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IN THE HIGH COURT OF JUSTICE
FAMILY DIVISION
[2021] EWHC 126 (Fam)



No. FD20P00877

Royal Courts of Justice
Strand
London, WC2A 2LL

Monday 18 January 2021

Before:

MR JUSTICE HOLMAN
(Sitting throughout in public)

B E T W E E N :

CAMBRIDGE UNIVERSITY HOSPITALS
NHS FOUNDATION TRUST

Applicants

- and -

(1) MOTHER OF E
(2) CHILD E
(by her children's guardian)

Respondents

MR V. SACHDEVA QC appeared on behalf of the applicants.

MS N. KOHN appeared on behalf of the first respondent.

MS M. CAREW appeared on behalf of the second respondent.

J U D G M E N T

(A s a p p r o v e d b y t h e j u d g e)

MR JUSTICE HOLMAN:

Introduction and background

- 1 E is now almost exactly seven and a half. When she was about three and a quarter, she manifested symptoms which were conclusively diagnosed as a classic, localised medulloblastoma; that is, cancer in the posterior fossa of her brain. Later molecular analysis established that E suffered, and still does suffer, from grade 3 medulloblastoma, which is a type that cannot be cured by surgery alone.

- 2 In October 2016 the tumour was resected by surgery at Addenbrookes Hospital in Cambridge, which is in the general area of England in which E and her mother live. It is a feature of grade 3 medulloblastoma that, although all traces may be macroscopically removed, so that the cancer may appear to the naked eye, or even by MRI scanning, to have been completely removed, microscopic traces are likely to remain adhering to the brain. One of the medical witnesses, Professor Barry Pizer, said that, although not visible even on an MRI scan, there could be a million cancerous cells in one millimetre of retained tissue. So it is necessary to follow up surgery with other therapies, for otherwise a tumour will inevitably return.

- 3 Available therapies are either chemotherapy or radiotherapy, or a combination of both. However, craniospinal radiotherapy (and I am not referring in this judgment to any other site of radiotherapy or any other form of cancer) is known to cause permanent damage to a young child's immature and developing brain. For that reason, it is not the practice in the United Kingdom to give craniospinal radiotherapy to a child below the age of about five, although, apparently, in America and some other parts of the world it is given to even younger children.

- 4 So after the surgery in October 2016 chemotherapy was the only option for E, who was then still under the age of three and a half. The doctors at Addenbrookes advised that she should have it, and the mother accepted their advice. The doctors did not anticipate, nor, therefore, warn of, any significant side effects from the chemotherapy as such. But, unpredictably, the effect upon E was rapidly catastrophic. Within a few days she fell into a coma, and she remained in intensive care for over a month. She remained very seriously ill for several months, and on more than one occasion was considered to be very close to death.
- 5 The treating paediatric oncologist, Dr James Nicholson, said that when E returned home she still had a nasogastric tube fitted, she showed signs of spasticity, and she could not speak. The mother showed me an album of photographs taken in that period and they are distressing to behold. E was so thin, so frail, so pallid, and so apparently lifeless. Even now, the doctors cannot give any medical explanation for the catastrophic reaction.
- 6 After many months, however, E did recover and was able to return home and, eventually, to pick up again on a normal life with her mother and wider maternal family, and to go to school. The result was, however, that the microscopic cancerous cells had not been treated. Predictably and inevitably, a tumour returned and was resected by surgery in January 2019. On this occasion, the surgery was performed far from home at Alder Hey Children's Hospital in Liverpool by Professor Conor Mallucci, a consultant paediatric neurosurgeon with a special interest in neuro-oncology. The reason that the surgery took place at Alder Hey, rather than at Addenbrookes, was that Alder Hey possessed, but Addenbrookes currently do not, specialist intra-operative MRI equipment. Professor Mallucci describes this, the second operation, as relatively straightforward. The recurrence was fairly local and well circumscribed, and there was no major invasion of the brain stem at that point. E was by now about five and a half.

- 7 Professor Mallucci says that he understood, or at any rate expected, that E would now have craniospinal radiotherapy at Addenbrookes to prevent recurrence. But she did not.
- 8 By then - early 2019 - if the decision was left to themselves, the treating doctors favoured a course of low-dose craniospinal radiotherapy; but, after all the advantages and disadvantages were explained to the mother, she decided against it. At that time, when E was still only about five and a half, the doctors considered the mother's decision to be one which they would accept and support, although they knew and advised that a tumour would inevitably recur. All were agreed that chemotherapy could not be attempted again.
- 9 An MRI scan in November 2020 confirmed that the tumour had indeed recurred, and on 3 December 2020 Professor Mallucci performed a further surgical resection at Alder Hey. This was the second recurrence and the third operation. As Professor Mallucci would have anticipated, the surgery this time was much more difficult, although there were no major complications. Professor Mallucci says that the tumour was now more extensive and multifocal, and adherent to, and more stuck to, the brain stem. Further, there was, predictably, so much scar tissue from the previous surgeries that it was much more difficult to effect a safe and straightforward operation. Professor Mallucci says that E was fortunate not to have any wound leaks, which become increasingly more likely the more times you operate.
- 10 Professor Mallucci, who gave oral evidence by telephone from Liverpool, has been a consultant paediatric neurosurgeon for 23 years. He is a national reference surgeon and is of international renown in his field. His skills as a surgeon, and his distinction in his field, are not in issue. In his written report dated 7 January 2021, now at bundle page C68, Professor Mallucci said at page C69,

“From my perspective, as a very experienced neuro-oncology surgeon, and I take on a lot of second and third surgeries for recurrences from both local and other centres, I can be very sure that, if this recurs again, surgery will be much higher risk and more likely to cause complications, both in terms of wound breakdown and in terms of chance of getting a clean resection.”

- 11 In his oral evidence, Professor Mallucci elaborated on that. He described how his second operation (E’s third) was much more difficult than his first due to the scar tissue and the tumour being much more stuck to the brain stem. He said that every time you re-operate the tumour will be much more stuck, much more invasive, and much more difficult to remove. He is far less confident that, at the recent operation, he achieved total removal of the tumour, and he would not be surprised at all if some microscopic tissue had been left behind. In his written report he said that it is almost an inevitability that the tumour will recur again if E is not given adjuvant therapy, and in this case craniospinal irradiation. In his oral evidence, he said that it is 99 per cent certain that it will recur without treatment. There is, he said, no chance of her being cured by the last operation alone. In his view, it is “obvious” that she needs radiotherapy. As to a fourth operation if the tumour does recur, Professor Mallucci said in his written report, now at bundle page C69, that

“If and when this tumour recurs again without radiotherapy, then it is almost certain that she will be incurable and the reason for re-operating on a fourth occasion would be predominantly palliative, and a fourth surgery will likely carry much higher complication risk and also will very likely result in incomplete resection due to further and more invasiveness.

In my opinion, E is in the best possible position now to receive the potentially curative craniospinal irradiation that she needs, now that she has just had a surgical clearance. Waiting for the tumour to return a third time, which in

my opinion is an inevitability without adjuvant treatment, puts E's life at unnecessary risk, as this tumour is not curable with surgery alone.”

12 In his oral evidence, Professor Mallucci said that he would be very reluctant to re-operate again and that, if he had to re-operate again, there is no chance of a cure and the procedure would be much more damaging. He did, however, reassure that, if and when a tumour did recur, he would assess E's situation and condition at the time and would be willing to operate if he felt he could benefit E by doing so.

13 The question now urgently arises: should E now undergo a course of low-dose (23.4 Gy) craniospinal radiotherapy or not? Optimally, it should commence about six weeks after the surgery, which elapsed last week, and certainly within two months (i.e. by the end of January 2021, at the very latest). All the treating doctors, both at Addenbrookes and at Alder Hey, feel strongly that E should now undergo low-dose craniospinal radiotherapy. They do not regard it as at all finely balanced now that E is seven and a half, and as she has already had two recurrences. E's mother does not agree or give her consent, so the hospital has, appropriately, applied to the High Court for a best interests decision and declaration.

E's father

14 It is convenient at this point to refer to E's father. The mother and father had a relationship for about a year prior to the birth of E, but he has had no involvement in her life since then. He did visit when she was in hospital for the first surgery in 2016, but she did not want to see him and he has not attempted to see her since. The case is urgent and has come on very quickly, and less attention was given than should have been given to the position of E's father. Paragraph 8 of the skeleton argument on behalf of the mother stated, incorrectly as it turns out, that the father does not have parental responsibility for E. It was only overnight between the first and second days of the hearing last week that I read in an attendance note

by the guardian, which had been supplied to me that day, that the father is named on the birth certificate. This means that, in fact, by statute, he does have parental responsibility for E, so I caused attempts to be made to locate him. I am immensely grateful to the mother's brother, J, who has attended the whole hearing, who managed to track the father down via Facebook, and to the advocate for Cafcass, Ms Melanie Carew, who managed to speak to the father by telephone on Friday, 15 January 2021. Ms Carew has now filed a short statement dated 18 January 2021 (today) describing her call.

15 In short, the father said that he wants everything good for E and wants her to live. He said that he feels that he, himself, could not make a decision, having not seen E since 2016. He also wants to support the mother, but he repeated that he wants E to live, to be able to have a happy life, to go to school and to have fun, and he wants the best for her. Ms Carew gave to the father an opportunity to ring back if he wanted to speak to the judge, but he did not do so.

16 In these circumstances, I am now satisfied that the father, who does have parental responsibility, has been sufficiently, if belatedly, informed of the subsistence of these proceedings and of the essential facts and issue. He has been afforded an opportunity to engage with the court if he wishes to do so. But, understandably in the circumstances, he is not able to make an informed decision himself, and certainly not able to give a formal consent to the treatment. I discharge him from his formal status under the rules as an automatic party to the proceedings, but I hope that Cafcass will ensure that in due course the father is able to read this judgment, if he wishes to do so.

17 I stress that in situations where lifesaving or other serious medical treatment of a child is under consideration (whether in the context of legal proceedings or not), it is extremely important always to establish at an early stage who may have parental responsibility for the child. Careful and express consideration needs to be given to whether all those persons

should be consulted. A parent, usually in this situation a father, should not be overlooked simply on the basis that he or she has “not been involved” in the life of the child.

The medical evidence

- 18 As well as from Professor Mallucci, I have read and heard oral evidence from each of Professor Barry Pizer, a consultant paediatric oncologist and professor of paediatric oncology at Alder Hey; Dr Thankamma Ajithkumar, consultant clinical oncologist at Addenbrookes, who would have oversight and charge of the actual radiotherapy if it took place there; and Dr James Nicholson, a consultant paediatric oncologist at Addenbrookes, who has had overall care of E since she was first admitted in 2016.
- 19 Frankly, all this evidence from doctors of international renown in their field is all one way and all to the same effect. As a result, I made clear at the outset of the hearing that, subject to cross-examination and unless any doctor or the evidence was discredited, I would be bound to accept it on the medical aspects of this case, which are, of course, central to the case. I said that, despite the urgency, I would give sympathetic consideration to any application for an adjournment for up to a week or so to enable the mother to adduce expert evidence of her own, and I gave a short adjournment while this was considered. I was then told that the mother and/or her legal team considered that they would be unlikely to be able to obtain any medical evidence to a contrary effect. It was said that Dr Simon Bailey, professor of paediatric neuro- oncology at Newcastle, is also of great renown in this field, but that the doctors in this case have already discussed this case with him and, it was said (but, of course, I disregard it as any evidence), that he agreed with them. So he could not be approached on behalf of the mother. On behalf of the mother, Ms Nicola Kohn said that they would not seek any adjournment and would address the case on the basis of the medical evidence as it is.

The benefits of radiotherapy

- 20 The available medical evidence is all to the same effect and consistent with that of Professor Mallucci, which I have already recorded in some detail. The doctors all say that it is highly likely, if not certain, that traces of grade 3 medulloblastoma (which is the highest risk type) remain in E's brain. They regard it as a virtual certainty that, without craniospinal radiotherapy, a tumour will recur, probably within about a year, and at most, realistically, within two years. Professor Pizer said that, without radiotherapy, the chances of it not recurring at all are zero and, he said, she will die. Group 3 medulloblastoma cannot be cured by surgery alone. He said that it is very, very likely that the interval before the next relapse will be shorter than last time, and Professor Pizer would be very surprised if she does not relapse within a year. He said that to date she has relapsed locally, but on the second occasion the tumour was much more infiltrative and there is now a significant chance of relapse elsewhere in her brain or spinal cord. If that occurs, it will be much more difficult to treat. If she does relapse metastatically, then significantly higher doses of radiotherapy would then be needed to treat her.
- 21 The overall opinion of Professor Pizer and the other doctors who gave evidence is that if E receives a six-week course of low-dose craniospinal radiotherapy now, there is a 50 per cent chance of a cure. That is, that the cancer will be eradicated and cured, and will not recur. She would then have a normal life expectancy. Of course, a cynic might regard a 50-50 prognosis as simply sitting on the fence or hedging one's bets, so that, whichever way it went, the doctors' opinions could not appear to have been wrong. But I am not entitled to cynicism and I must and do regard the medical evidence as being just that: if E undergoes radiotherapy, she has a 50 per cent prospect of complete cure and a normal life expectancy; although a 50 per cent prospect, also, that it will not eradicate the cancer and that it will recur. However, Dr Nicholson made the very important point that, if E does undergo

radiotherapy and even if it does not effect a lasting cure, it is still likely to confer some benefit and to extend her life by an additional two years or more to her life expectancy if she does not have radiotherapy at all. It happened that Dr Nicholson gave his oral evidence last, and this particular aspect had not been directly raised with the other witnesses, but I accept what Dr Nicholson said.

22 All the doctors are clear that if she does not undergo radiotherapy at all, E is likely to be dead within two years. It is possible, but unlikely, that when, inevitably, a tumour recurs if she does not have radiotherapy, it will once again be localised and capable of complete resection, followed by successful radiotherapy then, when E would be older. But Dr Nicholson described such a scenario as a gamble.

23 The benefit of radiotherapy is, therefore, clear. At best, there is a 50 per cent prospect of a complete cure and a normal life expectancy. Even failing that, it might add an additional two years to her life span. If she does not receive radiotherapy, she is likely to be dead within two years. There is, according to Dr Nicholson, the possibility that, even if she receives no radiotherapy now, a recurrence might still be localised and she could have a fourth operation followed by radiotherapy then. But that is, said Dr Nicholson, “a gamble”, and the evidence of Professor Mallucci stressed how difficult it would be likely to be successfully to operate a fourth time.

The burden or disadvantages of radiotherapy

24 There is no doubt that craniospinal radiotherapy does have both short-term and long-term side effects and that it causes permanent and significant damage. There is a long list of these side effects in a radiotherapy information sheet on radiotherapy treatment of medulloblastoma published by the Children’s Cancer Leukaemia Group (version 4, March 2017, next review date October 2022) now at bundle pages C8 and C9. The information

sheet is too long to reproduce here, but it is available online to anyone who wishes to read it.

It is worth noting that the information sheet begins “We *always* give radiation treatment (radiotherapy) after surgery or chemotherapy for medulloblastoma because the disease *always* comes back if we do not.” (my emphasis)

25 Short-term side effects include loss of hair, vomiting, and up to two to six weeks of tiredness and lethargy about four to six weeks after the treatment ends. As Ms Kohn points out, that posits lethargy for as long as 18 or 20 weeks after the start of the radiotherapy, so that if in the end, and despite radiotherapy, E only survived for a year, much of that year would have been blighted by, first, the radiotherapy and then the lethargy. The information sheet states that these side effects “usually settle down within six to nine months”. The long-term side effects may also be very significant and are permanent. Long-term side effects may include heart damage, strokes, cataracts (very treatable), damaged fertility, and early onset puberty. Growth in height may be permanently reduced by several inches.

26 Arguably most worryingly, IQ and intellectual and cognitive development may be permanently impaired by the damage to the brain. Professor Pizer said that this neuro-psychological damage is certain and definite, but variable in its extent. At the age of seven and a half, he said there is no doubt that there would be a permanent effect on IQ. The best estimate he can give is a loss of about 20 IQ points, which I regard as serious and significant. But he stressed that he would expect E still to be able to attend a mainstream school, to be able to have a job, and to live an independent life. In this regard it should be noted that the minutes of the best interests meeting held on 8 March 2019, now at bundle pages F118 to 121, refer at page F120 to “certainty of long-term neuro-cognitive deficits, such that it is unlikely that E would achieve independence as an adult.” That and the surrounding passage, however, was all addressing possible radiotherapy when E was aged five and a half, not seven and a half. That was indeed part of the reasoning why the doctors

accepted and supported the decision of the mother at that time. However, Dr Nicholson said that there is “a massive difference” between radiotherapy at the age of five and at the age of seven.

27 There is, therefore, the severe disadvantage, which I do not in the least underestimate, that craniospinal radiotherapy at the age of seven and a half will, knowingly, cause significant permanent damage to E, including, but not limited to, her intellectual and cognitive functioning, as well as the shorter-term side effects I have described. More transiently, the process itself may be distressing or upsetting and uncomfortable, although not actually painful, for the child, who has to be kept very still with a face mask fitted for about 20 minutes, although the actual radiation (itself painless) is for a much shorter time. It requires to be done daily five days a week for six weeks.

The fears of the mother

28 The mother is an intelligent and articulate person who has, of course, become very well informed about E’s condition and treatments. The mother’s first language is not English, and during the hearing an interpreter was used. However, the mother does have a reasonable grasp and use of English, and during her oral evidence she was able, most of the time, to communicate with me directly in English with no misunderstandings. She is a very loving mother who, with the support of her own family, has cared for E with the utmost attention and devotion ever since this terrible disease first appeared over four years ago.

29 There is no doubt that the whole terrible experience of the chemotherapy has coloured and influenced the mother’s views ever since. The mother rightly says that she was given no warning as to the catastrophic consequences which occurred and that even now the doctors, frankly, cannot explain them. Therefore, it is very understandable indeed that one of her fears - and indeed she said her greatest fear - is that, if E now undergoes radiotherapy, there

may be a similar adverse and catastrophic reaction. The mother said during her moving, but entirely measured, oral evidence that she is most worried that E's reaction to radiotherapy will be like her reaction to chemotherapy. She said that she is not so worried about hair loss, vomiting or lethargy. What really worries her is a very severe adverse reaction like last time, such as a coma or even dying. She said that she wants to trust the doctors, but she cannot because of what happened last time. She said that she is less concerned about the predicted long-term impact on E's intellectual functioning. It is about what happens now that she is most worried.

30 Insofar as the mother fears a severe and immediate reaction to radiotherapy, I perfectly understand her fears; but, on the basis of the medical evidence, I cannot accept that they are objectively well founded. Professor Pizer said that there is virtually no chance of E dying as a result of radiotherapy. There is a small risk of developing a tumour from the radiation, but such secondary tumours, if they occur at all, are late consequences, sometimes many years later. Any risk of dying as a result of the treatment is very small compared with the risk from her untreated tumour.

31 The mother expressed the fear that E might, as a result of radiotherapy, become a "vegetable". Her counsel apologised for the use of that unkind word, but it is expressive. Professor Pizer said that the chances of her becoming a vegetable were minimal, and he had never seen or heard of it in 35 years of specialising in this field.

32 Professor Pizer and the other doctors all stress that targeted radiotherapy is a completely different process from chemotherapy, which infuses the whole blood stream, and that there is simply no medical linkage at all between what happened after the chemotherapy and the proposed radiotherapy. Dr Nicholson said that it was like comparing apples and oranges. They are completely different.

33 Obviously, there is always the theoretical possibility of some catastrophe, such as a malfunction of the equipment and an accidental or inadvertent overdose, but I have to decide this case on the basis that the sort of repeat catastrophe that the mother fears of E becoming a vegetable simply will not occur

The mother's other concerns

34 There is, however, another and quite separate basis for the mother's resistance to radiotherapy. She feels that the 50-50 prognosis of cure is simply not high enough to justify subjecting E to further invasive and damaging treatment, and returning her day in and day out for six weeks to hospital, which, very understandably, E now dislikes, and subjecting her to such discomforts as having to wear the mask. The mother said that the third surgery had a lot of impact on E emotionally. E told her mother recently that she wants a healthy lifestyle so that she does not have to go back to hospital. The mother said that E will react very badly to a mask and will start moving around and crying. She said that E does not understand the seriousness of her condition and thinks she has, or has had, a lump in the back of her head and that she needs to eat healthy foods and to try not to get colds. The mother said, as her considered position, that, if E only has two years to live, she wants her to live those two years as a normal life with her, the mother. She said "As a mum, I would rather she lived the life that is left for her and fully enjoying it. No pain and no suffering. Live it to the full." The mother further said that, "It is very hard for me to see her going through all the suffering and ill effects and maybe still die."

35 During his own oral evidence, Dr Nicholson commented that for some parents it is cure at all costs. E's mother has been very focused on the quality of life. It is, Dr Nicholson said, a very brave decision by the mother.

36 Nothing could be more human and understandable than the mother's position, and I have tried very hard throughout the hearing to empathise and sympathise with the mother. But her answers which I have just quoted verbatim, do convey that, very understandably indeed, the mother is influenced, in part, by the pain for her, the mother, of seeing E undergo further treatment which may - 50-50 - prove to have been in vain. The duty of the court is to focus solely upon the best interests of E, giving full weight to the views and opinions of her mother, who knows her best and loves her the most, but not to her own subjective wishes.

The law

37 This case does not raise any new or unusual issue of law, and there is no dispute as to the relevant law. Often in these sad and difficult cases concerning terminally-ill children, it is the doctors who wish to withdraw or withhold a treatment which they consider to be unjustified or futile, and the parent or parents who wish to cling onto any prospect of survival or the prolongation of life. In other cases, of which this is one, it is the doctors who wish to embark upon the treatment, and the parent or parents who, often for very good and well-articulated reasons, do not consent.

38 I myself decided two very well-known and often cited cases on either of that divide. The first was *An NHS Trust v. MB* [2006] EWHC 507 (Fam.); the second was *The NHS Trust v. A* [2007] EWHC 1696 (Fam.). At paragraph 40 of my judgment in *A*, I explained that the approach of the law is the same whether it is the doctor or the parents who wish or do not wish to give the treatment involved. In *MB* I set out ten propositions of law which I repeated at paragraph 40 of my judgment in *A*.

39 Mr Vikram Sachdeva QC, who appears on behalf of the NHS Trust in the present case and who specialises in this field, said that those ten propositions remain the classic formulation

and are still cited daily. Although the nature of the disease and the treatment in point is quite different in the present case from that in *A*, the essential context of the decision facing me in the present case is very similar to that in *A*. For that reason, I incorporate by reference into the present judgment paragraphs 40 and 42-44 of my judgment in *A* (I omit paragraph 41 since consideration of religion has not featured in the evidence in the present case). Paragraph 42 contains the quotation from the judgment of Waite LJ in *Re T (Wardship: Medical Treatment)* which Ms Kohn rightly emphasised and relied upon. She submitted that the present case is at the end of the scale of a “highly problematic case where there is genuine scope for a difference of view between parent and judge”, as described by Waite LJ, and, accordingly, that

“...in the last analysis the best interests of every child include an expectation that difficult decisions affecting the length and quality of life will be taken for it by the parent to whom its care has been entrusted by nature.”

40 It remains the case, however, that once the jurisdiction of the court has been invoked, it is the role and duty of the court to exercise its own independent and objective judgment, applying the test of the best interests of the child.

41 In recent years, there has been a practice in these cases of one or more advocates drawing up a so-called balance sheet of benefits or advantages balanced against burdens, disbenefits or disadvantages. I have myself sometimes reproduced such balance sheets in judgments of my own in other cases. In the present case, Ms Melanie Carew of Cafcass, on behalf of the guardian, attached such a balance sheet to her final submissions. I was very grateful to Ms Carew and I will attach a copy of her balance sheet as an appendix to this judgment when it is transcribed and published. But I do caution against over reliance upon a balance sheet approach. A true accountancy balance sheet is based upon precise and arithmetical figures

or values, even if some are estimates. However, as Lord Donaldson of Lynton said long ago, it is impossible in cases such as this to weigh all the considerations mathematically. It is impossible to place an arithmetical or numerative value upon the continuation of a child's life, nor upon any inevitable pain and suffering, nor upon a side effect such as some loss of IQ.

The position of the guardian

42 A Cafcass guardian, Ms Emma Huntington, was appointed to represent the best interests of E. In the short time available, she investigated this case as fully as she could and had, in particular, a long meeting with the mother on 11 January 2021, assisted by an interpreter. Ms Huntington also spoke at some length with some of the treating doctors. She made a decision, with which I agree, not to seek to obtain independent expert evidence of her own as to the medical aspects of the case. Time was short. Any alternative expert of matching expertise to the doctors engaged in this case would be hard to find within the United Kingdom. The medical evidence is, in any event, clear, and already comes from no less than four doctors, not all based in the same hospital or institution. There is no report as such from the guardian, but, by her very careful position statement dated 12 January 2021, before the outset of the hearing, Ms Carew described that the guardian firmly supports that E undergoes the proposed radiotherapy. She said, in summary, at paragraph 25 of the position statement that:

“Taking into account all the evidence submitted and the lengthy discussions that she has had with E's mother and paternal grandmother and the information that she has been provided with, the guardian considers that the treatment proposed in the form of the six-week radiotherapy is in E's best interests as the alternatives are likely to be catastrophic for her and the

medical evidence is that this is her only chance of survival in the longer term. The guardian has come to this conclusion understanding that there are no guarantees as to whether the treatment will be successful in curing E; the doctors have offered only a 50 per cent chance of a cure, but far less without the treatment. The guardian also noted the evidence reflects that this proposed treatment is the standard, universal treatment for children of E's age with this diagnosis. Around 80 children in the UK per year would receive this proposed treatment. But once beyond three to five years of age, craniospinal radiotherapy is the standard of care universally throughout the world."

43 At the conclusion of the hearing and all the oral evidence, that remained the guardian's opinion and submission.

Analysis and outcome

44 During the course of her cogent and sensitive final submissions, Ms Kohn suggested that, if I make a declaration that craniospinal radiotherapy is in E's best interests, I would merely be "tossing a coin". Later she referred to a roll of the dice. I appreciate that the reference to tossing a coin is founded upon the 50-50 prospect of a cure, since there is a 50-50 chance that a tossed coin will fall with one side or the other facing up. But the analogy is not appropriate. I most certainly and emphatically am not tossing a coin nor rolling a dice, nor are the doctors. The best estimate of survival and cure that the doctors can give in this case happens to be 50-50, but that fact is only one of the many factors in the case, all of which have to be weighed. Ms Kohn also suggested at one stage during the course of the evidence that an adult might decide not to undergo invasive, and potentially damaging, treatment on a 50-50 prospect of cure. That may be so, but the situation of a person who may already have lived a relatively long and fulfilled life is not analogous with that of a young child still on the threshold of life.

45 I have to take a very person-specific decision, considering the overall best interests of E and E alone. As Baroness Hale of Richmond said in the case of *Aintree University Hospitals NHS Foundation Trust v. James* [2013] UKSC 67 at paragraph 39

“... decision makers must look at [a person’s] welfare in the widest sense, not just medical and 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 to the treatment is or would be likely to be; and they must consult others who are looking after him or interested in his welfare, in particular for their view of what his attitude would be.”

46 Although a 50 per cent prospect of a cure sounds frighteningly low, it is still a very real prospect. This child still has a very real prospect of a cure and a normal life expectancy if she undergoes the low-dose radiotherapy now. Even if she is not cured, there is, on the evidence of Dr Nicholson, the prospect of adding, perhaps, two additional years to her life, which at her age is an appreciable addition to her overall life span. In my view, that prospect does clearly outweigh all the predictable disadvantages and side effects of the proposed treatment. It must surely be worth some weeks or months of upset and distress, sickness, hair loss and lethargy now, to gain the prize of a lasting cure.

47 Although it weighed less with the mother, I have been very concerned about the very high likelihood of permanent neuro-psychological damage impacting forever E’s intelligence and cognitive functioning. It is a grave and terrible thing knowingly to inflict upon a child a

procedure which will permanently damage her very intelligence and intellectual functioning. But, as Professor Pizer stressed, she should still be able to attend mainstream school, obtain and hold down a job, and live an independent life. There may be some very loose analogy with inflicting permanent physical damage. For instance, a child may be suffering a form of cancer or gangrene, such that amputation of his or her legs is essential in order to save his or her life. Few would hesitate if the alternative was death. In the same way, it does, after due deliberation, seem to me acceptable and justifiable in the overall best interests of E to take a course which almost certainly will damage her neuro-psychological functioning, when the inevitable alternative (apart from Dr Nicholson's "gamble") is death. It does seem to me that a life with impaired intellectual functioning is preferable to, and better than, no life at all.

48 In reaching these conclusions, I take into account both the view and position of the guardian, and also the fact (as I was told, and as indeed the radiotherapy information sheet bears out) that certainly by the age of seven and a half, if not earlier, craniospinal radiotherapy is the standard universal treatment worldwide for medulloblastoma after surgical resection. The proposed treatment is not experimental. It is now orthodox, and standard, even although the absolute numbers so treated every year are small. Professor Pizer said, at the end of his written report dated 6 January 2021, now at bundle page C65,

“... delivery of craniospinal radiotherapy for medulloblastoma to a seven-year old child is a globally-accepted standard of care and, as above, represents her only chance of a cure ... Advocating on behalf of E herself, I would strongly recommend to the court that E has craniospinal radiotherapy as a potentially curative treatment.”

49 I hope that during the course of this hearing, as well as in this judgment, I have demonstrated my concern for the views and opinion of the mother, which I have very carefully considered and to which I do attach great weight. However, as I have explained, they have been understandably influenced by the reaction to the chemotherapy; but, as I have also explained, there is, objectively, no medical link between chemotherapy and radiotherapy. Further, the mother is influenced by her opinion stated in the last sentence of her written statement dated 12 January 2021 that “the reason why the majority of people are dying is not from cancer but the treatment itself and the side effects of the treatment.” I cannot accept that proposition.

50 The mother now has some faith in various alternative therapies, which were briefly discussed during the oral evidence. Some amount to no more than living a healthy lifestyle and eating a healthy diet, which is of course very commendable for any child. Others are more bizarre, such as drinking bicarbonate of soda mixed with vinegar, or administering coffee enemas. All the doctors were very clear that none of these alternative remedies or therapies could cure the cancer, although some represent a healthy lifestyle and are to be encouraged.

51 The human instinct to survive is in most people strong. In my view, it is likely that, if E had a full and adult capacity to consider and weigh all the medical evidence, as well as her own personal circumstances, she would herself grasp the prospect of living a full life which the proposed low-dose radiotherapy offers. I will, accordingly, declare, in the terms of the draft order, that “It is in E’s best interests to undergo low-dose craniospinal radiotherapy.”

Venue for treatment

52 The mother has lost confidence in the treating team at Addenbrookes. She has, in fact, made some trenchant criticisms of Dr Nicholson in particular, in her written statement. This hearing is correctly focused upon future treatment, not upon a trawl over whether there have been any past errors. The mother's criticisms were rightly not explored in oral evidence with either the mother or Dr Nicholson. Accordingly, I neither accept them nor dismiss them. I say nothing at all about them. Addenbrookes accept, however, that, if the radiotherapy is to proceed, it is very important that the mother (who has clearly said that she will co-operate with it) should feel as comfortable as possible with the setting and with the clinical staff. It was established during the hearing that the Queen Elizabeth Hospital in Birmingham is, in principle, willing and able to provide the required low-dose craniospinal radiotherapy, and the mother has expressed a preference that it should take place there. The doctors in Birmingham have not, however, had any opportunity yet to study all the medical records nor to examine or to assess E. Accordingly, they cannot yet provide a treatment plan. For that reason, the terms of my order will be very general, as I have just read out, and a declaration in principle only. I hope and expect that the more precise details of the treatment can now be agreed, consensually, between the doctors at the Queen Elizabeth Hospital in Birmingham and the mother. If, as I hope not, any further court ruling or declaration is required, it may be applied for on very short notice to me.

Last words

53 I cannot conclude this judgment without expressing my sincere thanks to Mr Sachdeva, Ms Kohn and Ms Carew for their very thorough and sensitive approach to this case and for the considerable help that they have all given me. But my last words are to E and her mother. Although I have reached a different decision from that of the mother, I have the utmost

respect for her and the utmost sympathy for the further ordeal which she, as well as E, must now face. My heart goes out to her. I know that the prospect of a cure is only 50-50, but my fervent hope is that E will be fortunate and will survive and thrive, and live a long, happy and fulfilling life. She will remain deeply in my thoughts.

Ms Carew's balance sheet

BENEFITS	BURDENS
<p>It is almost certain that there will be cancer cells which are undetectable on MRI scans which remain in E's brain despite the clean scan following surgery. Scans will not pick up cells until there are 400 million and no tests will detect all cells [Dr Ajithkumar]</p> <p>“It is almost an inevitability that the tumour will recur if she is not given appropriate adjuvant therapy”[Mr Mallucci C69]</p> <p>Further surgery to address a recurrence of the tumour would be palliative [Mr Mallucci evidence]</p> <p>“Based on everything I know about the disease she will definitely relapse “ “ Absolutely certain in my mind” “ clear in my mind that there is disease in E's head[Prof Pizer evidence]</p> <p>Radiotherapy (RT) will offer E a 50% chance of a recovery with no recurrence of tumour and the prospect of a normal life expectancy and the “potential to lead a happy and healthy life” [Prof Pizer evidence]</p> <p>Not to proceed with radiotherapy would convert a respectable chance of a cure with likely tolerable long term toxicity into a near certainty that E will die of her disease. [Dr Nicolson C40]</p> <p>Despite acknowledged side effects there is no chance of a patient dying during the treatment [Dr Ajithkumar evidence] “ the risk of dying from the treatment is extremely small [Prof Pizer evidence] and there's no evidence to support a link between a response to</p>	<p>E herself is very anxious about attending hospital [mother's evidence]</p> <p>E herself may not want to have the therapy and will be distressed by the procedure [mother's evidence]</p> <p>E may not be able to co operate with the treatment in terms of lying still and may have to be given general anaesthetic on a daily basis [guardians discussion with the doctors]</p> <p>E will have to spend some weeks away from home attending hospital without going to school (if it were to open)</p>

<p>chemotherapy and radiotherapy [Prof Pizer evidence]</p> <p>Delay in offering RT and waiting for further recurrence of the tumour and responding at that point would mean further surgery which would be more difficult and involve greater risk to E.[Mr Mallucci evidence] and a higher dose of radiotherapy to have a chance of a cure [Dr Nicolson] There is a risk that any recurrence may not be localised “ the majority of medullablastoma relapse metastatically” and therefore need higher doses of radiotherapy. Delay in offering RT carries number of other risks from surgery: neurological risks, poor wound healing, infection, and a high dose of RT with commensurate side effects. [Prof Pizer]</p> <p>RT is the only chance of a cure [Prof Pizer c 64]</p> <p>Chance of a cure to become disease free is 50% [C64]</p> <p>Following RT there is also a 50% chance of the tumour returning and the treatment not offering a complete cure but would provide respite and expected that E would not relapse for at least 2 years and likely for a period up to 5 years with each year reducing the likelihood of a recurrence [Dr Nicolson]</p> <p>Without the RT she will certainly relapse and is not likely to survive more than 2 years [Dr Nicolson]</p>	<p>There are side effects to the RT; immediate short term and long term [C8]</p> <p>During the treatment E will lose her hair, and may feel sick and have a sore throat. These are side effects which are uncomfortable rather than painful but need to be managed with further drugs.</p> <p>Some patients experience swelling of the brain which is treated with steroids</p> <p>Dr Ajithkumar’s evidence was that these side effects would last no longer than 6 weeks.</p> <p>Short term side effects include lethargy, headaches and sickness. Managed with support [Dr Arithkumar C5]</p> <p>Some children develop low blood counts which means that the second phase of treatment is started until the blood count increases [Dr Arithkumar c4]</p> <p>Long term side effects which are difficult to predict [C5] but the treatment will “be undoubtedly accompanied by some late effects”[Prof Pizer C65]</p> <p>Side effects likely to include a reduction in IQ of about 20 points, problems with short term memory, but within a range of impact and E should be able to attend mainstream school and be independent in the future. But no certainty [Prof Pizer]</p> <p>Unanimity in medical evidence that E will suffer some damage to her learning ability</p> <p>Potential side effects in decades to come which are hard to predict including growth restriction, development, heart problems, impact on pituitary gland and potential impact on puberty [C9]</p> <p>No absolute guarantee that there will not be a catastrophic response to radiotherapy despite risk extremely low [Prof Pizer] and Dr Ajitkumar not having seen such a response.</p>
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CERTIFICATE

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