

The Law Of Consent In England As Applied To The Sick Neonate

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Abstract

“Paediatricians are vocationally committed to promoting children's health, treating their illnesses and saving their lives. There are, however, occasionally tragic circumstances in which we are forced to wrestle with dreadful choices”

Professor David Baum, Founding President, RCPCH

GENERAL PRINCIPLES REGARDING CONSENT

“It is a general principle that valid consent must be obtained before starting treatment or physical investigation”¹. This ethical concept is enshrined in law. Those who do not respect this principle open themselves to a variety of possible actions. These include possible sanction under the criminal law or an action for assault or battery under civil law. Furthermore negligence could be alleged if the treatment leads to harm. Finally an examination or treatment without consent may be the subject of a complaint through either the employing hospital's procedures or a professional body.

THE CONSENT PROCESS

For consent to be valid it must be given voluntarily by an appropriately informed person. The person giving consent must have mental capacity to understand the nature of the proposed treatment based on information given in broad terms. Furthermore the capacity must extend into an understanding of the consequences of not agreeing to the proposed treatment. Patients need not give reasons for their refusal. As Lord Templeman once said “a patient may refuse for a good reason, a bad reason or no reason at all”.

THE EXTENT OF INFORMATION TO BE GIVEN

There is a fine balance between giving too much information and not giving enough. If told of all the possible side effects then the patient might well refuse a treatment that is in their

best interests to receive. If not given sufficient information then the person has not been appropriately informed and the consent will be invalid.

The law of consent was discussed at length in the case of Mrs Sidaway.² Mrs Sidaway complained of pain radiating down her arm. She sought advice from an orthopaedic surgeon who told her that the pain would be relieved by a laminectomy and foraminectomy at C4. He told her that a possible side effect could be the severing of the nerve roots at C4, thereby causing Mrs Sidaway to have a paralysed arm. She consented to the operation.

In fact, a much rarer side effect occurred - the surgeon severed her spinal cord and rendered Mrs Sidaway paraplegic. Mrs Sidaway sued and claimed that had she known of this rare side effect then she would never have agreed to the operation. In an appeal to the House of Lords, their Lordships discussed the general principle of consent, and how much information a doctor should reveal to a patient as part of the consent process. In order for consent to be valid the doctor should inform the patient of information that a reasonable body of medical opinion would inform. It was stated that Mrs Sidaway should have been informed of any side effects, the risks of which were greater than 1%. However this figure was for the case of Mrs Sidaway and should not be used as general point. The extent of information to be given to a patient to allow informed consent should be that which the reasonable body of medical opinion would give. Clearly this will vary from procedure to procedure and possibly from patient to patient.

Another case shows how it is now expected that those obtaining consent provide reasons as to why they may have failed to inform a patient of a particular side effect. Tina Pearce was 42 weeks pregnant and attended an obstetric

outpatient clinic.³ There she was told by a consultant of the risks of a Caesarian section and he recommended that she wait. A week later the fetus had died. Mrs Pearce sued claiming that had she known of the risk of stillbirth, she would have insisted on having a Caesarian section. The consultant stated that his reason for not informing her of this risk was because it was small (0.2%) and that he did not wish to worry her unduly at the antenatal appointment. The court held that this course of action would have been carried out by a reasonable body of obstetricians, was logical and was thus acceptable. However in situations of a significant risk there would have to be a logical reason as to why a patient was not being informed.

FEATURES OF OBTAINING CONSENT: GOOD MEDICAL PRACTICE

The person with overall responsibility for the patient's care should obtain consent. Where this is not possible it may be devolved to another member of the team, but that person should have knowledge of the proposed treatment and its side effects in order to be able to properly inform the patient. Consent should not be seen as a one off event but more as an ongoing process. The consent process is not dependent on the filling out and signing of a form – this is merely one form of record that an appropriate discussion has taken place.

CHILDREN – WHO CONSENTS?

Statute law in states that the age of consent to medical treatment is 16.⁴ The case of Gillick gives clear guidance as to when a mature minor may be able to give consent, but is a case outside the scope of this review.⁵ Where a child lacks the capacity to consent, then the parents, or those with parental responsibility, may consent on behalf of the child. As with adults giving consent on behalf of themselves, the parents need to be informed in a similar way. The parents must have capacity to make the decision themselves and be given sufficient information to make an informed choice on behalf of their child.

THE CHILDREN ACT 1989

This piece of legislation marked a landmark change in the way the courts dealt with children. An essential principle was the end to the old style consideration of 'parental rights' and its replacement with 'parental responsibilities'. At the centre of this Act is the desire for the welfare of the child to be of paramount importance:-

s1. —(1) When a court determines any question with respect

to— (a) the upbringing of a child; or (b) the administration of a child's property or the application of any income arising from it, the child's welfare shall be the court's paramount consideration.

s3. —(1) In this Act "parental responsibility" means all the rights, duties, powers, responsibilities and authority which by law a parent of a child has in relation to the child and his property.

Since the Act came into force there are essentially three ways in which the courts can protect children – any one of these three methods may be used in order to seek permission to treat or to withhold treatment from a child: -

- via wardship – As Lord Donaldson once said this is based on "the duty of the Crown to protect its subjects and particular its citizens"
- via the inherent jurisdiction - under s100(3) the local authority that already has a child under its care may seek advice from the court.
- via special powers – under s8 specific orders can be made forcing or preventing an action.

WHO CAN HAVE PARENTAL RESPONSIBILITY ?

- the child's parents if married to each other at the time of conception or birth;
- the child's mother, but not father if they were not married unless the father has acquired parental responsibility via a court order or a parental responsibility agreement or the couple subsequently marry;
- the child's legally appointed guardian;
- a person in whose favour the court has made a residence order concerning the child;
- a Local Authority designated in a care order in respect of the child;
- a Local Authority or other authorised person who holds an emergency protection order in respect of the child.

Anyone with parental responsibility may consent to medical treatment on behalf of a child. In a situation of there being a

disagreement between more than one person with parental responsibility, then the consent of one is sufficient to carry out the proposed treatment.

In most situations there will be agreement between the multi-disciplinary team and those with parental responsibility. Consent is obtained as discussed and the treatment is carried out. However there may be situations when there is not agreement. The remainder of this review will bring together cases, demonstrating how the courts have dealt with these situations.

CASE LAW DEALING WITH SICK NEONATES THE EARLY 1980S

Two cases reached the courts in 1981 in what Professor Brazier describes as “a blaze of publicity”⁶.

The first was a civil law case involving a neonate called Baby Alexandra⁷. Interestingly no cases were cited in the judgement of Lord Templeman, who described the case as “a very poignantly sad case”. B had Down syndrome with duodenal atresia. Her parents, with great sorrow, refused consent for B to have surgery. They took the view that proceeding without the operation would be in the best interests of B. B was then made a ward of court and the court gave permission for the operation to take place. B was transferred to another hospital for surgery. The surgeon refused to operate when he discovered the views of the parents. The case came back to court in the morning by which time another surgeon, who was prepared to operate, had been found. On this occasion the judge revoked his previous order that had granted permission for surgery, and the local authority appealed. The case was then referred to the Court of Appeal in the afternoon, with judgement being given on the same day.

The question before the court was whether it was in the child's best interests to be allowed to die from intestinal obstruction within a few days, or have the operation and live for 20-30 years with the physical and mental disabilities of Down Syndrome. “It devolves on this court in this particular instance to decide whether the life of this child is demonstrably going to be so awful that in effect the child must be condemned to die, or whether the life of this child is still so imponderable that it would be wrong for her to be condemned to die ... the choice ... is this : whether to allow an operation to take place which may result in the child living for 20 or 30 years as a mongoloid or whether to terminate the life of a mongoloid child because she also has

an intestinal complaint”. B had her operation.

A few months later the criminal courts were to be involved over not dissimilar medical facts⁸. John Pearson was born in 1981 with Down Syndrome, and he died 69 hours after birth from pneumonia. Dr Arthur, a consultant paediatrician, was initially charged with murder. The prosecution alleged that having been told that the parents had rejected the baby, Dr Arthur had ordered “nursing care only” and had prescribed an appetite suppressant drug so as to starve the baby to death. The prosecution further alleged that apart from the Down Syndrome, John was otherwise well and he died as a result of Dr Arthur's measures making him susceptible to pneumonia.

The defence were able to establish that John also suffered from severe brain damage and lung damage. Furthermore the defence were able to establish that Dr Arthur's management was an accepted medical practice, and that as babies are expected to lose weight in the first three days of life, he did not starve to death. The judge pointed out to the jury that there “...is no special law in this country that places doctors in a separate category and gives them special protection over the rest of us...”. The judge directed the jury that they had to be convinced that the steps taken by Dr Arthur were to cause the death of John Pearson. The jury acquitted Dr Arthur.

It should be noted that if a doctor prescribes a drug with the deliberate intention of hastening death then this will amount to murder. However the case of *R v Adams*, established that faced with a dying patient a doctor may prescribe drugs that shorten life, if the purpose of the prescription is to alleviate suffering or perform some other recognised treatment. There may well be situations that a drug prescribed for the purpose of relieving symptoms or some other treatment does indeed shorten life. As Devlin J said “...if the first purpose of medicine – the restoration of health – can no longer be achieved, there is still much for the doctor to do, and he is entitled to do all that is proper and necessary to relieve pain and suffering even if measures he takes may incidentally shorten life.”

THE LATE 1980S

The law was clarified by two cases both adjudicated by the then Master of the Rolls, Lord Donaldson.

The first involved a neonate suffering from severe hydrocephalus¹⁰. At 16 weeks her body size was that of a 4 week baby. The court heard that it was inevitable that she would die within a couple of months. The issue before the

court was whether, should it become necessary, she should be fed nasogastrically or given intravenous antibiotics. The view of the court was that the medical team should not be obliged to treat the baby in any way, but that the treatment should be directed at relieving the baby's suffering "... the hospital authority be at liberty to treat the minor to allow her life to come to an end peacefully and with dignity."

The second involved a premature neonate J, born at 27 weeks₁₁. The baby was thought to be blind, deaf and likely to be paralysed. He had already been ventilated twice. Medical opinion was that a further episode of ventilation would be fatal. The hospital obtained an order from a judge that if the baby collapsed again he would not be ventilated. An appeal was made to the Court of Appeal. The Court of Appeal held that this was a situation where a child suffered from such disabilities that his life would, from his point of view be so intolerable if he were to continue living that he would choose to die if he was in a position to make a sound judgement. In such a situation, if a child would die from natural causes without a particular treatment, that treatment need not be given. However the court would never sanction positive steps that would shorten a person's life.

The case of J thus produced a situation where the court was prepared to examine the best interests of the future life of the child through substituted judgement.

Lord Donaldson commentated on the relative roles of doctors, parents and the courts. "The doctors owe the child a duty to care for it in accordance with good medical practice recognised as appropriate by a competent body of professional opinion. The duty is, however, subject to the qualification that, if time permits, they must obtain the consent of the parents before undertaking serious invasive medical treatment. The parents owe the child a duty to give and withhold consent in the best interests of the child and without regard to their own interests. The court when exercising ... jurisdiction takes over the rights and interests of the parents, although this is not to say that the parents will be excluded from the decision-making process. Nevertheless in the end the responsibility for the decision whether to give or withhold consent is that of the court alone."

In their part, according to Lord Donaldson, the courts would examine the proposed treatment from the point of view of the handicapped patient – "even very severely handicapped people find a quality of life rewarding which to the unhandicapped would seem manifestly intolerable. People have an amazing adaptability. But in the end there will be

cases in which the answer must be that it is not in the interests of the child to subject it to treatment which will cause increased suffering and produce no commensurate benefit"

THE 1990S

These later cases were seen in the light of the Children Act 1989, whose provisions came into effect in April 1992. The first two cases appeared before the then President of the Family Division, Sir Stephen Brown, and both involved babies called C.

The first C was born at 32 weeks and developed meningitis₁₂. She had brain damage leading to seizures and required continuous mechanical ventilation. Expert evidence suggested that the child suffered pain and distress. The issue was whether the ventilator should be switched off. Four independent paediatric consultants had examined C and all concluded that the machine should be switched off. As C was a ward of court the court was asked for consent: "The courts do not instruct doctors how they should perform their clinical and professional duties. However, the courts are ready to assist with the taking of responsibility in cases of grave anxiety such as this case ... it is quite clear ... that the doctors ... all consider that it is in the best interests of this little baby that she should now cease to be artificially ventilated."

He further added, " ... it has been suggested that I should make observations as to when it is appropriate for doctors ... to seek the leave of the court. It would not be appropriate, in my judgement, to make any general observation ... each case must be considered on its own merits."

The second C₁₃ was born later the same year with spinal muscular atrophy, type 1. C was deteriorating and had been an in-patient requiring IPPV for two months. The medical team felt that it was not in the best interests of C to be ventilated further. C's parents were Orthodox Jews who had not consented to the treatment plan. An independent paediatric neurologist had examined C and agreed with the medical plan. The parents arranged for two further experts to review C – both of whom also agreed that it was not in the best interests of C to be further ventilated. The case was the first to analyse the situation of a sick child in the light of the Royal College guidelines detailed below₁₄.

In this case Sir Stephen Brown again invoked the principle that the court seeks the best interest of the child : "...in this desperate situation it is in the best interests of C that she

should now be taken off the ventilation...and that it should not be reimposed or restored if she should suffer further respiratory arrest. It is a desperately sad situation for all concerned. The anxiety of the doctors as well as the parents can be well understood. Their objective in their profession is to save and to preserve life but, as has been said in earlier cases that whilst the sanctity of life is vitally important, it is not the paramount consideration. The paramount consideration here is the best interests of little C”.

This last case of the 1990s demonstrates a similar approach but with a very different result. In this case the Court of Appeal considered that the best interest of the child lay in acquiescing to a parental refusal of treatment. T was born with biliary atresia¹⁵. An attempted Kasai procedure was carried out, but failed, when T was 3 weeks old. The mother's view was influenced by the pain and distress caused to T by the Kasai operation – both she and the father had decided that if the Kasai operation failed then they would not consent to T having a liver transplantation. T was nevertheless referred to a liver transplantation unit, and found to be a suitable candidate. It was considered that with the surgery T could look forward to many years of life with normal growth and the only treatment being immuno-suppressive drugs. T was placed on the transplant list and a suitable donor was found. However T had been taken by his mother to live with her father in a commonwealth country where no transplant facilities existed. No contact could be made and T missed this opportunity.

The local authority in England involved their child protection team, and a local visit in the commonwealth country was made. T was found to be well and happy. When T returned with his mother to England he was again referred for transplantation. Again his mother refused. The consultant took the view that owing to her previous job as a nurse the mother was unusually well informed and had taken the decision to refuse consent out of love for T and that this refusal should be respected. T then returned to live abroad with both his parents. The liver transplantation unit found a surgeon willing to operate. The local authority then applied to the court seeking a declaration that T be returned to the UK and be given the transplant. The judge agreed to this and the mother appealed to the Court of Appeal.

Lady Justice Butler-Sloss considered that it was not in the child's best interests to be forcefully returned to the UK and have the transplant. “To prolong life...is not the sole objective of the court and to require it at the expense of other considerations may not be in the child's best interests. I

would stress that, on the most unusual facts of this case with the enormous significance of the close attachment between mother and baby, the court is not concerned with the reasonableness of the mother's refusal to consent but with the consequences of that refusal and whether it is in the best interests of T for this court in effect to direct the mother to take on this total commitment when she does not agree with the course proposed.”

CASE LAW SINCE THE HUMAN RIGHTS ACT 1998

The Human Rights Act came into effect in October 2000. The relevant provisions are :-

ARTICLE 2 - RIGHT TO LIFE

Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law.

ARTICLE 3 - PROHIBITION OF TORTURE

No one shall be subjected to torture or to inhuman or degrading treatment or punishment.

There has been little testing of the Human Rights Act and how this will effect the law surrounding resuscitation. Many legal commentators feel that there will be little effect, and the case of *NHS v D* would suggest that this is the position¹⁶. Baby I was born prematurely and required prolonged ventilation for 50 days. He had severe brain, lung and hepatic damage. He had severe developmental delay. He was discharged home at nine months on continuous oxygen, but had been readmitted twice for two further periods requiring ventilation. Two hospital paediatricians felt that it would not be in I's best interests to be further resuscitated should he so need – a view with which an independent paediatrician concurred. All thought that I had a life expectancy of less than twelve months. His parents refused to consent to the Do-Not-Resuscitate order. The hospital sought a declaration that I not be further ventilated. The judge granted the order giving four principles that should be met :-

- The court's prime and paramount consideration must be for the best interests of the child
- The court had a clear duty for respect for the sanctity of human life
- A course aimed at terminating life or accelerating death could not be approved

- There could be no question of a court directing a doctor to provide treatment which the doctor was unwilling to give and which was contrary to that doctor's clinical judgment.

The declaration was granted. There was no infringement of article 2 as article 3 provided that the lack of treatment was in I's best interests as this article provided a right to die with dignity.

ROYAL COLLEGE OF PAEDIATRICS AND CHILD HEALTH (RCPCH) GUIDELINES (CHAPTER 3 PP19 – 20)

3.1 Consideration of withdrawal

In general the outcome for a clinical problem at the time of presentation is uncertain. The team must wait until enough facts (not feelings) are available to enable a clear decision on whether or not further treatment is available. All remediable causes for a child's condition must be excluded e.g. drugs, metabolic encephalopathy.

3.1.1 Decision making

...All members of the Health Care Team should be involved in the treatment plan based on their experience and perspective. Decisions should be made with the parents, on the basis of knowledge and trust. The clinical team has a legal and a moral duty to carry out this task, which in general should not be given to an independent body, such as an 'ethics committee'...

3.1.2 Second Opinion

Other major medical life decisions require a second opinion for legal reasons as well as clinical assurance e.g. termination of pregnancy, brain stem death. Perhaps this should be adopted for withdrawal of treatment...

3.1.3 Circumstances of withholding or withdrawing life saving treatment

The Brain Dead Child [Footnote to document - Definition : Brain death occurs when a child has suffered either (1) irreversible cessation of all functions of the entire brain or (2) irreversible cessation of all functions of the entire brain including the brain stem. A determination of death must be made in accordance with accepted medical standards¹⁷.]

Within the patient organs may function due to the extraordinary medical assistance: such assistance can appropriately be withdrawn. Brain death must be diagnosed

in the usual way by 2 medical practitioners.

The Permanent Vegetative State [Footnote to document – Definition : A state of unawareness of self and environment in which the patient breaths spontaneously, has a stable circulation and shows cycles of eye closure and eye opening which simulates sleep and waking, for a period of 12 months following a head injury or 6 months following other causes of brain damage.] The permanent vegetative state may follow insults such as trauma and hypoxia. The child or adult in such a state is reliant on others for all care, and does not react with the outside world. In such circumstances treatment, inclusive of tube feeding may be withdrawn whilst making the patient comfortable with nursing care.

The No Hope/Chance Situation Treatment is delaying death; it is not improving life quality or potential. There is no legal obligation for a doctor to provide and medical treatment if it is not in the best interests of the patient. Indeed, if this is done knowingly (futile treatment) it may constitute an assault.

The 'No Purpose' Situation If a child experiences such a degree of impairment that it would not be reasonable to expect him or her to bear it, then it is appropriate to withhold or withdraw treatment. Here the RCPCH envisage an 'impossibly poor life' either in the future, in which case treatment might reasonably not be initiated, or in the present with the likelihood of it continuing with no reasonable improvement, in which case treatment might reasonably be withdrawn. For instance this would apply to the newborn infant with profound neurological damage following severe asphyxia where microcephaly, profound development delay, blindness and quadriplegia are believed to be inevitable.

The Unbearable Situation This situation occurs when the child and/or family feel that further treatment is more than can be borne and they wish to have treatment withdrawn or wish to refuse treatment irrespective of medical opinion on its potential benefit, e.g. oncology patients who are offered further treatment.

3.1.4 Palliative care

Where treatment aimed at alleviation or cure of a condition has been withdrawn, the clinical team has a duty to offer palliative care...

DISCLAIMER

This article is review of legal principles. It does not constitute legal

advice and should not be used as such. This review pertains specifically to English law and presumptions should not be made regarding applicability to the law of other jurisdictions. As with all medico legal issues, each should be examined on a case by case basis.

Conflict of interest: None

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