#### IMPORTANT NOTICE

This judgment was delivered in private. The judge has given leave for this version of the judgment to be published on condition that (irrespective of what is contained in the judgment) in any published version of the judgment no person other than the advocates or the solicitors instructing them and other persons named in this version of the judgment may be identified by name or location and that in particular the anonymity of the child and members of his family must be strictly preserved. All persons, including representatives of the media, must ensure that this condition is strictly complied with. Failure to do so will be a contempt of court.

Case No: FD13C00026/FD12P00424

Neutral Citation Number: [2014] EWHC 1135 (Fam)

IN THE HIGH COURT OF JUSTICE FAMILY DIVISION

Royal Courts of Justice

Strand, London, WC2A 2LL

Date: 11/04/2014

# Before:

# THE HONOURABLE MR JUSTICE BAKER

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# IN THE MATTER OF THE SENIOR COURTS ACT 1981 AND IN THE MATTER OF THE CHILDREN ACT 1989 AND IN THE MATTER OF JA (A MINOR)

**Between:** 

AN NHS TRUST (1)

A LOCAL AUTHORITY (2)

- and -

MR A (1)

MRS A (2)

JA (3)

HIS CHILDREN'S GUARDIAN (4)

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Angus Moon QC and Susanna Rickard (instructed by a solicitor acting on behalf of the Trust)
for the First Applicant NHS Trust

Karl Rowley QC and Nicole Erlen (instructed by Local Authority Legal Department) for the Second Applicant Local Authority

Janet Bazley QC and Clare Garnham (instructed by Chambers Solicitors) for the First and Second Respondent Mr. and Mrs. A

App]

Respon

# Barbara Connolly QC and Sorrel Dixon (instructed by A and N Care Solicitors) for the Third Respondent, J

Taryn Lee QC (instructed by Howells Solicitors) for the Fourth Respondent, the Children's Guardian

Hearing dates: 24  $^{th}$  to 28  $^{th}$  February , 6  $^{th}$  March, 8  $^{th}$  April 2014

# Judgment

# The Honourable Mr. Justice Baker:

#### INTRODUCTION

1.

This reserved judgment is delivered following a hearing during which I considered two applications in respect of a 14-year-old boy, hereafter called J, one by an NHS Trust for declarations and orders concerning medical treatment, the other by his local authority for a care order under s.31 of the Children Act 1989.

2.

Shortly before I was planning to hand down the judgment, I received the sad news that J's father had tragically died. My initial inclination was to postpone the delivery of this judgment completely. Having convened an urgent telephone hearing, however, in which I discussed the situation with counsel, I have decided, for reasons which will become clear, to deliver a judgment dealing with some issues that have arisen in the course of the hearing. Other issues will have to be reconsidered in the light of the latest developments.

3.

Before I say anything else, however, I wish to express my deep condolences to J, his mother and older sibling. The evidence demonstrates that this was a close-knit and loving family, and the passing of J's father will be a terrible loss for all of them. Save for the single issue which lies at the heart of this case, this family would never have come to the attention of social services, let alone be the subject of court proceedings.

#### **BACKGROUND**

4.

J's mother and father, hereafter called Mr. and Mrs A, moved from overseas to this country about 20 years ago. They had two children of whom J, born in 1999 and therefore now aged rising 15, is the younger. His older sibling is at present studying at university.

5.

In every respect other than his medical condition and treatment, J is a normal teenager. He is making good progress at school, has many friends and enjoys sport, in particular football. But hanging over his life is the spectre of serious illness.

6.

J's parents are HIV positive. This has been confirmed by an analysis of their medical records but they themselves have been reluctant to accept the diagnosis. They have challenged the mainstream and

scientific opinion on HIV and AIDS. Over the years, they have expressed the view that their prescribed anti-retroviral therapy ("ART") has been responsible for adversely affecting their health.

7.

The possibility that J might be HIV positive first came to the attention of doctors as long ago as 2003. Attempts to engage the family at that stage were unsuccessful. A further referral was made in 2010 when J's mother was being treated. Appointments were made with Dr Z, the lead consultant for children with HIV at the local NHS Trust. The family failed to attend the appointments. As a result, they were referred by the Trust to the local authority and this led to the authority making an application for a child assessment order under section 43 of the Children Act 1989 in December 2011. At that stage, a children's guardian was appointed to the proceedings and the NHS Trust was joined as a party. J's parents indicated that J had been tested overseas. They would not agree to further testing. As the case related to health concerns, the Trust was invited to make its own application to the court. Accordingly, on 17<sup>th</sup> February 2012, the Trust made an application under the inherent jurisdiction, seeking initially an order that J undergo HIV testing. The same guardian was appointed in the application under the inherent jurisdiction. Leave was granted to the local authority to withdraw its application.

8.

At a hearing before Macur J in June 2012, it was ordered that J be made a ward of court until further order, that his parents should make J available for blood testing, and that it was lawful for the Trust to take such steps as were necessary to facilitate the consent of the child to the testing. J's parents were also ordered to hand over to the Tipstaff every passport relating to J or other document which would enable him to leave England and Wales.

9. On 5<sup>th</sup> July 2012, J told the guardian in the presence of his mother that he did not wish to be tested, but that he agreed to see Dr Z of the NHS Trust. J duly attended an appointment on the following day. At that point, he agreed to be tested if his mother was re-tested and found to be positive. His mother would not agree to be re-tested. At that point, J refused to speak further to the guardian.

10.

At the next hearing on 16<sup>th</sup> October 2012, on this occasion before Roderic Wood J, it was ordered that J's parents were to ensure his attendance at an appointment with Dr Z by 24<sup>th</sup> October (later varied to 1<sup>st</sup> November). An order was also made for the mother's hospital records to be disclosed. At the next hearing on 8<sup>th</sup> November, on this occasion before Moylan J, the court invited the local authority to consider (a) joining the proceedings as a party or (b) whether it was appropriate for them to commence care proceedings. At a further hearing before me on 4<sup>th</sup> December 2012, the guardian proposed that J should be seen by a psychologist to establish whether he was of an age or understanding to make a decision about the testing. I duly directed that Dr Nicholas Banks should be appointed to carry out that assessment. I further directed the local authority to provide its core assessment to the guardian by 21<sup>st</sup> December. That assessment concluded that there should not at that stage be any application for a care order.

11.

At the next hearing on 6<sup>th</sup> March 2013, on this occasion back before Moylan J, J's parents were ordered to engage with the psychologist Dr Banks and to make J available to meet him alone. The parents failed to comply with that order. Accordingly, on 2<sup>nd</sup> April, the guardian issued an application for their committal.

# 12.

That application came back before me on 10<sup>th</sup> April 2013. I took the view that committal was unlikely to be an effective remedy to achieve the aim of having J seen by Dr Banks and tested for HIV. On the other hand, it seemed to me that the circumstances were by that stage sufficiently serious to give rise to reasonable grounds for believing that J was suffering significant harm as a result of his parents' unreasonable attitude and, specifically, unreasonable refusal to allow him to see Dr Banks and Dr Z. Accordingly, I made a direction for a report under section 37 of the Children Act, and an interim care order under section 38 of that Act. I listed the matter for a further hearing two days later. The making of the care order automatically discharged the existing wardship. Following the making of the interim care order, the local authority removed J from his parents and placed him in foster care.

# 13.

At the hearing two days later on 12<sup>th</sup> April, I was informed that J had now agreed to have a blood test. At that stage, he was still indicating that he would not see Dr Banks, although appointments were made for this to take place. At this hearing, a further order was made under section 34(3) of the Children Act providing that, until further order, his parents were precluded during contact from discussing with him or making statements to him concerning the testing for HIV in general, or whether or not he should attend any appointments with Dr Z or Dr Banks.

# 14.

Following that hearing, the samples taken from J were tested. It was discovered that he was HIV positive. He was informed of this outcome at a meeting with Dr Z. Thereafter, J attended his first appointment with Dr Banks.

#### 15.

On 26<sup>th</sup> April, a further urgent telephone hearing before me was arranged at the request of the guardian, who was concerned that the local authority had permitted unsupervised contact between J and his parents. I directed a further urgent hearing before Moylan J on 2<sup>nd</sup> May. At that hearing, agreement was reached that there should be some unsupervised contact, but subject to a contract of expectations signed by the parents and J and approved by the court. It was also ordered that J should be separately represented. A further hearing was arranged before me on 14<sup>th</sup> May, at which further agreement was reached regarding contact pending the next hearing. By that stage, Dr Banks had produced his first report following his meeting with J. The local authority indicted that in the light of that report it intended to issue care proceedings. That application was duly filed on 21<sup>st</sup> May following the completion of the section 37 report. Meanwhile, J and his parents continued to cooperate with appointments with Dr Z and her team and with the local authority.

# 16.

At the next hearing on 4<sup>th</sup> June 2013, I extended the interim care order until 10<sup>th</sup> June and consolidated the care proceedings with the application under the inherent jurisdiction. By the date of the next hearing before me on 10<sup>th</sup> June, the professionals had all come to the conclusion that, given the strong feelings held by J and his parents, the better course was that J should return home under the interim care order, provided that terms could be agreed. During the course of the day, following negotiations and submissions, two contacts of expectations, one for J and the other for his parents, were drawn up and agreed. The contract of expectations concerning J provided that he would be expected inter alia to keep all appointments with Dr Z and her team; meet with his social worker and his guardian as required; and keep appointments with the dentist and optician as may be arranged. The contract with J's parents required inter alia that they would ensure that J kept all appointments with Dr Z; attend those appointments with Dr Z should she request them to attend; read letters and

information sent to them by Dr Z; contact Dr Z if they have any queries about J's health; allow J to meet his social worker and guardian; meet with the guardian and social worker themselves as required; and not discourage J from taking medication if he decides he would like to do so. On that basis, I directed that J be returned to the care of his parents by  $28^{th}$  June.

17.

At a further telephone hearing on 11<sup>th</sup> July, I gave permission to the parties to instruct Professor Margaret Johnson to analyse the parents' medical records and prepare a report on their medical history and treatment. Further directions were given, with a view to a 5 day final hearing listed in February 2014. Further agreed directions were made by me on 11<sup>th</sup> September 2013, and again on 2<sup>nd</sup> October 2013. Meanwhile, J continued to live with his parents. He attended all appointments with Dr Z, on most occasions accompanied by his father.

# THE HEARING

18.

At the outset of the hearing, the NHS Trust, supported by the local authority and children's guardian, was seeking a declaration that J was not Gillick competent to make decisions about taking ART or receiving other treatment and help for HIV. In addition, the local authority, supported by the Trust and the guardian, was seeking a final care order on the basis of a plan whereunder J and his parents would be expected to sign and adhere to further contracts of expectations. In the event that they failed to comply, consideration would be given to removing J into foster care again. Further, the NHS Trust asked the court to grant mandatory injunctions directing J to (1) commence taking ART daily, initially under direct observation and at the direction of the treating team; (2) attend the children's HIV summer camp in the summer of 2014; (3) attend the local peer support groups in his local area and (4) attend psychology appointments at the Trust. In addition, he would need to continue his regular attendance at the Trust to see his treating team and have check ups as to his medical condition. The guardian supported both these positions. Thus the professional parties were lined up behind a coercive approach to the problems arising from J's refusal to take his ART.

19.

By the end of the hearing, the respective positions of the professional parties had changed. All three maintained the position that J was not Gillick competent. The local authority continued to propose that an interim care order should be made, but indicated that "any anxiety concerning the power bestowed by an interim care order upon the local authority to determine where J will live can be dealt with by a recording on the face of any order that the authority would not propose to remove J from the care of his parents without first returning the matter to court, save in circumstances which would justify the making of an emergency protection order". Furthermore, the NHS Trust abandoned its application for a mandatory order directed against J. Instead, it sought declarations as to J's best interests, namely that it was in his best interests to receive ART, to undertake psychological therapy, to engage in peer support, and to comply with a contract of expectations, and an order directed at J's parents to comply with the contract of expectations. These amended positions advanced by the Trust and local authority were supported by the CAFCASS manager (the guardian having been unable to attend the hearing for personal reasons). The parents and J contended, as they had done throughout, that J was Gillick competent, that the parents' compliance with the contract of expectations should not be enforced by a court order, and that the court should consider making a supervision order, either a full order or interim order with or without a wardship order.

The issues at the conclusion of the hearing were therefore as follows:

i)

Is J Gillick competent to make decisions about whether to take ART and/or see a psychologist and/or engage in peer support?

ii)

Is it in J's best interests to make a declaration that J should commence daily ART?

iii)

Is it in J's best interests to make a declaration that J should see a psychologist and engage in peer support?

iv)

Have the threshold criteria for making orders under s.31 of the Children Act 1989 been satisfied?

v)

What orders should the court make? In particular, if the threshold criteria under s.31 are satisfied, should the court make a care order or a supervision order, either final or interim? Should J be made a ward of court again? What orders should be made against J's parents?

vi)

What should be the terms of the contract of expectations between the Trust, local authority, J and his parents?

#### 21.

Having heard evidence over several days, and received detailed written and oral submissions from all the parties on these issues, I reserved judgment. Shortly before I was due to send out a draft judgment to the parties, I received two important pieces of information. It is important to state that no evidence has yet been filed on either of these developments, so I simply record in outline what I have been told. First, the Trust has informed me that there has been a further deterioration in J's health. Secondly, as I have already stated, J's father has tragically died. My initial response was to adjourn delivery of this judgment completely but, after the hastily-convened telephone hearing with counsel, I have decided to continue to give judgment on issues (i) to (iii) above. All counsel agreed that it was important that these issues be resolved without further delay. The remaining issues will inevitably be affected by the recent developments, and a further hearing will be necessary to consider how they should be resolved.

# THE EVIDENCE

#### 22.

The very substantial volume of written material in these proceedings was reduced to a core bundle in which the principal documents were (1) a report from Dr Steven Welch, consultant in paediatric HIV and infectious diseases at Birmingham, (undated but, I believe, prepared in 2013 prior to J's HIV testing) summarising the current scientific knowledge about HIV and advising in general terms as to whether J should be tested and treated for HIV; (2) a report from Professor Johnson following her examination of the parents' medical records; (3) two reports from Dr Banks setting out his account of meetings with J on four occasions in April, May and November (twice) 2013, and containing a psychological assessment of J and a conclusion as to whether he is Gillick competent; (4) four statements from Dr Z, the physician responsible for treating J; (5) a report from Professor X, medical

director of the NHS Trust (6) reports from J's past and present social workers (7) statements from J's parents and (8) two statements from J himself.

23.

At the hearing, oral evidence was given by (in order) Dr Banks, the two social workers, Dr Z, J's mother and father, and Professor X. In addition, I had a meeting with J at which he answered questions posed by counsel and me. The conversation, which was transcribed by counsel, plainly forms part of the evidence, albeit unsworn.

#### Dr Welch

24.

I begin by summarising the written evidence of Dr Welch concerning the current state of scientific knowledge about HIV.

25.

Dr Welch advised the court that HIV is a viral infection spread between people by contact with infected bodily fluids, including sexual contact, contact with infected blood, childbirth and breast feeding. WHO data indicates that 34 million people across the world are infected with HIV and in this country estimates suggest that up to 100,000 adults, and about 1200 children have the infection.

26.

Dr Welch continued:

"The HIV virus infects cells of the human immune system, including most characteristically a cell called the CD4 cell which is an important part of the human immune response against infection. In the absence of drug treatment, HIV infection results in a falling level of CD4 cells over time, which results in serious overwhelming infections and other complications, which may be fatal. The time taken for the CD4 count to fall from normal to dangerous levels is highly variable between individuals. In particular, whilst 20% of children who acquire HIV infection at birth or in early infancy will be severely ill by the age of 12 months, 80% will not, and some will display no symptoms at all of HIV infection well into their teenage years. The term Acquired Immune Deficiency Syndrome (AIDS) refers to advanced HIV infection with severe manifestations of a weakened immune system. Twenty years ago, progression of HIV infection to AIDS and then death was considered inevitable, albeit with a timescale that varied enormously between individuals. Over the last 15 years, the availability of effective drug treatments for HIV has dramatically changed this picture. HIV cannot be cured, but treatment with combinations of usually three different drugs can prevent the progression of asymptomatic HIV to AIDS. Patients who already have advanced immune suppression or AIDS at the time of diagnosis can be treated, and a significant degree of recovery of the immune system can be achieved. However, the major barrier to successful treatment of HIV is late diagnosis, when the CD4 count has already fallen so low that complete recovery is impossible and irreversible life threatening complications may already have set in.

Drug treatments for HIV do have side-effects which can range from common relatively insignificant side-effects to uncommon but more severe side-effects. However large studies published in reputable medical journals have consistently shown that the benefits of treating HIV vastly outweigh the detrimental effects of antiviral medication. In the early days of my medical career, medical care of children with HIV consisted of providing relief of symptoms to dying children. It now consists of providing long-term health care to children with a chronic health condition, almost all of whom will

survive into adulthood. The only deaths I have seen in my own experience in the last five years have occurred with late diagnosis of HIV or not taking antiviral medication as prescribed."

27.

Dr Welch was supplied with a number of documents challenging the conventional scientific view about HIV and AIDS. He observed:

"It is important to note that this is not a scientific controversy where there is equipoise between two views held by similar numbers of scientists. Rather, the model of HIV I have outlined above is accepted by the overwhelming majority of the medical and scientific community. The views which contest HIV as the cause of AIDS are held by a tiny minority. These views have been further discredited over time by the impact that antiviral treatment has had on the number of patients developing AIDS and dying."

28.

Dr Welch proceeded to answer a number of specific questions concerning J's situation. He advised that if J had a significant illness or his CD4 count was below or far below a treatment initiation threshold, he would need to start antiretroviral therapy ("ART") which would be likely to be lifelong. He noted that there continued to be side-effects from medications, but the risk of severe side-effects has fallen in recent years, as has the number of tablets needed to be taken each day. Dr Welch said that he had no doubt that untreated HIV would be worse for J than the side-effects of ART.

# Professor Johnson

29.

Professor Margaret Johnson is a professor of HIV medicine at University College London and clinical lead for the Royal Free London Foundation Trust. She prepared reports dated 20<sup>th</sup> September 2013 analysing the parents' medical records.

30.

So far as the mother is concerned, Professor Johnson reports that in 2001 the mother was admitted to hospital with a number of medical conditions including tuberculosis. As this is a common infection in people with HIV, she was asked whether she wished to have a test. At that stage, she declined. In 2003, she was diagnosed with cryptococcal meningitis and admitted to hospital in London. During this admission, she agreed to an HIV test and was found to be HIV positive. She was started on treatment for HIV but subsequently developed side effects associated with one of the medications and as a result her ART therapy was changed. She was readmitted to hospital in November 2003 and March 2004 with further complications. In August 2004, she stopped taking all ART medication because of symptoms which she thought were side effects. In May 2005, she was readmitted to hospital. At this point, her immune system was very low and she had a very high HIV viral load. She had also developed painful ulcerations. She was started on a new ART regime which made her feel very weak but led to an improvement in her ulcers and her HIV viral load declined to almost undetectable levels.

31.

By 2010, apparently still on the same HIV regimen, her viral load was still reported as being undetectable although she was experiencing neuropathy causing pain in her feet. The ART medication was changed and it is reported that she coped well until the middle of 2012 but then stopped the medication due to severe side effects and thereafter reported that she felt much better.

Professor Johnson comments that the mother has had a number of complications from her HIV medications including anaemia, peripheral neuropathy, central nervous system side effects and diarrhoea. Professor Johnson observed, however, that a number of new ART drugs are now available which are much less toxic and much better tolerated. It is now much more feasible to find a drug regimen which is going to be well tolerated by the patient. Professor Johnson continues:

"If we were able to restart Mrs A on an HIV drug regimen, which she was able to tolerate, then it is likely that her viral load would suppress, her immunity would improve and this would greatly reduce the risk of her developing any future serious infections or malignancies (cancers) that can occur in patients with HIV and a low immune system. If Mrs A was able to take HIV treatment and we were able to suppress her viral load and improve her immunity, there is no reason why she would not benefit from enormous improvement in her life expectancy."

#### 33.

The father's medical records produced for analysis seem to have been much thinner. As a result, Professor Johnson's report does not give a complete picture. It is known, apparently, that in 2009 Mr A developed cryptococcal meningitis overseas. Seen in hospital in England in March 2010, it was confirmed that he was HIV positive. His CD4 count was very low and he also had a very high viral load. He was also found to be suffering from Hepatitis B. He was started on ART medication plus Septrin to prevent pneumocystis carinii pneumonia, a common infection suffered by HIV patients with a low immunity. By the end of 2010, his condition had improved although his CD4 count was still low. In April 2011, he was readmitted to hospital with abdominal pain. On this occasion his HIV viral load was undetectable (as a result of the medication) but his immune system was still very impaired. At this point, he was on a new ART regimen and still taking Septrin to prevent the pneumonia and other medication to prevent a recurrence of the meningitis. Following his discharge, it was recommended that he should continue on the same treatment. He apparently then failed to attend the next review and there is no evidence in his medical records to indicate whether or not he subsequently took any medication.

#### 34.

Professor Johnson concludes that Mr A "has very advanced HIV infection and if the diagnosis of cryptococcal meningitis was correct in 2010 he has had a severe opportunistic infection which would mean he has had an AIDS diagnosis. The ART drugs which he was prescribed in 2010 suppressed his viral load to undetectable levels which indicate they were controlling viral replication." Professor Johnson advised that, if Mr A continued on HIV treatment, he would hopefully see his immune system returning to normal and then could have an almost normal life expectancy. However, if he failed to take the medication, she predicted that he was likely to develop other serious infections or malignancies which could be life threatening or leave him with permanent disability.

# **Dr Banks**

#### 35.

Dr Banks carried out a psychological assessment of J in April and May 2013 and in particular addressed the question of whether or not J was Gillick competent. He prepared an addendum report in November 2013 based on two further interviews with J in that month.

# 36.

Dr Banks identified the threshold for Gillick competency as whether or not the child is of sufficient maturity and understanding to take a decision of the seriousness in question. In assessing whether or not a child is Gillick competent, consideration therefore has to be given to the specific medical

treatment under consideration. Being Gillick competent in relation to a particular treatment means that the child can consent to the treatment, but if the child refuses the treatment, that refusal would not prevail against the authority of the court or the child's parents.

37.

From his interviews, Dr Banks concluded that J's information concerning HIV comes from the direct observational experience of the HIV status of his parents, plus researches about the 'HIV/AIDS debate' on the internet. Dr Banks attached to his first report a verbatim transcript of his first interview with J, in the course of which J gave what Dr Banks described as a succinct summary of his views about the origins of HIV, in which J said;

"HIV is, from what I understand, it's something that a doctor made up in a laboratory, and he made that up because they were running out of money, and before it was called greed, and it was only possessed by people who were usually gay and because they took drugs that gave them the illness. But I believe it to be something that a doctor made up which is now getting to something worldwide and people would believe it to be a killer, but I don't believe it's a killer."

38.

In his first report, Dr Banks concluded that J was not Gillick competent. Although he has an IQ of 105 and is therefore sufficiently intelligent to be capable of making up his own mind, he did not have sufficient understanding of HIV, its aetiology and its potential outcome if medication is not taken. His decision-making appears to be based on what may be said to be a false premise from popular science of questionable empirical quality. He has not adequately understood the need to take greater account of, and weigh in his decision-making process, evidence-based medical opinion. He dismisses the value and merits of wider scientific opinion, preferring the more popular, entertainment media over the internet, to inform his opinion. Dr Banks added that it would appear that J is heavily influenced by his immediate family's views. In addition, his psychometric personality profile suggests a higher level of dependency than would normally be the case with similar age peers. From the psychometric testing, Dr Banks detected a particularly high influence of family control or direction where J may be fearful of independent type thinking that challenges family values and norms, to a much higher degree than would be expected in the day to day socialisation process. Dr Banks therefore concluded that J was incapable of making a reasonable assessment of the advantages and disadvantages of the proposed medical treatment.

39.

In his second report, Dr Banks reported that J remained clear that he did not believe that the HIV virus has proven scientific status or credibility. In this report, he added that J was of the view that the HIV virus has underlying racist elements as its recognition/detection is directed towards those of the African community. Dr Banks stated that J was likely to have been overwhelmed by the information he was receiving, both about his own condition and that of his parents. He thought that J was likely to experience considerable stress and conflict between the information received from professionals and that received from his parents in whom he clearly invests emotionally and who he has a need to trust. Dr Banks observed that information is not simply processed through a framework of rationality but also through an emotional framework where, when one was under pressure, siding with the known and trusted is likely to be the preferential route.

40.

Dr Banks advised that, if J were able to meet with other young people who are HIV positive and have the opportunity to discuss his own condition and relate this to their experiences, this would be of

great value in allowing him a peer supported network to process some of the significant emotional and cognitive conflict which he is currently experiencing in a less emotionally pressurised form. Dr Banks thought that a forum composed of similar aged young people may add much to his understanding and ability to further process information in reaching a decision about his future behaviour and options. Dr Banks thought it might be helpful for J to have an opportunity to visit a laboratory and see the process of HIV testing. Such an experience, coupled with the opportunity to discuss his HIV status with a supportive peer group, and the appointment of a support mentor or counselling psychologist, might begin the process of cognitive challenge of his parents' views. Dr Banks thought, however, that the emotional alignment with his parents would take some time to shift. He noted that J does have an openness to receiving further information, although he thought that progressing this openness to further action may be short circuited by his parents' perspectives and influence.

#### 41.

In his second report, Dr Banks thought that it was somewhat counterproductive to recommend that J should be removed from his family into the care of the local authority. He feared that, if he was placed in foster care against his wishes again, J would not engage with health professionals at all. Furthermore, given the evidence that J experienced significant distress when being removed from his family on the earlier occasion, coupled with the fall off in educational achievement during his period of foster care, the suggestion of a further removal into foster care seemed less attractive.

#### 42.

Dr Banks gave oral evidence at the start of the hearing. He maintained his view as to J's Gillick competence as set out in his reports. Given J's age and level of understanding, one would expect him to have a greater acceptance of the scientific evidence concerning HIV. Instead, despite regular meetings with Dr Z, J continues to hold views that are contrary to the mainstream thinking. Dr Banks thought that J could not suitably weigh the pros and cons of treatment as a result of his rejection of the evidence-based science. Dr Banks confirmed his opinion that J had a misinformed view that was not independent of his parents.

#### Dr Z

# 43.

Dr Z is the consultant paediatrician in infectious disease and immunology employed by the NHS Trust who has been responsible for J's care and treatment since 2012. In her written statements, she described the history of her involvement with J from her first meeting with him in July 2012 and her subsequent discussions with him and his parents.

# 44.

I note that, as long ago as her second statement dated November 2012, Dr Z was expressing the view that "it is clear he is capable of thinking through decisions about his own health however, it is impossible for me to tell whether he holds this current view because this is what his parents want him to say or because he genuinely has the same beliefs as his parents." Her third report describes the difficult process of testing J and then informing him of the results. She describes him as appearing stunned about the news, whereas his parents displayed a quiet acceptance. She noted that J and his mother were very prompt in agreeing to come back to see her in clinic for monitoring. On this occasion, Dr Z discussed with J the possibility of psychological involvement and peer support. She noted that, throughout the consultation, although Mr A was neither uncooperative nor angry, he did on several occasions remind her of his own views about HIV and his opinion that treatment was unnecessary. On the other hand, Dr Z thought that Mrs A seemed very positive about the need to

accept the result and move on. Dr Z suggested that, if Mrs A were to return to clinic herself for monitoring, that would be a good role model for J. Dr Z did not discuss this option with Mr A, knowing his strongly-held views.

#### 45.

In her final statement before this hearing, dated December 2013, Dr Z described subsequent meetings with J and his family. Clearly some of these meetings were very difficult. At one stage, the family said that they did not want J's GP to be informed of his diagnosis. Dr Z replied that, as J's CD4 count was low, he was at greater risk of infection and it was important that he was managed by somebody who knew of his HIV status and could treat him appropriately. She was concerned, however, that, if the GP was informed of J's HIV status, there was a risk that the family would not seek help from him if J became unwell. Dr Z repeatedly explained to the family how modern medication is now much better tolerated in terms of side effects. Recent data clearly shows that over the past 10 years the mortality rate in children with HIV has dropped dramatically over the period when new ART medication has been used.

#### 46.

At subsequent meetings with J alone, Dr Z went through Professor Johnson's reports about his parent's medical history. During those discussions, J told Dr Z that his father had never taken any ART medication, contrary to what is set out in the medical records. Dr Z believes that this is a reflection of Mr A's assertion that the report does not accurately reflect his health experience. Dr Z frankly told J that the only explanation for the reduction in his parents' viral load was that they had been taking ART medication. The next meeting on 4<sup>th</sup> December was clearly very difficult. On this occasion, J attended with his parents. His father was very angry about what J had been told about his and his wife's health reports. Both parents vocalised their distress and anger about Dr Z getting involved in their lives. Dr Z thought that, in some respects, the way in which Mr A spoke to her was aggressive and inappropriate. She was concerned as to whether his own untreated HIV may be having an impact on his brain functioning. On this occasion, Dr Z spoke to J alone but found that he remained firm in his assertion that he would not take ART medication.

# 47.

In her oral evidence, Dr Z began by reiterating the way in which HIV is known to undermine the immune system and the importance of taking ART medication at an early stage. The consensus held by clinicians across the world is that it is better to start taking medication at an early stage to prevent the deterioration in the immune system that results once HIV is contracted. Dr Z said that there is not a reasonable body of opinion that believes that HIV does not cause AIDS.

# 48.

Dr Z explained how a lower CD4 count led to a greater risk of infection, both a greater risk of adverse consequences from common infections and also an increased risk of opportunistic infections which would not be contracted if the immune system was normal. Once the CD4 count falls below a certain level, the risk of opportunistic infection increases to an extent that it is recommended that patients take prophylactic medication such as septrin.

# 49.

Dr Z said that there was at present no data to predict the extent to which there was a greater risk of death for HIV patients of this age group. There is a gap of information about patients between the ages of 10 and 25. Dr Z said that the reason why the data is unavailable for this age group is that until

recently none of them survived. She said that the reason they are now surviving is because of the ART medication.

50.

Dr Z gave further evidence about the impact of side effects from ART medication. She said that the risk of side effects was greater the lower the immune system was when the ART medication was started. The medication she would recommend for J was a combination of three drugs - abacavir, lamivudine and darunavir. This amounts to a total of three tablets taken once a day, ideally at the same time every day. Dr Z said that any drug could have side effects which have to be managed. In this case, typical side effects are nausea, headache and diarrhoea, but these normally settle over time. She had found the children on this regime coped with it very well. She said that the side effects which the mother described suffering herself were associated with a different combination of drugs which the mother had taken some years earlier. She noted that J had probably observed the impact of these side effects on his mother. She accepted that this feeds into his aversion about taking medication. Dr Z noted, however, that the analysis of the causation of the mother's side effects was complicated because alongside the ART medication she had also been taking medication for her TB. Dr Z thought that the peripheral neuropathy suffered by the mother could be attributable either to the ART or to the TB medication. Dr Z recognised the difficulty in taking ART at a time when the patient is not feeling unwell. In particular, if the consequences of taking the medication is to induce side effects which make the patient feel more ill than he did before he started taking it. She added, however, that side effects are generally well tolerated these days and the experience that J has of ART is coloured by his parents' perception of their own experiences.

#### 51.

Dr Z acknowledged that there are always difficulties prescribing teenage patients to take medication if they are feeling well. Thus, if and when J gets to the stage of wanting to take the medication, he will have to be sufficiently strong and determined to carry on taking it. Dr Z stressed the importance of the patient continuing taking medication once the treatment is started. If you have virus circulating in the blood stream, if the level of medication is insufficient to prevent replication of the virus, that allows the virus to mutate and become resistant to the medication. There is therefore a greater risk if the medication is only taken intermittently.

52.

Dr Z gave further oral evidence about her meetings with J and his parents. These discussions have been difficult because the family see her as someone who has destroyed their lives. She has found that, if she sees J first, they can usually have a reasonable discussion. J has remained cooperative about the ongoing clinical monitoring. It was notable that, at one point when describing her conversations with J, and in particular about trying to persuade him to take the medication, Dr Z became somewhat upset. She was being asked about whether or not she thought it would be better for J to be in foster care. She said that she would not like to see him in foster care again but "if I have a child who is refusing to take medication it places me in an acutely difficult clinical position which I am going to have to manage." She felt that she needed to have someone taking responsibility for ensuring that the child is kept safe.

53.

Dr Z said that she could not tell when J would be competent to make decisions about his treatment. She thinks that he can follow it intellectually but also is subject to an element of undue influence. She does not think that he has a problem understanding but the complexity of his parents' strong views feed into his thinking and make it a much more difficult process. Dr Z spoke of the further support

that can be provided for J. There are psychologists within the Trust who are available to provide appropriate support and, in addition, there is a well established support network of other young people with HIV, including a small number locally and a much larger group in London and elsewhere in the country. By the time Dr Z came to give her evidence, J and his parents had agreed that their GP should be informed of his HIV status. Dr Z regarded this as reassuring for the reasons spelt out in her report. She also advised that, when travelling abroad, he should carry some document to say that he is at greater risk of infection.

54.

Dr Z accepted a point put to her on J's behalf by Mrs Connolly that it would not be possible to have adherence to medication without J's cooperation. She saw it as her duty to ensure that he has received information that the longer he waits before taking the medication, the more difficult adherence will be in the future. She thought that, if the court records in an order that it recommends that the medication be taken, that would very much validate the Tust's position.

55.

Dr Z was an extremely impressive witness. She demonstrated a shrewd and insightful understanding of J's medical condition and his wider difficult personal and social circumstances. She manifestly cares deeply about her patient and his predicament. Her evidence made a deep impression on me and, more importantly, on J.

# J's Parents - Mr and Mrs A

56.

Mr and Mrs A each provided a statement to the court and both gave oral evidence before me. In her statement, Mrs A described how she had been diagnosed with HIV some years earlier, had taken medication for a number of years but had suffered severe side effects – a rash, severe headaches, nausea and neurological weakness in her feet. She attributed this to the medication that she was prescribed for HIV, in particular septrin. When she went to abroad for a period, she stopped taking the medication and, although she suffered some withdrawal symptoms, in due course her health improved. She says that on her return, she did not resume taking medication but did not tell the doctors that she had taken this step. She said that she has not taken any ART medication since then, and now believes that she is in better health than she has been for a very long time.

57.

Mrs A maintained this position in her oral evidence. She said that she did not accept the diagnosis that she is HIV positive nor could she accept her husband's diagnosis. Initially she said that she accepted that J had been given the diagnosis and, although she could not be sure that it was accurate, she accepted "it's probably a true diagnosis". Later, however, she seemed to retreat from this position. Cross-examined by Mr Moon QC on behalf of the Trust, she said that she thought that HIV had been made up for people to make money, that HIV does not exist and HIV does not cause AIDS. Mrs A is a practising Christian. In answer to a question from me, she agreed that, if people get ill, it is "God's will". She agreed, however, that she would ensure that J continued to attend Dr Z's clinic and that she would take him for psychological counselling and peer support. She was also content for J's GP to be aware of his diagnosis. She insisted it would be a matter for J to decide whether or not to take medication.

58.

The father's position was more intransigent than the mother's. In his statement, he said that the beliefs held by himself and his wife had not altered and will never alter. He did not accept his

diagnosis of HIV nor that HIV causes AIDS. In oral evidence, he said that, when he went to abroad in 2009, he stopped taking the ART medication that he had been prescribed and started taking what amounts to alternative or herbal medicine such as pumpkin seeds and fermented papaya. Since then, his condition has improved. Like his wife, he holds a somewhat fatalistic view of life, believing that, if someone has a good life but dies age 14, that is what was meant to be.

59.

Mr A's intransigent attitude was most obvious when reiterating in oral evidence that it was still his position that, if J became unwell, he would not tell Dr Z, nor would he tell any doctor treating J about his HIV diagnosis. Like the mother, however, Mr A insisted that it was J's decision whether or not to take medication. He firmly denied that he and his wife had indoctrinated J. He said that his son had a will of his own.

# J's Evidence

60.

J's position was carefully set out in his written statements. He demonstrated that he had an understanding of HIV and the consequences of the diagnosis. He said that his views about HIV have come essentially from his parents. He said that he had listened carefully to the views of Dr Z and understood what she had said even though he did not agree with it. His prime objection to taking HIV medications is that he is fearful of the side effects. As a child, he witnessed his mother being seriously ill but since she stopped taking her medication she has been healthier and happier. He is therefore fearful about how medication might affect him and how he may feel both physically and emotionally. He said that he regarded this as a "very fundamental issue". He was therefore not willing to take the medication directed by Dr Z. On the other hand, he indicated that he was willing to accept the other proposals, including attending appointments with Dr Z and her team and also psychological appointments.

# 61.

In addition to reading his statement, I was anxious to have an opportunity to speak to J myself. After some discussion, it was agreed that, rather than his giving formal evidence, he would answer questions from me and counsel in a rather less formal setting. As a result, we all sat round the table in the well of the court. Only J, counsel and I were present. The conversation was transcribed by Ms Rickard, junior counsel for the Trust. It proved particularly illuminating and has had a significant impact upon the outcome of this case.

62.

After some initial discussion about football, J was asked why he wanted to speak to the court today. He said that he wanted to get his point across and show everyone that what he says has come from him rather than from his parents. He wanted to show that he was mature. He had asked for his parents not to be present because he did not want the court to think that he was looking over to them for support, although he was happy that his parents could see everything that he said to me. Ms Connolly then asked him about the HIV test. The conversation continued:

"Counsel: You have had your HIV test and you know that you are said to be positive. Do you accept that you are?

J: Yeah I accept it. Yeah.

Judge: You've heard your mum and dad say how they feel about themselves and theirs [diagnosis] do you accept it's true?

J: I still think I've got a way to go before I think it's true or not and still a way to go to believe it.

Judge: How do you feel at the moment about your diagnosis? Is it probably true, possibly true? How would you put it".

J: I can't tell you cos...well okay right now, I don't think it's true.

Judge: Why?

J: I don't have the proof.

Judge: The test has been taken it's gone to the laboratory, the lab has done the test, the result has come back on paper, why can't you accept it?

J: I don't feel like a piece of paper is enough. I like to see what is going on."

J said that he thought it might help quite a lot to have a chance to go to the laboratory. He wanted to have information and thought that the best way of getting it would be through appointments with Dr Z, with other HIV specialists and support adding: "so I can see what other people have gone through just to get different sorts of views. I don't want someone lecturing me, I want an exchange of views where I can talk about it". To date, he has told just one friend. He is concerned about becoming an outcast and therefore doesn't want special treatment from teachers in case friends ask what is going on. He said he was concerned that attending clinic too often with Dr Z may lead to his missing a lot of school and would therefore rather see a doctor closer to home. He was happy, however, to keep on seeing Dr Z. He agreed with me that Dr Z was really dedicated to his care. He said he thought that Dr Z was acting in his best interests "from her point of view". He said he had been impressed with Dr Z's evidence, and also by the fact that she got upset at one point when giving it, because that showed she really cared. He agreed to ongoing blood tests saying "because I do need to know how healthy I am and what risk I have of getting ill." He thought that Dr Z "could be right, so I'm happy to be monitored get more info." He thought it better to go by himself to see Dr Z, because "it's a lot calmer when it's just me."

63.

J was clear, however, he will not take medication at the moment. He is still too afraid of the side effects, observing: "it's the most important factor in my decision making...the side effects are a bigger fear than the HIV." If he was ordered to take the medication, or removed from home in an effort to persuade him to take it, he would stop cooperating. He agreed that, if he did take the medication and did not get any side effects, his views might change. But if he started taking the medication and got side effects, he would want to stop, although he knew that would make it worse because "it's even worse to stop." He understood that it did not follow that he would get side effects just because his mother had. He agreed that it would be useful to talk to someone who had been on the medications and had side effects so he would understand how bad they were. He had heard Dr Z say that, if he did not take the medication, there was a risk he would contract a more serious condition such as TB or pneumocystis, but he took a different view from Dr Z and did not think that the risk is high that he would get those illnesses. He agreed, however, that if he was convinced that the risk was high, the balance would come down in favour of taking the medication. He said:

"I can't say that I'm never ever going to change my view, I know there's a possibility I will. When I grow up other people might influence my decisions. Like at university or even sixth form college. My partner – she could have different views and we might talk about it and I might go on to medication. I'm not saying that my view won't change."

He thought that if he decided to take the medication, his parents would not find it easy, but they would come to terms with it. He thought his father would definitely find it harder than his mother.

#### 64.

In addition to ongoing blood tests, J could see why he might need psychological therapy. Although he did not have much anxiety right now, he thought he might need it in future. Unlike his father, J thought his GP and emergency services should be aware of his HIV diagnosis. He was willing to give peer support a try, although he was not keen on the proposal that he attend a summer camp for young people with the diagnosis. He would prefer one to one meetings with someone his age or a bit older, preferably from somewhere other than his local area. He would not need to know their views in advance. He thought that was something they could talk about when they met.

#### 65.

I explained the legal consequences of a care order – that the local authority would share parental responsibility with his parents although his parents could not go against what the local authority decided was best. I said I thought that his parents had influenced him to which he replied: "Yeah they have influenced me but I can get information from other people and I'm willing to, but I just don't really like being held back by this care order, and the way I can go forward I don't think my parents could force me not to have it. I don't see them stopping me if I do eventually say I want to take it. "He agreed with me that he had heard things that his parents had said. He agreed with me that it was quite hard for him to live with the fact that his parents had been diagnosed with HIV, have lived with it and have strong views. He added, however, that things had changed since their experience and that's why he thought their influence was not as strong as it used to be. He agreed with me that he felt protective of his parents and that made it a bit harder to do something they didn't want. He said: "If there's a way it can be worked out that it doesn't have to be a care order, and they have less control over me, I'm willing to talk about that".

# 66.

In addition to the above witnesses, the court heard oral evidence from the social workers concerning their involvement with J, and also from Professor X, the medical director of the Trust. In addition to giving details as to the support available for J, Professor X's evidence was substantially directed at the issues surrounding whether or not an order should be made against J requiring him to take the medication. In the event, as already indicated, the Trust ultimately abandoned this argument. It is therefore unnecessary for this judgment to consider Professor X's evidence on this issue interesting though it was.

# **GILLICK COMPETENCE**

# 67.

I am very grateful to Mr Moon QC and Ms Rickard on behalf of the NHS Trust for their comprehensive exposition of the law on this aspect of the case. The principles, in so far as they apply to the decisions which now have to be made in this case, can be summarised as follows.

68.

A child under the age of 16 is deemed to have legal capacity to consent to medical examination and treatment if he or she has sufficient maturity and intelligence to understand the nature and implications of the proposed treatment: Gillick v West Norfolk and Wisbech Are Health Authority and DHSS [1986] AC 112. To be Gillick competent, a child must (a) understand the nature and implications of the treatment, which would include the likely effects and potential side effects; (b) understand the implications of not pursuing the treatment, including the nature, likely progress and consequences of any illness that would result from not receiving the treatment; (c) retain the above information long enough for the decision making process to take place and (d) be of sufficient intelligence and maturity to weigh up the information and arrive at a decision.

69.

Two further points should be made about Gillick competence. First, it is decision-specific. Thus, a young person may be Gillick competent in respect of decisions about some treatments but not others. Secondly, Gillick competence is a question of fact for the judge: see Gillick, supra, per Lord Fraser at page 172C. Whilst appropriate attention must be paid to the opinion of medical experts, those opinions need to be considered in the context of all the other evidence. As always in children's proceedings, the roles of the Court and the expert are distinct. It is the Court that is in a position to weigh up expert evidence against the other evidence: see A County Council v K D & L [2005] EWHC 144 Fam [2005] 1 FLR 851 per Charles J.

70.

When a child is found to be Gillick competent, medical treatment can be lawfully administered in reliance on the child's own consent. Where, however, a Gillick competent child refuses to give his or her consent to treatment, the court may, in the exercise of its inherent jurisdiction, override that child's wishes in its best interests and give its consent for the treatment to take place: Re W (A minor) (medical treatment: courts jurisdiction) [1993] Fam 64. In that case, the Court of Appeal was faced with an appeal on behalf of a sixteen-year-old girl suffering from anorexia who had been found by the judge at first instance to have sufficient understanding to make an informed decision about treatment but in respect of whom the judge had ordered treatment against her wishes. The Court of Appeal held that, while a sufficiently mature minor could consent to treatment, his or her refusal to give consent could not overrule the court's grant of consent under its inherent jurisdiction. Whilst in exercising that jurisdiction the court would take account of the child's wishes, those wishes could be overridden where his or her best interests so required. In his judgment in the case, Lord Donaldson of Lymington said, at page 81 C –D:

"There can...be no doubt that [the court] has power to override the refusal of a minor, whether over the age of 16 or under that age but 'Gillick competent'. It does not do so by ordering the doctors to treat which, even if within the court's powers, would be an abuse of them or by ordering the minor to accept treatment, but by authorising the doctors to treat the minor in accordance with their clinical judgment, subject to any restriction the court may impose."

# At page 84 A-B, Lord Donaldson added:

"No minor of whatever age has power by refusing consent to treatment to override a consent to treatment by someone who has parental responsibility for the minor and a fortiori a consent by the court. Nevertheless such a refusal is a very important consideration in making clinical judgments and for parents and the court in deciding whether themselves to give consent. Its importance increases with the age and maturity of the minor."

The paramount consideration of the exercise by the court of this jurisdiction is the child's welfare. The child's wishes and feelings are an important consideration and, as Lord Donaldson observed in the passage just cited, their importance increases with the age and maturity of the child, but they are not necessarily determinative of the issue.

#### 72.

It is plain that J is an intelligent, thoughtful and articulate teenager. He has received a very considerable amount of information about HIV and AIDS from a variety of sources. He has received an exhaustive analysis of his own medical history as explained by Dr Z. Dr Banks has concluded, however, that J does not have sufficient understanding of HIV, its aetiology, and its potential outcome if medication is not taken. Furthermore, Dr Banks concludes that J has not adequately understood the need to take greater account of, and weigh in his decision making process, evidence-based medical opinion, preferring the views set out on the internet and those expressed by his family.

#### 73.

Of course, the interviews with Dr Banks took place some months ago and it was clear to me from his informal oral evidence that J's views have evolved in several respects. First, I am satisfied that he now recognises, understands and respects Dr Z's view to a much greater degree than he did previously. He was plainly impressed and affected by Dr Z's painstaking exposition of his case in several hours of questioning during her oral evidence. Secondly, like all teenagers, J is in the process of separating emotionally and psychologically from his parents. This is illustrated in part by his recognition in his informal oral evidence that he has protective feelings towards his parents and their predicament, and that it will be better if hereafter he saw Dr Z on his own. In my judgment, he now genuinely sees the importance of reaching a decision independent of his parents. Thirdly, as he indicated at several points in his informal oral evidence, he acknowledges that his own views may evolve further.

# 74.

On the other hand, in what I regard as the key exchange with the court during his informal oral evidence, J stated that he did not think the diagnosis of HIV given to him was true because he did not have the proof. He did not feel a piece of paper was enough. If he does not accept the diagnosis, it must follow, in my judgment, that he does not fully understand the implication of not receiving the treatment. He therefore lacks the understanding necessary to weigh up the information and arrive at a decision. Applying the test laid down by the House of Lords, this points to a conclusion that he is not Gillick competent.

# 75.

To an extent, however, there is an element of unreality about this analysis. It could be argued, that if J were to give his consent, his parents having indicated that they would not oppose the treatment, the Trust would in reality provide the treatment without delay. In those circumstances, it could be argued that J falls into the category of patients identified in Re W, supra, namely someone capable of giving consent but whose refusal to give consent is capable of being overridden by the court.

# 76.

Drawing all these threads together, and having regard to the other submissions made by counsel on this topic in the course of closing speeches, I conclude that, as J does not accept his diagnosis, he does lack the understanding of the consequences of not taking ART medication and therefore the understanding needed to weigh up the pros and cons before making a decision as to whether to take the medication. On balance, at this precise point in time, he is therefore not Gillick competent to make a decision as to whether or not to take ART.

As set out above, the test for Gillick competence is decision-specific. A person who is not Gillick competent in respect of some treatments may be Gillick competent in respect of others. The decision to take ART is a complex decision which turns in part on J's acceptance of the diagnosis. The decision to undergo monitoring, blood tests and chest x-rays is less complex, and in any event in this case J has agreed to these measures. Equally, the decision to accept psychotherapy and peer support is less complex. These decisions are not specifically dependent on J's acceptance of his diagnosis but rather on the fact that the diagnosis has been given. He needs psychotherapy and peer support whether or not he accepts the diagnosis. Importantly, J accepts that he should have both psychotherapy and peer support. In all the circumstances, I conclude that he is Gillick competent in respect of decisions whether to undergo monitoring, and receive psychotherapy and peer support.

#### **DECLARATIONS CONCERNING TREATMENT**

# 78.

The medical evidence in this case is clear and can be summarised as follows. J has been diagnosed as being HIV positive. Unless he starts ART medication he is likely to develop AIDS, suffer severe infection and die prematurely. If he takes ART, he is likely to avoid infection and survive much longer. Although there is a risk of side effects if he takes ART, that risk, and the seriousness of side effects attributable to medication, have been reduced in recent years as a result of advances in treatment. The risk of side effects is much less than the risk of not taking the medication. Once medication is started, it should be adhered to, since intermittent taking of medication reduces its effectiveness. The longer J waits before starting ART, the greater the risk he will develop AIDS and the more serious the side effects will be.

79.

In these circumstances, the NHS Trust, local authority and the CAFCASS manager (substituting for the Guardian who has been absent during the hearing) invite the court to make a declaration that it is in J's interests to receive ART. On behalf of J's parents, Miss Bazley QC and Miss Garnham are unable to consent to such a declaration but submit that any declaration granted by the court should include a reference to J deciding to accept treatment, and should therefore be couched in terms such as "it would be in J's best interests to decide that he will commence and maintain ART treatment".

80.

On behalf of J, Ms Connolly and Miss Dixon submit that a decision whether or not to take ART is not straightforward. She submits that, to those unaffected, it is perhaps easier to regard it somewhat simplistically – take the medication and prolong life. She submits, however, the decision not just whether or not, but when, to start treatment is far more complex since, to be effective ART requires an extremely high level of adherence, and commitment, in reality to a lifelong therapy. In addition, there is a very real risk of side effects. Whilst she acknowledges on J's behalf that modern medication is now said to be less toxic and much better tolerated, the risk remains that J would experience some side effects. She also submits that less is known about the long-term toxicities of newer drugs. She submits that even common non-dangerous side effects may cause disturbance to daily life which may affect, for example, J's football performance. This in turn may affect his commitment to regular adherence to the treatment. She submits that it is therefore easy to understand the reluctance of a young adolescent who is otherwise fit and well to embark upon a course of medication that may make him feel unwell. Taking medication in those circumstances is, she submits, counter intuitive. In addition, for J, he has the experience and knowledge of the severe side effects experienced by his mother.

#### 81.

I well understand J's anxieties and have great sympathy for his predicament. I recognise that in his circumstances a decision to take ART is not straight forward, involving as it does (1) the need to adhere permanently to the treatment (2) the risk of side effects and (3) going against his parents' views. I am satisfied, however, that the evidence clearly establishes beyond reasonable doubt that it is in his best interests to take the medication as soon as possible. I accept the expert evidence about HIV generally given by Dr Welch and Dr Z, and the specific evidence about J's condition given by Dr Z.

#### 82.

In deciding whether or not to make a declaration, I apply section 1(1) of the Children Act 1989. J's welfare is my paramount consideration. Although section 1(3) does not strictly speaking apply to my decision whether or not to grant a declaration, I do find the checklist useful in these circumstances. In this case, I find that J's physical needs, and the risk of harm if he does not take the medication, outweigh the risk of harm through side effects, the risk of emotional harm of going against his parents' views and his own expressed wishes and feelings.

#### 83.

I therefore declare that it is in J's best interests to start antiretroviral therapy medication as quickly as possible.

#### 84.

I also express the view, and if necessary will so declare, that it is in his best interests to receive psychotherapy and peer support. The evidence shows that these measures play an important part in helping young people with HIV come to terms with their condition and preparing them to meet the challenges that will arise in living with the diagnosis.

# 85.

At this point, I was intending to move on to consider whether the threshold criteria under s.31 are satisfied, what orders should be made, and the terms of the proposed contract of expectations. In the light of recent events, I propose to adjourn those matters for further consideration. Meanwhile, I would be grateful if counsel could agree the terms of a draft interim order which will include directions for evidence as to the latest developments. The interim care order should continue for the time being. The order should provide for liberty to apply at short notice, all applications reserved to me if available.

[Postscript - The proceedings subsequently concluded with an agreed finding that the threshold criteria under s.31 of the Children Act 1989 were satisfied on the grounds that J's parents did not consent to his being tested for HIV in April 2013 and J was made subject of a supervision order for 12 months. No further order was made under the inherent jurisdiction. Responsibility for J's medical care and treatment passed to another hospital.]