Children and Consent to Medical Treatment
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I am going to talk to you today about the law around children and their autonomy in relation to their medical care, particularly very unwell children who refuse treatment. Let me start with an example.

So, imagine you are the judge on call and a hospital comes to you with a terrible dilemma. They are treating a very ill child, only 15 years old, 15 years and 10 months to be precise. He has leukemia, a type of cancer, and he needs medications to help him hopefully get better. If he has these conventional treatments, there is an 80% to 90% chance he will go into full remission. There's an alternative treatment but will give him only a 60% chance of remission.

But there's a problem. Taking some of the conventional medicines will mean he will need transfusions of blood from time to time, and he (and his family) has made it clear that he does not want a transfusion, because it is against his faith as a Jehovah's Witness to accept the blood of another person into his body. The hospital has respected this and gave him the alternative treatment instead.

Two weeks later, it isn't working well enough and the hospital fears that the small amount of progress he's made won't be sustained if this course of treatment continues. His chances have dropped to 40% or 50% and if his hemoglobin levels fall any further, he might suffer a stroke or blindness, or even a heart attack.

The hospital is deeply worried and applies to you as the judge to give them permission to give him the conventional treatment and, if needed, blood transfusions.

You are faced with a seemingly impossible choice. Do you respect this eloquent, thoughtful, brave boy… perhaps we might be close even to calling him a young man… so committed to his faith… do you respect his choice that he so strongly wants to make, knowing full well it will cost him his life?

Or do you decide that no, he is too young, too much a child, however competent he may be, however considered in his thinking, and his choice cannot be respected if it will end his short life. Do you decide to give the doctors the permission to go ahead with the transfusion if they think it is best?

This is precisely the position in which Mr Justice Ward found himself, one September day in 1991, in what we now refer to as the *Re E* case.[1] And it is these kinds of cases that I want to explore with you here today.

What did he decide to do? Well, let's wait a little and see…

Introduction

So, welcome to the first in my series of lectures on some topics in medical law. Before I begin, I want to tell you a bit about how I intend to approach these three lectures, each of which concerns a controversial topic. First, I don't intend to try to convince you I'm right about what the law should do. I do intend to explain the law and the issues to you, and give you some ways of thinking about them, and then hopefully give you both the knowledge to form your own opinions. I want to do this because the topics I cover are ones that potentially concern us all, and they're ones on which people clearly have strong views, because they raise complicated ethical questions about how the law should regulate some very personal aspects of our lives. And in the

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[1] *Re E (A Minor) (Wardship: Medical Treatment)* [1992] 2 FCR 219.

question time, I want to hear your views, because I think we make the best law in medicine by, amongst other things, listening to the community about people's standards, experiences, moral positions, and I always want to feed what I learn about people's actual thoughts into my work.

Now, when I planned my lecture series, in this first lecture I had intended to talk to you about the very specific topic of how doctors (and parents) should talk to their children about illness, and particularly what should happen if parents and doctors disagree about what a child should be told. I promise you I will still talk about this, however, since then, a number of particularly fascinating cases on children and decisions about medical treatment have been decided, so if you'll forgive me for perhaps mis-selling, I'd like to broaden out to talking about children and decisions about their healthcare more generally – specifically their rights, their capacities (including their capacity to take on board and use information), how we respect their views, how we protect them and how sometimes we fail to allow them their say. But I shall weave through this the question of what we need to tell children to enable them to make decisions and how the law deals with this. And throughout this discussion, I want to get you thinking about the bigger question of to what extent we should allow children their autonomy in relation to their medical care, and whether the law needs to change.

Treatment, Consent and Information: Adults

To understand how the law regulates decisions about children and medical care, we first need an idea of how the law approaches medical decision-making in adults – as the approach to children sits within this wider general framework.

Doctors are under legal duties to their patients, and we think of them as having this duty because they have assumed responsibility for a patient once they accept them into their care. This is important, because it means the doctor is responsible both for her actions and her *failures* to act, which can include a failure to provide information, or more usually, warn of the risks of a procedure or outline alternatives. Doctors are held to both professional standards and legal standards. The law requires that the doctor requires consent to perform procedures that involve anything that interacts with the patient's body (more on this later), and they must meet the standard of a *responsible doctor* or they may be liable in negligence.

This standard, which derives from McNair J's direction to the jury in the case of *Bolam v Friern Hospital Management Committee*,[2] requires doctors to act (or refrain from acting) in accordance with a 'responsible body of medical opinion'. This standard means that the medical profession, rather than the courts, determines what is appropriate medical practice, but this is moderated to a degree now by what is often called the '*Bolitho* gloss' (after the very tragic case of *Bolitho v Hackney Health Authority*) which requires the court to be satisfied that the body of opinion has a logical basis, and in particular, that in forming this opinion, the experts have 'directed their minds to the questions of comparative risks and benefits and have reached defensible conclusion on the matter'.[3] A failure to meet this standard, which then causes harm to the patient, will mean that the doctor has been negligent (and will likely also face professional sanction).

In meeting this standard, a doctor will *offer* options to the patient which must be non-negligent options, and the patient is given the space in which to *choose* what he or she wants to do --- they can *consent* to a particular option or refuse it (or refuse all of them). Patients cannot, however, demand to be given a particular treatment,[4] and doctors cannot be compelled to offer treatments they do not consider to be in a patient's best interests.

Now we come to questions of autonomy, capacity and information provision. A adult who has capacity (and adults are *presumed* to have such capacity) is permitted to make his or her own decisions about medical treatment, including refusing treatment even if their decision is unwise, unreasonable or will result in injury or death.

Only if the adult lacks capacity will a decision be taken for them, and even then they will be involved in that decision as far as is possible, and their wishes accounted for as much as can be. An adult will only be considered to lack capacity if, in accordance with Section 3(1) of the *Mental Capacity Act 2005* (MCA 2005), they are unable—

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[2] *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582 per McNair J.

[3] *Bolitho v Hackney HA* [1997] 4 All ER 771 (Lord Browne-Wilkinson at 242).

[4] *Re Burke (on the application of) v General Medical Council & Ors* [2005] EWCA Civ 1003

a) to **understand** the information relevant to the decision,

b) to **retain** that information,

c) to **use or weigh** that information as part of the process of making the decision, or

d) to **communicate** his decision (whether by talking, using sign language or any other means).

Capacity will be lost if, according to section 2(1),:

> at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.

If this is the case, another authorised person can make the decision on their behalf in their best interests (Section 1(5) MCA 2005).

Very importantly for our discussion is Section 1(4):

4) A person is not to be treated as unable to make a decision merely because he makes an unwise decision.

This does not mean the fact that a person is wanting to make an unwise decision (it may be a relevant consideration in determining whether, on the facts, the person actually lacks capacity). But the mere fact that the decision is one others would not make is not, in and of itself, a basis to declare a lack of capacity and override the patient's autonomy to make a decision on their behalf. We will return to this principle when we considered older children and young people.

Treatments and procedures cannot be performed on an adult without their consent, and for that consent to be valid and effective, it must be *informed.* There are two main legal avenues for addressing a lack of consent, and both have different informational requirements. There is no free-standing legal *right* to information in medical care as such, rather a failure of information will be dealt with via one of these two avenues relating to consent.

First, is via the law on battery. 'Battery' refers to a direct and intentional bodily contact without consent, although consent cannot render any and every touching lawful.[5] Very serious, harmful touchings, that is 'grievous bodily harm', cannot be defended as lawful simply because the victim consented, and this matters in the context of medicine, and treatments like surgery are effectively the same as cutting someone with a knife – a grievous harm which consent alone would not make lawful most likely. In the medical context, it is the patient's consent plus the fact that the act is a 'reasonable' bodily interference (because it treats the patient's illness) that brings it within the public interest exception to the position that consent is not a sufficient defence alone to the infliction of grievous bodily harm.[6]

For consent to a responsible medical procedure to be sufficient to render the touching lawful, the patient must understand the nature of what is to happen and why. To be sufficient, it must be *real* ---the patient must be consenting to what is actually done, either in terms of the exact act, or some important aspects of the act, including the doctor's *intentions.* So, if the patient consents to having an amputation of her foot, but her hand is removed, obviously consent will not render that lawful. But it can also be the case that the *act* is the same, but some other element is not what the patient thought they were consenting to. A good example is the case of *R v Tabassum*, in which a man told a series of women he was a doctor and convinced the women to allow him to teach them how to perform a breast self-exam on this basis. This consent was not real because it was founded on a misrepresentation about his identity --- he was not a doctor --- and the women consented only because they believed that he was in fact a doctor. Consequently, he was convicted of sexual assault.

For consent to be sufficient, then, the patient need only have been informed accurately of the nature and purpose of the procedure. This threshold is relatively low, and hence most cases of failure to disclose information are dealt with via the second avenue --- negligence, which is better suited to instances where

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[5] See, eg, *Chatterton v Gerson* [1981] 1 All ER 257. There is some debate as to whether it is part of the definition of battery that it occurs without consent (ie that lack of consent is an element of battery) or whether the relevance of consent is as a defence. See further, eg, E Cave and C Purshouse, 'Think of the Children: Liability for Non-Disclosure of Information Post-*Montgomery*' (2019) 28(2) *Medical Law Review* 270.

[6] See, for example, Lord Mustill's explanation of this approach in *R v Brown* [1994] 1 AC 212 and also in *Airedale NHS Trust v Bland* [1993] AC 789.

the patient knows the essential nature and purpose, but important information may not have been conveyed. Under negligence, a doctor will be in breach of his or her duty of care if he or she *ought* to have told the patient something, and did not, and this failure then can be causally linked to the harm (usually, because the patient can show that had she known the information, she would not have consented to the procedure and so would have avoided the harm).

How Much Information Must Adults Be Given?

Now we get to an issue that is relevant to how we talk to children, and which has been an area of change in the law recently. For many years, the law took a 'doctors knows best' approach to what information should be given to patients. Deciding which risks to disclose is part of the doctor's general duty of care.[7] For some time, the '*Bolam* test' approach was also applied to decisions by doctors about what information they should provide to patients. By and large, if a responsible body of medical professionals would not have disclosed a particular risk or piece of information, then it was not negligent to withhold it from a patient.

There was, however, some judicial opinion that some risks *ought* to be disclosed regardless, due to their seriousness, or because the patient wanted to know about particular risks, and over time the courts moved away from this approach, culminating eventually in the Supreme Court decision in *Montgomery v Lanarkshire Health Board* in 2015. In that case, the Supreme Court tackled head on the question of whether a doctor would be negligent if she withheld information about a risk because in her clinical judgment it was better for the patient not to inform them. The Supreme Court were unanimous that this was a breach of duty, and broke firmly away from the *Bolam* approach to risk disclosure in holding that a medical professional. They declared that

> An adult person of sound mind is entitled to decide which, if any, of the available forms of treatment to undergo …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.[8]

The test for materiality of a risk is, the majority went on,

> 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.[9]

This then requires doctors to disclose risks that they believe a person *like* the patient would want to know (the 'objective' part) and also risks they think the *actual* patient would want to know (the 'subjective' part). Of course, you could say how could they know what those are? Much has been written about the problems with the subjective aspect, as it suggests that the more proactive, confident patient will be told more than the nervous, reticent, intimidated patient, which is of course problematic.[10] The solution is in part that they can extrapolate from what they do know, but there is where the ethics guidance comes in as well as much of what was said in the case. While *Montgomery* is a *legal* shift, as much of the professional guidance pointed out in its wake, the shift meant the law moved much more in line with what was already considered good clinical practice[11] --- that doctors should be in a dialogue with patients, and work to discern what their values and beliefs are, should listen closely and then try to see what risks they the particular patient cares about. They should encourage the patient to ask questions.

This approach has the additional dimension of what is called the 'therapeutic exception', which permits the doctor to withhold information and not breach her duty, if she believes that giving the information to the patient will cause them serious harm. Importantly, this harm cannot be the harm that they would suffer if they decided *not* to have the treatment due to the disclosure of the risk --- so they cannot say "if I told them, they would refuse the treatment and then their disease would worsen and this would be harming". It must be a

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[7] *Sidaway v Board of Governors of the Bethlem Royal Hospital* [1985] AC 871.

[8] *Montgomery v Lanarkshire Health Board* [2015] UKSC 11 [87].

[9] *Montgomery* [87].

[10] Margaret Brazier, 'Patient Autonomy and Consent to Treatment: The Role of the Law?' (1987) 7 *Legal Studies* 169-93.

[11] See, eg, British Medical Association, *Consent and refusal by adults with decision-making capacity A toolkit for doctors* (2019), 9.

harm of another kind – physical or mental. Put another, the harm cannot simply be the harm that might flow from a refusal of the treatment. This is what the Supreme Court meant when it said the therapeutic exception is not to be used to withhold information so that the patient will agree to the treatment that the doctor thinks is in her best interests. This was in fact exactly what had happened in *Montgomery* and the Supreme Court made it clear that the defendant doctor had breached her duty in withholding information for this reason.

This, then, then is the information requirement for adults with capacity, and a failure in disclosure will be a breach of the doctor's duty of care.

So that, in quite a large nutshell I'm afraid, is how the law deals with adults in the context of medicine. They can make up their own minds, but they need to have sufficient information to do so, and if that is not provided, then the doctor will be liable for harms they suffer. We assume they are competent unless there is evidence to the contrary, and if they are, we leave them to the consequences of their own decisions. There are people who believe this approach is wrong, that we should be more paternalistic but that's a debate for another lecture another day.

Considering whether we should be 'paternalistic', is however, an appropriate segue into what we are really interested in today --- how children fit into all of this.

The best way to approach this is to break it down into three groups, as the law approaches it that way. These groups break down by capacity, because as children age we know that their ability to understand information and make choices increases. The law recognises three classes of children in this context – those who don't (and won't be found) to have capacity; those who *might* be found to have it; and those who are presumed to have it.

Decisions about Very Young Children

The first group are children who are so young, that there is no chance that they can be considered competent to make their own decisions. This includes pre-verbal children and those in early childhood. With such children, the parents have the authority to consent on her behalf. As Lord Scarman put it in *Gillick:*

> 'It is abundantly plain that the law recognises that there is a right and a duty of parents to determine whether or not to seek medical advice in respect of their child, and, having received advice, to give or withhold consent to medical treatment'[12]

But those 'rights' are better seen as responsibilities and are contingent on being exercised in the child's best interests. Lord Fraser was clear on this in *Gillick:*

> "Parental rights to control a child do not exist for the benefit of the parent. They exist for the benefit of the child and they are justified only in so far as they enable the parent to perform his duties towards the child, and towards other children in the family."[13]

And Lord Justice Ward made a similar point fifteen years later in *Re A* when he said:

> parental authority "exist[s] for the performance of their duties and responsibilities to the child" and hence "must be exercised in the best interests of the child".[14]

Where a parent is alleged not to be making a decision in the child's best interests, there are a range of legal avenues by which the court can be called upon to make a determination on what should happen.[15] We won't go into those complexities here, but either via the *Children Act* or via its 'inherent jurisdiction' the court's authority can be invoked. As Justice Francis put it in the Charlie Gard case,

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[12] *Gillick v. West Norfolk and Wisbech Area Health Authority* [1986] AC 112, per Lord Scarman
[13] *Gillick v. West Norfolk and Wisbech Area Health Authority* [1986] AC 112 at p 170 (Lord Fraser)
[14] *Re A (Children) [2001] 1 Fam 147 (HL)*, Lord Justice Ward.
[15] See, eg, *Portsmouth Hospitals NHS Trust v Wyatt* [2005] EWCA Civ 1181.

> although the parents have parental responsibility, overriding control is by law vested in the court exercising its independent and objective judgment in the child's best interests.[16]

This most often happens when the medical professional caring for the child is concerned that the parent's decision is not best for the child. When the court makes a decision, it must regard the welfare of the child as paramount, look at the situation from the point of view of the child, and tends to strongly lean towards a course of action that will prolong life (though this presumption is rebuttable). 'Best interests' encompasses medical, emotional, and all other welfare issues, and the court conducts a 'balancing exercise' to determine what is best.[17] This is what happened in the recent series of cases involving disputes between parents and doctors, where the child was too young and not competent to have any say at all, such as the cases of Charlie Gard, Alfie Evans and Tafida Raqeeb.

Talking to Children about Illness

But just because a child is very young and is not competent to make decisions, does not mean that we should to talk to them about their illness. We turn now to how clinicians approach talking to children, before moving on to those older children where the interaction between what we tell them, how we approach their competence, and the extent to which we respect their autonomy interact.

One of the really important things to understand about how medical practice is regulated, is that this is done via a combination of law and professional regulation and guidance, that essentially the medical profession in part polices itself, but also provides its members with guidance on how to manage patient care and interactions. This holds true for children and how medical professionals provide information about their diagnosis, the nature of their condition and their treatment options.

As we've seen briefly, the law requires medical professionals to provide information not so much because people have a 'right' to information *per se*, but as part of the process of obtaining consent to treat. But setting this aside for a moment, we can think first about how the medical profession directs itself to talk to children. There are a range of sources of professional guidance for doctors and other medics about how to communicate with children, and these include policy documents, ethical guidance and 'toolkits', that have practical, nuts-and-bolts advice. All of these take a very similar approach.

One of the key principles we can distil this plethora of guidance is that effective communication is considered essential to the provision of good care.[18] So, while as we will see in more detail later, information provision is necessarily tied up with the wider question of consent, it is also in and of itself an important element of caring for children who are ill and making the best decisions for and with them. As the Royal College of Paediatrics and Child Health has commented,

> Optimal ethical decision making requires: open and timely communication between members of the healthcare team and the child and family; respecting the values and beliefs of those involved; and the application of fundamental ethical principles, including respect for human rights.[19]

All of the professional guidance stresses that children and young people should be kept as fully informed as they wish, and as is possible, about their care and treatment.[20] What children are told, however, should be adapted for their age and competence, and should be delivered in in a form that the child can understand, and at a pace that allows them to take in what they are being told. They should be given the chance to ask questions, and these should be answered honestly.

The BMA, in adult guidance that is likely to inform doctors who are working with older children and young people, emphasises that providing information should not been as simply a matter of handing over hard cold facts, but rather should, the BMA explains, be a dialogue, in which patients are encouraged to ask questions, and are given time to reflect. Doctors providing information should also take the time to 'understand the

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[16] *Great Ormond Street Hospital v Yates [2017]* per Francis J.

[17] See variously: *Portsmouth Hospitals NHS Trust v Wyatt* [2005] EWCA Civ 1181; *Re J; Re A.*

[18] General Medical Council, *0–18 years: guidance for all doctors* (2018, 2nd edition).

[19] Royal College of Paediatrics and Child Health, *Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice* (V Larcher et al, Arch Dis Child 2015, 100 (Supp 2) s1-23, s12.

[20] See, eg, British Medical Association, *Children and Young People Tool Kit* (2010), 5.

patient's values, wishes and knowledge of their own condition' during these discussions.[21]

This guidance applies to all children, so even though the law itself does not direct or require children to be informed (when they are not giving consent), professional practice does require it, which in effect means that doctors will be speaking to children about their illness.

But how much must children be told to be able to consent? Because as we shall see shortly, some children *can* give legally valid consent to treatment on their own behalf, but this then raises questions about *what* they need to be told and whether the standards that apply to adults (the *Montgomery* standard) apply to children.

Before we move on to this, however, we should briefly note that it is not considered good clinical practice to *withhold* information from children when they are ill. The GMC, for example, makes it clear that information should not be withheld from children or young people unless:

> a) it would cause them serious harm (and not just upset them or make them more likely to want to refuse treatment)
>
> b) they ask you to, because they would prefer someone else to make decisions for them.

The question, of course, is what constitutes 'serious harm' in practice, and how do doctors navigate this. This 'serious harm' approach is similar to the 'therapeutic privilege' caveat in *Montgomery*, and for young children who are not consenting to treatment themselves, there will be a fair degree of scope to make a decision on their welfare. However, for older, potentially competent children, the picture becomes murkier. But we will return to this issue once we have a clearer understanding of how the law approaches children who have the capacity to make decisions for themselves.

Treatment of Young People: Consent and Capacity

At the other end of the spectrum from these children who are too young to give their consent to care are those children who, by virtue of their age, are *presumed* to be competent. Section 8 of the *Family Law Reform Act 1969* states that

> 1) The consent of a minor who has attained the age of sixteen years to any surgical, medical or dental treatment which, in the absence of consent, would constitute a trespass to his person, shall be as effective as it would be if he were of full age; and where a minor has by virtue of this section given an effective consent to any treatment it shall not be necessary to obtain any consent for it from his parent or guardian.[22]

Let's unpack this. It says two things. First, that a young person (the term usually used for children who are 16 or 17 years old), can give consent *that is as effective as that of an adult*. This means that consent by a young person will, if informed, operate in the same was as the valid consents made by adults to bodily interferences do. So, if a parent doesn't give consent, it would seem the child can instead and this will be sufficient. Such children are regarded as presumptively competent Therefore, unlike with those children whose capacity must be tested (which we will come to in a moment), there is no need to test 16 and 17 year old children for competence.

But that section *also* says that:

> 3) Nothing in this section shall be construed as making ineffective any consent which would have been effective if this section had not been enacted.

This section has been the subject of intense judicial and academic debate about its precise meaning and effect. Why? We'll get to that soon, but for now, what I can say it that the dominant interpretation in the courts has been that this section *preserves the right of parents to consent when the child does not*. So, if the child

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[21] British Medical Association, *Consent and refusal by adults with decision- making capacity A toolkit for doctors* (2019), 9.

[22] 'Treatment' includes diagnosis and procedures associated with treatment such as anaesthesia, but it does not include decisions about *non-therapeutic* procedures, such as organ donation and participation in research. For such decisions, the *Gillick*-competence requirement applies: *Mental Capacity Act Code of Practice*, 216.

has not consented (perhaps they don't want to make a decision, or they are unconscious), this would mean that there is an alternative person who can tell the doctor 'yes, do go ahead with the procedure'.

As they are presumed to be capacitous, most of the provisions of the *Mental Capacity Act* 2005 (MCA) therefore apply to 16 and 17 year olds,[23] particularly the general principles which inform that Act's provisions.

Before we move, let's recall two things about how the law approaches *lack of capacity in adults.* First, that an adult (and so presumably a young person) will be found to *lack* capacity and so a decision may be made for them in their best interests, if they cannot understand, retain and weigh the information needed to make the decision. And remember too that capacity will be lost if, according to section 2(1):

1) at the material time he is unable to make a decision for himself in relation to the matter *because of an impairment of, or a disturbance in the functioning of, the mind or brain.*

Second, under the MCA 2005, let's remind ourselves that section 1(4) states that:

4) A person is not to be treated as unable to make a decision merely because he makes an unwise decision.

These provisions *should* apply to young people if the MCA 2005 applies to them as it appears it does.

I want you to keep these points in mind when we move into some of the more difficult cases involving children soon.

Treatment of Older Children: 'Gillick competence'

Sitting between these presumptively competent children and child too young to make decisions are those who *might* be legally competent if are deemed to have sufficient capacity. Such children can can give consent to a treatment decision that will be sufficient to protect a doctor who (responsibly) offers that treatment, even if a parent objects. Children in this category are referred to as *Gillick*-competent if they are have the capacity to make such decisions.

The term '*Gillick*-competence' derives from the case of *Gillick v West Norfolk and Wisbech AHA*, and it is worth spending a little time talking through the facts and decision in *Gillick* to understand the law as it now stands. Mrs Gillick was the mother of five girls and she was concerned that contraceptive advice or treatment might be given to one of her daughters before they reached 16 years old, and that she might neither be told nor given the opportunity to withhold consent. In a Memorandum of Guidance, the Department of Health and Social Security had stated that a doctor could, in some circumstances, give such advice or treatment to under-16s without parental consent. Mrs Gillick wanted the health authority to agree that her daughters would not be given such advice or treatment without her consent, but the health authority refused to do so. Mrs Gillick brought a challenge against the Memorandum of Guidance as being unlawful. The matter made its way all the way to the House of Lords, where the Memorandum was upheld.

In considering the case, their Lordships explored what a doctor could do in such a situation. Lord Fraser discussed the situation from the perspective of what was in the child's best interests, within which he touched upon the child's ability to understand.[24] Lord Scarman, however, went substantially further, and considered the issue from the perspective of whether a child could be sufficiently competent such that she could give lawful consent to the receipt of the advice or treatment.

> I would hold that as a matter of law the parental right to determine whether or not their minor child below the age of 16 will have medical treatment terminates if and when the child achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed. It will be a question of fact whether a child seeking advice has sufficient understanding of what is involved to give a consent valid in law. Until the child achieves the capacity to consent, the parental right to make the decision continues save only in exceptional circumstances.[25]

Over time, Lord Scarman's approach has been adopted in numerous cases. The test is not one of age, but of whether the individual child has the ability to understand what is proposed. As Lord Donaldson put it in *Re*

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[23] Children under the age of 16 are excluded: MCA s.2(5).

[24] *Gillick v West Norfolk and Wisbech AHA* [1986] 1 AC 112, 174 (per Lord Fraser).

[25] *Gillick v West Norfolk and Wisbech AHA* [1986] 1 AC 112, 189 (per Lord Scarman).

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> What is really being looked at is an *A* assessment of mental and emotional age, as contrasted with chronological age.[26]

The courts have given added details as to what constitutes sufficiency of understanding. The determination of competence is *decision-specific* --- that is, a child can be competent in relation to some decisions but not others.[27]

Lord Donaldson explained in *Re R* that competence was a matter of

> not merely an ability to understand the nature of the proposed treatment…but a full understanding and appreciation of the consequences both of the treatment in terms of intended and possible side effects and, equally important, the anticipated consequences of a failure to treat.[28]

In the twenty-five years since the decision in *Gillick*, the courts have explored the boundaries of a competent child's autonomy, and have found variously that a child who is *Gillick*-competent can consent in the following situations:

- Pregnant girls under the age of 16 can consent to an abortion (including one as young as 13);[29]
- Children experiencing gender dysphoria can consent to the administration of puberty blocking medications;[30]

Consent by children to what a doctor considers is in their best interests is rarely contentious, unless the parent disagrees. But for these children, using Lord Scarman's 'flak jacket' analogy – that consent 'protects' a doctor like a flak jacket from being liable for doing things that would otherwise be unlawful, the child's consent should be sufficient for the procedure to be lawfully performed. And indeed, in *Axon,*[31] decided in 2006, Justice Silber affirmed this in the context of a 16 year old being found *Gillick*-competent to consent to an abortion, and Justice Mostyn took a similar view in relation to a 13 year old girl in the 2014 case of *An NHS Trust v A.*[32] In both cases, the child's consent was sufficient as long as the doctor also considered the treatment to be in the child's best interests, so in one sense these were uncontentious because the child agreed to what was, in the professional's view, the appropriate treatment (and in most cases, the courts concur, and so could have overridden any parental objection).

In terms of what information such children must be given for their consent to be sufficiently informed (and hence valid), again this is not entirely legally clear, but what is evident is that. Providing a child with information is partly wrapped up with the consent process, because to determine competence, the child needs to be given information relevant to the decision and be found able to retaining it and weigh it. Professional guidance indicates that such information must include: the nature and purpose of the proposed intervention, its risks and side-effects, and the alternatives to the proposed intervention (the risks the alternative carries).[33] Mere delivery is not enough, the GMC stresses. Rather, doctors must 'make sure that all relevant information has been provided and thoroughly discussed before deciding whether or not a child or young person has the capacity to consent', and the child must be able to understand, retain, weigh that information, to use it to make a decision and then be able to communicate that decision.[34]

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[26] *Re R* 26H.

[27] See, eg, the dicta of Baker J in *Re JA (A Minor) (Medical Treatment: Child Diagnosed with HIV)* [2014] EWHC 1135 (Fam).

[28] *Re R*, 26

[29] *R (on the application of Axon) v Secretary of State for Health* [2006] EWCH 37 (Admin); *An NHS Trust v A, B and C* [2014] EWHC 1445 (Fam).

[30] *Bell v Tavistock* [2021] EWCA Civ 1363.

[31] *R (on the application of Axon) v Secretary of State for Health* [2006] EWCH 37 (Admin); *An NHS Trust v A, B and C* [2014] EWHC 1445 (Fam).

[32] *An NHS Trust v A.*

[33] British Medical Association, *Children and Young People Tool Kit* (2010), 7.

[34] General Medical Council, *0–18 years: guidance for all doctors* (2018, 2nd edition), 11.

Complexities with Competent Children Making Decisions

So all of this seems quite straightforward. Why, then, have I rather provocatively suggested that it gets murkier? Well, there are some contexts in which it is not so simple, either legally or ethically. The two key areas where this is the case that I want to look at are:

- When information is withheld from children; and
- When competent children refuse treatment.

Through looking at these, I want to tease out for you some of the thorny questions about:

- The impact of not informing children on how (and by whom) valid consent can be given;
- How the law evaluates competence; and
- Debates around what competence in a child does mean and should mean for their decision-making authority, including whether we are holding children to a *higher* standard of competence.

1. Withholding Information from Children

We will start with a series of cases in which children were not given all the information we might consider relevant to a decision about our care, and certainly below what the decision in *Montgomery* would say ought to be given to adults. One prime example is the case of *Re L*, in which a 14 year old girl wanted to refuse a blood transfusion that was needed to save her life on the basis of her beliefs as a Jehovah's witness. The court held that she lacked capacity because she did not appreciate the nature of the death she would suffer if she refused, but that this was due to that information having been deliberately withheld from her.

While in *Re L* it was made clear that even had she had the information and been found competent under *Gillick*, her refusal would still have been overridden due to the serious nature of the situation, but that is slightly beside the point. It is deeply problematic that in this case, she was not *given* that information and *then* permitted to express her views, but instead the court allowed the failure to properly inform her to simply undermine her competence entirely. This is precisely the approach the decision in *Montgomery* stands against, holding as it does that patients must be appropriately informed. Good clinical practice would demand the same, and so this decision is especially disappointing, but such cases are rare for the most part.

2. Older Children Found to Lack *Gillick*-Competence

In other cases, children are found simply to lack the capacity to make the decision before them, usually to refuse treatment. This is what happened in the case with which I commenced my lecture, to which we now return.

In that case, the boy, A, was 15 years and 10 months old, and one of the questions for Justice Ward was whether he had sufficient competence to make a decision about his own care. He rejected the argument that 15 year and 10 months was so close to 16 years that he ought to draw on the approach in the FLRA and regard him as competent due to his age.

Justice Ward declined to take this approach, and took the view (in line with *Gillick*) that competence is a matter of capacity, not age as such. Therefore, it fell to assess this boy's competence, and as part of his assessment of the situation, he went to visit A in hospital so that he could speak with him. He found that he lacked the capacity to make his own decisions. But what is really important is *how* he came to this conclusion. Let's look at what he said:

> I find that A is a boy of sufficient intelligence to be able to take decisions about his own well-being, but I also find that there is a range of decisions of which some are outside his ability fully to grasp their implications. Impressed though I was by his obvious intelligence, by his calm discussion of the implications, by his assertion

> even that he would refuse well knowing that he may die as a result, in my judgment A does not have a full understanding of the whole implication of what the refusal of that treatment involves.[35]

Let's remember that we presume someone who is 18 has capacity, and they only lose it if they lack the ability to understand, retain, weigh and use information about their condition and communicate their decision. But here, Justice Ward arguably wants rather more to find this boy competent --- he wants him to appreciate 'the whole implication' of his refusal.

But let's unpack that a bit.

In the next paragraph, he goes on to explain that A, the boy, does not appreciate how frightening it will be when he begins to have to fight for breath. He notes that the doctor, Dr T, feels it is not 'necessary' to spell out to A how frightening this will be, and Justice Ward agrees, saying he did not feel it was appropriate for him to spell it out to A either.

He then goes on to say

> I am quite satisfied that A does not have any sufficient comprehension of the pain he has yet to suffer, of the fear that he will be undergoing, of the distress not only occasioned by that fear but also – and importantly – the distress he will inevitably suffer as he, a loving son, helplessly watches his parents' and his family's distress. … I find that he has no realization of the full implications which lie before him as to the process of dying. He may have some concept of the fact that he will die, but as to the manner of his death and to the extent of his and his family's suffering I find he has not the ability to turn his mind to it nor the will to do so. Who can blame him for that?[36]

And this is precisely why *how* we talk to children and how we approach questions of competence are so bound up together. Because part of the reason, arguably, he lacks this understanding is because those around him are withholding information from him.

But more than this, he is being asked to understand arguably more than an adult must understand. He must understand the distress he will cause his family. He must turn his mind to what it means to die. And on top of this, his ability to form a true religious conviction is called into doubt, for Justice Ward openly doubts whether A can form a free opinion due to the influence of the religion of which he and his family are a part. He says:

> I am far from satisfied that at the age of 15 his will is fully free, He may assert it, but his volition has been conditioned by the very powerful expressions of faith to which all members of the creed adhere. When making this decision, which is a decision of life or death, I have to take account of the fact that teenagers often express views with vehemence and conviction – all the vehemence and conviction of youth! Those of us who have passed beyond callow youth can all remember the convictions we have loudly proclaimed which now we find somewhat embarrassing. I respect this boy's profession of faith, but I cannot discount at least the possibility that he may in later years suffer some diminution in his convictions.[37]

Was the approach taken to the woman who wanted to refuse dialysis? Or to S when she refused a caesarean? Seemingly not.

Having declared A not competent to make his own decision, Justice Ward then comes to make a decision on his behalf, where as we know, his welfare must be the paramount consideration. He concludes that while he must try to respect the boy's faith, he must override his decision (and that of his parents), because he considers it 'essential for his well-being to protect him from himself and his parents', for as he said 'is this choice of death one which a Judge in wardship can find to be consistent with the welfare of the child? The father supplied the answer himself – life is precious.'[38] Ultimately, the boy's welfare was better served, he felt, by keeping alive rather than respecting his choice.

This approach is seen in numerous cases, where the court finds the child to lack competence, and so the path to permitting the doctors (and parents, in some cases) to proceed to treat in what are thought to be the

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[35] *Re E (A Minor) (Wardship: Medical Treatment)* [1993] 1 FLR 386.
[36] *Re E (A Minor) (Wardship: Medical Treatment)* [1993] 1 FLR 386.
[37] *Re E (A Minor) (Wardship: Medical Treatment)* [1993] 1 FLR 386.
[38] *Re E (A Minor) (Wardship: Medical Treatment)* [1993] 1 FLR 386.

child's best interests.[39] Very often, the child's capacity is considered insufficient *relative to the seriousness of the decision*. So unlike adults, where capacity is determined by understanding and weighing, for children there is also a requirement to understand where the *implications* are more grave. Whether this imposes a higher standard for capacity on children is a matter of some debate, which will cover shortly once we have looked at how the law approaches those children it *does* regard as competent.

3. When Children and Young People Refuse Treatment: Retreating from *Gillick*?

The third group of cases that I want to look at are those where a competent child has refused treatment and had his or her decision overridden. For while a competent adult can refuse treatment, even if to do so will result in her death, even if her decision is unwise, children who have been found competent are not afforded the same respect for their decision to refuse a treatment that the doctor considers to be in their best interests (and to which their parent may be consenting).

To give a sense of *how* strong a competent adult's right to refuse treatment is, I will give you some situations that the law has dealt with. In all of them, the adult was competent and their decision to refuse treatment was respected. With some, there are complexities that I won't go into here, but the key message in all of them is that an adult who has been deemed competent can refuse treatment even if it leads to his or her death.

- A woman in the late stages of pregnancy did not agree to having a caesarean section (needed to save both her life and that of her foetus). She was declared incompetent at the time and the c-section performed. The court later found that she had been competent and declared:
    - 'Even when his or her own life depends on receiving medical treatment, an adult of sound mind is entitled to refuse it. This reflects the autonomy of each individual and the right of self-determination… how can a forced invasion of a competent adult's body against her will even for the most laudable of motives (the preservation of life) be ordered without irremediably damaging the principle of self-determination?... the autonomy of each individual requires continuing protection even, perhaps particularly, when the motive for interfering with it is readily understandable, and indeed to many would appear commendable: hence the importance of remembering Lord Reid's warning against making "even minor concessions.".'[40]
- A woman who needed kidney dialysis to survive, was free to refuse it because she did not want to become old, ugly and poor and preferred her life to end.[41]

Perhaps Dame Butler-Sloss said it best when she said, *obiter*, in *Re MB:*

> A competent woman who has the capacity to decide may, for religious reasons, other reasons, for rational or irrational reasons or for no reason at all, choose not to have medical intervention, even though... the consequence may be death.[42]

So the law is *very* clear that competent adults can make decisions that lead them to harm or death, and this must be respected. There are, of course, those who disagree with this position, but for our purposes what matters is that the law is crystal clear.

For competent *children* (whether young people or those who are *Gillick* competent), however, the situation differs markedly. While the courts will place considerable weight on such a child's views, they are not determinative in the same ways as an adult's when the child is *refusing* care.

What I want to tease out here is first *how* the courts have dealt with these refusal cases over the years, and then think about what this says about the law's attitude to children's decision-making and autonomy more generally. In doing this, I will work through some strands of the debate around the extent to which children's autonomy should be respected.

The best way to look at the refusal cases is chronologically, starting with where the law seemingly stood post-*Gillick*, and then working through what is often referred to as the 'retreat from *Gillick*'.

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[39] Other examples include *Re S (A Minor) (Consent to Medical Treatment)* [1994] 2 FLR 1065.
[40] *St. George's Healthcare N.H.S. Trust v S* [1998] 3 W.L.R. 936 per Judge LJ.
[41] *King's College Hospital NHS Foundation Trust v C* [2015] EWCOP 80.
[42] *In re M.B. (An Adult: Medical Treatment)* [1997] 2 F.C.R. 541

We have seen that in *Gillick* there was a range of views, the most staunchly in favour of respecting a child's *decisions* rather than just their *consent* was Lord Scarman. He made a particular point that we need to keep in mind. He said:

> I would hold that as a matter of law the parental right to determine whether or not their minor child below the age of 16 will have medical treatment terminates if and when the child achieves a sufficient understanding and intelligence to enable him or her to understand fully what is proposed.[43]

What this seems to suggest, it has been argued, is that once competence is achieved, the parents lose their right to consent on behalf of the child. This would suggest that if the child refuses care, then the parent cannot give valid consent in lieu of this to enable the doctor to proceed. And if we applied the further logic of competence that applies to competent adults as we've just seen, that competent refusal would have to be respected, even if it led to harm to the child. Whether Lord Scarman meant to go this far is not clear, but as Emily Jackson has pointed out, he did not go so far as to assert that such a child could make *any* decision, but rather that she would be free to 'exercise a wise choice in his over her own interests'.[44] What he actually intended need not concern us, because only a few years post-*Gillick* a series of decisions saw the courts step back from this commitment to child autonomy and this approach has held considerable sway in the subsequent years.

There is some overlap between cases concerning children under- and over-16 years of age, but also some important distinctions that I will try to keep clear. But we need to consider a case from each group to begin, as these two cases from 1992 are the two decisions that really set in motion this so-called retreat, and have influenced later courts greatly. They also sparked a strong critical response from academics, which we will explore, but we will avoid the more technical legal debates.

Re R[45] is one of the primary cases in which it was confirmed that the court could override the refusal of a *Gillick*-competent child. In that case, a fifteen year old child had refused to take anti-psychotic medication. The local authority wanted leave to permit the psychiatric unit where she was held to be permitted to administer the medication despite her refusal. The Court of Appeal held that it had jurisdiction to override a minor's consent or refusal to treatment, regardless of the child's competence. Lord Donaldson stated that:

> In a case in which the *"Gillick* competent" child refuses treatment, but the parents' consent, that consent *enables* treatment to be undertaken lawfully.[46]

He thought this must be the case in part because *Gillick* competence can fluctuate – a child can be competent for one decision, but not another. It would be impossible if the achievement of *Gillick* competence extinguished the parental right to consent (or refuse) entirely.

His essential position was that

> [a *Gillick*-competent] child can consent, but if he or she declines to do so or refuses, consent can be given by someone else who has parental rights or responsibilities. The failure or refusal of the "Gillick competent" child is a very important factor in the doctor's decision whether or not to treat, but does not prevent the necessary consent being obtained from another competent source.[47]

So, both the court and parents retained a right to consent or refuse, and if one or both consented to the treatment, then this would give the necessary protection to the doctor (or, put another way, would make undertaking the treatment lawful). Now I deliberately phrase it this way because this view of the doctor as 'protected' is an important focus of the critique of this and the following decision, *Re W*. Let us look at that one too before we explore the criticism of them.

The *Re W*[48] case followed on not long after *Re R*, and again involved Lord Donaldson, but this time the child in question was 16 and so presumptively competent according to the *Family Law Reform Act 1969* (FLRA) as we've seen. She suffered from anorexia nervosa, and the local authority sought leave to transfer to her to

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[43] *Gillick.*

[44] E Jackson, *Medical Law: Text, Cases and Materials*, 4th edn (Oxford: Oxford University Press, 2016), 300.

[45] *In Re R (A Minor) (Wardship: Consent to Treatment)* [1992] Fam 11.

[46] *In Re R (A Minor) (Wardship: Consent to Treatment)* [1992] Fam 11, 23G.

[47] *In Re R (A Minor) (Wardship: Consent to Treatment)* [1992] Fam 11, 24H.

[48] *In re W (A Minor) (Medical Treatment: Courts Jurisdiction)* [1993] Fam 64.

facility and for her to have treatment, if needed, without her consent. W argued that the FLRA gave her the same right as an adult to refuse treatment.

In the Court of Appeal it was held that the FLRA did not confer on young people an absolute right to make decisions about their healthcare, nor a right of refusal. Rather, the court retained the right to effectively consent on behalf of young person (via its inherent jurisdiction) where it considered treatment to be in the young person's best interests. The court would, it was made clear, listen to the child's views and take account of them, but these would not be determinative. In this case, treatment *was* considered to be best for W, and her refusal was overridden. Lord Donaldson made clear his view that:

> There is ample authority for the proposition that the inherent powers Q of the court under its *parens patriae* jurisdiction are theoretically limitless and that they certainly extend beyond the powers of a natural parent … There can therefore be no doubt that it has power to override the refusal of a minor, whether over the age of 16 or under that age but '*Gillick* competent.' … by authorising the doctors to treat the minor in accordance with their clinical judgment, subject to any restrictions which the court may impose.[49]

So in short, s.8(1) only provided a right to consent, not to refuse, and parents (and the court) retained the authority to override refusal (via the action of section 8(3)).[50]

The upshot of both decisions was that whatever the source of competence, a child who refuses can have that refusal overridden because both their parents and the court have the authority to provide consent on their behalf to treatment that is considered in the child or young person's best interests. This view of the law has been confirmed in multiple cases since.[51]

There has been some recent exploration of whether parents retain a right to consent even when the child achieves *Gillick*-competence, in the case of *AB v CD and others*.[52] Mrs Justice Lieven considered the question directly, as High Court's decision in *Bell v Tavistock* had cast doubt on a minor's capacity to consent to puberty blockers (this decision has since been overturned by the Court of Appeal). The parent and child did not conflict in that case, so the issue was whether, given *Bell*, the parent *could* consent for the child (who also wanted to take the puberty blockers). Mrs Justice Lieven examined *Re R, Re W* and related cases and on the question of 'whether the parents' ability to consent disappears once the child achieves Gillick competence in respect of the specific decision even where both the parents and child agree' that:

> it does not. The parents retain parental responsibility in law and the rights and duties that go with that. One of those duties is to make a decision as to consent in medical treatment cases where the child cannot do so.[53]

This enables the parents to consent if the child does not wish to make a decision, or cannot (reasons for it not be extinguished and hence remove all their ability to act in the child's best interests). It must, however, be exercised as always in the child's best interests, and if it were not, the court of course retained its authority to override the parent's decision.

None of this means that the child's view are lightly set aside. Many recent cases have very much emphasised the weight to be given to children's views, but have not given ground on retaining the ability to override them. For example, in *An NHS Trust v CX* [2019], a 14 year old Jehovah's Witness child was *Gillick*-competent, but his refusal of blood products was overridden on the basis of it being in his best interests to receive treatment. But Mrs Justice Roberts was careful to emphasise that the Trust should (and she expected they would) 'consider all alternative forms of management which can be undertaken' and would reduce 'the use of blood products to the lowest level necessary to keep him safe.' In doing so, she hoped that blood products would be given only when there was no reasonable alternative left, and in this she hoped that insofar as was possible, 'appropriate respect for the views of CX and his mother [could] be accommodated within the

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[49] *In re W (A Minor) (Medical Treatment: Courts Jurisdiction)* [1993] Fam 64, 81.

[50] There is considerable academic criticism of this interpretation of the force of s.8(3), but it is beyond the scope of this talk to delve into it here. If you are interested, see further: M Freeman, 'Rethinking *Gillick*' in M Freeman (ed), *Children's Health and Children's Rights* (Brill, 2006) 201–217.

[51] See, eg, *University Hospitals Plymouth NHS Trust v B (A Minor) (Urgent Medical Treatment)* [2019] EWHC 1670 (Fam); *Re K, W and H (Minors) (Medical Treatment)* [1993] Fam 64 (CA); *Re P (A Child)* [2014] EWCH 1650 (Fam); *A NHS Trust v X* [2021] EWHC 65 (Fam); *An NHS Trust v C NHS Trust & Ors* [2019] EWHC 3033 (Fam).

[52] [2021] EWHC 741 (Fam).

[53] *AB v CD and others* [2021] EWHC 741 (Fam), [68].

proposed treatment plan.'[54]

Before we explore some of the criticisms of these cases, it is important, though, to balance out the positions taken in these cases with others. For example, Sir James Munby has made it very clear in *Re X (A Child) (Capacity to Consent to Termination)*[55] that the courts will not lightly override a child's wishes, whether they are competent or not. That case concerned a 13 year old girl who was pregnant and did not wish to have the pregnancy terminated. Although she lacked capacity to refuse, the court would not order one to be performed upon her, even if it were in her best interests in some sense, if she were not 'compliant' and 'accepting'.[56] This approach was recently affirmed in *A NHS Trust v X (In the matter of X (A Child) (No. 2),* in which a child's refusal of blood was overridden but Sir James Munby, who again reiterated that the court retain the power to override, but would remain open to the possibility of situations in which the child's view would be determinative.[57] This reflects clinical practice, and also guidance such as from the Department of Health that emphasises that children's views should not be lightly overridden.

And there are cases of the courts respecting refusals, although these are rare. In one case, a girl of 13 was not overridden when she refused a heart transplant, but the context was quite distinct.[58] She had been unwell for a long time, and it seems the courts are more inclined to support refusals where the child has experience of the burdens of treatment and is more likely to understand their condition and situation, perhaps.[59] Sometimes, too, it is likely that the clinical team choose not to contest the child's refusal.

So What Might We Think About All This?

Consent But Not Refuse

One of the key criticisms of the law's approach to cases of competent refusal is that these children are considered competent to *consent* but not to *refuse*, a criticism that has even more force in relation to young people who are assumed to have the same capacity as adults, and yet their decisions as have seen have been overridden because they are considered unable to make such a serious decision, or they should be protected from themselves.[60]

Some suggest that it makes no sense to say someone is competent to consent but not to refuse.

Others focus on the fact that if the law is protecting 'autonomy', then this must include both the power to consent and to refuse, as both are part of making decisions for oneself. For example, in *Re W*, James Munby, then a QC (but as you may have noticed, later a judge in many of these cases) and Roderic Wood argued that people (including children) have a right of *self-determination*, rather than a right to consent, and that this encompasses both the right 'to consent to treatment, and therefore to choose who shall treat and the form of treatment, and … as a corollary, to choose not to be treated.'[61]

But Emma Cave and Craig Purshouse point out that this arguably *isn't* what the law is trying to do – it's not trying to protect a child's autonomy, but rather their *welfare*,[62] and these are not be same thing, although certainly having the ability to make one's own decisions and live life according to one's own values is an important element of well-being. But it is not the whole of welfare, and so the law, with its commitment to protecting the child's welfare, takes the view that sometimes overriding a child's choice is overall better for them.

The question to consider is whether, in fact, this is true. If that child can form settled, committed views about their values and what they feel is good for them, why is a court better placed to know what will be good for

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[54] *An NHS Trust v C NHS Trust & Ors* [2019] EWHC 3033 (Fam).

[55] [2014] EWHC 1871 (Fam).

[56] *Re X (A Child) (Capacity to Consent to Termination)* [2014] EWHC 1871 (HC).

[57] [2021] EWHC 65 (Fam).

[58] But compare: *Re M (Medical Treatment: Consent)* [1999] 2 FLR 1097 in which a similar refusal was overridden.

[59] E Jackson, *Medical Law: Text, Cases and Materials* 4th edn, (Oxford: OUP, 2016), 304.

[60] See, eg, M Freeman, 'Rethinking *Gillick*' in M Freeman (ed), *Children's Health and Children's Rights* (Brill, 2006) 201; J Murphy, 'W(h)ither Adolescent Autonomy?' (1992) 14 JSWFL 529; J Harris, 'Consent and End of Life Decisions' (2003) 29 JME 10.

[61] *Re W*.

[62] E Cave and C Purshouse, 'Think of the Children: Liability for Non-Disclosure of Information Post-*Montgomery*' (2019) 28(2) *Medical Law Review* 270, 276.

them than they are themselves? Particularly if they have been found to be competent. And of course, this idea of people knowing what is best for them and being permitted to make their own decisions is what underpins the law on adults and consent, and is what is considered to be problematic about paternalism.

Are children, then, a different class? And if we think they are, we need to consider *why* we think that.

Children's Right to Self-Determination?

So this is why the other strand of criticism is that this area of law fails to sufficiently protect children's right to self-determination. Some, such as Michael Freeman, make the point that the position in *Re R* and *Re W* is out of step with the philosophy of the Children Act 1989 (as it was when he was writing) and its focus on empowering children.[63] Over the past few decades, there has been a very clear shift away from paternalistic approaches in medicine towards recognising patient autonomy, and we see this in human rights instruments, in clinical practice, and one argument here then is that this should also be how we approach children – and indeed, the United Nations Convention on the Rights of the Child does assert the need for children to have their autonomy respected as far as is possible

The UNCRC makes it clear in Article 12 that a child should be consulted to ascertain their views, and that a child who is capable of forming his or her own views has the right to express those views freely in all matters affecting the child, and furthermore, that the views of the child being given due weight in accordance with the age and maturity of the child. The UNCRC also emphasises that children should have the right of free religious belief and the right to *manifest* that belief (Article 14).

Really, the question is – when do we stop being paternalistic towards older children and young people and allow them this autonomy? And further, is the protection of these children from, as Lord Justice Nolan put it in *Re W*, 'grave and irreversible mental or physical harm', a sufficient ground to override autonomy? We don't consider protection from harm a good enough ground to override competent adults, so we need to think it is sufficient when it comes to *competent* children.

One of the responses of course is that children, even older children, may lack the ability to make decisions because of their developmental stage, so they are never *really* competent. In some jurisdictions, such as the United States, there have been moves to use neuroscientific information about brain development to answer questions about children's capacity, such as evidence that older children are affected by their peer group, or that they are more likely to take riskier decisions, but there are many reasons why we should resist that. The science isn't there yet, but mostly to take a *general* conclusion and apply it to a *particular* child is always dangerous, particularly a child who, unlike most, might have lived with an illness for a long time, and potentially have a more considered understanding of their condition and what it might mean to die than many adults.

We might also note that the UNCRC itself also asserts that a child's best interests should be the primary focus for institutions (Article 3), and that 'States Parties shall ensure to the maximum extent possible the survival and development of the child' (Article 6(2)). These principles need to be considered in tandem with the need to protect a child's autonomy, and are clearly sometimes in tension with it.

Essentially, the approach being taken is to treat children's voices as *consultative* but not *authoritative*, as Harry Brighouse puts it --- that this tension is navigated by taking those voices very seriously, feeding their views into an evaluation of what is best for the child, but still permitting there to be other factors that mean they cannot be determinative. The real problem comes when those factors are merely the *outcome* (ie the child will die), rather than a proper articulation of why, given the child's competent views, this is reason to override them, when the child knows they will die yet chooses to refuse regardless --- have they gone against their own self-interest? Is this the real basis that might justify not allowing them to decide what is best?

The courts would benefit from exploring these questions via the framework suggested by the philosopher John Harris, who explains that a choice might not be fully autonomous (and hence not fully deserving of respect) is there is a *defect* of autonomy, and this might be one of four things: control, reasoning, information or stability. He means that we might be out of control in our thinking (eg due to a mental illness), our reasoning might be flawed (we believe one thing leads to another but we are mistaken), or information might be wrong, or our beliefs are not stable (our commitment to our values might change).[64] I think a lot of the time, as some

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[63] M Freeman, 'Rethinking *Gillick*' in M Freeman (ed), *Children's Health and Children's Rights* (Brill, 2006) 201, 203–4.

[64] John Harris as cited in M Brazier and C Bridge, 'Coercion or Caring: Analysing Adolescent Autonomy' (1996) 16(1) *Legal Studies* 84, 91.

of the reasoning we've heard, it is the final defect that courts suspect of children --- that they will change their minds, because teenagers views do change. Harris would reply 'well we all change our minds' and he is right, but this, I think, should be a focus for us to think about – is it generally true of teenagers? Maybe. But is it true of *this teenager*? Why do we think that? This is how the court could try to approach it to navigate its problem.

Children Held to a Higher Standard?

And this should lead us to think about just what are we asking of these children when we ask 'are they competent?' As Emily Jackson comments

> most adults do not fully understand what it is like to die, and it could therefore be argued that children like A [in *Re E*] are being held to an excessively demanding test for capacity.[65]

This is a point many academic commentators have rightly made,[66] for as we saw in the discussion of *Re E* and other refusal cases, children are required to understand more about their choices and their implications than competent adults. And even when they demonstrate, as A and others have, a committed belief in a religion and a considered view on how they will act on that commitment, their decisions are overridden, while a woman is permitted to refuse dialysis because she does not want to live a life without sparkle. Or we might also compare them with the case of *Re C*, in which an elderly patient held in Broadmoor, suffering schizophrenia and holding delusional views about his former life as a world famous surgeon, was found sufficiently competent to refuse the optimal treatment of his gangrenous leg, even when this meant he faced a very strong chance of dying as a result. As Michael Freeman has sagely put it, were the reasoning of Justice Ward in *Re E* applied to an adult, 'it is dubious whether refusal would ever be allowed'[67]… and yet we know that such refusals by competent adults *are* allowed all the time.

So what is that the courts think children lack? In *Re L*, the court held that a 14 year old Jehovah's Witness lacked 'the constructive formulation of an opinion', suggesting that this comes only 'with adult experience'.[68] Other courts suggest that a child can be overwhelmed by the choice in front of them *(Re M*, a refusal of a heart transplant) or, as in *Re E*, the court doesn't believe that a child can hold a stable religious commitment, and so sets them a higher standard to test it (such as whether they really appreciate what the consequences and implications are). Academics such as David Archard and Marit Skivenes have rightly criticised this, stating that as a matter of equity, 'a child should not be judged against a standard of competence by which even most adults would fail'.[69] Michael Freeman puts it even more bluntly but arguably fairly when he says that the retreat from *Gillick* 'exposes the pretence that is competence' because, he argues, courts are so reluctant to find competence that they hold children to a higher standard, and even when they meet it, it is clear that competence 'is irrelevant where the really important questions are addressed'.[70]

And this is why many academics have called for the courts to be more honest and be clear that it isn't about competence, but about something else, or be more clear on what it is about children's ability to reason that requires them to be tested more. It may be that they think, as it seems, that their thinking is more easily overborne or influenced (as was the case in *Re E* and other religious cases).

Conclusion

What should we do? Jane Fortin suggests that the solution lies not in assessing competence so much as recognising that society 'has an interest in protecting underage minors, irrespective of competence, from their own dangerous mistakes until they attain their majority'. Such an approach, perhaps we might think of it as calling a spade a spade would at least, Fortin says, 'not demean the minor by suggesting that his or her

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[65] E Jackson, *Medical Law: Text, Cases and Materials* 4th edn, (Oxford: OUP, 2016), 303.
[66] See, eg, P Lewis, 'Feeding Anorexic Patients Who Refuse Food' (1999) 7 *Medical Law Review* 21, 23.
[67] M Freeman, 'Rethinking *Gillick*' in M Freeman (ed), *Children's Health and Children's Rights* (Brill, 2006) 201, 208.
[68] *Re L (A Minor)* [1998] 2 FLR 810*,* 812.
[69] D Archard and M Skivenes, 'Balancing a Child's Best interested and a Child's View' (2009) 17 *Int J Child Rights* 1, 10.
[70] M Freeman, 'Rethinking *Gillick*' in M Freeman (ed), *Children's Health and Children's Rights* (Brill, 2006) 201, 211.

emotional maturity is fundamentally flawed'.[71] In a sense, this reflects somewhat the view of Lord Justice Nolan in *Re W*, that the courts might have a duty to ensure as best they can that a child reaches adulthood.[72] So we might just want to be open about saying until you are 18, your parents or the court retains the right to be, really, paternalistic. But within that, we should still strive very much to be open, honest and transparent with children, as clinical practice certainly directs, whether or not the law clearly demands it.

But balanced against this always is the concern that any such approach necessarily sets aside a child or young person's own views, own convictions. If we are to do this, we can only do it if we accept that they simply cannot form views that are worthy of respect. I find this a very difficult thing to accept, to believe that no child, even one months from adulthood, is incapable of forming sufficiently genuine, considered views. I also find it hard to accept that we could come to this conclusion, but resist the view that some adults cannot or have not formed such views, and yet we do not override their choices because we have decided that for them, their self-determination is more important, even when they exercise it unwisely and to their detriment.

Whatever we do, I agree with Rob Heywood and Andrew Grubb that we should not be pretending to respect children's decisions, and then overriding them --- it would be better to be honest about the court's approach. We also need to listen to doctors and the community about how they see this question, rather than assuming that the court is the right final arbiter of such personal decisions.

And what the course also needs to do is work out articulating what it is about adolescent decision-making that distinguishes it such that it can be overridden in a way that adult decision-making cannot. Finally, the courts should continue to be highly reluctant to override children's seriously considered refusals. Perhaps some children have unstable views, or cannot understand what it will mean to die. But some can, particularly those with far more experience of illness and facing their own mortality than many adults, and we should respect their competence, no matter how difficult that may sometimes be.

Final conclusion

And what happened with boy who refused the transfusion? He was transfused against his wishes for three years and he survived to adulthood. But Justice Ward proved to be mistaken in his belief that perhaps the boy might 'suffer some diminution in his convictions'.[73] When the boy reached adulthood and his decisions could not be overridden, he refused further transfusions and some time later died from his illness.[74] In the end, his convictions did not falter, he knew his own mind at 15 as much as he knew it at 18, and once he was permitted at last to act upon his beliefs, he did. Whether this would be true of all children, no one can really say, but it should at least give us pause to consider before we assume it is right to take away a child's autonomy.[75]

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[71] Jane Fortin as cited in M Freeman, 'Rethinking *Gillick*' in M Freeman (ed), *Children's Health and Children's Rights* (Brill, 2006) 201.

[72] *Re W* per Nolan LJ.

[73] *Re E (A Minor) (Wardship: Medical Treatment)* [1993] 1 FLR 386.

[74] We know this as it was reported by Johnson J in a similar case that followed a few years later: *Re S (A Minor) (Medical Treatment)* [1994] 2 FLR 1065; [1994] 1 FCR 604.

[75] Nolan LJ made similarly strong comments in *Re W*.