Neutral Citation Number: [2019] EWCOP 12

Case No: COP 13216755

IN THE COURT OF PROTECTION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 29/03/2019

Before :

THE HONOURABLE MR JUSTICE HAYDEN
VICE PRESIDENT OF THE COURT OF PROTECTION

- -

Between :

HOUNSLOW CLINICAL COMMISSIONING GROUP	**Applicant**
- and -	
RW	**1st Respondent**
(by his litigation friend, the Official Solicitor)	
- and –	
PT	**2nd Respondent**
- and –	
PW	**3rd Respondent**
- and –	
MW	**4th Respondent**
- and –	
BW	**5th Respondent**

- -
- -

Ms Katie Scott (instructed by Capsticks) for the Applicant
Ms Emma Sutton (instructed by the Official Solicitor) for the 1st Respondent
PT (2nd Respondent) acting in person.

Hearing date: 29 March 2019

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Approved Judgment

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

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THE HONOURABLE MR JUSTICE HAYDEN

This judgment was delivered in open court.

The Honourable Mr Justice Hayden :

1. This is an application brought by the Hounslow Clinical Commissioning Group concerning RW a 78-year-old man, suffering from vascular dementia. On any view he is at the end stage of this remorseless condition. RW was able to live in his own home for much longer than had been contemplated. There were, no doubt, many reasons for this but two emerge distinctly. Firstly, he has a will of steel, as the evidence has demonstrated both at this hearing and at the hearing twelve months ago before Parker J.

2. I am satisfied that RW has fought to live. He has wanted to be at home and his vigour and indominable spirit has contradicted the expectation of the doctors who gave evidence before Parker J in April 2018. At that hearing a dispute had arisen as to whether it was in RW's best interest to continue to receive Clinically Assisted Nutrition and Hydration (CANH), via a naso-gastric tube (NG tube). Parker J concluded that it was not in his best interest and made a declaration to that effect. An appeal against her decision was unsuccessful (see **Re: RW [2018] EWCA Civ 1067**). I doubt any of the professionals involved in that hearing would have envisaged a hearing at the end of March 2019 with RW still alive. RW is represented today by the Official Solicitor. No transcript was prepared in relation to Parker J's judgment. As is my practice when an ex-tempore judgment is required, I have asked counsel to make an agreed note, refined it in accordance with the principles in, **Piglowska v Piglowski [1999] UKHL 27** and approved it in order that it can be placed in the public domain with reasonable expedition.

3. The second reason that RW has been able to live as long as he has at his home is due to the love, care, sensitivity, and commitment of his family, his boys, but chiefly PT (his youngest son). In this court room, this afternoon, PT has brought his father's personality into the hearing. This has included not only RW's strengths but his weaknesses too. As RW declined in his capacity to cope with life independently, his son PT, at every stage, rose to the new challenge. That deterioration I have no doubt would have been slow and inexorable, but it is obvious that there are landmarks within the process.

4. PT told me with absolute clarity of recall about an occasion, now years ago, when it dawned upon him suddenly and clearly, that his father had not been eating. He remembers it because it called for a shift in the pattern of care RW required. PT had regularly been bringing his father food, which he left in the fridge for him but he told me how, one afternoon, he arrived and discovered the fridge was still full. He was concerned that his father had been confused and had been trying to eat food directly from the freezer.

5. Thereafter PT not only brought the food but prepared it and ensured his father ate it whilst he was there. It sticks in his mind, no doubt for many reasons, but I suspect it was a day that had an impact on PT's own life. It is clear that he recognised that he would have to be significantly more involved in his father's day to day care. As PW (another brother) has said, PT shares many of the characteristics of his father. PW, with some sensitivity, in communicating the similarity of their character profiles was

able to communicate that both men are strong minded, uncompromising, dogged and very determined. I have certainly seen those characteristics in PT during the hearing. I pause for a moment to record that as PT was telling me about his father, his approach to life and his personality generally, he illustrated an occasion when, at the early stages of his dementia, he had taken him on holiday to Israel. This had been a country that RW very much wanted to see and it was obvious, as PT recounted the story, that he recognised that time was limited. He described how one afternoon, swimming in the Dead sea, his father swam too far out, rather dangerously and against the protestation of the life guard. Both brothers laughed together, in court, as PT related this story, particularly when PT said it was the sort of thing their father would do even before the dementia. That was the way he was.

6. As is plain from the judgment of the Court of Appeal, Parker J had identified RW as *'a fighter'*. I agree. So too is PT. He has been absolutely determined to keep his father alive. RW survives today because of this coalition of willpower.

7. There is voluminous evidence that at home, RW was cared for, practically, in a way which is entirely redundant of any criticism. Though carers were going in to the home every day, the reality is that PT has cared for his father almost single handedly for many months. He has been kept comfortable, clean, kempt and well cared for. His dressings were changed by PT, he was turned by PT, he was washed and cleaned by PT and no task has been too onerous or too intimate. Every act of care has been an act of love and requires to be identified as such.

8. But what is clear is that PT has strenuously objected to a regime that he regarded as slowly starving his father to death. This he sees to be the reality of the earlier court orders. For PT the preservation of his father's life is a moral obligation. It matters not, to him, that his father's condition is futile nor that the preservation of it may merely serve to continue pain. Since RW returned home to his son's care without any means of artificial nutrition or hydration PT has provided these by any means he could. He prepares small syringes of water, moist trifles, soft custard tarts which he considers his father enjoys. His objective is to keep his father alive.

9. But none of this occludes the simple fact of RW's condition. He is in end stage vascular dementia. Throughout May of last year, it is noticeable that the range of professionals admitted to RW's home, gradually began to fall away. This occurred entirely because in his stress, anxiety, and driven by his fear for his father's survival PT was aware that the situation was becoming very difficult to manage. PT can undoubtedly be extremely intimidating to those who have not had, or taken the time to try and understand the man he is.

10. The carers found him difficult, the nurses found him aggressive. Eventually, the nurses declined to attend and the GP eventually took RW off his register. At some time, I'm not entirely clear when, RW put on a cycle helmet with a fitted camera, videoing his interactions with the professionals who visited the home. He did so because he had become hostile and litigious in his mindset. On some intellectual level, for he is a bright man, PT knows how he comes across to people. He is not able to do anything about his behaviour. In my assessment he has some insight into it but has done nothing to tackle it. It is triggered by anxiety and panic. It also requires to be said that it has never resulted in any incident of physical aggression, nor does PT have any record for violent offending.

11. Concerns continued throughout May and are catalogued in the report of MW, the director of Joint Commissioning at the Clinical Commissioning Group (CCG). They relate to the catheter; the obtaining of catheter bags and they reflect PT's increasing loss of patience in the care given by the care agencies. Matters came to a head, eventually, as inevitably they were bound to, when on 30th June 2018, the family called the out of hours doctors to report that RW's lower leg had become very discoloured and was deteriorating. PT told me about this, in detail, in his evidence. I should record that he often speaks with remarkable and occasionally quite alarming candour.

12. I am not sure, but I suspect it is PT who called the out of hours' doctor. PT told me, in evidence, that he was concerned by the striking change in the appearance of his father's leg. It had become swollen and discoloured. He told me that he realised he had not been doing the right thing. Faced with this realisation and notwithstanding his complete resistance to engaging with medical services PT was able to suppress his anxieties and to call the ambulance. This is significant, it illustrates PT's capacity, at the moment of crisis, to put his father's needs above his own fear. It reveals the substance of who he is behind the loud and intimidating behaviour.

13. Characteristically, he was angry and voluble in the way he behaved. I look at what he did and not the manner in which he did it. Following the admission to hospital, RW was returned home and PT resumed caring for him. I should record that on 11 July, Dr C who is the palliative care consultant noted the condition of RW's left leg. She described the lower half as 'ischemic' to the extent that it had become demarcated. There did not appear to be wide systemic effect, nor did there seem to be superadded infection to the limb that was being devitalised. In layman's terms it was dying. Arrangements were made to provide dressings and somebody (he cannot remember who) told PT that the application of Manuka honey to the leg would be productive.

14. On 30th November, Dr P, RW's GP, attended the home. He noted that RW looked comfortable and clean and saw no signs of neglect. Though he was not responsive the GP noted that RW looked at him when he was spoken to. The district nurses were plainly unhappy to prescribe dressings when they were not being allowed to attend to the condition. The GP noted that PT was using actilite dressings on the top of the lower leg where there was exudate and duoderm signal or extra thin dressings elsewhere. RW needed more dressings. The GP noted that PT was using oposite flexifix as a water proof dressing to protect the wounds. Again, I note and emphasis that PT drew to the GP's attention that his father's leg was getting progressively worse. He had placed a cushion appliance between the legs in an attempt to prevent further pressure sores. It is sad to note that the next entry in the records is PT enquiring whether Manuka honey could be available on prescription.

15. Manifestly, matters were deteriorating from January of this year. It is, I think, detectable that PT became more stressed, louder and, it has to be said, verbally abusive to the carers. There was concern that he had inserted an NG tube, but having listened to Dr I today, who examined the nose, I conclude that did not occur. There was no attrition to the nasal passages and no evidence of supporting plasters having been used. That it was thought that PT had been applying an NG tube is, I find, a reflection of the tension, confusion and mistrust that had developed and it has to be said, generated by PT's behaviour.

16. Gradually it became clear that management of RW's condition at home was becoming increasingly unviable. The pressure ulcers were significant, it was almost impossible to manage and monitor the catheter care and there was ongoing anxiety regarding the necrotic leg.

17. On 23rd January 2019 the CCG held a meeting and concluded that it would seek legal advice with a view to bringing the matter before the court. There then followed a period of significant and wholly unacceptable delay. Delay in bringing proceedings is far too common. It is entirely unacceptable and it is not to be tolerated. Delay is itself entirely inconsistent with the obligation on the CCG to protect RW's welfare interests. Urgent decisions need to be made today because RW's circumstances are so profoundly grave. I do not have the time to investigate the reasons for the delay in bringing this matter to court but I can say that there can be no justifiable reason for it.

18. In due course the application came before Mrs Justice Knowles on 22nd March this year. The judge asked a number of important questions, but it was clear that she was primarily concerned about the necrosis of the leg. To her direct question (as I understand it) PT responded that about 10 days ago *'the leg detached completely'* when he was turning his father. This was, to say the least, disturbing and shocking evidence. I have never heard of a situation like this and I sensed the doctors were equally alarmed. When I asked PT about it today, I was concerned that nobody had been able to identify where the leg is. PT told me he had wrapped it in cling film and put it in the freezer.

19. When she discovered this, it is not surprising that Knowles J decided that RW should be removed to hospital immediately. Having had the opportunity of listening to PT at some length this afternoon I am sure that he believes that what he is doing is the right thing. He told me that he had strong views as to which hospital should be selected and he was able to choose the St Peters Hospital Trust in Chertsey. Since the order was made by Knowles J, RW has been assessed. PW has been able to assist in providing the history. He told the hospital that he had been looking after his father at home and that he had been feeding him small teaspoons of yoghurt, soup and jelly, and as I referred to earlier, regular syringes of water. He told them how he had changed the catheter himself three months ago and was entirely clear regarding the treatment he had been providing to his father's leg, and how he responded when the lower leg separated. There was no spreading of any infection from the detached left leg to the rest of the body, it had been regularly coated in Manuka honey and dressed by PT. It appears to have been entirely effective.

20. Even at this latest admission, the doctors comment on how well kept RW is. How looked after he is. But it is impossible to ignore the deterioration in him. The muscle loss has been significant, he is extremely frail, he is (despite the best efforts of his son) very malnourished. He has a number of pressure ulcers (six), one of them unstageable, likely stage 4. His position is truly parlous. A number of doctors have examined him who specialise in palliative care. He has been seen by Dr D (a palliative care consultant), Dr A (a vascular surgeon) and of course he has been seen by Dr I who is a consultant in respiratory and general internal medicine. Each of them is clear that RW has reached the very end of his life.

21. Though it is always extremely challenging to apply, the framework of the applicable law is uncontroversial. Mental Capacity Act 2005 Sec 4 sets out a non-exhaustive

'checklist' of factors which must be considered when determining the best interests of a person who lacks capacity. It provides:

> *"(1) In determining for the purposes of this Act what is in a person's best interests, the person making the determination must not make it merely on the basis of –*
>
> *(a) the person's age or appearance, or*
>
> *(b) a condition of his, or an aspect of his behaviour, which might lead others to make unjustified assumptions about what might be in his best interests.*
>
> *(2) The person making the determination must consider all the relevant circumstances and, in particular, take the following steps.*
>
> *(3) He must consider –*
>
> *(a) whether it is likely that the person will at some time have capacity in relation to the matter in question, and*
>
> *(b) if it appears likely that he will, when that is likely to be.*
>
> *(4) He must, so far as reasonably practicable, permit and encourage the person to participate, or to improve his ability to participate, as fully as possible in any act done for him and any decision affecting him.*
>
> *(5) Where the determination relates to life-sustaining treatment he must not, in considering whether the treatment is in the best interests of the person concerned, be motivated by a desire to bring about his death.*
>
> *(6) He must consider, so far as is reasonably ascertainable –*
>
> *(a) the person's past and present wishes and feelings (and, in particular, any relevant written statement made by him when he had capacity),*
>
> *(b) the beliefs and values that would be likely to influence his decision if he had capacity, and*
>
> *(c) the other factors that he would be likely to consider if he were able to do so.*
>
> *(7) He must take into account, if it is practicable and appropriate to consult them, the views of –*
>
> *(a) anyone named by the person as someone to be consulted on the matter in question or on matters of that kind,*

> *(b) anyone engaged in caring for the person or interested in his welfare,*
>
> *(c) anyone of a lasting power of attorney granted by the person, and*
>
> *(d) any deputy appointed for the person by the court,*
> *as to what would be in the person's best interests and, in particular, as to the matters mentioned in subsection (6).*
>
> *(8) The duties imposed by subsections (1) to (7) also apply in relation to the exercise of any powers which –*
>
> *(a) are exercisable under a lasting power of attorney, or*
>
> *(b) are exercisable by a person under this Act where he reasonably believes that another person lacks capacity.*
>
> *(9) In the case of an act done, or a decision made, by a person other than the court, there is sufficient compliance with this section if (having complied with the requirements of subsections (1) to (7)) he reasonably believes that what he does or decides is in the best interests of the person concerned.*
>
> *(10) "Life-sustaining treatment" means treatment which in the view of a person providing health care for the person concerned is necessary to sustain life.*
>
> *(11) "Relevant circumstances" are those –*
>
> *(a) of which the person making the determination is aware, and*
>
> *(b) which it would be reasonable to regard as relevant."*

22. Though it is entirely unnecessary to review the case law here it is apposite to note the remarks of Baroness Hale in **Aintree v James [2014] [2013] UKSC 67; A. C591**, at para 45:

> *"The purpose of the best interests test is to consider matters from the patient's point of view. That is not to say that his wishes must prevail, any more than those of a fully capable patient must prevail. We cannot always have what we want. Nor will it always be possible to ascertain what an incapable patient's wishes are. Even if it is possible to determine what his views were in the past, they might well have changed in the light of the stresses and strains of his current predicament."*

23. The position is different to that which came before Mrs Justice Parker. That is not in any way remarkable. What is remarkable is that RW has survived as long as he has. I

accept the professional consensus that he is at the end of his life, with a prognosis that can be measured in days, possibly weeks, and that it requires palliation.

24. The first issue that I have to consider when looking at the applicant's plan is, to my mind, whether RW experiences pain. On this point, PT is not at all clear. I am satisfied that there is a likelihood that RW can still experience pain. His resistance to being moved illustrates this. He has exposed nerve endings at the stump of his leg which Dr I tells me are likely to be painful. There are now very significant ulcers and RW is dehydrated. Even if I was not satisfied on the evidence that RW continues to feel pain it seems to me that the clinicians would be right to work on the assumption that he may do so. That of itself would indicate the necessity of the contemplated pain relief. PT, though so intuitive in so many aspects of his father's care, is unable to engage with this thought process. I do not speculate why but consider it to be a facet of his own distress.

25. I am told RW requires Morphine. I understand that he will require it in small amounts in the course of the day and night. I accept the evidence that in anticipation of agitation, Midazolam should also be prescribed. I am also satisfied, on the evidence, that RW is beyond the stage where he is sufficiently vital to take either nutrition or hydration in any meaningful way. He has very advanced vascular dementia. Again, I do not consider that PT can accept this or, at least, he is not able to articulate it.

26. RW now requires peace, privacy and hopefully to have his boys around him at the end of his life. There is nothing more that can be done. PT has done his very best for his father. I pay tribute to him. It is impossible not to be moved by his resistance to aspects of the palliative plan. At this stage however, I am satisfied that issues concerning withdrawal of nutrition and hydration have long since passed. We are, as I have emphasised and as the applicants asserts, considering what is the most appropriate end of life plan.

27. I would very much have liked to have been able to endorse a plan which permitted RW to return home. There is no doubt at all, as the history of this case shows, that RW would want to die at home. I do not know whether he would survive the transition but I should have been prepared to take that risk. However, PT would, in my judgement, continue to try to give his father food and water. As I speak these words he indicates to me that this is precisely what he would do. I have been told by Ms I that, at this stage, if PT were to attempt to feed his father there is a real risk that he would asphyxiate on any food given. I cannot permit RW to be exposed to the risk of ending his life in this way and, if I may say so, I would not be prepared to take that risk for PT either, especially having regard to all the loving care he has provided for his father.

28. I endorse the applicant's plan. I indicate that it is in RW's best interest to have his sons with him as much as possible. I am not prepared to be prescriptive of the times and the circumstances in which the sons may visit. In this I reject the applicant's proposals in this respect.

I hope that a note of this judgment can be provided quickly and that those involved in RW's care are given an opportunity to read it in order to enable them to understand that there is much more to PT than the rather agitated and angry man they see. He is a man who has cared for his father in a way that few

would have the resources and energy to do. I have no doubt at all, that RW would be proud of him and all his brothers.