of State for Justice and others* Case No CO/6421/2016.

but the debate was no doubt the richer for the range of views expressed in the very full judgments of the Supreme Court.

## 9. CONCLUSION

79. To recap, we have seen that, in law of medicine and the individual, there was quite recently a fork in the road. One road led to reinforcing the paternalist role of doctors – trust the doctors to make the right decision and to tell you what you need to know – and other road led to informational rights and autonomy. Our courts have chosen the latter. Autonomy has been clearly established, with all the good consequences that liberty and freedom can bring. Disclosure of all the material risks is an important precondition to autonomy: it is the best safeguard we have for ensuring that when people exercise their autonomy they are genuinely exercising their free will and are not, for instance, acting under some deceit or coercion or just giving deference to the views of others.
80. Does the move to recognition of patient autonomy have implications for the role of the courts in regulating the relationship between doctor and patient? Clearly the law has to provide a legal framework and a means of settling disputes when it is said that a clinician committed some wrong. That means that there must be a fair process in which both sides can put their case, and in which the court acts only on the evidence in the case. That is what a judicial system provides for a normal dispute.
81. But do the courts shape medical practice or respond to it? The traditional approach is that the courts defer to the wisdom of the medical profession and that the law should not second-guess the medical judgment of clinicians in medical matters (see *Bolam*). That would mean that the courts do not shape medical practice but respond to it. In

recent times, however, as I have explained, this particular pendulum has swung in the other direction, that of shaping medical practice. *Montgomery* has had a considerable effect in practice on the way clinicians conduct themselves in relation to their patients.

82. As I have noted, the implementation of the decision in *Montgomery* through Royal College of Surgeons guidelines shows how the regulation of the medical profession must in a significant part be left to the profession. But there are situations within the field of law and medicine when the courts have to take the lead, as the Supreme Court has done in the UK in *Montgomery* on the question of the disclosure to be made of the risks of treatment which he or she is about to undergo.
83. Decisions in the field of medicine call for great wisdom and for reflection from our judges: examples of that are the cases of *Bland* (medical interventions for a person in persistent vegetative state), the conjoined twins (surgical separation) and *Aintree* (healthcare decisions for a person who has lost capacity). The UK courts have given considerable weight to autonomy, and shown great sensitivity in recognising the needs of patients in the modern era. Patients have been greatly empowered as a result. But the wishes of the patient are not always the determining factor or the be-all and end-all, as we have seen from the assisted dying cases, like *Nicklinson*, *Pretty* and *Conway*. Those decisions are in the field of assisted dying, but the point can equally be made in other fields of medicine such as reproductive medicine, surrogacy and abortion.
84. As I see it, the law on the doctor/patient relationship needs further work. I have cautiously suggested that it needs in some way to give more weight to the significance of trust. We are not, I think, at the end of the road on the issues. We should

anticipate that there will be a ripple effect with further developments in the law about disclosure of treatment risks.

85. India brings to discussion of difficult legal issues internationally both its scholarship and deep understanding of justice, as I am sure Chief Justice Desai would have shown. Long may India continue to do so, and to contribute to the international community.

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