Neutral citation number: [2024] EWCOP 25

Case Number:12968544

Court

In the Court of Protection

Location

First Avenue House, 42-49 High Holborn, London WC1V 6NP

DESCRIPTION

Heard on 22 February 2024 & 12 march 2024

Judgment given on 5 April 2024

Before

SENOIR JUDGE HILDER

Between

UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST

(ANONYMITY DIRECTION NOT MADE)

Appellant

and

HER

Respondent

SR

-

Representation:

For the Appellant: Conrad Hallin (instructed by Hempsons LLP) for the Applicant

For the Respondents: Alex Cisneros (instructed by Irwin Mitchell LLP) for the First Respondent

The Second Respondent appeared in person

APPROVED NOTE OF ORAL JUDGMENT

The numbers in bold typeface refer to pages of the hearing bundle.

Issued on 2 May 2024

1. I am concerned with the best interests of HER.

2. The Court is asked to determine whether or not it is in her best interests to be given medical care and treatment recommended by her clinicians at University College London Hospital NHS Foundation Trust. Her sister, SR, says that is not.

3. Because of the shared surname, and since SR indicated on the first day of the hearing that it would acceptable to her, I am going to refer to the sisters today as '[HER]' and '[SR].' No discourtesy is intended by the use of their first names. I hope it will avoid confusion.

4. The hearing of this matter was spread across two days, because the original time estimate proved to be insufficient. I am now delivering this judgment orally, on a third day, as the quickest way to hand down the decision of the Court and to ensure that SR hears the reasons behind it. The days when evidence was heard were conducted in person at First Avenue House. Today, the parties appear remotely so as to minimise inconvenience and travel costs, particularly for SR.

5. The Trust has been represented by Mr. Hallin of counsel. HER has been represented by Mr. Cisneros, instructed by the Official Solicitor who has been appointed as HER's litigation friend. SR is not represented.

Factual Background

6. HER is now 53 years old. She lives at a supported living placement where she has a 24 hour package of care. She has lived at this placement since 2017, and there is no suggestion that she is anything but settled and well-cared for there.

7. In early childhood HER had a stroke-like episode, which has had a lasting effect on a large part of her brain. She now has learning difficulties and epilepsy. She has also been diagnosed as

having a metabolic disorder called ornithine transcarbamylase deficiency – "OTC" for short. This condition gives rise to intermittent episodes of acute encephalopathy – a confused state. HER presently experiences epileptic seizures a few times a month, without warning. The epilepsy gives rise to risk of Sudden Unexpected Death.

Current Proceedings

8. There have been earlier proceedings about HER, although not before me and I have not seen any documents relating to them. In 2017, it was declared that HER lacked capacity to conduct those proceedings, and to make decisions about her residence, care and treatment. In these proceedings, I have read a report dated 20th January 2023 by Professor Sallie Baxendale (consultant neuropsychiatrist) [**24 – 39**]. After careful consideration by HER's litigation friend, it is now accepted by all parties that HER lacks capacity to make decisions about her medical care treatment and to conduct these proceedings. I accept that conclusion.

9. These current proceedings were begun by COP1 application dated 14th June 2023 [**4**], according to that form "due to an ongoing dispute between [HER's] treating team and her sister."

10. The first attended hearing took place on 1st August 2023, when SR confirmed that she would not attend the only relevant appointment scheduled before the next hearing. That had been listed to take place on 2nd November last year, but it was put back by consent to allow time for the Trust to file evidence concerning a proposed change of medication.

11. It is necessary to be clear about the matters which I have considered in reaching my decision:
    a. I have read the full 536 e-bundle prepared for the hearing, including four statements from Dr. Murphy, two statements by Professor Walker, one statement by Betsey Lau-Robinson, and two statements by SR. I have also considered two supplementary bundles of medical records – one also electronic, running to 164 pages; and the other on paper, in a lever arch file of 160 pages. I also have the benefit of position statements - one by Mr. Hallin for the Trust, one by Mr. Cisneros for HER, and two by SR.
    b. On 22nd February, I heard oral evidence from Dr. Elaine Murphy, Professor Matthew Walker and Betsey Lau-Robinson.
    c. On 12th March I heard oral evidence from SR, and submissions from each party.

12. Regrettably, I must first consider a question of law and procedure:

13. The first question I need to determine is how to treat SR's evidence:

    a. On behalf of the Trust, Mr. Hallin says that large parts of it are essentially SR's 'opinion' on matters of medical expertise. Relying on section 3(2) of the Civil Evidence Act 1972, he asserts that statements of SR's opinion on medical matters are inadmissible, because she is not qualified to give expert medical evidence.

    b. Specifically, Mr. Hallin contends that SR's view on:
        i. HER's diagnosis
        ii. her statements of what one would expect from OTC deficiency

    iii. her assertions of other conditions (such as vitamin B12 deficiency) being overlooked
    iv. her estimations of effectiveness and prescription level of medications and
    v. her conclusions of cause and effect of medications

  are all matters of opinion evidence which SR is not qualified to give and are therefore inadmissible.

c. Mr. Hallin accepts that SR may give evidence of relevant facts "personally perceived" by her but considers that such "will have very limited relevance to matters requiring medical expertise to comment."

d. SR herself, in response, has described herself as 'an expert by experience' (in her first position statement at para 29); and as "an expert as regards HER" (same position statement para 47). She does not contend that she is "a medical expert". Rather she says that she has unrivalled knowledge of HER, and HER's experience of life and medical treatment.

e. On behalf of HER, the Official Solicitor is concerned at the Trust's approach to SR's evidence, pointing out that if it is deemed inadmissible, SR's involvement in these proceedings will be "effectively nullified."

f. The OS accepts that SR's evidence "does blur the line between her opinion about what clinicians have told her and her opinion about medical matters" but considers that, in reality, "there is no danger of the court erroneously relying on her opinion about those aspects."

g. Mr. Cisneros submits that, in accordance with the power pursuant to Rule 14.2 of the Court of Protection Rules 2017 to "control evidence", the Court should allow SR's evidence to stand but "attach appropriate weight to it given that fact that she is not an expert" – that is, I should "put no weight on the aspects of her evidence which strays (sic) into expert evidence."

14. How should I determine this conundrum? First, I remind myself of relevant Rules and definitions:

    a. The Court of Protection has some rules of its own about expert evidence, in Part 15 of the 2017 Rules. There is no definition of "expert" but, pursuant to Rule 15.1, a "reference to an expert" is "to an expert who has been instructed to give or prepare evidence for the purpose of court proceedings", not including the author of a report pursuant to section 49 of the Act.

    b. The standard definition of an 'expert' according to the Oxford dictionary is "a person who has great knowledge or skill in a particular area".

    c. Most explanations of an expert witness focus on a level of specialised knowledge or skill in a particular field, often including reference to acquisition of such skill by study or practice or both, which qualifies a person to present their opinion about the facts of a case.

d. Practice Direction 15A sets out general requirements of an expert witness, including that the expert should:
    i. provide “objective, unbiased opinion on matters with the expert’s expertise (para 4);
    ii. consider all material facts, including those which might detract from the expert’s opinion (para 5).

15. In fact, there has not been any direction for an expert’s report in these proceedings:

    a. on 22nd February at the end of the first day of the hearing, I refused SR’s lately-made oral application for permission to obtain independent expert cardiology evidence;

    b. Professor Walker and Dr. Murphy have given evidence as HER’s treating clinicians, not as independently instructed experts; and

    c. SR is joined as party to the proceedings because she is HER’s most involved relative, and clearly interested in her welfare.

16. It is clear to me that there is a distinction to be drawn between the witnesses from whom I have heard.

17. On the one hand:
    a. Professor Walker is a professor of neurology at the UCL Queens Square Institute of Neurology, and an Honorary Consultant at the Trust. He is past President of the British branch of the International League against Epilepsy, the current char of the European part of that organisation and chair of Epilepsy Research UK. He has been involved in the care of people with epilepsy since 1992. He has published over 300 papers, chapters and books on epilepsy and related subjects. He has sat on advisory boards of pharmaceutical companies but he has no financial interest in any companies other than EpilepsyGtx, of which he is a co-founder, and which is solely involved in the development of gene therapies for epilepsy. In short, he is a medical professional of standing and repute.

    and

    b. Dr. Murphy is a Consultant in Adult Inherited Metabolic Disease at the National Hospital for Neurology and Neurosurgery. She has previously held a post at the Charles Dent Metabolic Unit, which manages more than 1500 individuals with rare inherited disorders of metabolism. She too is a medical professional of standing and repute.

    So,

    c. they both have years of learning (tested by examination) and practice (giving rise to experience) of medical issues in question. They have professional reputations to protect but no other interest in HER than as patient for whom they are professionally responsible. As a starting point then, the Court must place great weight on their professional opinions on matters of medical diagnosis and treatment, unless and until there is shown to be good reason not to.

18. In contrast: SR is a devoted sister, who has obviously spent a great deal of time and effort trying to educate herself about HER's condition. She has closely observed HER for pretty much all of her life, and therefore has much to say by way of describing HER's reactions to treatment. However, she comes to the issues before the Court as a technical lay-person. Her insight into the relevant medical science is limited to that which can be picked up from publicly available documents - in her evidence she has referred to consulting "Dr. Google" [**239**]. It is untested by examination or qualification or professional discourse, unconstrained by ethical regulation, and uninformed by practice. She is naturally not an objective observer but has an emotional investment in HER.

19. So how should the Court treat SR's evidence? In reality, there seems to me to be little difference in the practical evidential effect of the approaches taken by the Trust and by the Official Solicitor: one says I should exclude the evidence, the other says I should put no weight on it.

20. There does however seem to me to be a significant difference in how SR is likely to experience the fairness of litigation. If her evidence is excluded, it is as if she had never articulated her position to the Court. If it is admitted but no weight is put upon such matters as she lacks expertise to opine upon, at least she has been heard.

21. I therefore take the following very practical approach to the issue of admissibility of SR's evidence:

    a. in reality, both of SR's statements were admitted as evidence in these proceedings, and read by me, before any argument to the contrary was raised by the Trust; and I have heard oral evidence from SR, without any contrary application by the Trust.
    b. Therefore, I can only now consider the Trust's argument of inadmissibility as an application that, having already been admitted, SR's evidence should be disregarded in so far as it ventures into matters of medical expertise.

    c. Without wishing to lose any of the respect intended in the term "expert by experience", I am clear that this is not the "expertise" for which the Court looks in questions of medical diagnosis and treatment. I do not regard SR as appropriately positioned to give expert evidence about medical matters. In so far as SR's evidence crosses the line into matters which are properly the domain of medical expertise, it can therefore be of no weight.

    d. Looking at it in the round, I regard SR's evidence as the attempt of an intelligent non-expert to understand what is being done for and to her much loved sister. In so far as SR's evidence expresses her observations of HER's experience of or reaction to medical treatment to date, I shall consider it as evidence of fact.

22. Whilst I am diverted into matters of law, it may be helpful to confirm the matters to which I have regard when considering the issue to be determined.

23. I bear in mind the principles of section 1 of the Mental Capacity Act 2005, specifically reminding myself that a decision made on behalf of a person who lacks capacity to make it for themselves must be made in that person's best interests.

24. In considering HER's best interests, I have regard to the provisions of section 4 of the Act:

    a. There is no suggestion that HER will gain capacity to make the decisions which the Court is asked to make, for herself.

    b. HER's participation in these proceedings has been secured by representation through a litigation friend, including attendance notes of direct engagement with HER which set out her wishes and feelings, beliefs and values in so far as it has been possible to ascertain them.

    c. I regard SR as a person whose views need to be taken into account pursuant to section 4(7).

    d. That doesn't mean that SR's views can or should be decisive; but

    e. I have striven to ensure that SR has had an opportunity to explain to the Court what her views are, in writing and orally.

25. I turn now to the position and evidence of each of the parties.

26. The Applicant Trust seeks authorisation from the Court to take the following steps:

    a. to treat HER in accordance with the treatment plan as updated in March, during the course of these proceedings;

    b. and specifically, gradually, to transition HER from sodium benzoate medication to glycerol phenylbutyrate instead.

27. The Trust also seeks resolution of 3 other issues:
    a. whether it is in HER's best interests to undergo additional diagnostic tests for OTC deficiency?
    b. how to manage SR's attendance at any of HER's medical appointments which are concerned with epilepsy or the OTC – specifically, for her to be excluded; and
    c. how to deal with SR's interactions directly with HER about her epilepsy and OTC.

28. As to HER's condition and medical needs, the Trust's position may be summarised in 16 'bullet points' as follows:
    a. OTC is a rare urea cycle defect, occurring once in about 62000–70000 people.

    b. HER's clinical presentation – a normal birth and early milestones, with a stroke-like event around the age of 2.5 to 3 – is typical for OTC deficiency in a symptomatic female.

    c. Encephalopathy – confused states – are caused by hyperammonaemia, that is, high levels of ammonia. When things work properly, the urea cycle in the liver detoxifies ammonia and allows it to be excreted harmlessly as urine. HER's OTC deficiency means that the ammonia in HER's body is not so detoxified.

d. OTC deficiency is alone sufficient to explain HER’s hyperammonaemia.

e. Hyperammonaemia has led to HER’s brain damage and epilepsy.

f. Presently, HER’s seizures are less frequent than they have been at times in the past but, to improve her life prospects, they need to be still better controlled. Her present risk of Sudden Unexplained Death in Epilepsy is about 1/200 per year. The goal of the Trust is to reduce this.

g. The treatments for OTC and epilepsy are linked in that, when HER’s OTC is not well controlled, high ammonia levels make her seizures worse.

h. The focus on the OTC control is really important because the chances of getting HER free of seizures with ani-seizure medication alone is thought to be less than 5%.

i. Some individuals with OTC can appear to tolerate high ammonia concentrations but there is no evidence that HER has improved clinically with higher ammonia levels – such hypothesis makes ‘no biological sense,’ since ammonia is neurotoxic.

j. The treatment HER has received from the Trust’s clinicians has been in line with all national and internationally-agreed guidelines for the management of OTC deficiency. Overall it has worked well.

k. HER has experienced no side effects attributable to either sodium benzoate or lacosamide.

l. HER has no known heart problems. She has had ECG tests in March 2020 and October 2022. The computer report on the last ECG suggested ‘anterior infarct old’ but this is an incidental finding, has no relevance to her neurological problems or medication, and is probably due to misplaced electrodes. A further ECG will be undertaken in any event.

m. Dr Murphy now wishes to transfer HER to a new medication, glycerol phenylbutyrate. The hope is that this medication will:
   i. lower HER’s plasma ammonia and glutamine;
   ii. by reducing HER’s baseline ammonia levels, reduce episodes of hyperammonaemia confusion and the need for hospitalisation.

n. IF (which is not known) HER’s reported mood swings are related to higher ammonia levels, then the new medication may also bring about a happier HER, with less distress and consequential risk of harm BUT it is not expected to improve HER’s cognition or reduce the frequency of her seizures.

o. Glycerol phenylbutyrate has advantages of practicality over HER’s current medication – it’s a liquid medication, taken in small volumes, as compared to the 18 tablets a day which HER currently takes. The transition can be managed as an outpatient, the proposal being transition over two weeks, with 4-6 weeks of weekly monitoring.

p. Dr. Murphy's experience of the new medication, as explained in her oral evidence, is that so far she has moved 18 of her patients over to it and none of them have needed to go back again. Some of them now have normal ammonia levels for the first time in their lives. Dr. Murphy is willing to undertake the transition in a week when HER's most experienced carers [Tl and Tm] are on duty.

q. The ureagenesis test which is currently part of a Zurich research project is not available at UCLH. When it does become available, HER is unlikely to be within the cohort of suitable candidates. She would have no direct benefits from the testing because it would not change the treatment approach.

29. In contrast, SR disputes the diagnosis and considers that the treatment plan is misconceived. Trying to crystallise SR's evidence:

a. She gives a different explanation of the onset of HER's difficulties:
   i. SR believes that HER's brain damage followed "questionable medical treatment whilst at GOSH, and also by [her GP surgery] and [local hospital]" and "it was iatrogenic-induced liver damage that caused the hyperammonaemia" in 1973 [**226**].
   ii. She believes that HER recovered well once out of hospital "due entirely to the love and diligent care provided by our parents." What was diagnosed as epilepsy when HER was about 11 was in fact "a funny turn" from "a fright whilst in a stable with a friend's horse." [**227**]
   iii. HER experienced high levels of seizure whilst on medication but far fewer when her mother "took the decision to wean her off the drugs completely" – down to seizures only across a 3 day period, always at the same time of the month, "just on or after full moon."
   iv. SR does not accept the diagnosis of OTC.

b. Recently, she has become aware that HER's sample for the gene sequencing tests was labelled as a venous blood sample, when in fact a saliva sample had been given. She regards Dr. Murphy's account of the "correction" of the labelling error as insufficient and is concerned that two different DNA samples have been muddled up [**418**] so the test results may have nothing to do with HER at all.

c. SR does not accept that HER's ammonia levels are problematic in the way the clinicians contend. She describes HER as being "angry and aggressive" when ammonia was "normal"; and "calm and relaxed" when ammonia had "shot up again" – contrary to normal presentation of hyperammonaemia due to OTC. She believes that HER has become chronically hyperammonaemic in response to medication [**234**]. She believes that HER's "body is quite capable of removing excess ammonia… the ammonia is not the cause of the problem but the body's reaction to the problem. The ammonia is the cure." [**252**]

d. SR considers that treating clinicians have failed to understand her position. In her own words, at para 45 of her second position statement:
    i. "I DO NOT WANT H[ER] TO HAVE ROUTINELY HIGH AMMONIA LEVELS. I want her to have NORMAL AMMONIA LEVELS and be WELL – which is why I want her OFF the ammonia-elevating drugs. The ONLY time higher ammonia levels help her is WHEN SHE IS ILL FOR ANOTHER REASON and the ammonia goes up to compensate. In those situations, her cognitive function massively improves when her ammonia levels rise."

    And

    ii. "There is NO RISK from H[ER] being OFF ammonia scavengers – she managed perfectly well without them for forty five years, and never, ever had metabolic decompensation in those 45 years. The only tricky bit is the weaning off process, which could temporarily upset her ammonia levels. But once she's off the drugs and they're out of her system, the ammonia levels will go DOWN."

e. SR has previously given to the Trust via Mrs. Lau-Robinson a list of 54 safeguarding concerns – in an e-mail timed at 19.33 on 1st November 2022 [**155**]. Number 10 gives the flavour: "H[ER]'s treatment has been, and continues to be, based on assumption, supposition, guesswork, incorrect assertions, and inaccurate/false information, and sometimes downright lies." She alleges that Professor Walker personally receives payments for prescriptions of certain medications to HER.

f. SR's view of HER's treating clinicians is summed up at page [**238**]: "Because I won't agree with their appalling treatment plans, because they are wrong, and will end in tragedy for my sister, they are trying to cancel me, so they can do whatever they please to my helpless sister, ad infinitum. This would render her a perpetual lab-rat, utterly at their mercy, until they ultimately succeeded in killing her, which they undoubtedly will."

g. SR would like a different treatment plan for HER. To use her words at [**419**], "What I really want … is a fundamental change in treatment, based on targeted, high dose vitamin/mineral treatment, with judicious use of phytomedicines and possibly certain amino acids. 50 years of doing the same thing hasn't worked." This is expanded at paragraph 55 of her first position statement to the following 'shopping' list:
    i. repeat DNA sequencing analysis
    ii. the Zurich ureagenesis test
    iii. a second opinion from Salford, to include her direct input
    iv. a fresh appraisal of treatment options
    v. transfer of HER's care away from UCLH
    vi. prohibition of any drug known to cause hyperammonaemia, increased seizures or heart problems;
    vii. prohibition of brain surgery or vagal nerve stimulation;
    viii. no restrictions on SR' s access to HER's records; and
    ix. meaningful input into treatment decisions, preferably by her own appointment as welfare deputy for HER.

h. SR's expectation, set out at [**240**], is that "taking H[ER] off all the drugs would undoubtedly improve her cognitive function and memory eventually, although the time it would take to achieve a reasonable improvement, and the degree of improvement that could be made, would depend on how severe the neurological damage caused by the sodium benzoate and lacosamide treatment has been, and whether that neurological damage has become permanent or whether it can be reversed."

30. How does the Court square the circle of such differing positions?

31. I am grateful for the input of HER's own representatives. It is clear to me that they have put considerable effort into consideration of SR's experience and viewpoint. In particular, they formulated a series of questions based upon that experience and viewpoint, which were put to Professor Walker and Dr. Murphy. I have incorporated their answers into the summary of the Trust's position above but notably their response includes clearly stated views that SR is simply wrong in that:

    a. HER has *never* presented with symptoms which are "paradoxical" or inconsistent with a diagnosis of OTC;

    b. there is no evidence that HER has improved clinically with higher ammonia levels. (Elsewhere, in respect of SR's observation that HER's ammonia levels go up when she is ill for other reasons, and then go down by themselves when she's better, Dr Murphy has stated that "I don't know of any evidence that this is an appropriate response to illness – it's not a normal compensatory mechanism." She is "not happy NOT to intervene when HER's ammonia levels are higher because it is causing damage to her brain.")
    c. as to giving HER *no* medication, Dr. Murphy considers that this would put HER at "unnecessary risk of hyperammonaemia crisis". Side-effects not presently being an issue for HER, that risk is not clinically appropriate.

    d. [**379**] the joint response of Professor Walker and Dr Murphy to SR's proposed treatment plan is that:
        i. they are happy to accept SR's request for complete vitamin and micronutrient profile at HER's next face to face appointment – it's a non-invasive blood test; and
        ii. if any deficiencies are identified, they would be treated as per standard guidelines. However, there is no evidence that OTC deficiency can be treated by supratherapeutic vitamins and minerals alone. Rigorous systemic review has concluded that there is no reliable evidence to support routine use of vitamins in patients with epilepsy.

32. So, I turn to the position on behalf of HER.

33. HER's solicitor, Mr. Butler, has filed attendance notes of his engagement with her. When asked about her medical treatment or this application, HER did not express any clear views. Either she expressed no opinion or, if pushed gently, she was equivocal. Generally, HER appeared unconcerned about her medical treatment but would prefer to talk about things that make her happy.

34. The Official Solicitor concludes that the Trust's treatment plan *is* in HER's best interests, having regard in particular to the following factors:

    a. The diagnosis of OTC has been confirmed by gene sequencing in 2013. SR at first accepted this. In so far as her faith in it has since been shaken by acknowledged misdescription in the labelling, there is no cogent evidence that this 'error' undermines the underlying conclusion. Dr. Murphy's evidence (that it does not) is accepted.

    b. HER's history of hyperammonaemia is a matter on which both the Trust and SR are agreed. Given the result of the gene sequencing and the clinician's confidence in the OTC diagnosis, there is simply "not enough strong evidence" to depart from the Trust's analysis of causation.

    c. There is no meaningful evidence in HER's records or otherwise to support SR's contention that HER improves with higher ammonia levels. SR has provided a table of results which appears to demonstrate that HER's ammonia levels have been low at times when she is not receiving treatment, and high when she is, but the happening of low ammonia at times of no medication is not necessarily evidence that ammonia levels have been controlled at those times.

    d. SR has not provided any conclusive evidence of the paradoxical symptoms on which she relies, from HER's medical records or otherwise.

    e. SR accepts that taking HER off all ammonia-reducing medication would come with risks. HER's representatives consider that, where all her treating clinicians are of the view that improvement with elevated ammonia is not possible, and HER is not experiencing neurotoxicity, such risk should not be taken.

    f. Although SR asserts that HER's treatment "has not worked", in fact HER's quality of life and wellbeing are remarkably good in light of her health complications and the prognosis for individuals with OTC.

35. And so to my conclusions as to HER's treatment.

36. The treatment which SR proposes is not being offered by the Trust. It is therefore not an option which HER could choose for herself if she had capacity to do so, and so not an option before the Court. This Court cannot compel clinicians to give a course of treatment against their own professional judgment. So, to be clear, the decision which I have to make in these proceedings is **not** whether I prefer the Trust's treatment plan or SR's. It is more narrow than that – namely, whether I am satisfied that the Trust's treatment plan is in HER's best interests, taking into consideration SR's views about it.

37. I accept the medical expertise of both Professor Walker and Dr. Murphy. They both struck me as diligent, careful witnesses. I note that, notwithstanding that they come to HER's treatment from differing specialisms, conscious that the approaches of one impact on the concerns of the other, they are in full agreement with each other as to how to treat HER's complex condition.

38. I also note that Professor Walker's description, at [**192**], that he "specialises in complex epilepsy within a large multidisciplinary group (one of the largest world-wide)….. [HER's] case will be

discussed at our multi-disciplinary team meeting where other neurology consultants specialising in epilepsy (usually 5-8), neuropsychiatrists, neuropsychologists and neurosurgeons can all give their opinion about further treatment options." This team approach is reassurance against any concern – which in any event I am satisfied is not remotely made out – that clinicians are somehow motivated by personal interests as opposed to HER's welfare.

39. I do not doubt that SR is genuinely motivated by concern for her sister's wellbeing but I do not accept that SR's observations of HER over time are sufficient to cast any real doubt on HER's diagnosis, or on the treatment plans of the clinicians who bear responsibility for her care. Where SR's observations are at odds with the clinicians' informed medical views, I prefer the evidence of the clinicians, who are qualified and widely experienced in the relevant medical science. I am concerned that SR's approach pays too little regard to risk, in pursuit of an agenda which is driven in part at least by historical grievance rather than objective current evaluation. I am concerned that her characterisation of HER's experience in the care of treating clinicians so far is markedly different to the independent observation of HER's own representatives that, actually, HER is experiencing a good quality of life, happy and settled in her care arrangements.

40. I have regard to the support of HER's own representatives for the plan which is proposed by her treating clinicians, and the evidence that, whilst she lacks capacity to understand it, she is compliant with and undistressed by her treatment regime.

41. I turn to the best interests analysis.

42. *The factors in* favour of the Trust's treatment plan seem to me to be as follows:

    a. It is recommended by qualified and experienced medical practitioners, in line with national and internationally-agreed guidelines.

    b. It has been working relatively well so far, and in so far as it incorporates a change to new medication, the treating clinicians experience to date is that the new medication has improved the experience of patients.

    c. HER is compliant with medication and does not express any views against taking it, suggesting that the process of medication does not cause her distress. It seems likely that she would want to be a healthy as she can be.

    d. If HER's OTC deficiency is not medically treated, there is unquantified risk that her seizures will get worse and the odds of sudden death will increase. Even SR accepts that there is unknown risk in such approach. The evidence of clinicians, which I accept, is that even if treatment cannot completely remove seizures, the proposed treatment plan offers the prospect of better control – and that is a significant benefit to HER.

    e. It has the support of HER's independent representatives.

43. The only factor against the Trust's treatment plan is that it is contrary to the wishes and beliefs of HER's closest family member, her sister SR. SR's familial support of her sister is important but she is not a medical expert. Moreover, she doesn't actually oppose all of the treatment plan – in particular, she does *not* object to the admission for telemetry [**317**]. Her opposition is really to the medication proposals and possibility of surgery:

    a. I can give no weight to SR's concerns about the medical science behind the medication, and I am satisfied that the treating clinicians are very well aware of interactions of the various medications on the list in the care plan and HER's past experience, for example, lacosamide. So, SR's opposition is outweighed by their support; and

    b. no possibility of surgery presently arises. (More of this in a moment.)

44. I am not persuaded by SR's evidence that there is any substantial basis for doubting the proposed treatment plan. Taking all the circumstances into account, I am satisfied that it is HER's best interests to be treated for OTC and epilepsy in accordance with the March care plan filed in these proceedings. A copy of that plan will be attached to today's order, so that there is absolute clarity as to what the Court has endorsed.

45. I turn next to the question of how delivery of the treatment plan can best be facilitated and, in particular, the question of SR's participation in HER's appointments.

46. I am informed that, in the earlier proceedings, an order was made on 30th April 2018 which permitted SR to attend HER's clinical appointments unless she (HER) objected, and conditional on SR's adherence to a behaviour protocol.

47. The statutory obligation of section 4(7) is that a best interests decision-maker takes into account the views of anyone interested in the welfare of the person for whom the decision needs to be taken, i.e. SR, "if it is practicable and appropriate to consult them". It is an important, but qualified, obligation.

48. The Trust's position is that, such has been the state of interactions between the Trust and SR, it is no longer practicable to welcome SR into HER's appointments about OTC or epilepsy:

    a. Dr Murphy has described how HER's behaviour in consultations is quite different according to whether SR is present or not – "my impression is that she wants to say things SR will agree with" [**170**].

    b. I heard oral evidence from Betsey Lau-Robinson, who is a registered nurse and Head of Safeguarding for Adults, the Mental Capacity Act & Prevent at UCLH. (Her involvement was initiated by Professor Walker after receipt of an e-mail from SR sent on 16th July 2021.) It has been Mrs. Lau-Robinson's role to "support and signpost the clinician team to the right resources in what is a very challenging matter." [**116]** At times she has been SR's point of contact with the Trust.

c. Mrs. Lau-Robinson has set out in her statement dated 5th June 2023 and in her oral evidence her account of how events unfolded at the best interests meeting and the consultation on 21st September 2022. She describes SR having raised her voice several times, appearing aggressive, finger-pointing, saying that HER was being used as a 'lab rat' and 'they were killing her,' pacing, fidgeting and shaking her legs constantly. She also describes HER as 'look[ing] more and more anxious and distressed.' Mrs. Lau-Robinson asked Professor Walker to pause the consultation and escorted SR out.

d. Professor Walker's evidence is that having SR present severely impacts his ability to make consultations with HER a positive and constructive experience for his patient. He has had to end a consultation prematurely.

49. SR does not accept this characterisation of her involvement in HER's appointments. She accepts that she has been frustrated at times, and she accepts [**243**] that she was "doing the Ministry of Silly Walks" in the best interests meeting but says that this was because she was having "severe CRAMP", which she explained at the time and for which she apologised. She appreciates (now) that it was "probably difficult" to carry on with discussions with her doing that. Otherwise she says the accounts of Professor Walker and Mrs. Lau-Robinson are "lies."

50. When I strive to weigh up these differing accounts, I am assisted by the documentary evidence, and in particular by SR's own written communications. By way of example:

a. [**132**] an e-mail from SR to Mrs. Lau Robinson timed at 16.46 on 2nd September 2021 uses the terms 'lab-rat', and 'harmful, life-shortening drug treatment'; and includes threats to bring legal action for negligence of gross negligence manslaughter.

b. [**195**] an e-mail from SR to Professor Walker timed at 08.58 on 24th December 2021 is angry and abusive in tone, challenging treatment recommendations in very hostile terms:
    i. "It is said that the definition of stupidity is doing the same thing over and over again and expecting a different result. So what does that make you?"
    ii. "Maybe you're reluctant to take her off LCM because of the personal payments you receive from the drug company."
    iii. "Your massive ego and blinkered, arrogant, prejudiced, dogmatic views, along with your unshakeable but sadly mistaken belief that no-one's published, peer-reviewed research except you own has any merit…"
    iv. "I hope you have/had a truly shitty Christmas, because you sure as Hell have ruined mine."

51. In my view those written communication give a very good idea of how SR would be likely to behave in consultations where things were being said with which she profoundly disagrees. Where their accounts differ, I prefer the account of Mrs. Lau-Robinson to that of SR. The behaviour which she describes is consistent with the e-mails from SR. In the hearing, I saw for myself that SR raises her voice and 'shouts' aggressively without apparently being aware that she is doing it. It is much more plausible that Mrs. Lau-Robinson's account is objectively accurate than that she has concocted "lies".

52. So, I accept that SR's attendance at HER's appointments related to OTC deficiency and/or epilepsy would be likely to be unhelpful, even actually harmful to HER in that it would prevent the appointment from being conducted in the best way possible. I am satisfied that it is in HER's best interests that SR does NOT attend these appointments. It would be helpful if [Tm] and/or [Tl] were able to accompany her instead.

53. Do I need to go any further than that? The Trust seeks formal undertakings from SR but, if they are not offered, asks me to make injunctive orders prohibiting SR from attending or attempting to attend these appointments.

54. In her submissions, SR said that she no longer wished to attend HER's appointments in respect of OTC or epilepsy, as long as [Tl] or [Tm] were there. She was not willing to give undertakings not to attend because "I might change my mind". She objects to injunctions because she considers there is no need for them – all she has done is "question the doctors" and in any event she will 'of course' abide by the decision of the court.

55. I regard it as important to note that the Trust has informed the Court of "a plan that will be put into effect in relation to how [SR] is consulted in the future" about medical treatment not covered by these proceedings. As explained in Mr. Hallin's position statement, the Trust is not asking for Court approval of this plan. Rather, it has made the plan as a public law decision, which means that it can only be challenged by judicial review proceedings.

56. So, beyond these proceedings, the Trust now plans to consult SR *only* if the Trust considers it practicable and appropriate, only by e-mail and only to a maximum length of 3 typed pages of A4 except in exceptional circumstances. The plan is to exclude SR from UCLH premises except in respect of her own treatment or visiting a patient other than HER. If HER is admitted as an in-patient, UCLH will notify SR of permitted visiting arrangements, with any conditions. SR will not be permitted to attend any of HER's appointments, whether routine or urgent, in person or remotely.

57. The Official Solicitor on behalf of HER agrees that a plan for consulting SR going forwards is needed, because there is no longer any realistic prospect of SR's attendance at appointments relating to epilepsy or OTC being constructive and there is evidence that conflict at the appointments distresses HER. However, her representatives do not agree that injunctions are required at present.

58. In my view, the Trust's planned approach beyond the scope of these proceedings is stringent. I recognise that this position has only been reached after HER's care at three other specialist centres has already broken down with similar issues, leaving only one other medical centre equipped to meet HER's needs - and that one is geographically very distant for HER.

59. It is vitally important for HER that she is able to access medical care. HER's representatives do not support another change of treating team – they consider that any further move at this point would not be justified by any evidence that current clinicians are acting unreasonably but would be merely to appease SR, when previous moves have obviously failed to resolve SR's scepticism.

60. Having made a clear best interests decision that SR should not attend HER's appointments in respect of epilepsy or OTC deficiency, I have regard to:
    a. the ordinary mechanisms which the Trust has for arranging appointments on that basis – as demonstrated in the plan it will be adopting for matters beyond these proceedings; and

    b. SR's own assurances to the Court that of course she will abide by the decision of the Court; and
    c. the views of HER's own representatives that injunctions are not necessary;

and I conclude that it is not presently either necessary or proportionate to make an injunctive order to back up the best interests conclusions.

61. I am satisfied that this Court has jurisdiction to make the injunctions sought but I am also satisfied SR has understood, from discussions/submissions in the hearing, the meaning of injunctions and that injunctions would be the next step IF the best interests decision is not fully respected.

62. In a related fashion, the Trust also sought undertakings or - if not offered - injunctions, to prevent SR from discussing her treatment for epilepsy or OTC deficiency with HER. I regard it as very serious that SR has – she accepts – deliberately tried to 'frighten' HER about her treatment plans – or, more accurately, what SR fears may become her treatment plans. [**246**] SR accepts that she told HER "there was a chance that she would be left with a permanently hoarse voice, which would seriously impact her ability to sing." I understand why the Trust seeks the serious measure of injunctions to prevent it from happening again.

63. However, I am also mindful that there are – presently - no restrictions on contact between SR and HER. As Mr. Cisneros points out, in those circumstances, practical enforceability of court-imposed prohibitions must be questionable. In reality, the more effective control would be in respect of contact arrangements. (No one asks the Court to take such steps at present.)

64. More positively, SR herself has now acknowledged that, even in her own desperation, deliberately trying to frighten HER into refusing treatment was not an appropriate thing to do. In my view, that acknowledgment is the best hope that she will not behave in such a way again.

65. At this point, I do not consider it proportionate or appropriate to impose this second requested injunction either. I accept SR's assertion, repeated several times during the hearing, that of course she will abide by the order of the Court. She should have an opportunity to be as good as her word. If she is, then she has nothing to fear from further court proceedings. If she proves not to be, then the Court can reconsider the position in the light of circumstances at the time.

66. There are still three other issues raised, which need to be addressed (briefly).

67. Firstly, SR's first statement [**242**] and position statement raised the possibility of appointment of a welfare deputy. There is no such application before the Court to determine but some observations at this point may be helpful:
    a. in these proceedings, the Court has determined the welfare issue, so there is no need for appointment of a welfare deputy;
    b. should circumstances so change that welfare deputyship is a plausible need, it is unlikely – on the basis of experience to date - that SR could be considered sufficiently neutral and objective in matters of HER's welfare to be an appropriate candidate.

68. Secondly, SR has raised the possibility of prohibiting the Trust from prescribing certain medications ('AED's) which cause hyperammonaemia:
    a. on the evidence before me, I am satisfied that there is no reason to be concerned that the clinicians would willingly give HER medication likely to destabilise her ammonia levels;
    b. in as far as the treatment plan before amendment included reference to medications which HER has previously responded to not well, I accept Professor Walker's

explanation both of the ‘cut and paste’ error and of how the list of medications would be approached.

69. Thirdly, what happens after the telemetry?

    a. The treatment plan sets out that HER will be offered a week-long admission for video-EEG telemetry “to determine if there is an area of the brain where the seizures start that can be safely removed to get H[ER] seizure free.” The outcome of the telemetry will be discussed at a multi-disciplinary meeting, which will “make a recommendation and determine whether to offer surgery, or whether to try something else instead.”

    b. It is abundantly clear that the prospect of HER undergoing “brain surgery” “terrifies” SR – “terrifies” is her word. Passing awareness of the history of brain surgery and its portrayal to the mass public makes this entirely unsurprising. It is important that the Court does what it can allay that fear.

    c. The Trust is, I am confident, already aware that nothing in the Court’s determination today extends to authorisation to undertake brain surgery on HER.

    d. Professor Walker’s current opinion [**187**] is that surgery “is unlikely to be an option for H[ER]” anyway; but

    e. If such is proposed, it is highly likely that SR will object [**317**] – “I will never, ever agree to brain surgery.”
    f. I therefore state categorically and unequivocally that further proceedings will be required if HER’s treating clinicians ever get to the point of considering brain surgery to be in HER’s best interests.

Conclusion

70. So finally, to sum up, I am satisfied that
    a. HER lacks capacity to conduct these proceedings, and to make decisions about her medical care and treatment, specifically in respect of OTC deficiency and epilepsy;
    b. it IS in HER’s best interests to be treated according to the amended plan filed within the course of this hearing;
    c. it is NOT in HER’s best interests for SR to attend her appointments in respect of epilepsy or OTC deficiency; and
    d. it is not presently appropriate to make injunctive orders, affording SR one opportunity to demonstrate her assurance that she will abide by the Court’s decision with recourse to such measures.

71. I apologise for the length of this oral judgment but I hope that the conclusion of these proceedings can now be the beginning of a more effective, constructive era for HER’s care where those who have professional responsibility for her treatment, and those who love her, can each give of their best to help HER lead the most fulfilling life she can.

Postscript

72. Following the delivery of this judgement, SR asked whether she would be entitled to copies of HER's medical records. I considered this and, consistent with my decisions set out above, concluded that it would not be in HER's best interests for SR to be provided with copies of HER's medical records, unless HER's treating clinicians consider that such disclosure is in HER's best interests.