

Neutral Citation Number: [2019] EWCOP 16

Case No: COP 3415524

# **COURT OF PROTECTION**

Royal Courts of Justice Strand, London, WC2A 2LL

Date: 2 May 2019

Before :

# Mr Justice Williams

Between :

University Hospitals of Derby and BurtonApplicantNHS Foundation Trust- and -JJKespondent(by her litigation friend, the Official Solicitor)

(Medical Treatment: Best Interests)

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**Sophia Roper** (instructed by **Browne Jacobson LLP**) for the **Applicant Michael Horne QC** (instructed by **the Official Solicitor**) for the **Respondent** 

Hearing dates: 2 May 2019

# **Approved Judgment**

I direct that pursuant to FPR 27.9 no official shorthand note shall be taken of this Judgment and that copies of this version as handed down may be treated as authentic.

# MR JUSTICE WILLIAMS

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This judgment was delivered in public. 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 the anonymity of the incapacitated person and members of their 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.

# Mr Justice Williams :

- 1. I am concerned with the welfare of a young woman, who I shall call Anne for the purposes of this judgment. She is the subject of an application brought by the University Hospitals of Derby and Burton NHS Foundation Trust for declarations that it is in Anne's best interests to undergo a hysterectomy and bilateral salpingo-oophorectomy and a colonoscopy, and that, in order to enable those to be undertaken, it is in her best interests for a transfer plan to be implemented which will involve her sedation and a level of deception to ensure her presence at hospital for the procedures to be undertaken. The application arises because it is said that Anne lacks capacity.
- 2. Anne is the respondent to the application and is represented by her litigation friend, the Official Solicitor.
- 3. Anne's parents are not respondents to the application, but have attended court and have filed a statement.
- 4. Both the Official Solicitor and Anne's parents agree that Anne lacks capacity, and that it is in her best interests for the treatment to be undertaken and for the care plan to be implemented. Given the facts of this case, the applicant NHS Trust rightly issued this application for the decision to be taken by the court, not by agreement between those concerned.

#### Background

- 5. This is set out in the statement of Anne's mother (which is made on her behalf and on behalf of Anne's father) and in the statement of Anne's consultant obstetrician and gynaecologist.
- 6. Anne has a diagnosis of autistic spectrum disorder and a severe learning disability. At times her behaviour can be very challenging. Since she started menstruating as a teenager her monthly cycle has affected her behaviour and mood, which has in turn restricted her lifestyle. She is very upset at the sight of blood, and her distress manifests itself in various forms which I do not consider it necessary to set out in this judgment, they being highly personal and sensitive. In addition, the hormonal changes (linked to the production of progesterone) prompt an increase in her aggressive and challenging behaviour. Anne lives at home with her mother and father and it is clear from their statement that caring for Anne has become the central focus of their lives.
- 7. Over the years Anne's treating consultants have tried a range of treatments, including oral contraceptives, and an IUD. These helped stabilise the problem but ultimately failed, and Anne experienced severe crises in her mental health in 2010 and 2012. She remains fearful about this experience.
- 8. In 2012 she was started on 3 monthly injections of Decapeptyl which suppresses normal hormonal activity including menstruation. It is licensed for 6 months' use, but Anne has been on it far longer. It is known to cause osteoporosis and the effects of its long-term usage are unknown. Because of that risk Anne was tried on an alternative medication following a minor operation, and this was drastically unsuccessful, with Anne experiencing severe side effects including psychosis and violent aggression, as well as vertigo. She returned to Decapeptyl use. This involves injections being given

every 3 months by her GP at home. These have been reasonably successful in preventing menstruation (and so the linked distress that Anne experiences) and have moderated her behavioural difficulties, albeit her parents believe that when the medication is starting to wear off, she becomes more aggressive. However, Anne finds the injections extremely distressing, both in advance and during their administration.

- 9. In addition to these symptoms, Anne was also found to have endometriosis. She also experiences severe abdominal pain related to going to the toilet. This may be indicative of large bowel upset, although it could be linked to endometriosis. Testing has suggested an inflammation of the bowel which might be caused by a disease such as Crohn's or ulcerative colitis. This needs further investigation.
- 10. Since about 2015 Anne has been unwilling or unable to travel out of her home save on very rare occasions, for instance when she was in such pain from a tooth that she willingly travelled to hospital. However, she suffers from vertigo, which appears to be exacerbated by travel. On one occasion she struck her father and attempted to leave the moving car, and her distaste for travel by vehicle has now become more embedded. She will not willingly go on a journey in a vehicle, whether car or ambulance. Very recently, when she was experiencing severe abdominal pain, she did agree to an ambulance being called, and thus it is possible that, if in sufficient pain, she might agree to travel by vehicle, but otherwise it is likely that she would not. On one occasion she insisted on walking 9 miles home from hospital because of her aversion to travel in a vehicle.
- 11. It appears that the issue of a hysterectomy has been discussed at various times over the years; 2008, 2012-13, and more recently. A hysterectomy and/or removal of Anne's ovaries were rejected by her parents and her treating doctors for various reasons, including the effect on her fertility. Since 2014 Anne has been under the care of her current consultant obstetrician and gynaecologist. She has now concluded that a hysterectomy is the last realistic option given that Decapeptyl injections cannot be used long-term.

### The proposed treatment

- 12. The surgery proposed is a hysterectomy with bilateral salpingo-oophorectomy ('HBSO'). This will remove Anne's uterus, fallopian tubes, cervix and both ovaries. Self-evidently it will lead to the end of Anne's ability to bear children. A hysterectomy on its own would prevent menstrual bleeding but would not prevent the hormonal cycle responsible for the increased aggression and challenging behaviour. The removal of the ovaries would be necessary to deal with the impact of the hormonal cycle related behavioural difficulties. The negative consequences of ovary removal can be counteracted by long-term oestrogen administered as a gel. The removal of the ovaries alone leaving the uterus intact would expose Anne to a very high risk of endometrial cancer, which could only be counteracted by progesterone, which would lead to the return of the unwanted bleeding and hormonal changes.
- 13. The surgery would be done laparoscopically and would last about 90 minutes. If no bowel surgery was necessary, she could be discharged the day after the operation. Thereafter oestrogen hormonal replacement therapy could be given until the age of

natural menopause. This carries minimal risks and would reduce the risk of osteoporosis.

- 14. Quite separately the colonoscopy is required to identify whether there is a specific treatable cause for Anne's bowel symptoms. Anne would need to be on a special liquid diet and laxatives for 2 days preceding the operation to enable the colonoscopy to be effective. She would therefore need to come into hospital 2 days in advance to ensure her compliance with the liquid diet required, and also so that her home remains the safe space, rather than being associated with a distressing medical intervention. She would require a general anaesthetic for the colonoscopy and it would be carried out alongside the proposed HBSO.
- 15. The colonoscopy might have 4 possible outcomes
  - i) nothing identified,
  - ii) a problem identified which could be treated at the time e.g. a polyp,
  - iii) a problem identified which could be treated with medication,
  - iv) a problem identified which could be treated with surgery on another occasion.
- 16. If minor surgery was required, it could be done during the operation.
- 17. The total operation time for both the HBSO and the colonoscopy would be around 2 hours, perhaps 3, depending on whether further surgery arose from the colonoscopy. Anne would have a general anaesthetic. The recovery period in hospital might be extended to 2 to 5 days. The only additional risk from the 2 procedures being done in one operation is a slight increase risk of DVT or pulmonary embolism but these are standard risks of general anaesthetic. The usual measures would be in place to reduce those risks.
- 18. Because of Anne's acute anxiety in relation to travel, a detailed transfer plan has been prepared. This would involve her GP giving her a sedative injection and a team of 3 from the ambulance service would then escort her to hospital. Transfer home would likely involve a similar process; albeit it might be easier to persuade her to go home. Anne would believe that the sedative injection was her usual injection of Decapeptyl and so there would be an element of deception.
- 19. Anne's treating consultant has sought a 2<sup>nd</sup> opinion within the treating trust who is supportive of the proposed HBSO. He opined that her life would be dramatically better afterwards.

### Expert opinion.

- 20. An opinion has also been sought from Professor Shaughn O'Brien, who is one of the leading experts in this field. He has not examined Anne but has provided an opinion based on the papers. Some of the points he makes are:
  - i) Long-term use of Decapeptyl is a theoretical option but its long-term safety is unknown and osteoporosis is almost inevitable. Injections would need to continue every 3 months for the next 25 years or so.

- ii) The best-known risk of such medication is bone thinning/degradation. The potential impact on Anne would be significant, with the possibility of fractures in her femurs and her confinement to a wheelchair. These would very considerably affect the quality of her life, given that she enjoys some physical activity.
- iii) For patients such as Anne it is routine to offer and carry out an HBSO, acknowledging the risks of any surgery. There is no physiological reason why Anne should face higher risks of surgical complications than any other patient.
- iv) Hysterectomy will end her menstruation and the BSO is likely to end any symptoms related to the ovarian (hormonal) cycle. She will be able to stop the Decapeptyl injections.
- v) Removal of the ovaries is a necessary part of the surgery. Removing the ovaries but conserving the uterus would mean her periods would continue, and she would need progesterone to prevent endometrial cancer. This would be more than likely to re-stimulate her premenstrual disorder/premenstrual exaggeration.
- vi) Equally, removing the uterus but conserving the ovaries would end her periods but the hormonal cycle would continue, causing the ongoing problems of premenstrual disorder/premenstrual exaggeration.
- vii) The cervix would also need to be removed. Not doing so risks leaving some endometrial lining which would then require the administration of progesterone.
- viii) He has no doubt that the proposed surgery is appropriate for Anne and is in her best interests. At worst it might only improve the menstrual bleeding aspect but not the hormonal cycle related aggression and behavioural issues. However, it would stop the injections and the near certainty of osteoporosis.
- ix) At best her life would be transformed from the menstrual/ovarian cycle point of view. The hormonal cycle (premenstrual exaggeration) behavioural issues would be eased. It would eliminate the periods and would end the need for long-term medication with the associated risks of osteoporosis.

### The parties' positions

21. Given the unanimity between Anne's treating consultants, the internal second opinion and the expert opinion of Professor O'Brien, the applicant NHS Trust submits that it is clear that Anne's best interests will be promoted by the authorisation of the HBSO and the colonoscopy and the implementation of the care plan. Anne's learning disability team also support the proposal. Her consultant psychiatrist, who has been involved with her over a number of years, opined that an effective intervention to minimise the monthly fluctuation in her mood and resolution of the abdominal pain she is experiencing will certainly make her behaviours more manageable and thus improve her quality of life.

- 22. Anne's parents are also in support of the proposal. Indeed, they believe it should have been undertaken some years ago and express a degree of frustration that Anne has had to experience the ongoing consequences over the last 5 to 6 years. They have noticed a deterioration in her quality of life over that period.
- 23. The Official Solicitor supports a final declaration being made that Anne lacks capacity to conduct these proceedings, and a final declaration that she lacks capacity to decide what medical investigation and treatment she should receive for her health care needs, including for premenstrual syndrome and abdominal pain. The Official Solicitor supports an order being made which gives consent to the HBSO, the colonoscopy and any associated treatment, and the transfer plan. The Official Solicitor notes that this is significant life changing surgery which will impact profoundly upon Anne's personal autonomy, bodily integrity and reproductive rights. Nevertheless, he supports the gynaecological intervention (and other interventions) as being in her best interests and thus lawful. They are necessary and proportionate interferences with her rights. The medical and other evidence in support of these conclusions on best interests is clear. In relation to Anne's ability to bear children, the Official Solicitor notes that this is a theoretical rather than real loss, because as a result of her lack of capacity to consent to sexual relations she will not bear children and is most unlikely ever to be able to parent a child. The Official Solicitor notes that Anne is herself unable to express a clear view about the operation. She has indicated that she does not want to have menstrual bleeding or a child.

# **Capacity**

- 24. Anne's capacity has been assessed by her consultant psychiatrist and is set out in a series of letters, in his witness statement and in the COP 3. His conclusions may be summarised as follows.
  - i) Anne's ability to understand information: she is able to understand information related to her daily life choices and use of medications provided it is provided in simple language and repeated in an environment that she is comfortable with and by people who she is familiar with. She is particularly anxious about going to hospitals as well as medical procedures, and her ability to understand information may be adversely affected by anxiety. She would struggle to understand the information related to the hysterectomy other than that it is a procedure to stop her from having periods.
  - ii) Anne's ability to retain information: she can retain simple information over long periods of time or remarks without the full context. This may present problems for her ability to retain information about the need for surgery, what happens as part of the surgery, as well as potential risks.
  - iii) Anne's ability to weigh information related to the procedure and come to a decision: she would not be able to weigh the benefits and risks related to a procedure like the hysterectomy or come to a decision.
  - iv) Anne's learning disability, and other conditions, and the anxiety related to them, impact on her information-processing as well as her use of that information. Her condition is enduring and lifelong.

- v) She does not have capacity to consent to sexual intercourse.
- 25. The Official Solicitor's own analysis of the material relating to Anne's capacity leads him to conclude that it is consistent with her having a severe learning disability and autism. She also experiences anxiety and depression. The Official Solicitor accepts that Anne lacks subject matter capacity to make a decision relating to the proposed medical treatment and also that she lacks litigation capacity. Her limited capacity to understand, retain and weigh information and make decisions results in a lack of litigation and subject matter capacity.

### These proceedings

- 26. The application was made on 5 April 2019 and came before Mrs Justice Lieven on 17 April 2019. She timetabled the application for a hearing on 2 May.
- 27. I have had the benefit of detailed position statements on behalf of the applicant NHS Trust and on behalf of the Official Solicitor. I have had the benefit of brief oral submissions in support of those documents and I also heard from Anne's parents. I have been able to read various statements and reports from Anne's family, from her treating clinicians, from Professor O'Brien, and notes from meetings by the Official Solicitor.

#### The Substantive Application: Legal Framework and Analysis.

- 28. The Mental Capacity Act 2005 sets out the statutory scheme in respect of individuals aged over 16 who lack capacity. Section 15 gives the court the power to make declarations as to whether a person lacks capacity to make a specified decision, and the lawfulness or otherwise of any act done or to be done in relation to that person. Section 16 gives the court the power to make an order and make the decision on a person's behalf. Section 48 gives the court a discretion to make an order on an interim basis if it is in the person's best interests to make the order without delay.
- 29. The Court of Protection has jurisdiction over a person habitually resident in England and Wales: MCA 2005 Sch.3 Part 2 paragraphs 7(1)(a). Anne is clearly habitually resident in England and Wales.
- 30. Section 2(1) of the Act provides that a person lacks capacity if,

'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.'

It does not matter whether the impairment or disturbance is permanent or temporary. The determination of whether a person lacks capacity is to be made on the balance of probabilities. Section 3 sets out various criteria by which the court should determine whether a person is unable to make a decision. Section 2 imposes a 'diagnostic threshold.' I am satisfied on the basis of the medical evidence set out above that Anne currently lacks capacity to take a decision for herself on the issue of her medical treatment both gynaecological and gastro-intestinal. There is no means by which she could currently be enabled to make a decision and the lack of capacity is likely to be

permanent. On balance the lack of capacity arises from an impairment or disturbance of the brain arising out of her severe learning disability and autism.

31. Section 1 of the Act sets out the principles applicable under the Act. Sub-section (5) provides that

'An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.

32. Section 4 of the Act deals with 'Best interests'

(1)In determining for the purposes of this Act what is in a person's best interests, the person making the determination must not make it merely on the basis of—(a)the person's age or appearance, or

(b)a condition of his, or an aspect of his behaviour, which might lead others to make unjustified assumptions about what might be in his best interests.

(2)*The person making the determination must consider all the relevant circumstances and, in particular, take the following steps.* 

(3)He must consider—

(a)whether it is likely that the person will at some time have capacity in relation to the matter in question, and

(b)if it appears likely that he will, when that is likely to be.

(4)He must, so far as reasonably practicable, permit and encourage the person to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him.

(5)Where the determination relates to life-sustaining treatment he must not, in considering whether the treatment is in the best interests of the person concerned, be motivated by a desire to bring about his death.

(6)*He must consider, so far as is reasonably ascertainable—* 

(a)the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),

(b)the beliefs and values that would be likely to influence his decision if he had capacity, and

(c)the other factors that he would be likely to consider if he were able to do so.

(7)*He must take into account, if it is practicable and appropriate to consult them, the views of*—

(a) anyone named by the person as someone to be consulted on the matter in question or on matters of that kind,

(b)anyone engaged in caring for the person or interested in his welfare,

(c)any donee of a lasting power of attorney granted by the person, and

(d)any deputy appointed for the person by the court,

as to what would be in the person's best interests and, in particular, as to the matters mentioned in subsection (6).

(8)*The duties imposed by subsections* (1) *to* (7) *also apply in relation to the exercise of any powers which*—

(a)are exercisable under a lasting power of attorney, or

(b)are exercisable by a person under this Act where he reasonably believes that another person lacks capacity.

(9)In the case of an act done, or a decision made, by a person other than the court, there is sufficient compliance with this section if (having complied with the

requirements of subsections (1) to (7)) he reasonably believes that what he does or decides is in the best interests of the person concerned. (10) "Life-sustaining treatment" means treatment which in the view of a person providing health care for the person concerned is necessary to sustain life. (11) "Relevant circumstances" are those— (a) of which the person making the determination is aware, and (b) which it would be reasonable to regard as relevant.

- 33. The courts have emphasised in a variety of contexts that 'best interests' (or welfare) can be a very broad concept.
  - i) *Re G (Education: Religious Upbringing)* [2012] EWCA Civ 1233, 2013 1 FLR 677. Best interests must be taken in its widest sense and its evaluation will change according to developments in society. It need not be confined to the short-term but should look at the medium to long term and can take account of anything that might affect the best interests.
  - ii) In Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67, [2014] AC 591

[39]The most that can be said, therefore, is that in considering the best interests of this particular patient at this particular time, decision-makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves and its prospects of success; they must consider what the outcome of that treatment for the patient is likely to be; they must try and put themselves in the place of the individual patient and ask what his attitude towards the treatment is or would be likely to be; and they must consult others who are looking after him or are interested in his welfare, in particular for their view of what his attitude would be

iii) An NHS Trust v MB & Anor [2006] EWHC 507 (Fam), Holman J:

That test is the best interests of the patient at this particular time. Is it in THIS patient's best interests to receive this treatment? Best interests are used in the widest sense and include every kind of consideration capable of impacting on the decision. In particular they must include the nature of the medical treatment in question, what it involves and its prospects of success and the short, medium and longer-term outcome, best interests goes far beyond the purely medical interests. They must also include non-exhaustively medical, emotional, social, psychological, sensory (pleasure, pain and suffering) and instinctive (the human instinct to survive) considerations.

34. It is a fact of the proposed care plan that it will involve an element of deception of Anne. In *NHS Trust v K and Ors* [2012] EWCOP 2922; *Re AB* [2016] EWCOP 66; *Re P* [2018] EWCOP 10 and *NHS Trust (1) and (2) v FG* [2014] EWCOP 30 the court has confirmed that this is compliant with the individual's Article 8 rights provided the best interests exercise has been carried out. It seems to me that if it is in P's best interests for deception or misrepresentation to take place then the court would be

obliged to authorise that. The question of the level of deception would no doubt feed into the evaluation of whether the best interests of P were met by the plan which involved that deception; the greater the deception the more it might potentially weigh against P's best interest and vice versa, but as a matter of principle it seems to me that deception cannot be a bar to authorisation of a procedure. To hold otherwise would be to supplant the best interests of P by some other principle, perhaps of public policy, that the court should not condone white lies.

35. A distinction is drawn in the cases between a therapeutic sterilisation for medical reasons (such as we are concerned with here) and a non-therapeutic sterilisation carried out for contraceptive purposes. Ultimately the principles are the same albeit their application may differ; the lodestar is the best interests of the patient evaluated by reference to the provisions of the MCA 2005.

# **Evaluation**

- 36. So the evaluation of what order is in Anne's best interests involves a broader survey than whether the proposed operations will have any medical benefit to her. It includes every consideration that might bear on what is in her best interests.
- 37. Her family members support the proposed treatment.
- 38. The Official Solicitor has carried out a balance sheet analysis which concludes that the benefits outweigh the disbenefits. Although the list of disbenefits in relation to each of the aspects of the treatment outweighs (numerically speaking) the list of benefits, the weight to be given to the benefits is clearly vastly more than the disbenefits. The Official Solicitor identifies in particular the following issues:
  - i) Continuation of Decapeptyl injections will cause Anne significant anxiety and distress for years to come.
  - ii) Osteoporosis will occur if those injections are continued and it is a significant morbidity and mortality risk. In particular the Official Solicitor emphasises that during telephone discussions with Professor O'Brien he identified that Anne would be at high risk of fracture later in life and that this would have a significant potential impact on her life. He considered it would be negligent to continue to administer that drug.
  - iii) Whilst the Official Solicitor expressed some 'light touch' caution over the extent to which Anne's cyclical behavioural disturbance is attributable to the production of progesterone, in oral submissions he acknowledged that the balance of the evidence supported the conclusion that the procedures would be likely to have a significant benefit even if they did not completely eradicate the cyclical behavioural disturbance.
  - iv) Anne will find the whole experience of transfer to hospital, her stay, surgery, and her recovery, a distressing and difficult experience.
  - v) HBSO will permanently remove the ability of Anne to bear a child of her own.
  - vi) Anne has endometriosis and the treatment would remove its hormonal drivers.

- vii) Anne's own wishes and feelings as far as they can be ascertained support the treatment. The court can infer from her reaction to menstruation that it is anathema to her and she would wish it to stop. Equally she does not like injections and would be likely to prefer a one-off treatment. Her active interests would be significantly affected by osteoporosis and thus the court could infer she would prefer to avoid this. She has indicated she does not wish to have children.
- viii) The unanimous view of all those caring for Anne is in favour of the proposed treatment.
- 39. Section 4(6) requires that in evaluating 'best interests' I consider past and present wishes, beliefs and values that would be likely to influence Anne's decision if she had capacity and the other factors she would be likely to consider if she were able to do so. The evidence demonstrates that Anne approves of medical treatments which relieve her of pain and distress; her overcoming her dislike of travel to attend to her dental problems and her support for an ambulance being called when recently in severe pain illustrate her approach.
- 40. The following matters all appear to me to be relevant in determining whether it is in Anne's best interests to undergo the operations proposed with the accompanying intervention in relation to getting her to hospital and managing her whilst at hospital.
  - i) The opinion of the treating clinicians is very clear that the HBSO will be of medical benefit to Anne because it will prevent menstrual bleeding and more likely than not will eliminate or at least significantly reduce the cyclical hormonal changes which exacerbate Anne's challenging behaviour. In respect of the colonoscopy, including both the investigative and surgical elements, they will enable the identification of any underlying condition and its remedying which will probably reduce the pain that Anne experiences in relation to bowel function.
  - ii) Professor O'Brien, probably one of the world's leading experts in this field, is clear that more conservative treatment has been exhausted and that the continuation of the Decapeptyl should not continue long term (another quarter of a century or so) given the almost inevitable onset of osteoporosis. For Anne, whose quality of life relies, perhaps to a greater degree than many others, on the simple but active pleasures like walking, for example, the risks of serious fractures and consequent impact on her mobility acquire a greater prominence than they might in respect of other individuals. He also is of the view that the benefits to Anne, both in respect of the cessation of menstrual bleeding and also the cessation of cyclical hormonal changes will be of benefit to her in terms of reducing or eliminating the distress she experiences and reducing or eliminating the exacerbation of her behavioural difficulties. Whilst it is right to note that Professor O'Brien is unable to give a definitive opinion that the HBSO will entirely address the behavioural issues linked to the cyclical hormonal changes, the probability is that it will have at least a significant impact.
  - iii) From Anne's perspective the beneficial consequences are manifold. She will no longer have to deal with either the distress or the possibility of distress

linked to her monthly cycle. She will not have to deal with the anxiety and distress of the 3 monthly injections. She will not have to deal with the full extent of the behavioural challenges of the cyclical hormonal changes. In addition, the risk of pregnancy and the associated bewilderment or distress which might come with that were it to occur will be eliminated. The beneficial impact on her behaviour is likely to mean that her devoted parents will be able to care for her for longer than might be the case otherwise. Clearly as they get older and face their own challenges, their capacity to care for Anne may reduce; anything which has the capacity to prolong their ability to care for her at home is a huge benefit to Anne. It may also be that in time the beneficial impact of the elimination or reduction in symptoms associated with her menstrual cycle will enable Anne to resume some parts of her social life that in more recent years have been unavailable to her. She clearly enjoyed being able to socialise with other young people, and if she were able to resume this aspect of her life, that will clearly be of significant benefit. The proposed treatment would tend to promote the likelihood of Anne resuming a fuller life.

- iv) Given Anne's aversion to leaving her home and travelling by vehicle and the distress and behavioural challenge that getting her to hospital would present, it is plainly in her best interests that a plan is implemented which both enables her to undergo the HBSO and the colonoscopy and which minimises the impact on her of so doing. If that requires both a level of deception and the use of sedation, that is clearly in her best interests; the means is completely justified by the end.
- 41. On the other hand, of course, some factors potentially weigh against the conclusion that the procedures are in Anne's best interests. A more detailed summary is contained in the Official Solicitor's balance sheet analysis. The most significant I consider to be as follows
  - i) The effect of the HBSO will be to permanently remove Anne's ability to bear children. However in Anne's case she does not have the capacity to consent to sexual intercourse so as to conceive a child. More significantly the medical evidence and that of her parents is that Anne does not wish to become a mother, would probably experience pregnancy and birth as highly distressing and bewildering, and would be unable to look after any child she bore. Thus the impact of the loss of her ability to have children is of a very different nature for Anne compared to many other women.
  - ii) There are of course some risks associated with the proposed treatment.
    - a) Firstly, there are always risks associated with surgical treatment albeit they are assessed at a low level in this respect.
    - b) There are some risks associated with long-term oestrogen use; albeit in this case again they are low.
    - c) There is some chance that the HBSO will not lead to the full range of benefits, in particular in relation to the cyclical hormonal changes that have been identified. However, even as a worst case Professor O'Brien opined that at least it would remove the menstrual bleeding aspect and

the need for 3 monthly Decapeptyl injections with the consequent risks of osteoporosis.

iii) Anne may be unhappy at the implementation of a care plan that does not keep her fully informed of what is happening to her. It is my decision to approve the plan, not that of her parents, and so I very much hope that she will not hold it against them. If she holds it against anybody it should be me.

# **Conclusion**

- 42. The overall balance in the evaluation of Anne's best interests is overwhelmingly in favour of the proposed HBSO, the colonoscopy and the care plan which will facilitate those surgical procedures being undertaken. The medical evidence both from the treating clinicians and also, and highly significantly, from one of the country's leading experts in the field is compelling. That it happens to be aligned with the views of Anne's parents is fortunate but no coincidence. The parents' experience and they know their daughter best of anybody is of course the human perception or experience of matters which are ultimately rooted in medical science, as confirmed by the treating clinicians and Professor O'Brien.
- 43. As Anne's parents noted, it is unfortunate (to say the least) that it has taken so long to reach this point for Anne. The statement prepared by Anne's mother and endorsed by her father provides a vivid picture of the consequences for Anne and those around her, most particularly her parents, of the difficulties associated with her menstrual cycle. That Anne and her parents have had to contend with those difficulties for so long and with such consequences for Anne and for those around her is profoundly regrettable. The pressure which the family have been living under is plainly taking its toll on Anne's parents but their devotion to her is self-evident and remarkable. Many might have succumbed but they have put their daughter's interests above any other; particularly their own. Anne and her family live every day with the consequences of her severe learning disability and autism and any step which makes life better for her and thus for her family should be implemented as rapidly as possible. If there is any lesson to be learned for the future from Anne's case, it seems to me it is that the human cost to the individual and their family should never be underestimated, even when dealing with what for the vast majority of the female population is part and parcel of womanhood. For an individual such as Anne, that biological reality has translated into a truly debilitating and distressing condition. The true welfare of the particular individual (which encompasses not just medical welfare) must not be obscured by other considerations, which might be fundamental to the vast majority of women but which are displaced by other considerations for that individual.
- 44. It is entirely right that cases such as this, where medical decisions and the plan for their implementation impact so profoundly on P's personal autonomy, bodily integrity and reproductive rights, should be considered by the Court of Protection at High Court level, and as this case demonstrates, once in the hands of the court and the Official Solicitor they can be dealt with rapidly.
- 45. I therefore have no hesitation in declaring that it is in Anne's best interests to undergo HBSO and colonoscopy (and associated surgical procedures) and for the care plan to be implemented in its final amended form. That includes provision for an earlier carrying out of the procedures in the event that Anne needs to be admitted to hospital

because of the pain she has recently been suffering in her abdomen. It will also include a mechanism which, should the procedures be postponed, will allow a reference back to the Official Solicitor to enable him to consider whether there is any need to restore the matter to court.

- 46. I would wish to express my best wishes to Anne, in particular for the coming weeks but also for the years ahead, and my hope that this decision does lead to an improvement in her quality of life. I would also like to express my thanks to the legal teams and clinicians for the care which they have given to this case and which has been of huge assistance to me. Last, but most, I would like to pay tribute to Anne's parents, not only for the assistance they have given to me and their dignified presentation in court, but most importantly for their dedication to Anne's welfare. Too often this court deals with parents who have fallen far short of the parenting that children are entitled to; in this case it is profoundly reassuring to know that Anne has parents who soar above that standard.
- 47. That is my judgment.