Neutral Citation Number: [2021] EWCOP 23

Case No: 13712176

COURT OF PROTECTION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 24/03/2021

Before:

MR JUSTICE WILLIAMS

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Between:

Applicant

A London NHS Trust

- and –

(1) CD **Respondent**
(by her litigation friend, the Official Solicitor)
(2) EF
(3) AB

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Mr Mungo Wenban-Smith (instructed by **Capsticks LLP solicitors**) for the Applicant
Miss Nageena Khalique QC (instructed by **the Official Solicitor**) for the **First Respondent**
Ms Alev Giz (instructed by Mills & Reeve LLP solicitors) for the Second Respondent
Ms Ulele Burnham (instructed by Duncan Lewis solicitors) for the Third Respondent

Hearing dates: 22 and 24 March 2021

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JUDGMENT

In this Approved Judgment

I direct that pursuant to CPR PD 39A para 6.1 no official shorthand note shall be taken of this Judgment and that copies of this version as handed down may be treated as authentic.

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This judgment was delivered in public subject to a transparency order. 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. If this has been emailed to you it is to be treated as'read-only'

MR JUSTICE WILLIAMS

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Williams J :

1. I am concerned with a young woman, CD, who I shall call Lilia for the purposes of this judgment. As a judge assigned to the Family Division but also nominated to sit in the Court of Protection the facts of this tragic case bring painfully into the spotlight for me one dimension of the potential consequences of prolonged parental conflict for the children at the heart of a family dispute.

2. On 18 January 2021 Lilia tied a sheet around her neck, tied it to the taps of a sink and attempted to kill herself. She left a suicide note. Part of it reads

   "*I have always done my best to take care of you all, I'm so sorry for the pain this will cause you. You can be angry if you want, I understand. But most likely, you'll just be devastated. I won't be there to comfort you, I'm sorry. …….Please use the money to hire grief counsellors. It's the last thing I can do for you. Please don't blame yourselves, I'm the one that can't cope in this world. I love you all so much.*

3. Lilia was discovered by staff at the unit she was a patient at, CPR was administered, and she was taken to a London Hospital where she has remained in intensive care since. Her father commenced proceedings on 26 January 2021 seeking to be appointed her welfare deputy. On 15 February 2021 her mother applied to be appointed along with others as Lilia's welfare and property and affairs deputy. At an initial hearing, Mr Justice Newton approved consent orders joining Lilia and appointing the Official Solicitor to represent her and for the NHS trust to file evidence.

4. The dispute between her parents that had dogged the lives of the family and most importantly their children at least since their separation therefore continued into this court but now on quite literally a matter of life and death. I simply note that as a fact; I express no views on who is responsible for the parental conflict; that is not the purpose of these proceedings, is not justiciable within them and would probably serve no purpose. Almost inevitably Lilia's mother and father must have been asking themselves could they have done anything differently which might have altered Lilia's trajectory in life which has led here. I doubt that they will find any answer to those questions and it is highly likely that the causes of Lilia's psychiatric and psychological conditions and her attempt to end her life are complex and multi-faceted; it seems that Lilia's psychological and psychiatric well-being was also significantly affected by the pandemic generated lock-down. Only the parents can have some sense of whether they might have done things differently and given Lilia a childhood less complex and troubled than that which she lived. They certainly owe it to their other daughter to try.

5. On 9 March 2021, the case came before me where I gave further directions and listed the case for final determination today. On 9 March 2021 I made a final declaration that Lilia lacked the capacity to conduct these proceedings and to make decisions as to her care and treatment. The evidence before the court then from Dr A Lilia's neuro critical care consultant, Dr B, her consultant neurologist and an external second opinion from Dr Andrew Hanrahan Consultant in Neurorehabilitation and Clinical End of Life Care Lead at the Royal Hospital for Neurodisability, all agreed that Lilia had sustained extensive hypoxic brain damage as a result of the attempted suicide and was either in a persistent vegetative state or the lower level of a minimally conscious state. Her treating team supported by her mother and sister had reached the conclusion that it was not in Lilia's best interests for life sustaining treatment, specifically clinically assisted

nutrition and hydration ("CANH"), to continue to be provided. Her father believed that there was some chance that her condition would improve and wished to seek a further opinion. He also believed that Lilia's wishes would be to continue to live.

6. I therefore permitted the father to instruct an independent expert, Dr Chris Danbury, a consultant intensive care physician who subsequently saw Lilia and provided a report which confirmed the conclusions reached by the treating team and the second opinion. I listed the application for a final hearing before me on the 22 March 2021.

7. On that day I heard from Dr Hanrahan, Dr A , the mother and the father, read the bundle and heard submissions from counsel. At the conclusion of the day at 5.30pm I gave my decision with short reasons to be followed by a written judgment.

Background

8. Lilia is aged 20. Her parents separated when she a child (aged 9 and when her sister was aged 6). In the last few years Lilia was a university student. Since starting her course, she lived either in her university accommodation or with her mother and sister, residing with them for a continuous period from March to 30 December 2020. Lilia had been troubled for some time and had been under the care of Dr S, Consultant Psychiatrist, from December 2019. On 27 and 28 December 2020, Lilia took a staggered overdose of paracetamol for which she was in A & E on 29 December. On 30 December 2020, she was admitted on a voluntary basis to a private psychiatric hospital for treatment for her depression and Post Traumatic Stress Disorder (PTSD). She had also been diagnosed with Emotionally Unstable Personality Disorder (EUPD) and had a history of self-harming behaviours. On 18 January 2021, whilst still an inpatient at the private psychiatric hospital and between observations Lilia tried to end her life. She was discovered and CPR was administered by the hospital staff. Lilia was taken by air ambulance to a London Hospital where she was admitted to the General ICU and, on 22 January 2021, to the Endoscopy ITU for ongoing Neuro Critical Care, where she has remained to date. The unanimous medical opinion is that Lilia has suffered a catastrophic global brain injury which has resulted in prolonged disorder of consciousness, from which she has not emerged and remains in a vegetative state.

The Parties' Positions

9. The Trust's clinical treating team considers that continuing treatment is futile concluding that with no prospect of any meaningful recovery, it is inimical to Lilia's best interests to continue to provide life sustaining treatment or administer cardiopulmonary resuscitation in the event of a cardiac arrest. The clinicians at the Trust have concluded that continued respiratory support, provision of CANH and/or treatment and ICU interventions are invasive and burdensome for Lilia who has no real prospect of recovery. They are concerned that continued treatment would be unethical.

10. Lilia's mother and sister agree with the clinicians caring for Lilia and do not wish for treatment to be continued. Based on her understanding of Lilia's personality, values, active and varied lifestyle and her previous conversations with her, Lilia's sister ("VP") and friends, her mother considers that Lilia "*would not want to live with a catastrophic brain injury in a vegetative or minimally conscious state deprived of that which gave her joy in life*"

11. Lilia's father considers that Lilia would wish for treatment to continue and believes that she would derive some pleasure from her existence, despite the prognosis and limitations that would inevitably exist. He indicated that:

    i) Even if the clinical picture were as bleak as indicated by the evidence of Dr. Hanrahan, cited in the report of Dr. Danbury at paragraph 9.22, there is up to a 15% chance that Lilia may improve to an MCS minus state after three years.

    ii) It is not clear why if Lilia were able to become aware of her "catastrophic predicament", why she would not also be able to be have some sensory awareness which might include experiencing pleasure from music or from touch.

    iii) It is also not clear that if Lilia is not in pain, i.e. if the "dominant physical stimulus at the time", that is say in three years' time, is not pain, why she would not be able to experience stimuli other than pain and distress.

The father does not accept that mother's view of what Lilia would want is in fact what she would want. He does not consider that Lilia's wishes – as pertinent to this precise situation – are as clear as mother contends. Lilia's father also has clear views about what Lilia would want that he wishes to communicate to the court in full he loves his daughter deeply and holds the genuine view that she would consider the life she could be expected to lead, with all its risks and limitations, as one that would be worth living. **The Substantive Application: Legal Framework**

12. 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 discretion to make an order on an interim basis and in particular if it is in the person's best interests to make the order without delay.

13. 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.

14. 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.*

15. 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.

16. 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.

    ii) *Re A (A Child*) 2016 EWCA 759.

    iii) *An NHS Trust v MB & Anor* [2006] EWHC 507 (Fam).

    iv) *Re G (TJ)* [2010] EWHC 3005 (COP).

    v) *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [2014] AC 591.

17. Whether or not a person has the capacity to make decisions for herself, she is entitled to the protection of the European Convention on Human Rights. The fundamental principle of the sanctity of human life is enshrined in Article 2 of the Convention: everyone's right to life shall be protected by law. Further in the present context, Article 3 (protection from inhuman or degrading treatment) is relevant. In addition, it is an aim of the UN Convention on the Rights of Persons with Disabilities to secure the full enjoyment of human rights by disabled people and to ensure they have full equality under the law. In cases such as *Lambert-v-France* (20160 62 EHRR 2) the European Court of Human Rights has confirmed that the withdrawal of life sustaining treatment engages a State's positive obligations under Article 2 but that permitting withdrawal and the circumstances under which it was permitted and how the balance was struck between the right to life and the protection of their right to respect for their private life and autonomy were within the margin of appreciation of states. The ECtHR retains a right to review whether in any particular case an individual's Article 2 rights had been infringed or were within the margin of appreciation.

18. In *Aintree University Hospital NHS Trust v James* [2013] UKSC 67, the Supreme Court considered the first case to come before it under the MCA. Baroness Hale, giving the judgment of the court, stated at paragraph [22]:

> *'[22] Hence the focus is on whether it is in the patient's best interests to give the treatment rather than whether it is in his best interests to withhold or withdraw it. If the treatment is not in his best interests, the court will not be able to give its consent on his behalf and it will follow that it will be lawful to withhold or withdraw it. Indeed, it will follow that it will not be lawful to give it. It also follows that (provided of course they have acted reasonably and without negligence) the clinical team will not be in breach of any duty toward the patient if they withhold or withdraw it.'*
>
> *'[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.'*

19. At [44-45] it is said that the purpose of the best interests test is to consider matters from the patient's point of view. Where a patient is suffering from an incurable disability, the question is whether she would regard her future life as worthwhile. As was made clear in *Re J* [1991] Fam 33, it is not for others to say that a life which a patient would regard as worthwhile is not worth living. Likewise, dignity in life and death is a difficult subject which is not readily susceptible to objective definition. What one woman with her own subjective values and beliefs regards as undignified may not be regarded as so by another with a different set of values and beliefs. Thus, an intense focus on the patient concerned and understanding how they would likely view the situation is important rather than the imposition of some societal or cultural norm.

20. Where the patients' condition may improve a best interests decision may be based on an evaluation which incorporates consideration of the 'best case' scenario. A person who is in a vegetative state and has no awareness can still suffer physical harm

21. Whilst the application of the law relating to giving, withholding or withdrawing medical treatment quires sensitivity and care, it is now clear and well-established. In *Re A (A Child*) 2016 EWCA 759, the Court of Appeal said:

> *In considering the balancing exercise to be conducted:*
>
> *"'1. The decision must be objective; not what the judge might make for him or herself, for themselves or a child;*
>
> *2. Best interest considerations cannot be mathematically weighed and include all considerations, which include (non-exhaustively), medical, emotional, sensory (pleasure, pain and suffering) and instinctive (the human instinct to survive) considerations;*
>
> *3. There is considerable weight or a strong presumption for the prolongation of life but it is not absolute;*
>
> *4. … account must be taken of the pain and suffering and quality of life, and the pain and suffering involved in proposed treatment against a recognition that even very severely handicapped people find a quality of life rewarding.*
>
> *5. Cases are all fact specific.*"

22. The weight to be attributed to P's wishes and feelings will differ depending on such matters as how frequently they are expressed, how consistent the views are, the complexity of the decision and how close to the borderline of capacity the person is. (See [35] *RM, ITW v Z* [2009] EWHC 2525(COP) [2011] 1WLR 344). In *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67 the Supreme Court made it clear that the court below had been wrong to focus on what "the reasonable patient" would decide, and emphasised that the patient's own wishes and feeling must be properly considered: "the things which were important to him… should be taken into account because they are a component in making the choice which is right for him as an individual human being."

23. Several cases after Aintree have considered weight to be placed on the wishes and feelings of an incapable adult in the best interests' assessment. In *M v N (by her litigation friend, the OS), Bury Clinical Commissioning Group* [2015] EWCOP 9 Hayden J (paras. 28, 30):

> *".....where the wishes, views and feelings of P can be ascertained with reasonable confidence, they are always to be afforded great respect. That said, they will rarely, if ever, be determinative of P's 'best interests'. Respecting individual autonomy does not always require P's wishes to be afforded predominant weight. Sometimes it will be right to do so, sometimes it will not. The factors that fall to be considered in this intensely complex process are infinitely variable e.g. the nature of the contemplated treatment, how intrusive such treatment might be and crucially what the outcome of that treatment maybe for the individual patient. Into that complex matrix the appropriate weight to be given to P's wishes will vary. What must be stressed is the obligation imposed by statute to inquire into these matters and for the decision maker fully to consider them. Finally, I would observe that an assessment of P's wishes, views and attitudes are not to be confined within the narrow parameters of what P may have said. Strong feelings are often expressed non-verbally, sometimes in contradistinction to what is actually said. Evaluating the wider canvass may involve deriving an understanding of P's views from what he may have done in the past in circumstances which may cast light on the strength of his views on the contemplated treatment. Mr Patel, counsel acting on behalf of M, has pointed to recent case law which he submits, and I agree, has emphasised the importance of giving proper weight to P's wishes, feelings, beliefs and values see Wye Valley NHS Trust v B*

24. The Court must take account of paragraphs 5.31 – 5.35 of the Code of Practice when making decisions about life-sustaining treatment:

> *"5.29 A special factor in the checklist applies to decisions about treatment which is necessary to keep the person alive ('life-sustaining treatment') and this is set out in section 4(5) of the Act. The fundamental rule is that anyone who is deciding whether or not life-sustaining treatment is in the best interests of someone who lacks capacity to consent to or refuse such treatment must not be motivated by a desire to bring about the person's death.*
>
> *5.30 Whether a treatment is 'life-sustaining' depends not only on the type of treatment, but also on the particular circumstances in which it may be prescribed. For example, in some situations giving antibiotics may be life-sustaining, whereas in other circumstances antibiotics are used to treat a non-life- threatening condition. It is up to the doctor or healthcare professional providing treatment to assess whether the treatment is life-sustaining in each particular situation.*
>
> *5.31 All reasonable steps which are in the person's best interests should be taken to prolong their life. There will be a limited number of cases where treatment is futile, overly burdensome to the patient or where there is no prospect of recovery. In circumstances such as these, it may be that an assessment of best interests leads to*

the conclusion that it would be in the best interests of the patient to withdraw or withhold life-sustaining treatment, even if this may result in the person's death. The decision-maker must make a decision based on the best interests of the person who lacks capacity. They must not be motivated by a desire to bring about the person's death for whatever reason, even if this is from a sense of compassion. Healthcare and social care staff should also refer to relevant professional guidance when making decisions regarding life-sustaining treatment.

5.32 As with all decisions, before deciding to withdraw or withhold life-sustaining treatment, the decision-maker must consider the range of treatment options available to work out what would be in the person's best interests. All the factors in the best interests checklist should be considered, and in particular, the decision-maker should consider any statements that the person has previously made about their wishes and feelings about life-sustaining treatment.

5.33 Importantly, section 4(5) cannot be interpreted to mean that doctors are under an obligation to provide, or to continue to provide, life-sustaining treatment where that treatment is not in the best interests of the person, even where the person's death is foreseen. Doctors must apply the best interests' checklist and use their professional skills to decide whether life-sustaining treatment is in the person's best interests. If the doctor's assessment is disputed, and there is no other way of resolving the dispute, ultimately the Court of Protection may be asked to decide what is in the person's best interests.

5.34 Where a person has made a written statement in advance that requests particular medical treatments, such as artificial nutrition and hydration (ANH), these requests should be taken into account by the treating doctor in the same way as requests made by a patient who has the capacity to make such decisions. Like anyone else involved in making this decision, the doctor must weigh written statements alongside all other relevant factors to decide whether it is in the best interests of the patient to provide or continue life-sustaining treatment.

5.35 If someone has made an advance decision to refuse life-sustaining treatment, specific rules apply. More information about these can be found in chapter 9 and in paragraph 5.45 below. 5.36 As mentioned in paragraph 5.33 above, where there is any doubt about the patient's best interests, an application should be made to the Court of Protection for a decision as to whether withholding or withdrawing life-sustaining treatment is in the patient's best interests."

25. Therefore, a host of matters must all go into the balance when the judge seeks to arrive at his objective assessment of whether **this** treatment is in **this** patient's best interests. In particular I must consider the values and beliefs of Lilia as well as any views she expressed when she had capacity that shed light on the likely choice she would make if she were able to and what she would have considered relevant or important. Where those views can be ascertained with sufficient certainty, they should carry great weight and usually should be followed; as they would be for a person with capacity who did express such views.

Medical Evidence

26. On 18 January 2021, Lilia was found by staff. CPR was attempted and paramedics attended, she had a low Glasgow Coma Score (GCS), incompatible with spontaneous breathing and life and she was taken by ambulance to a London Hospital and admitted to the major trauma unit. It was reported that she had suffered prolonged hypoxia, for a maximum period of 20 minutes – this being between observations.

27. Dr AA, Lilia's treating Neurocritical Care Consultant at the Trust sets out the details of her treatment so far. She updated that in her oral evidence; telling me that there were signs that Lilia had an infection and that her tongue injury was showing some signs of healing but might need debridement. In short, Lilia has undergone numerous investigations and interventions (including MRI and brain imaging scans, EEG reports, blood and urine tests, neurophysiology, pharmacy reviews, microbiology advice, nursing therapy and medical care from other specialities and neurosurgical observations and testing) to understand the nature of her injury and maximise her potential for recovery.

28. Despite coming off sedation on 24 January 2021 there has been no reported spontaneous or induced behaviour to suggest Lilia has awareness of herself or the environment she is in (on ITU) - save that twitching, jerking and movements have been seen – for example, it was noted on 30 January 2021 that she had begun to demonstrate flexion of her arms to a painful stimulus, whilst previously the clinicians had not been able to elicit any motor responses. Further observations noted shivering, leg twitching and abnormal movement which were considered to be "*neither seizures or myoclonus, but rather sub-cortically driven phenomena related to her significant hypoxic ischaemic encephalopathy*"

29. She currently receives the following treatment;

    i) Ventilatory support: (i) via an endotracheal tube to maintain a patent airway; and (ii) from the ventilator to provide adequate tidal volumes (to overcome the increased effort required to breathe through an endotracheal tube);

    ii) Antibiotic treatment of recurrent acquired infections;

    iii) Vasopressor (noradrenaline) support to reverse hypotension due to infection;

    iv) Clinically assisted nutrition and hydration, via nasogastric tube;

    v) Administration of numerous regular medications;

    vi) Maintenance of nasogastric tube, intravenous, cannula, and indwelling urethral catheter in situ;

    She is also treated for other matters as and when they arise, for instance she bit her tongue and caused a 2 cm laceration.

30. Dr B, the treating neurologist assessed Lilia on 15 February 2021 and 2 March 2021 and concludes as follows

    In my opinion, the severe encephalopathy seen on EEGs has a hypoxic-ischaemic basis with minimal or no contribution from medications which may have a sedative effect deemed necessary to treat Lilia. Consistent with the severity of Lilia's hypoxic-

ischaemic brain insult, her initial presentation was complicated by anoxic myoclonus [limb shaking]. Although this settled with leviteracetam and clonazepam, anoxic myoclonus is often correlated with limited neurological recovery and in-hospital death and is widely accepted as a poor prognostic sign. Lilia presents in a state of disordered consciousness and, given the time that has elapsed, she is in a state of prolonged disorder of consciousness (PDOC). In my opinion, within the bracket of PDOC, Lilia 's presentation best fits with a continuing vegetative state. This means that she has periods of sleep and wakefulness but when awake, there is no awareness of herself or her surroundings. In my assessments, I was unable to demonstrate any meaningful signs of responsiveness to any stimulus (auditory, visual, tactile, noxious).

In my opinion, this represents an extremely poor quality of life, sometimes requiring mechanical assistance with breathing, tubes for feeding, double incontinence sometimes requiring mechanical assistance with a urinary catheter, full nursing care and vulnerability to a variety of medical insults. In my opinion, given time, I think it is much less likely, but possible, that Lilia could show signs of emergence from her vegetative state to a minimally conscious state (MCS). In this eventuality, I expect that this will be at the severe end of that spectrum (MCS minus) and will still be associated with all aspects of poverty of life-quality described above but with some appreciation of pain and discomfort, translating to a worsened quality of life. In my opinion, it is highly unlikely that Lilia will emerge to a better standard of MCS (MCS plus).

31. Both Dr A and Dr B conclude that Lilia will have a reduced life expectancy and require ongoing complex interventions such as ongoing ventilatory support including a tracheostomy, physical care including CANH, probable percutaneous endoscopic gastrostomy (tube feeding into stomach)_ catheter and incontinence support, washing, positioning and physical therapy to avoid bed sores, treatment for ongoing chest and urinary infections.

32. It is the treating team's belief that there is no prospect of significant neurological recovery; the best would not involve regaining consciousness but possibly some awareness which is more likely to result in an increased perception of pain or discomfort. The Trust's belief in terms of Lilia's approach is that

> *"We do not believe Lilia would consent to any of these interventions to prolong life if she were in a position to participate in the decision. It is therefore the strongly and universally held view of the multidisciplinary team that continuing such treatment of Lilia is morally, ethically and medically unjustifiable".*

33. Dr A sets out a detailed and staged plan as to how life-sustaining treatment would be managed and what palliative care would be administered. She said:

This would involve the removal of the endotracheal tube and therefore discontinuation of ventilatory support, and the cessation of clinically assisted nutrition and hydration, accompanied by the removal of the nasogastric tube. Should treatment be withdrawn, we would plan to discontinue any treatments intended to prolong life, and continue only those intended to manage symptoms associated with end of life, such as respiratory 'distress' (indicated by physiological parameters such as tachypnoea rather than a subjective experience of distress, which Lilia is not capable of in her current neurological condition). This might include the administration of opiates or benzodiazepines, for example, to alleviate these

symptoms. In this circumstance, we would expect Lilia's life expectancy to be measured in 'days to weeks'. If the withdrawal of ventilatory support leads to rapid deterioration and ventilatory insufficiency, we would expect Lilia to pass away within hours to days. If she stabilises from a respiratory point of view, then we would expect her to survive for up to 2-3 weeks, which would be the timeframe consistent with death following the withdrawal of clinically assisted nutrition and hydration.

34. Dr A says that at all times preserving her dignity is a priority. Although she has no awareness, she would have medication to manage the physiological symptoms which might arise. Wider interests include the family, some distressful appearing symptoms are managed to alleviate distress of family. Renal failure usually brings about death after a couple of weeks and that is managed on the ward or a specialist unit; that is usually peaceful.

35. Dr Hanrahan's independent second report and his evidence sets out the following.

i) *Lilia has sustained an anoxic brain injury after prolonged hypoxia from a respiratory cause resulting in a profound global brain injury;*

Using nationally recommended low awareness assessments as recommended in the Royal College of Physicians Guideline March 2020 on Prolonged Disorders of Consciousness Lilia is in a vegetative state; Her state is at the lower end of a spectrum – coma at one end to consciousness. VS might involve eyes open but total unawareness, moving along to MCS which is a very wide part of the spectrum – it is very variable with MCS minus is lowest end to MCS + at the highest end and then emergence to neurological consciousness which is different to functional consciousness. Neuriological consciousness is not functional. The spectrum and the boundaries are blurred and not linear – can move from eyes closed to eyes open coma through a variety of causes.

There is no evidence at any level that Lilia extracts any meaning from her plethora of daily stimuli and she is not aware of others' presence; it is very unlikely she experiences pain and distress with invasive, pain-giving, uncomfortable procedures (nasogastric tube insertion, bladder catheterisation, IV access. Her brain stem, or elements of it are working but her higher functioning brain which is dependent on connectivity across the parts of the brain has been catastrophically damaged and the network of connections is not.

ii) *Lilia's life expectancy if CANH is continued may be decades whereas if it is no longer provided, death will ensue between approximately two to four weeks "given her youth, robust organ systems, good nutrition & hydration till the point it is withdrawn, and the relative lack of complications so far that would predispose her to an earlier death";*

iii) *"there is nothing significant than can be done to improve her chances of positive change or maximise her chances of having positive experiences. She will thus not benefit from any further pharmacological or other sensory neuro-stimulation, 'rehabilitation' in the common use of the term or transfer to such a specialist environment for the purpose of an immediate diagnosis"*

iv) *In terms of Dr Danbury's report which put the chance in improvement to MCS – being 15% ; some experts use a quantification prognosis – the question is to personalise it to Lilia – National Guideline of March 2020 is very careful about using words like improvement – it cautions against it – the Vegetative state is very much like a MCS minus – the prognosis is the same – it is anoxic brain injury – global catastrophic damage and the prognosis is much clearer – as you move towards 2-3m mark it becomes a chronic disorder of consciousness.*

v) *Her pathology, how it happened, observation and trajectory of change – at 2month mark it remains essentially the same as it was when he saw her on 15 Feb. It is functionally arid – it makes no difference to quality of life.*

vi) *In terms of the possibility of Lilia experiencing some pleasure he said that in the event the body is capable of experiencing any sensation the painful sensations are most likely to be experienced as they are the most basic. Beyond that if there was a bandwidth in the conscious brain to experience anything it would likely be taken up with the messages that the body sends about what it is experiencing; pressure on the bowel, bladder, pressure sore, cramp etc.*

vii) *In terms of experiencing music or other conscious experience – it is unlikely she can experience it. Her ear as a microphone might hear it, her brain stem might generate an auditory reflex or other sub-cortical response as music and other things like language can leave a sub-cortical imprint, but this is reflexive not the brain associating it with pleasure. Even if there was an improvement to a level of consciousness the bandwidth available would be taken up with the other sensations. A face can move to look like a smile – but that is simply the brain stem and body – there is no association between the movement and the conscious brain.*

36. I concluded that his opinion was that it is most unlikely that she will experience any awareness of her condition because that would be so far beyond the level of improvement in consciousness that she is likely to experience. He said though we cannot know, the science and understanding of how the brain functions as a network with the need for each part to talk to the other it is highly unlikely that those processes would in her case be sufficient to engage functional awareness; if she reaches any it would be a much lower level of awareness and she is unlikely to experience even the lower levels of arousal and awareness.

37. I gave the father permission to seek a further opinion from Dr Danbury. He was not called to give evidence. His conclusions are as follows.

i) Lilia has a devastating brain injury caused by strangulation. *the serial CT, MRI scans taken together with the EEGs show a massive, irreversible amount of damage to her brain. They do not show improvement as hoped for by* [father]"

ii) She is currently in a vegetative state

iii) She has had a sufficient duration of observation that her current condition and prognosis can be determined with a high degree of accuracy

iv) She will, more likely than not, remain in a vegetative state. the chance of Lilia improving to a minimally conscious state (minus), is less than 15% after 3 years from the initial injury. There is no possibility of her improving to a level of function where she could undertake any of the activities that she used to enjoy.

v) It may be the case that Dr A is of the view that the treatments outlined in the appendices to his report are adverse to Lilia's clinical needs and represent an intolerable burden. "I have sympathy with that view and would similarly struggle as to whether or not to offer the treatments outlined in the appendices to Lilia.

vi) If her mother and sisters evidence is preferred by the court, then it is his opinion that it is not in Lilia's best interests to receive any of the treatments outlined in the appendices.

vii) If the court prefers the evidence of the father, then if the court accepts the father's evidence that Lilia equated withdrawal of life-sustaining treatment with active killing then it would be his opinion that any treatments offered would be in Lilia's best interests.

Evidence of Lilia's Wishes and other the views of her family

Lilia

38. There is no Advance Decision which sets out her wishes in this situation.

39. Dr S confirmed that Lilia named her mother as her next of kin. However, she did say her father had been surprisingly supportive when she rang to tell him of her admission. She had recurrent suicidal thoughts whilst also stating she did not want to die earlier in her treatment but spoke about how hard recovery was compared to death. She found life hard and could not see the point of it at times when distressed by her thoughts.

40. In her counselling session shortly prior to her attempt to take her life she said that life scared her as it is full of pain, but death scared her too. When she spoke about attempting to kill herself, she acknowledged that brain damage was a possible consequence and that was bad. She told her counsellor that she was pathologically selfless.

Her Mother

41. Lilia's mother provided a summary of all that Lilia enjoyed in life, ranging from outdoor pursuits, appreciation of nature, a passion for a range of arts and crafts, for reading, for travel, for music and in particular for Japan, encompassing its language, music, and culture, including pop culture. The mother emphasised the high level of Lilia's academic ability and intelligence, her kindness and compassion to others, her close friendships and in particular the very close relationship she enjoyed with her sister. She said that "*Lilia is one of the sweetest, kindest, thoughtful people you will ever meet. She would not want to live with catastrophic brain injury in a vegetative/minimally conscious state* ***deprived of that in which she found joy in life.***"

42. The mother considers that Lilia felt overwhelmed by the demands her father placed on her and her letters to her father and extracts from her notebook illustrate some of the difficulties. She wrote;

> *"To Dad. For some time, you've wanted to understand how I feel about you, and why our relationship has deteriorated. So I'm going to explain how I feel. As a child, you would tell me many things about the animosity between you and mum that were very setting for me. Serious conflicts with terrible implications. Conflicts that I never needed to be involved in, that should have been kept between adults. You were frustrated, you wanted me to understand how you felt. But I wasn't your confidant, your friend or your counsellor. I was just a child, your child. All I wanted was to be protected…… When I raise a concern or say I don't like what you are doing, you assume the thought has been planted there by someone. You assume my feelings are not my own and immediately try to hunt down the puppet master instead of respectfully accepting and validating my feelings."*

Her Sister

43. From her statement and the attendance note of the Official Solicitor I extract the following.

i) Because of the conflict between the parents over the divorce and what should happen to the girls they relied on each other a lot. In particular Lilia looked after VP, her sister and VP often saw her as a parental figure. The focus was on VP and her struggling to cope, not Lilia.

ii) Both Lilia and VP considered that the father did not acknowledge that any of the unhappiness arose from the way he behaved.

iii) Lilia would not wish to be forced to live in the state that she was in now. She was active and loved outdoors and doing things. Being stuck inside herself with no way of communicating would be a state worse than death for her the fact that it was her father who was seeking to achieve this shows he does not know her.

Her Friends

44. The Official Solicitor has obtained statements from two of Lilia's friends. I set out below some of what I consider to be the relevant extracts

i) *I do not think she would want [to] be in [a] vegetative or minimally conscious state for the rest of her time. From knowing her - she loved aspects of life but all the things she loved about life she cannot do anymore*

ii) *What she loved about life was being outdoors and making things and experiencing things. She treasured experiences the most. …. She liked Kew and the plants there. She loved exhibitions at museums, going to the cinema doing other activities outdoors.*

iii) *It's so not how she would want to live her life – she would not have wanted this at all.*

iv) *She was not religious but was an atheist although she did not want her parents to know. In 2020 she had decided to cut off contact with her dad as she viewed him as manipulative and intense and how he sought ways to go against what she wanted.*

v) *She loved life but she didn't do things without thinking about them and it was a long struggle for her and she thought about things a lot –though the act can be impulsive – she was a person that was not rushed – she was so strong and all kinds of smart and funny, witty, colourful – such an amazing presence.*

vi) *They had a conversation once where Lilia said she wouldn't want to remain in a coma; this was in the context of watching The Mentalist where a character is in a coma. It was only a passing conversation*

vii) *During their last conversation she had said she wanted to die and that when she attempted suicide the first time it was a relief that she wouldn't have to wake up and do the day.*

45. Between them her maternal Grandparents made the following observations

i) *She is a young woman of principle and compassion. Lilia was protective of her family. When her parents were divorcing, she was often interviewed by social workers. At one point she told me, "I just don't say anything to the social workers anymore. Every time I do, either my mum or my dad gets in trouble." Years after the divorce, when one person made a disparaging comment about her dad, I heard Lilia say, "Hey, that's my dad. You just don't understand him like I do." When she went to university and could better see things from a different point of view, she began to realize things were not as they had seemed growing up. It was heart wrenching when I heard that she said, "I'm finding out that my dad isn't the person I thought he was," while she was at university.*

ii) *My granddaughter Lilia is a kind, gentle soul. She enjoyed the wonders of nature and being with other family members doing things together. She would not want to prolong this type of existence. I believe she would consider it to be no existence at all.*

<u>The Father</u>

46. The father's position is that he believes that life is precious albeit he does not believe it would be appropriate to maintain life-sustaining treatment for Lilia if he thought that she did not want that. He says that his belief is that she has made better incremental gains than the clinicians had originally anticipated. His understanding of his daughter is that she believed passionately in the preservation of life and intrinsically valued life more than most and that she would want to continue her life and be cared for by her family

> *I understand that the question for the court today is whether she would want to live in the compromised condition if treatment continued. My view is that* [Lilia] *would want to live irrespective of the circumstances and, if there is a*

prospect of her transitioning into MCS then I believe it would be appropriate to continue treatment until is it clearer either that that transition would not be possible or that the conditions of her existence would not amount to a life she would value. I believe that it is too early at present to answer these questions with sufficient certainty to stop providing life-sustaining treatment.

My views on what [Lilia] *would want, derive from how she lived her life, the things that she felt were most important".*

47. He believed that her emotionally unstable personality disorder and her ongoing medical treatment needed to be factored into her attitude to life and her suicidal ideation. In the circumstances it was difficult to know what her past wishes would be as to life in these circumstances.

48. The hospital recorded the father's views as follows;

Father described Lilia as loving, tender-hearted, kind and warm. In the best interests meeting we asked him to explain his reasons for wanting Lilia to continue to receive treatment. He described one of his last contacts with her in the private psychiatric hospital, when her phone had been removed, and she was keen for it to be returned in order to watch Japanese animation and listen to music. He believes that if she achieved a level of awareness to hear music that she would appreciate that, and that it would be a fulfilment of her wish to have her music returned to her. He also recounts that she asked him to continue to provide her with private health insurance and not cancel it. (Of note, there is a recent episode described by mother, in which father reportedly "threatened" to withdraw support of VP's private healthcare when he disagreed with the opinion of her psychiatrist). He believes that continuing to provide Lilia with ongoing healthcare would therefore be satisfying one of her final requests. He also explained that she was a vegetarian and cared greatly about animals and would "not even have killed a spider". He places considerable significance on this as he believes this represents her view that life is precious and that she would therefore wish hers to be prolonged at all costs. At one point he described any of the outcomes presented by Dr Hanrahan, including that of a persistently vegetative state as 'ideal'.

49. In the Best Interests Meeting he also expressed his views on Lilia's wishes

i) *Lilia…has a moral system, which gives very, very high value on the value of life, even the life of the spider, which I would typically on my own I would just step on it because…. I want to look and see is Lilia around, maybe I shouldn't maybe I shouldn't do that. And my value system is that I would step on a spider, right? I eat meat, and I love meat. I love beef, specifically Argentine beef- it's amazing, delicious. So my value system, personally, doesn't involve that very very high value placed on life. There are certain religions where there's a tradition of not harming even an ant or spider.*

50. In his evidence he emphasised that he thought that Lilia would value a shared experience with family members and that he thought there was some benefit to her from this if she improved to an MCS-.

Evaluation

51. The medical evidence is essentially unambiguous in terms of the extent of Lilia's brain injury. She has suffered catastrophic hypoxic brain damage which has left her in vegetative state. Thus, the diagnostic and functional criteria establishing her lack of capacity are agreed. The evidence demonstrates that the parts of the Lilia's brain that made her who she was have been profoundly damaged most importantly in their connectivity or networking capacity which is central to who we are and the brain's ability to interpret the senses, to process information and to generate responses. Whilst Lilia's brainstem is still functioning even that has sustained some damage and whilst it may be capable of maintaining the basic functioning of the body, including the drive to breathe (although that appears to be compromised to some extent according to Dr A A) that is continuing the life of Lilia's body but not Lilia as an individual personality. Dr Hanrahan was clear that her current condition is consistent with her having no awareness of anything at all even the most basic sensations such as pain. Evidence about her moving her limbs or biting her tongue are not responses to external factors but are involuntary movements.

52. It is also clear on the balance of probabilities that the prognosis is that she will remain in this state. The best prognosis – rated by Dr Danbury at less than 15% chance is for an increase to a minimally conscious state (MCS) minus. Dr Hanrahan both in his evidence and during the best interest discussion expressed a disinclination to discuss the prognosis in percentage chances. His evidence was clear that the prognosis for patients with brain damage arising from anoxia is generally at the lowest end of the spectrum for improvement because of the nature of the injury concerned and that the greater the period of time that passed without neurological change (he was reluctant to describe it as improvement) the greater the likelihood that the current condition would persist. His evidence, which the other clinicians and experts aligned themselves with was that on the balance of probabilities and as I understood his evidence a high balance of probabilities was that Lilia would remain in a vegetative state.

53. The evidence also emphasised that even were that prognosis to be confounded and that Lilia were to move along the spectrum from vegetative state to minimally conscious state to describe that as an improvement had the potential to be misunderstood. A neurological change could include some very limited reflex movement but that would not indicate that Lilia was developing awareness. Dr Hanrahan was clear in his oral evidence and indeed this is consistent with the overall effect of the other expert evidence that were Lilia to demonstrate neurological change that moved along the spectrum from vegetative state to MCS minus this would not mean that she had regained some sort of awareness which might lead her to an appreciation of her condition. What this sort of neurological change might involve was Lilia's brain receiving some signals from her body at a very basic level. The evidence was that a neurological change was most likely to involve the brain sensing something internal to the body; a very primal or basic functions such as awareness of the bladder or bowel being full or pain from a pressure point. Dr Hanrahan also explained that were a neurological change of this sort to occur the (as he described it) bandwidth available would be narrow and would be taken up by such internal and basic interpretation of sensations. He was clear that this should not be confused with any higher functioning of the connected brain. He gave the example of Lilia's ear being able to hear and perhaps there being some auditory reflex but this

should not be confused with listening which required an association provided by the connected brain to the information that the ear might be seeking to provide and that this was highly unlikely. He accepted that one could not know for certain what Lilia could experience because no one in a prolonged disorder of consciousness could ever describe it. As he said if you could remember anything you could not have been in a prolonged disorder of consciousness; the two were mutually incompatible. However, he was clear that in terms of probabilities or in applying both theoretical and clinical understanding of the way the brain worked and the damage which it had sustained it was completely inconsistent with any experience or awareness of anything other than the most basic internal physical sensations. He explained that some individuals might appear to respond to familiar voices or music but this would not be because they had any conscious awareness but rather because sound could leave an imprint in the network of the brain but such a response was sub- cortical which I understood to mean a physical response like an auditory response to noise rather than indicative of awareness or appreciation of the connected brain.

54. Thus, the totality of the evidence points to the conclusion on the balance of probabilities that Lilia will remain in a vegetative state and that this could be for a period of many years. There is a remote possibility of neurological change that would place her in the minimally conscious state minus, but this would involve neurological change that would not result in Lilia's becoming aware of anything other than the most basic physiological sensations. There may even be an unquantifiable possibility of her demonstrating neurological change that would move her along the spectrum into the MCS plus; they cannot be completely ruled out because nothing is impossible. However even this seems to me to be largely theoretical and illusory possibility would still not bring her into the category described by Dr Hanrahan of neurological consciousness functional consciousness.

55. The father considered that Lilia if she improved to MCS- or even more so if she moved to MCS + that she might have the capacity to gain some benefit from being in the company of her family or having music played to her or the familiar voices or being held by them. I can understand why he would wish to believe this possible. It must be almost impossibly difficult to contemplate the annihilation of the person that Lilia was and thus one clings to a hope that because one cannot know for certain that this allows for the possibility of Lilia continuing to have the capacity to exist in some familiar domain. I was left unsure at the conclusion of his evidence whether the father simply did not understand the effect of the evidence of the treating clinicians, Dr Hanrahan and Dr Danbury or whether it amounted to a conscious refusal or subconscious inability to accept the overwhelming weight of the evidence because it was inconsistent with what he wished to believe. Regrettably though, his position is not supported by the medical evidence and his insistence on maintaining the possibility of Lilia regaining some awareness of any sort which would be recognisable to who she was before, is to deny the reality that confronts his daughter. To make decisions on the basis of his own wish as to what he wants her position to be rather than on the basis of what her position actually is, inevitably is likely to lead to flawed decision making.

56. Thus the evidence establishes that the likelihood for Lilia is that she will remain in a vegetative state entirely unaware of anything; her body will live but no residual part of who she was as a personality will return, nor even will she have the ability to experience the most basic sensations that a body can be aware of such as pain or discomfort, still

less the more developed sense of the touch of a warm hand. She will never be capable again of enjoying the beat of the music she loved, of appreciating the majesty of a giant redwood, being entertained by anime or feeling a loved one hold her hand and speak to her. Her body and thus to that extent Lilia will be alive. Life is of value. Lilia appears to have been an atheist and so probably would accept this life is her only life. What would Lilia likely think about that life? What would she think about a life with somewhat more neurological activity – an MCS minus life or even an MCS + life.

57. However, to remain alive will on a balance of probabilities require on-going medical interventions. A tracheostomy, a PEG to enable her to be fed, she will likely require anti-biotics to deal with chest or urinary tract infections. Dr A said that she is currently experiencing a raised temperature and her bloods suggest an infection. She will need washing and moving. Although she may not be aware of these treatments and may not suffer discomfort whilst in a vegetative state this does not mean they are not being done to her and certainly in respect of some aspects are causing physical injury and harm to her. How would she feel about this? How would she feel about the possibility of her life encompassing some basic sensations including pain or discomfort or better but even then with medication which would assist with those negative sensations also probably eliminating any possible positive aspects.

58. In contrast how would she feel about the discontinuation of life sustaining treatment. Dr AA has set out both her prognosis for Lilia and the palliative medical treatment that might be required. Although she identified that Lilia sometimes requires assistance from her ventilator to support her breathing she thought on balance that Lilia would maintain spontaneous breathing if taken off the ventilator and would not die suddenly but rather her body would slowly pass into renal failure and eventual death as a consequence of her not receiving nutrition or hydration. This might take 3-4 weeks during which she would be in receipt of opiate or benzodiazepine medication to relieve the discomfort or pain. How would she likely feel about this?

59. It is not possible to know what Lilia would want for herself now. There is no categorical statement from her upon which heavy reliance can be placed. She has not made an Advance Decision. No one had an in-depth conversation or repeated conversation with her about the profound issues engaged here which would shine a spotlight on her views.

60. However, there are many sources of information about her character and her views that throw beams of light on what her views are likely to have been and which ultimately for me appear to illuminate them to my mind clearly and reliably. Save for the father's interpretation of her views on the absolute sanctity and value of life, the sources of light all point to Lilia's likely wish being not to be given treatment to prolong her life for she would see it as a life without quality or purpose and a burden to her and to those she loves. Those sources show that she loved experiences and sensations; the beauty of the natural world, culture and music, caring for others. They also show that she preferred to care for others than be cared for by others. She appears as a young woman of spirit and independence.

61. The father's interpretation of the value she put on the life of all creatures, whether sentient or not and her unwillingness to take life may be an accurate account of his perception of her views. They are views which are commonly encountered and entirely understandable. However, his extrapolation from them that Lilia would under no circumstances have wished for her life to be taken (as the father would put it) or for

treatment not be given and to be withdrawn leading to her death is not in my view a reliable one. Her respect for the life of other human beings and her respect for the life of even the simplest of living creatures seems to me to be an aspect of her caring and selfless nature which generated her willingness or need to care for her younger sister and which perhaps played a part in her desire to combine her caring nature with her interest in science in order to become a paediatric audiologist. That caring and selfless nature to others and her respect for the lives of non-sentient creatures does not necessarily translate into an absolute respect for life and in particular her life. It is entirely consistent with what one knows of Lilia that she would not support or herself take the life of another creature; that seems to me to be a facet of her respect for others and her unwillingness to impose herself or her decisions on them. However, the evidence points to Lilia as being an independent young woman whose autonomy was important to her. Absent some belief system which she adhered to in which sanctity of life was an absolute which allowed no human intervention to bring to an end I am unable to identify anything in the evidence of her friends and family, save her father, which leads to the conclusion that Lilia viewed her own life as sacred and outside her own power to end. The evidence suggests that Lilia had become an atheist although perhaps not openly to her mother and father who are I believe both Christians.

62. On the contrary the evidence of her own actions in December 2020 in taking a staged overdose and in January in attempting to end her own life support the conclusion that she considered that the continuation or termination of her life lay in her hands. The evidence from the private psychiatric hospital, in particular her therapy session on 18 January 2021 and the terms of her suicide note give no hint at all of her feeling either that it was not in her power to end her life or that there was some principle to which she adhered which made ending her life inconsistent with it.

63. Rather the evidence suggests that Lilia was a young woman who had struggled with the balance of positive and negative in her life for a considerable period of time and in particular in the latter part of 2020 and the first 18 days of 2021. The evidence supports the conclusion that her own perception of the balance of good and bad in her own life fluctuated but that by 18 January 2021 the balance had moved clearly into the negative saying that she could not cope with the world anymore. The evidence supports the conclusion that Lilia was considering where the balance lay for some period of time before 18 January 2021.

64. It also emerges from the evidence of Lilia's communications with her father and the evidence of her sister that Lilia did not feel that the father understood her but sought to reframe her expressed views to fit with what he wished to believe. Her decision to prevent him having access to information about her medical treatment also suggests she wished to distance herself from him, did not wish to share her most personal situation at this time and that is consistent with the other evidence of how she had reduced her contact with him in recent months. The evidence of a more positive telephone call in early January does not come close to demonstrating a change in Lilia's then attitudes to her father. Thus, in evaluating the fathers evidence of his understanding of Lilia's likely wishes and her views or beliefs which bear upon the decision seems to me one has to bear in mind that Lilia thought that the father did not understand her or wilfully misunderstood her. I also bear in mind his apparent inability to understand or accept the import of the medical evidence.

65. I therefore conclude that the weight of the evidence demonstrates that Lilia did not view her own life as sacrosanct but rather that she viewed it as within her right to make decisions which she acted on 18 January 2021. Thus, I do not consider that the fathers evidence that Lilia would have wished to remain alive as a matter of principle is established. Although he may be right that the question now is whether Lilia would wish to live the life now available to her rather than be dead, rather than whether she would wish to live the life previously available to her rather than that which is now available to her, once one has reached the conclusion that Lilia did not regard life as sacrosanct one then moves into a consideration of what her likely wishes would be in respect of continuing this life or discontinuing treatment and passing from this world.

66. The mother placed significant reliance on Lilia's conversations with her friend about not wanting to live in a coma. She also placed considerable reliance on Lilia's own decision to end her life. Lilia is recorded as having said to her therapist that causing brain damage and being in a coma was bad. The father cautions against placing too much reliance on either the suicide note or Lilia's actions, on a passing conversation with a friend or limited comments to the therapist. It seems to me that what Lilia said to her friend and her observations to her therapist are far from determinative on the important issue of what her wishes would be in the current situation. A passing conversation arising out of a shared experience of a television programme is of some weight as well in that there was no suggestion from Lilia that she viewed life as sacrosanct, but this was not a prolonged or in-depth conversation arising out of some real-life event which required her to consider one of life's profound existential questions. Equally her suicide note was written and acted upon at a time where plainly the balance had moved unequivocally into the negative for Lilia but I do not think one can automatically extrapolate from that that she would not wish to continue with life-sustaining treatment now. Nor her saying to the therapist that being in a coma with brain damage was bad. However, when one adds those to everything else that I know about Lilia it is my conclusion that a clear likely wish can be discerned. Lilia's quality of life seems to have focused in significant measure on experiences and sensations. I do not get a sense that Lilia regarded the interchanges of her human relationships as the most important aspect of her life; perhaps her relationships with her mother and father and even her sister had been complicated. She clearly valued them and her friendships and her estrangement from her father may not have been long-term. I do not have sufficient information available to me to draw any firm conclusions but the impression from what she has said about her childhood experiences was that it was marred by conflict between those who should have been the most important figures in her life; her mother and father. It seems likely that her enjoyment of experiences and sensations may have been some escape from the complex thoughts which troubled her. Her inability now to enjoy any of the experiences and sensations which were a significant component of the positive side of her balance sheet would I am sure weigh heavily with her. Being trapped inside her body and unable to access the experiences which seem likely to have been an escape or release for her would be viewed by Lilia as intolerable. As an independent young woman, I am also sure that she would find the inability to take decisions or to act upon them a significant negative. Her concern for others, most poignantly expressed in her suicide note would I am sure have guided her wishes and it seems inconsistent with her nature for her to adopt a decision which would of necessity mean that mother, her sister, her father her grandparents and friends would continue to live their lives knowing of her attenuated existence and perhaps making her the centre of their patterns of life with all of the limitations that would place upon their ability to live their own

lives rather than lives which revolved around her. If she was, as she seems to have been, a person who put others before herself I have little doubt that in the balance that she might have undertaken she would have concluded that it was far more important that they live their lives as fully as they could than it was that she should continue to exist merely for existences sake or as some comfort to them in particular her father.

67. Taking into account all of the medical components of her situation and what I conclude are her likely wishes I'm satisfied that she would not have wished to continue life-sustaining treatment but that she would have opted for its cessation and for the implementation of a palliative care regime which would enable her to pass from this life leaving her family to make the best that they could of theirs. I do not believe that she would have wished to live the attenuated existence of a vegetative state or a minimally conscious state minus, to endure the profound limitations on her autonomy including what I believe she would have perceived as the indignity of being cared for in every component of her personal care, unable to take decisions or act on them, to impose the burden of her attenuated life on her family and friends. I believe she would have wished to end the treatment.

Conclusion

68. Factoring in objectively the medical evidence of her current condition and prognosis, even allowing for the limited and remote possibilities of neurological improvement and the absence of any meaningful quality of life, the harm that further medical treatment will inevitably involve (albeit probably not with any awareness for Lilia), what I'm sure would have been perceived by Lilia as the indignity of her condition and her need for lifelong physical care, and all of her wishes as analysed above, the views of her family and friends, the opinions of all her treating team and the independent experts, I'm satisfied that it is not in Lilia's best interests to administer life-sustaining medical treatment but rather that it is in her best interests to implement a palliative care regime the consequence of which (but not the aim) will be the end of her life but that I think will be an ending to her story essentially of her choosing and one which I feel confident she would endorse.

69. This is my judgment.