EUROPEAN COURT OF HUMAN RIGHTS
COUR EUROPÉENNE DES DROITS DE L'HOMME

FOURTH SECTION

DECISION

Application no. 18533/21
Paula PARFITT
against the United Kingdom

The European Court of Human Rights (Fourth Section), sitting on 20 April 2021 as a Chamber composed of:

Yonko Grozev, *President,*
Tim Eicke,
Faris Vehabović,
Armen Harutyunyan,
Gabriele Kucsko-Stadlmayer,
Pere Pastor Vilanova,
Ana Maria Guerra Martins, *judges,*
and Andrea Tamietti, *Section Registrar,*

Having regard to the above application lodged on 9 April 2021,

Having regard to the interim measure indicated to the respondent Government under Rule 39 of the Rules of Court,

Having regard to the decision to grant priority to the above application under Rule 41 of the Rules of Court,

Having deliberated, decides as follows:

THE FACTS

1. The applicant is a British national, who was born in 1979 and lives in Kent. She was represented before the Court by Mr G.H. Moore, who also lives in Kent.

A. The circumstances of the case

2. The facts of the case, as submitted by the applicant, may be summarised as follows.

3. The applicant' s daughter ("P.K.") was born in April 2015. When she was twenty months' old, she was diagnosed with a rare and usually terminal

condition called Acute Necrotising Encephalopathy ("ANE"). As a result, she suffered from severe brain damage and in the following months her health deteriorated rapidly. On the basis of the available medical evidence, her condition can be summarised as follows:

a) She has suffered very severe brain damage as a result of ANE;
b) She is in a persistent vegetative state;
c) She has no conscious awareness of herself or her environment;
d) On the balance of probabilities she cannot experience pain or discomfort;
e) On the balance of probabilities she cannot derive any pleasure from her environment or interaction with others;
f) She has random movements of her neck, head, and limbs but has no purposeful movement. She shows no response to visual, auditory, or tactile stimulation;
g) She is wholly dependent on others for all her care;
h) She has no respiratory effort – she cannot breathe at all and is wholly reliant on mechanical ventilation;
i) She has respiratory instability with frequent desaturations which require specialist nursing and physiotherapy interventions;
j) She is doubly incontinent;
k) She has cortical blindness;
l) Her condition has been static for well over a year and there is no prospect of any improvement.

4. The frequent "desaturations" (when her oxygen saturation falls) occur because she has poor oxygen reserve and because there is a tendency for her lungs to collapse, and secretions and saliva to accumulate in her airway caused by her inability to swallow or cough and the absence of a gag reflex. To address these problems, she receives regular respiratory physiotherapy, and spends at least two hours a day in a prone position to remove pressure on the back of her lungs and build up her oxygen reserves. She also receives assistance two or three times a day from a cough-assist machine, administering saline under pressure and then reversing the flow to stimulate a cough, and undergoes a process called saline lavage, which involves instilling large amounts of saline into the lungs, giving large breaths with the oxygen bag, turning the patient, and using manual techniques alongside the bag breaths and suction to clear secretions. Mouth suctioning is also performed throughout the day and night. Even with these interventions, P.K. experiences desaturations every one to four hours, which are treated in a variety of ways including by deep suctioning, by adjustments to the ventilator pressures, and by the use of anaesthetic bagging which introduces oxygen under pressure. Once a week, on average, she experiences a more serious episode of desaturation. In such cases a respiratory physiotherapist

may have to be summoned urgently to add to the efforts to bring her oxygen levels back to an acceptable range.

1. The proceedings before the High Court

5. On 9 March 2020 the National Health Service ("NHS") Trust responsible for the children's hospital where P.K. is being treated applied to the court for declarations and orders that would permit the withdrawal of life-sustaining treatment. P.K. was represented separately by her children's guardian. The children's guardian is an independent person who the court is required to appoint to represent the best interests of a child in proceedings in which the child is the subject or to which she has been made a party. In this case the children's guardian, who was represented by lawyers instructed on P.K.'s behalf, supported the application by the Trust. The applicant opposed the application and instead proposed that P.K. be returned home and her condition managed there.

6. In the proceedings before the High Court, both the applicant and the Trust were represented by experienced lawyers and the judge had the benefit of evidence from twelve highly respected, specialist doctors.

7. The hospital's clinicians were unanimously of the view that the applicant' s proposal was contrary to P.K.'s best interests. However, some of the independent specialists took a different view. In particular, Dr W, consultant respiratory paediatrician at Great Ormond Street Hospital for Children, gave evidence that P.K. could be managed outside the critical care unit. He was broadly supported by Drs P and C, respectively a consultant paediatric intensivist and a clinical specialist paediatric respiratory physiotherapist.

8. Dr W advised that a number of steps would have to be taken for P.K. to be managed in a home environment or a step-down unit. She would need to be transferred to a portable ventilator for use at home or in a step-down unit and it would need to be demonstrated that this ventilator could maintain her respiration and gas exchange; she would need a tracheostomy to safely deliver ventilation, and also a gastrostomy to replace her current nasogastric tube feeding; and she would need a team of trained carers and relatives in place who could be present twenty-four hours a day.

9. The whole process of trial and transition to home care would likely take at least six months. It was Dr W's view that overall there was a one in four chance of P.K. reaching the point of being discharged home, but if the initial trial were successful there would then be a ninety percent chance that she would progress from the transition unit to home. In this regard, he accepted that

> "[P.K.]'s clinical condition is at the absolute outer limits of what might be achievable at home. It is rare that a child with complete absence of ventilatory drive, failure to cope with secretions, absent cough and susceptibility to aspiration and atelectasis has, in the absence of consciousness, been put forward for home care."

10. The independent specialists all acknowledged that P.K.'s life expectancy would be shorter at home than if she remained on the Paediatric Intensive Care Unit ("PICU").

11. The treating clinicians were of the unanimous view that there was no realistic chance that P.K. could survive more than a very short time at home. Furthermore, they were not willing to perform a tracheostomy for the purpose of a trial, believing that the exercise would be futile. The judge summarised their reasons as follows:

> "(a) [P.K.] needs a PICU ventilator which can be frequently adjusted as needed. A portable ventilator of the sort that would have to be used at home has a limited number of settings. ... In contrast the PICU ventilator can be operated with multiple adjustments during the day and night.
>
> (b) As agreed by the respiratory physiotherapists Ms F and Dr [C]:
>
> i. An anaesthetic bag of the kind currently used to rescue [P.K.] when she desaturates cannot be used to administer oxygen in the community. Only an AMBU bag could be used, albeit with ' entrained' oxygen rather than merely with air.
>
> ii. There are no community respiratory physicians in the area of [P.K.]'s family home. ... There would be no possibility of a respiratory physician visiting [P.K.] on a weekly or even monthly basis, let alone being on call in case of emergencies upon an episode of profound desaturation.
>
> iii. Saline lavage cannot be practised in the community – it is too risky.
>
> (c) Proning would be potentially hazardous if practised in the community: ... when a child with a tracheostomy tube is in the prone position it is difficult to monitor whether the tube is still in situ. With [P.K.]'s unpredictable head and neck movements, she could dislodge the tube without the disconnection being noted, with catastrophic results.
>
> (d) Home care would involve a team of between 12 and 15 qualified nurses working in shifts and providing care 24 hours a day. ... It would be very difficult to recruit such a team of nurses who could manage [P.K.]'s respiratory condition.
>
> (e) There is currently no funding in place for a sufficient package of home care, and no other Trust approached by the Applicant has yet agreed to undertake the transition process (the Trust itself being unwilling to perform a tracheostomy on [P.K.], which would be an essential part of the transition)."

12. In a judgment delivered on 8 January 2021, the High Court judge identified the available options as follows:

A. Continuation of life-sustaining mechanical ventilatory support and treatment within a PICU setting;
B. A trial of portable ventilation with a view to transition to long term ventilation and life-sustaining treatment at home;
C. Withdrawal of life-sustaining mechanical ventilatory support.

13. None of the medical experts contended that option "A" would be in P.K.'s best interests. The judge nevertheless considered it because the

applicant had made it clear that she would prefer option "A" to option "C", and if he were to conclude that a trial of portable ventilation was in P.K.'s best interests, and the trial subsequently failed, the parties were likely to remain in dispute about the availability of option "A".

14. Having considered all the evidence, the judge agreed that option "A" would not be in P.K.'s best interest. As she was in a persistent vegetative state with no prospect of improvement with time or treatment, there was no subjective benefit to her from being kept alive in the PICU. The judge rejected the applicant's argument that in the absence of conscious awareness no harm could be caused by the continuation of medical treatment:

> "I do not accept ... that no physical harm can be caused by medical treatment to a person with no capacity to feel pain and no conscious awareness. Physical interventions to prolong life should not be regarded as irrelevant to the consideration of welfare, just because the patient has no conscious awareness and cannot experience pain. Any proper assessment of welfare in a case involving life sustaining treatment ought to take into account the nature and extent of the interventions necessary to keep the patient alive. Clearly much greater weight should be given to the harm caused by those interventions if the patient can feel pain or discomfort. If [P.K.] were able to experience pain and discomfort when undergoing the multiple invasive procedures she undergoes each day, that would be highly material to the assessment of her welfare. But her loss of conscious awareness does not mean that those interventions can now be wholly disregarded. In [P.K.]'s own case she not only requires artificial ventilation, nutrition, and hydration, but, day and night, she requires other interventions including suctioning, bagging, proning, and use of the cough assist machine, as well as other less frequent interventions such as saline lavage. Both her ongoing condition and her necessary treatments in the PICU constitute burdens upon her person notwithstanding her lack of conscious awareness. In any event, the absence of pain is not the same as the absence of harm. The fact that a person has no conscious awareness does not give their clinicians, or anyone else, licence to perform procedures on them irrespective of their benefit. ... The losses of freedom, function, and ability to enjoy childhood, that severe disability, including severe brain damage, cause someone such as P.K., are a form of harm which should be considered in assessing her welfare, whether or not they can feel pain and whether or not they have any conscious awareness."

15. While the judge accepted that P.K.'s life had worth and value which could be seen most clearly in what it brought to others, the assessment of best interests had to be made from the point of view of the child. P.K.'s condition rendered her unaware of the benefits she brought to others and it would be wrong to take into account the welfare of others when determining her best interests. He continued:

> "Is it inconsistent to find that a young child with no conscious awareness suffers burdens but enjoys no benefits from the prolongation of life? I do not believe so. The profound loss of function and the daily invasion of her bodily integrity necessary to prolong her life constitute objectively identifiable burdens on [P.K.]'s person. Factors that might constitute some kind of benefit to an adult or young person, such as affirmation of deeply held values, or respect for autonomy, do not apply to a very young child such as [P.K.]."

16. The judge concluded:

> "Notwithstanding the presumption that life should be preserved, it is not in her best interests that her life should be prolonged... . She has no conscious awareness and she gains no benefit from life but she daily bears the dual burdens of her profoundly disabling condition and the intensive treatment she requires to prevent it from ending her life. ... . there is no hope of improvement in her condition and no medical benefit from prolonging her life on the PICU. I cannot identify any nonmedical benefits to P.K. from continued ventilation on the PICU, whether social, emotional, psychological, or otherwise. ... Taking a broad view of [P.K.]'s medical and non-medical interests, but with her welfare as the paramount consideration, I conclude that it is not in her best interests to continue to receive mechanical ventilation on the PICU."

17. As for option "B" (see paragraph 12 above), the judge took full account of Dr W's experience and his evidence to the court (see paragraphs 7 to 10 above). He also accepted that there might be several adjustments that could be made to optimise the chances of success of the trial and transition. Nevertheless he concluded that Dr W's assessment of a one in four chance of a successful transfer to long term ventilation at home was too optimistic, and could not easily be reconciled with Dr W's observation that P.K.'s condition was "at the absolute outer limits of what might be achievable at home". He further noted that here had been no assessment of the suitability of P.K.'s family's home for accommodating her, her equipment, and the necessary care team. He was therefore not reassured that her envisaged package of home care was practically achievable.

18. He expressed his conclusions as follows:

> "[P.K.] has had only a handful of respiratory infections during nearly two years on the PICU. Considerable thought, effort, and resources have been put into managing her complex respiratory problems. Even so, she has suffered numerous profound desaturations, and would have suffered more had her desaturations not been intensively and expertly managed. Against that background it is difficult to see how transfer to a less sophisticated ventilator and the removal of some of the interventions that have so far protected [P.K.], could realistically alleviate her respiratory problems or lead to fewer or less profound desaturations, even with adjustments to her management. I give weight to the direct knowledge of managing [P.K.] that the Trust's witnesses have and which informs their pessimism about the prospects of a trial and transition to home care. I also take into account the chances of a fatal complication occurring during the transition period, and the practical difficulties in setting up a care regime at home. Weighing all the evidence I have read and heard, I am satisfied that the chances of [P.K.] being able to be transferred to long term ventilation at home are remote. There is only a remote possibility of the trial and transition succeeding such that she could be discharged home."

19. The judge then addressed the views of P.K.'s family, and in particular the applicant. Although he accepted that the court should take into account the wishes of those close to P.K. to care for her at home, he considered that it should do so "only as part of the broad assessment of [her] best interests": the assessment of best interests had to be made from her

perspective and not through the prism of her mother's interests. As for P.K.'s own wishes, the judge accepted that she would have been likely to have wanted to be at home rather than in hospital, but in reality if she were to be cared for at home she would not be aware that she was there.

20. The judge also found on the evidence that a transfer to home care would not benefit P.K.'s medical condition: she would remain unaware of her environment or of interactions with others. In fact, as home care could never replicate the exceptional standards of PICU care, transfer home would, if anything, be a detriment to her. In addition, he was unable to discern any non-medical benefit to her welfare from her care being at home. P.K. would continue to bear nearly all of the burdens of her condition and treatment that she had on the PICU. Any benefits of home care would fall to her family, rather than to P.K., who has no conscious awareness and derives no benefit from interactions with others, including family members.

21. Finally, the judge addressed the question of whether there was anything to lose by trying to transfer P.K. to home ventilation if the alternative was the withdrawal of life sustaining treatment. However, he considered that the loss would be the continuing burdens to P.K. caused by maintaining a regime of ventilatory support and other life sustaining treatment to prolong her life, when to do so would bring her no benefit.

22. The judge concluded:

> "In my judgement, balancing all the relevant factors including the views and wishes set out above, the presumption that life should be preserved, the benefits and burdens to [P.K.] of long term ventilation at home, the fact that she would remain without conscious awareness and would have no hope of improvement, the remote chance of the goal of home care being achieved, her limited life expectancy on home ventilation, and the long process involving continued ventilation in a hospital setting that would be required before home care could begin, I have reached the firm conclusion that it is not in her best interests to embark on a trial of portable ventilation and the transition process towards home care."

23. Therefore, the High Court judge granted the Trust's application and made declarations that it was lawful and in P.K.'s best interests that she not be provided with a tracheotomy; that mechanical ventilation be withdrawn; and that there be clearly defined limits on what treatment would be available to her following the withdrawal of treatment, with the effect that she would be allowed to die.

2. The Court of Appeal

24. The applicant sought permission to appeal on four grounds: (i) the judge erred in finding that medical treatment to prolong life constituted a physical harm to P.K. notwithstanding that she does not experience pain and has no conscious awareness; (ii) the judge erred in finding that there could be no non-medical benefit to P.K. by prolonging her life so that she could be cared for at home surrounded by her family due to her lack of awareness

and young age; (iii) the judge failed to give adequate weight to the views of the applicant as to her best interests, in circumstances where her view was supported by a reasonable body of medical opinion and P.K. did not experience pain from ongoing treatment; and (iv) the judge's conclusion that it was not in P.K.'s best interests to embark on a trial of portable ventilation was flawed.

25. In a judgment handed down on 19 March 2021, the Court of Appeal refused permission on the first, third and fourth ground. In respect of the first ground, it considered that the proposition that no physical harm can be caused to a person with no conscious awareness was "plainly wrong". The judge had therefore been entitled to conclude that P.K. could experience physical harm from her condition and medical treatment notwithstanding that she has no capacity to feel pain and no conscious awareness. In respect of the third ground, the Court of Appeal noted that the judge had set out the applicant's views in considerable detail and manifestly took those views into consideration when analysing both the option of continuing ventilation on the PICU and the option of a trial of portable ventilation leading to home care. The weight he attached to the applicant's views was carefully calibrated and justified on the evidence. In respect of the fourth ground, the court did not agree with that the judge failed to grapple with the medical and expert evidence and to give reasons for departing from Dr W's opinion.

26. The court granted permission on the second ground but dismissed the appeal. In doing so, it considered it plain that, in conducting the balancing exercise, the judge had taken into account the non-medical benefits to be derived from living at home alongside arguments in favour of a trial but concluded that they were outweighed by the other factors which indicated that such a trial would be contrary to P.K.'s best interests.

27. On 1 April 2021 the Supreme Court refused permission to appeal.

28. On 12 April 2021 the applicant sought and obtained an interim measure under Rule 39 of the Rules of Court staying the withdrawal of life-sustaining treatment from P.K.

B. Relevant domestic law and practice

29. The relevant domestic law and practice is set out *in Gard and Others v. the United Kingdom* ((dec.), no. 39793/17, §§ 40-50, 27 June 2017).

C. Relevant international law and practice

30. The relevant international law and practice is also set out in *Gard and Others*, cited above, §§ 51-54.

COMPLAINTS

31. The applicant argued that the withdrawal of life-sustaining treatment violated P.K.'s rights under Article 2 of the Convention. She further complained under Article 8 of the Convention that the decision regarding P.K.'s care was taken by the State and not by her, as the child's mother; and that the domestic courts had insufficient regard to the family life of mother and child.

32. The applicant further complained under Article 3 of the Convention, that the administration of opiate drugs to P.K. would be inhuman and degrading; under Article 6 of the Convention, that the domestic courts were not independent and that the case should instead have been determined by a jury of her peers; under Article 1 of Protocol 12, that the family had been discriminated against on the basis of the social and national origins; under Article 1 of Protocol 13, that the courts had effectively imposed the death penalty; under Article 13 of the Convention, that they had been denied an effective remedy before the domestic courts; and that there had been a violation of P.K.'s rights under Article 14 of the Convention, read together with Articles 2 and 8, because she had been treated differently on account of her medical condition.

THE LAW

A. Preliminary remarks

33. The Court notes, at the outset, that possible issues arise in respect of standing, under Article 34 of the Convention, and, as the applicant did not rely on her Convention rights at the domestic level, the rule of exhaustion of domestic remedies in Article 35 § 1 of the Convention. However, in view of its conclusions at paragraphs 45 and 53-56 below, it is not necessary for the Court to reach any final conclusion on these issues.

B. Article 2 of the Convention

34. The applicant argued that the withdrawal of life-sustaining treatment violated P.K.'s rights under Article 2 of the Convention.

35. Insofar as relevant, this provision provides:

> "1. Everyone' s right to life shall be protected by law. No one shall be deprived of his life intentionally..."

36. In *Lambert and Others v. France* ([GC], no. 46043/14, § 124, ECHR 2015 (extracts)) the Court examined the question of the withdrawal of life-sustaining treatment solely from the standpoint of the State's positive obligations, as it distinguished between "therapeutic abstention" and the

"intentional taking of life". The same approach should therefore be taken here.

37. The Court has identified the following principles which it will take into account in examining whether the State complied with its positive obligations flowing from Article 2 (see *Lambert and Others*, cited above, § 143; see also *Gard and Others* (dec.), no. 39793/17, § 80, 27 June 2017):

i. the existence in domestic law and practice of a regulatory framework compatible with the requirements of Article 2;
ii. whether account had been taken of the patient's previously expressed wishes and those of the persons close to him, as well as the opinions of other medical personnel;
iii. the possibility to approach the courts in the event of doubts as to the best decision to take in the patient's interests.

38. The Court has further acknowledged that in this sphere concerning the end of life, as in that concerning the beginning of life, States must be afforded a margin of appreciation, not just as to whether or not to permit the withdrawal of artificial life-sustaining treatment and the detailed arrangements governing such withdrawal, but also as regards the means of striking a balance between the protection of patients' right to life and the protection of their right to respect for their private life and their personal autonomy. However, this margin of appreciation is not unlimited and the Court reserves the power to review whether or not the State has complied with its obligations under Article 2 (see *Lambert and Others*, cited above, § 148; see also *Gard and Others*, cited above, § 84).

39. As to the first of the three elements set out on paragraph 37 above, the Court has consistently acknowledged that the relevant regulatory framework in the United Kingdom does not disclose any shortcomings which could lay the basis of an arguable claim of a breach of the domestic authorities' obligation to protect the right to life (see *Gard and Others*, cited above, § 81; see also *Glass v. the United Kingdom*, no. 61827/00, (dec.), 18 March 2003).

40. The third element is likewise satisfied. Pursuant to the regulatory framework in place in the United Kingdom there was a duty to approach the courts in the event of conflict (see *Gard and Others*, cited above, §§ 40-45); and the Hospital Trust quite properly approached the High Court to obtain the necessary declarations and orders (see paragraph 5 above).

41. As to the second element, the High Court judge had before him the evidence of twelve highly respected, specialist doctors (see paragraph 6 above). The issue central to the case was whether P.K. could be cared for at home, but on this issue even the independent specialists appointed by the applicant acknowledged that P.K.'s condition was "at the absolute outer limits of what might be achievable at home" (see paragraphs 9 and 17

above); that there was only a one in four chance of her being successfully transferred to a home environment (see paragraph 9 above); and that her life expectancy would be shorter at home than if she remained on the PICU (see paragraph 10 above). While the judge acknowledged the expertise of all the specialists (see paragraph 17 above), on balance he gave weight to the evidence of the clinicians responsible for P.K.'s day-to-day care on this issue (see paragraph 18 above) and, ultimately, was satisfied that the chances of P.K. being able to be transferred to long term ventilation at home were remote (see paragraph 18 above).

42. In reaching his conclusions, the judge gave due consideration both to the clear presumption that life should be preserved and to the wishes of the applicant (see paragraphs 22 and 19 above). The applicant was represented throughout by an experienced legal team (see paragraph 6 above) and, as the Court of Appeal noted, the judge set out her wishes in great detail and manifestly took them into consideration (see paragraph 25 above). While his conclusions did not accord with her wishes, the Court of Appeal considered that the weight he attached to them was nevertheless carefully calibrated and justified on the evidence (see paragraph 25 above). The Court further notes that although P.K. was too young to have expressed any wishes of her own, her interests were separately represented by a guardian appointed by the court and by lawyers instructed on her behalf, who supported the Trust's application (see paragraph 5 above). The judge also had full regard to the fact that if she could have been asked, P.K. would likely have wanted to be at home rather than in hospital, but that the sad reality was that as she lacked conscious awareness she would not derive any benefit from being home. She would not even know that she was there (see paragraph 19 above).

43. Nonetheless, the judge considered whether there would be "anything to lose" from transferring P.K. home, since none of the experts considered it to be in her best interests to remain on mechanical ventilation on the PICU, and the general consensus was that she was unlikely to feel pain. However, he concluded that her invasive care regime was a continuing burden which brought her no benefit (see paragraph 21 above).

44. Finally, even though none of the medical experts considered that it was in her best interests to remain on the PICU, as the applicant preferred option "A" to option "C", the judge also addressed the question of whether it would be in P.K.'s best interests (see paragraph 13 above). He took a broad view of her medical and non-medical interests, and her likely wishes and those of the applicant, but again, notwithstanding the presumption that life should be preserved, he considered that it was not in her best interests that her life should be prolonged (see paragraph 16 above).

45. In light of the foregoing, the Court considers that the second element was also satisfied. Therefore, having regard to the margin of appreciation afforded to the authorities in such cases (see the case-law quoted in paragraph 37 above), the Court finds that the applicant's complaint under

Article 2 of the Convention is manifestly ill-founded and should therefore be rejected pursuant to Article 35 § 3(a) of the Convention.

C. Article 8 of the Convention

46. The applicant complained that the decision regarding P.K.'s care was taken by the State and not by her, as the child's mother, and that the domestic courts had insufficient regard to the family life of mother and child.

47. She invoked Article 8 of the Convention which, insofar as relevant, provides as follows:

> "1. Everyone has the right to respect for his private and family life ....
>
> 2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others."

48. The Court accepts that the decision of the High Court interfered with the applicant's right to respect for her family life. As that interference was both in accordance with the law and pursued the legitimate aim of protecting the rights and freedoms of P.K., the only issue before the Court is whether it was proportionate to the legitimate aim pursued.

49. In this regard, the Court recalls that it declared a similar complaint inadmissible as manifestly ill-founded in *Gard and Others* (cited above, §§ 114-125). In particular, the Court noted that it had itself stressed the importance of having access to the supervision of the national courts and, consequently, the appropriateness of the hospital turning to the courts where there is a difference of opinion between the parent(s) and the treating clinicians. Therefore, the fact that the regulatory framework in the United Kingdom vests responsibility for such decisions with the courts, and not with the parent(s), cannot be impugned.

50. Moreover, the decisions of the domestic courts in this case could not be described as "arbitrary". At both levels of jurisdiction the courts' examination was meticulous and thorough; all concerned were separately represented throughout; extensive and high-quality expert evidence was heard; weight was accorded to all the arguments raised; and the courts gave clear and extensive reasoning to support their conclusions.

51. It is true that the test applied by the High Court was that of "the best interest of the child', and that in *Gard and Others* the Court did not consider it necessary to determine whether this was the appropriate test or whether the courts should instead ask if there was a risk of "significant harm" to the child (see *Gard and Others*, cited above, §§ 118-119). However, in that case the Court also acknowledged the existence of a broad consensus in international law that in all decisions concerning children, their best

interests must be paramount (*Gard and Others*, cited above, § 118). More recently, in *Vavřička and Others v. the Czech Republic* ([GC], nos. 47621/13, 3867/14, 73094/14, 19298/15, 19306/15 and 43883/15, § 288, 8 April 2021) the Court expressly held that "there is an obligation on States to place the best interests of the child, and also those of children as a group, at the centre of all decisions affecting their health and development". In doing so, it rejected the applicants' contention that it should primarily be for the parents to determine how the best interests of the child are to be served and protected, and that State intervention could be accepted only as a last resort in extreme circumstances (see *Vavřička and Others*, cited above, §§ 286-288). Consequently, the decision to apply the "best interests of the child" test in a case such as the one at hand cannot be said to fall outside the margin of appreciation afforded to States in striking a balance between the protection of patients' right to life and the protection of their right to respect for their private life and their personal autonomy (see the case-law quoted in paragraph 38 above).

52. In any event, in the present case, in determining the best interests of P.K., the judge clearly found that both the constant invasions to her person required to keep her alive and the ongoing loss of freedom, function, and ability to enjoy childhood did cause her continuing and ongoing harm (see paragraph 14 above). While he acknowledged that the harm would be greater had she been able to feel pain and discomfort, he did not consider that it could be disregarded as insignificant (see paragraph 14 above). This finding formed the basis of the applicant's first ground of appeal (see paragraph 24 above), but the Court of Appeal agreed with the High Court judge that the existence of physical harm was not dependent either on conscious awareness or on the ability to feel pain (see paragraph 25 above).

53. In view of the foregoing, the Court considers that the applicant's complaint under Article 8 of the Convention should also be rejected as manifestly ill-founded pursuant to Article 35 § 3(a) of the Convention.

D. The applicant's remaining complaints

54. The applicant's complaints under Articles 3 and 6 of the Convention, Article 1 of Protocol 13, and Article 14 of the Convention, read together with Articles 2 and 8, were not raised, even in substance, before the domestic courts and in any event are wholly unsubstantiated. They must therefore be rejected as manifestly ill-founded pursuant to Article 35 § 3 (a) of the Convention.

55. The complaint under Article 13 of the Convention must also be rejected as manifestly ill-founded as the applicant's arguments were heard in full by the High Court and she was able to appeal against its decision to the Court of Appeal.

56. Finally, the applicant's complaint under Article 1 of Protocol 12 of the Convention must be rejected as incompatible *ratione personae* as the United Kingdom has neither signed nor ratified this Protocol.

E. Conclusion

57. The applicant's complaints must therefore be declared inadmissible. Consequently, it is appropriate to discontinue the application of Rule 39 of the Rules of Court (see paragraph 28 above).

For these reasons, the Court, unanimously,

Declares the application inadmissible.

Done in English and notified in writing on 21 April 2021.

{signature_p_2}

Andrea Tamietti
Registrar

Yonko Grozev
President