

CASE COMMENTARY

SSH...DON'T TELL THE CHILDREN! (NO DUTY TO WARN DESCENDANTS THAT THEY MAY HAVE INHERITED A SERIOUS MEDICAL CONDITION)

ABC (Claimant) v (1) St George's Healthcare NHS Trust (2) South West London And St George's Mental Health NHS Trust (3) Sussex Partnership NHS Foundation Trust (Defendants) [2015] EWHC 1394 (QB)

*Karen Dyer**

1. INTRODUCTION

In this edition of the *Denning Law Journal* we are celebrating the 800 years of the Magna Carta, but compared to some declarations the Magna Carta is a mere fledgling. Those with knowledge of the medical profession will be well versed in the Hippocratic Oath,¹ which garnered a fundamental role in medical training during the Hellenic period.² In more recent years, the Hippocratic Oath has been revitalised in the form of the Declaration of Geneva,³ and is still used as part of medical training today. Over time the Oath has been modified to adopt a more progressive stance,⁴ nevertheless in one key ethical principle remains untouched, that of confidentiality.

* Senior Lecturer in Law, University of Buckingham

¹ Named after Hippocrates who was born on the Greek island of Cos. He lived between 460-380 BC approximately. He was a renowned physician and teacher of medicine and belonged to a guild of doctors known as the Asclepiadae. Although attributed to him, some believe the oath 'predates his own school': see JK Mason and GT Laurie, *Mason & McCall Smith's Law and Medical Ethics* (9th edition, Oxford University Press 2013) 3.

² From 510-323 BC Classical Greece.

³ First adopted by the General Assembly of the World Medical Association at Geneva 1948, the most recent version was modified and agreed in 2006 at Divonne-les-Bains, France.

⁴ The introduction of the Abortion Act 1967 could be considered a flagrant breach of the Hippocratic Oath.

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English law pays great respect to the principle of confidentiality; as noted by the Supreme Court in 2013 it is “*an overriding principle and is central to trust between patients and doctors*”.⁵ English law also ensures that the “*obligation of confidence is capable of surviving the death of the patient*”.⁶ This does not mean that a patient’s confidentiality is always maintained, and there are a number of situations where information is shared with third parties,⁷ for example where the law demands disclosure,⁸ if a doctor suspects his or her patient is the victim of abuse,⁹ or where significant public interests exists.¹⁰ However, in the recent High Court decision in *ABC (Claimant) v St George’s Healthcare NHS Trust and Others*¹¹ the Court was emphatic that a duty of care in regards to disclosure of confidential information was not owed to the direct descendants of those with severe hereditary conditions.

2. BACKGROUND TO THE CASE

In 2007, the claimant’s (ABC’s) father (F) shot and killed ABC’s mother (F’s wife). He was convicted of voluntary manslaughter on the grounds of diminished responsibility. However it was not until 2009 that the underlying cause of the “diminished responsibility” was identified

⁵ *West London Mental Health NHS Trust (Respondent) v Chhabra (Appellant)* [2013] UKSC 80, [33] (Lord Hodge).

⁶ *Lewis v Secretary of State for Health* [2008] EWHC 2196 [24] echoing the Declaration of Geneva which states ‘I will respect the secrets which are confided in me, even after the patient has died’.

⁷ The least controversial situation will occur where the patient themselves, authorises medical information to be shared to a third party.

⁸ For example if there is a statutory requirement that a patient has a notifiable disease e.g. cholera or smallpox.

⁹ *R v Alan Wilson* [1996] Crim LR 573; *R v Emmett* [1999] EWCA Crim 1710.

¹⁰ *W v Egdell* [1990] 1 All ER 835.

¹¹ *ABC (Claimant) v (1) St George’s Healthcare NHS Trust (2) South West London And St George’s Mental Health NHS Trust (3) Sussex Partnership NHS Foundation Trust (Defendants)* [2015] EWHC 1394 (QB) (*ABC v others*). This was an application by the defendants to strike out the claim. (If the Courts find that a case does not specify a cause of action, or that there is no reasonable grounds for either bringing or defending the claim they have the power to strike out part or all of it and bring an end to proceedings quickly).

when a full medical diagnosis of Huntington's disease (HD) made.¹² As part of his rehabilitation, family counselling was engaged between F and his daughters, (one of whom was the claimant, ABC). When his HD was first diagnosed, F demanded that doctors obey their duty of confidentiality and withhold knowledge of the condition from ABC. Four meetings occurred in 2009 between F and ABC with a representative of the family therapy team. Additionally, ABC submitted that she had attended various multi-disciplinary meetings relating to her father's care. During these conferences, healthcare workers honoured F's desire to keep his diagnosis a secret from ABC, albeit that there had been discussions among staff as to whether the Claimant should be informed about the diagnosis,¹³ particularly as she was pregnant at the time.

ABC gave birth to her daughter in April 2010, oblivious to her father's diagnosis of HD. She may have remained ignorant of this indefinitely had she not been accidentally informed of it in August of that year by one of her father's doctors.¹⁴ The discovery of this, at the time and in the manner that it occurred, was said to have caused psychiatric injury to ABC. At this point it is apposite to discuss HD to understand the rationale behind the claim and its defence.

3. HUNTINGDON'S DISEASE (HD)

HD is the result of a genetic error. There are some 20,000 to 25,000 genes in the human body, (usually) arranged in 46 chromosomes: 22 pairs of autosomes, and one "pair" of sex chromosomes. HD is caused by a mutation to one specific gene, known as the *HTT* gene, located on autosome 4. This *HTT* gene is responsible for producing a protein, known as Huntingtin.¹⁵ A mutation to the *HTT* gene causes the body to produce a rogue version of this protein.¹⁶ For reasons as yet unknown by scientists,

¹² This is also known as Huntington's chorea. Chorea was extrapolated from the Greek word 'khoreia' which means 'dancing' as those with this condition often develop random limb movements which can appear to be dance-like.

¹³ *ABC v Others* [5].

¹⁴ *Ibid* [2].

¹⁵ This gene was discovered in 1993. Those with HD produce a mutated version of Huntingtin.

¹⁶ The mutation involves segment known as a CAG trinucleotide repeat. This segment is composed of 3 out of 4 nucleo-base, namely cytosine, adenine, and guanine (the other being thymine). To operate fully, this CAG segment needs to repeat 10 to 35 times within the gene, but for those with HD the CAG segment is repeated 36 to 'more than 120 times'. The more repeats that occur, the more

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the mutant form of protein ultimately inflicts damage to nerve cells in various regions of the brain including the basal ganglia and the sub-cortex. Amongst other physical symptoms,¹⁷ the damage leads to “behavioural problems”.¹⁸

Unlike autosomal recessive hereditary conditions which require both parents to be sufferers of the condition or carriers of the faulty gene in order to inherit the full condition,¹⁹ HD is an autosomal dominant condition.²⁰ Therefore if one parent has the faulty gene, there is a 50 *per cent* chance that each of their progeny will inherit the gene, and ultimately develop HD.²¹ As with many conditions, symptoms vary enormously from person to person. Some will face only mild alternations to their daily routines whereas for others symptoms will be “profound”, affecting everyone around them.²² F’s condition was “thought to have had some bearing” on the murder of his wife.²³

Having discovered her father’s condition, ABC grew concerned for not just her well-being but additionally that of her daughter. In 2013 her fears were confirmed that she had inherited HD. She was additionally concerned for the welfare of her child. As of date it is unknown whether her daughter has inherited that disease as well, as testing for HD does not take place before the age of majority.²⁴ However, ABC contended that had she known that she had a heredity condition, she would have undergone a termination of her pregnancy.

severe the condition is likely to be. Genetics Home Reference (US National Library of Medicine), ‘What is Huntington Disease?’

<http://ghr.nlm.nih.gov/condition/huntington-disease> accessed 2 July 2015.

¹⁷ Such as the ‘dance-like’ physical movements, (see further n 12).

¹⁸ Huntingdon’s Disease Association, ‘Behaviour Problems’ (May 2012) <http://hda.org.uk/hda/factsheets/> accessed 2 July 2015.

¹⁹ Such is case, for example with those born with Congenital Adrenal Hyperplasia (CAH).

²⁰ Occasionally a sufferer will have a spontaneous mutation without his or her parents passing on the condition, but it may be the case the in the parent the condition is extremely mild and it has not been diagnosed.

²¹ As there will always be at least a 50:50 chance that they inherit the autosome 4 which is carrying the faulty gene. (If both parents have the condition the chance of inheritance will be greater.)

²² Huntingdon’s Disease Association, ‘Behaviour Problems’ (May 2012) <http://hda.org.uk/hda/factsheets/> accessed 2 July 2015.

²³ *ABC v Others* [17].

²⁴ In England this is 18 years of age: section 1 Family Law Reform Act 1969.

ABC therefore argued that the defendants, (doctors and other professionals) owed her a duty of care to disclose her father's HD, and in not informing her, doctors had breached their duty of care towards her. She contended that she had suffered psychiatric harm as a result of the lack of disclosure. Not only that, ABC submitted that if her daughter has also inherited the disease, this would cause additional financial expense. She further argued that the defendants had violated her rights under Article 8 of the European Convention of Human Rights (ECHR). By contrast, the defendants sought a motion to strike out the claim at an early stage on the basis of no reasonable cause of action, i.e. that firstly, although the duty of confidentiality might not always be absolute, this did not create a duty of care; and secondly, that no breach of Article 8 ECHR could be proved in this particular claim.

In regard to the claim in negligence, the Defendants relied on the leading judgment of *Caparo v Dickman*,²⁵ which specifies the three-part test to be used when assessing if a duty of care is owed in novel situations. Interestingly the Defendants were prepared to accept that there was "sufficient proximity" between themselves and ABC and that any injury ABC suffered as a result of non-disclosure would have been "reasonably foreseeable."²⁶ However, they argued, there was no reasonable prospect of the Claimant establishing that it would be fair, just or reasonable to impose on the Defendants a duty of care towards the Claimant in this regard,²⁷ and put forward nine reasons why a duty of care should not be found.²⁸

- i. What was put against the public interest in preserving confidence in the present context was not a public interest in disclosure, but the private interest of the Claimant.
- ii. The law of confidence allowed a doctor to disclose confidential information in certain circumstances (...) The Claimant was contending for a duty to do so. Consciously or unconsciously, this might encourage doctors to breach confidence where it might not otherwise have been justified.

²⁵ *Caparo v Dickman* [1990] 2 AC 605.

²⁶ *ABC v Others* [11].

²⁷ *Ibid.*

²⁸ *Ibid* [13]. These submissions are discussed later.

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- iii. Doctors would be subject to conflicting duties, liable to be sued by their patient if they disclose information which should have remained confidential, liable to be sued by a third party, such as the Claimant, if they fail to disclose information which they should have revealed.
- iv. If a doctor is subject to a duty of care in some situations to disclose information to third parties, it will undermine the trust and confidence which is so important to the doctor/patient relationship. It may lead to patients being less candid with their doctors. (...)
- v. If doctors owed a duty of care to third parties, it may result in doctors putting pressure on their patients to agree to disclosure to avoid the risk of being sued by third parties.
- vi. Some third parties may not wish to receive information. Yet a doctor may not be able to explore whether this is the case without effectively imparting the information itself.
- vii. It is possible that the third party may suffer psychiatric harm if he or she is told the information in question. The doctor will be in a dilemma as to how to explore whether this is the case when the third party is not or may not be his or her patient.
- viii. Doctors receive a very great deal of confidential information. It would be burdensome to place on them a duty to consider whether any of it needs to be disclosed to third parties. The time and resources committed to this will be a distraction from treating patients.
- ix. This significant extension of a doctor's duty of care would be contrary to the incremental way in which the law of negligence ought to progress.

In summary, whilst it was noted that on occasions there are times when doctors are owed a positive duty to breach confidentiality, it was

argued that it would “not make it fair, just or reasonable”, to impose a duty of care on the Defendants to the Claimant, “in the current case.”²⁹

Conversely the counsel for ABC argued, *inter alia*, that the claimant was “not just any third party,”³⁰ but F’s daughter; that F’s ability to make an informed decision to withhold his diagnosis had not been properly addressed by his healthcare workers,³¹ moreover that, the General Medical Council Guidance indicated that doctors “might be under a positive duty to do disclose information” on occasions. In conclusion counsel argued that finding a duty of care in this situation would not be “so novel a development as the Defendants submitted”.³² Nicol J found that the claimants had relied on cases which were conventional doctor-patient relationships,³³ consequently to find a duty of care in this case would be a novel departure.

By comparison, the Defendants relied on the House of Lords decision of *X v Bedfordshire County Council*³⁴ and the subsequent Court of Appeal decision in *Powell v Boladz*.³⁵ These stipulated categorically that no duty of care was owed to those with close family connections, but merely to the person themselves. Further the case of *X* warned of the danger of

²⁹ Ibid.

³⁰ Ibid [15].

³¹ Ibid.

³² Ibid [16].

³³ *A v East Kent Hospitals University NHS Foundation Trust* [2015] EWHC 1038 (QB) where a mother to be complained that she had not been told during antenatal visits that her baby might be suffering from a chromosomal abnormality. She would have terminated the pregnancy had she known. Nor was the case of *Angela P v St James and Seacroft University Hospital NHS Trust* [2001] EWCA Civ 560 of any help to the claimant. In this case a woman had given birth to a child with a disability after undergoing sterilisation. It was held that the hospital was liable for the costs of bringing up a disabled child, but not the costs which would have been incurred in bringing up a healthy child.

³⁴ *X v Bedfordshire County Council* [1995] 2 AC 633, where parents, having had their children removed from them for fear of abuse, brought claims in negligence against those authorities responsible on the ground that the abuse assessments were carelessly made. The claims were said to offer no reasonable cause of action and were struck out.

³⁵ *Powell v Boladz* [1998] Lloyds Rep Med 116. In this case, parents brought a claim in negligence, alleging, that the father suffered psychiatric damaged on discovering that various records connected with his young son’s treatment had been altered after his death. The court was emphatic that the doctor owed no duty of care to the parents, only to the son.

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imposing additional levels of duty of care on public bodies lest they adopted a defensive mode of performance.³⁶

Very little argument was put forward as regards the Article 8 issue. It was specified that the Claimant had to prove “that the positive duty implicit in Article 8 required the Defendants to disclose her father’s condition to her”.³⁷ The Judge did not find this was the case. Overall Nichol J held that to found a duty of care would be a “radical departure”³⁸ from current law and that overall “the balance (came) down decisively against the Claimant” and acceded to the defendants’ request to strike out the claim.³⁹

4. DISCUSSION

This is an unpopular decision.⁴⁰ It is certainly unsatisfactory in a number of respects. Gilbar and Foster point out that ABC’s autonomy and her reproductive rights, at least equalled that of F’s right to confidentiality,⁴¹ and that the decision in this action “is embarrassingly at odds” with the leading judgments of *Montgomery v Lanarkshire Health Board*⁴² and *Chester v Afshar*.⁴³ They further emphasize the importance of the specific epidemiology of HD itself as HD “carries an immutable death sentence”.⁴⁴

When looking at the nine points point forward by counsel for the defence, it seems relatively easy to rebut a number of them.⁴⁵ At point (i) it was noted that this was not a matter of “public interest in disclosure, but the private interest of the Claimant” and further (iv) that would undermine the trust and confidence in the doctor/patient relationship. It is

³⁶ *X v Bedfordshire County Council* [1995] 2 AC 633 [750].

³⁷ *ABC v others* [37].

³⁸ *Ibid* [27].

³⁹ *Ibid* [38].

⁴⁰ Roy Gilbar Charles Foster, ‘Do I Have a Right to Access my Father’s Genetic Account?’ *Practical Ethics* (Oxford, 29 May 2015) <http://blog.practicaethics.ox.ac.uk/2015/05/do-i-have-a-right-to-access-my-fathers-genetic-account/> accessed 5 July 2015.

⁴¹ *Ibid*.

⁴² *Montgomery v Lanarkshire Health Board* [2015] UKSC 11.

⁴³ *Chester v Afshar* [2004] UKHL 41.

⁴⁴ Gilbar and Foster (n 40).

⁴⁵ *ABC v Others* [13]. It is submitted that point ix) the ‘significant extension of a doctor’s duty of care would be contrary to the incremental way in which the law of negligence ought to progress’ is a matter of opinion rather than law.

acknowledged that there was a private interest of the client, but it can also be argued that it is in the general interest to understand the morphology behind a murder charge. It is submitted when a serious crime is committed it is in everyone's interest to understand a contributory factor to this. Point (ii) suggested that this "might encourage doctors to breach confidence where it might not otherwise have been justified". It is submitted that this would not be the case in general. Point (ii) puts the opposing view that if a duty was found in this case, in the future a doctor may be sued for non-disclosure in similar circumstances, or put pressure on patients to disclose (v). It is possible that this is the case, but narrowing down the duty to direct descendants would limit the scope of the duty. This would also mitigate the argument put forward in point (viii) in terms of relieving the burden and (perhaps more pertinently) the cost of the extent of the disclosure.

The most interesting tensions occur at points (vi) and (vii). These arguments suggest that "third parties may not wish to receive information" and "may suffer psychiatric harm if...told the information in question." Whilst the first of these propositions is a valid concern, current English law already addresses this latter issue succinctly. By virtue of the Data Protection Act 1998⁴⁶ (DPA) and its supporting secondary legislation, the Data Protection (Subject Access Modification) (Health) Order 2000 (SI 2000/413),⁴⁷ Article 5(1) specifies that exceptions from disclosure under section 7 DPA apply if such disclosure "may cause serious harm to the physical or mental health" of the person concerned, "or any other person".⁴⁸ Furthermore, the courts have confirmed that access to information is not an unqualified right, provided the non-disclosure can be justified.⁴⁹ It is submitted that if ABC was considered competent, and capable of receiving vitally important information about her health, that this should have been recognised, and her father's diagnosis disclosed, particularly in light of all the surrounding facts.

F had murdered his wife. In order to reconcile F and his daughters family therapy was employed. It is submitted that it would have been

⁴⁶ Section 7 of the DPA specifies that individuals may make a written request to an organisation to see any personal information held about them by that organisation.

⁴⁷ This replaced the Data Protection (Subject Access Modification) (Health) Order 1987 (SI No 1903).

⁴⁸ Article 5(1) provides that 'Personal data to which this Order applies are exempt from section 7 in any case to the extent to which the application of that section would be likely to cause serious harm to the physical or mental health or condition of the data subject or any other person'.

⁴⁹ *Roberts v Nottinghamshire Healthcare NHS Trust* [2008] EWHC 1934 (QB).

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conducive to all if F's condition were discussed in an open forum. It is difficult for children to come to terms with the murder of one parent by another and to discover that, in part, this was caused by a circumstance beyond F's control would have assisted in this matter. Further, having discovered that F had such a condition, and knowing that his daughters consequently had a 50 per cent of inheriting this, it seems unreasonable that silence should prevail.⁵⁰ To encourage situations where the law upholds non-disclosure is perilously close to creating legal obligations to withhold essential health information from the persons concerned. A move in this direction would be unduly harsh. Whilst not wishing to add to their burdens, it does not seem unreasonable that a doctor's duty is extended to disclosing genetic information to direct descendants.⁵¹

This decision potentially creates a further barrier to those who wish to understand their medical conditions. It has long been the situation that testing for HD cannot be undertaken until a young person reaches the age of 18. This means that direct descendants of those with HD, who often witness the demise of their parents or grandparents, are left in limbo until they are old enough to be tested themselves. This is not a satisfactory position. A considerable length of time has passed since Professor Dickenson's article promoting the right to earlier testing was published,⁵² but although many are in argument with the stance taken by Dickenson, the situation remains the same. Let us hope that common sense will prevail, and this case does not act to prevent any further disclosure of truth.

⁵⁰ Albeit that HD cannot be prevented, the symptoms can at least be ameliorated with medicine, knowledge and care.

⁵¹ Even if such information was not to be disclosed until children reached the age of 18.

⁵² Donna L Dickenson, 'Can Children and Young People Consent to be Tested for Adult Onset Genetic Disorders?' (1999) 318 *BMJ* 1063.