Neutral Citation Number: [2020] EWCOP 16

Case No: 1353507T

IN THE COURT OF PROTECTION

Nottingham Civil Justice Centre
60 Canal Street
Nottingham
NG1 7EJ

Date: 27/03/2020

Before :

MR JUSTICE MOSTYN

- -

Between :

A CLINICAL COMMISSIONING GROUP — **Applicant**

- and -

AF
(by his litigation friend the Official Solicitor) — **1st Respondent**

- and -

SJ — **2nd Respondent**

- and -

A GP — **3rd Respondent**

- and -

A LOCAL AUTHORITY — **4th Respondent**

- -
- -

Nageena Khalique QC (instructed by **Mills & Reeve LLP**) for the **Applicant**
Sophia Roper (instructed by **The Official Solicitor**) for the **1st Respondent**
Peter Mant (instructed by **MJC Law**) for the **2nd Respondent**
John McKendrick QC (instructed by **DAC Beachcroft**) for the **3rd Respondent**
Edward Lamb (instructed by **Local Authority Legal Services**) for the **4th Respondent**

Hearing dates: **17-20 March 2020**

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MR JUSTICE MOSTYN

This anonymised version of the judgment may be published. However, in any report it is strictly forbidden to allude directly or indirectly to the true identities of the anonymised persons. Breach of this direction will amount to contempt of court and may attract severe penalties.

Mr Justice Mostyn:

1. The first question I have to decide is whether AF has the capacity to decide whether to continue to receive CANH[1] via a PEG tube[2] inserted into his stomach. All are agreed that he does not, and I also agree. He suffers from a grossly incapacitated mind resulting from a stroke on 5 May 2016.

2. The next question is whether it is in his best interests to continue to receive CANH. His daughter, SJ, argues that it is not. With the exception of the CCG and the local authority, the other parties, namely AF's GP and AF himself acting by his litigation friend the Official Solicitor, say that it is. The CCG remained neutral, but highlighted aspects of the evidence in closing submissions whilst local authority adopts a strictly neutral position.

3. I am strongly satisfied on the evidence, although it is not all one way, that were CANH to be withdrawn AF would not take sufficient food and drink orally to sustain life and would, sooner or later (probably sooner) expire. Let there be no doubt: that is the devout wish of SJ. In her moving evidence she told me "I am fighting for the right of my father to die". SJ's evidence was clear that she did not want her father to die and she was "fighting for his right to die" because she believes that is what he wanted. There is no question that she wishes her father to die for her sake or out of her own interests.

4. There is no room for any beating about the bush. If I were to agree with SJ, then I would be deciding that it was in AF's best interests that he be set on a path which will have the overwhelmingly likely consequence of his early death. Therefore, I have to answer on AF's behalf Prince Hamlet's question.

5. In making the best interests evaluation mandated by section 4 of the Mental Capacity Act 2005 I have clearly decided on the evidence it would not be in AF's best interests to discontinue CANH. Had I reached the opposite conclusion this would have given rise to distinctly complex legal and ethical questions. I would have had to have considered in depth the impact of article 2.1 of the European Convention on Human Rights (incorporated by the Human Rights Act 1998). As is well-known, this provides: "Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally …" This is subject to four exceptions, none of which is relevant to this case. Further, I would have had to have grappled with the somewhat impenetrable meaning of section 4(5) of the Mental Capacity Act 2005 which provides that "where the determination relates to life-sustaining treatment [the decision-maker] 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. These provisions, therefore, are not directly relevant to the decision I have reached. However, they do fortify the very strong presumption in favour of the preservation of life which is mentioned in numerous authorities. I have received, at my request, further written submissions about article 2 and section 4(5). I have reached the conclusion that I do not need to address these points in the light of the very clear decision about best interests which I have reached. I apologise for the extra work to

[1] Clinically Assisted Nutrition and Hydration
[2] Percutaneous Endoscopic Gastrostomy tube.

which I have put counsel. However, I am not sure that an expression of sceptical obiter dicta by me as a first instance judge is going to be particularly helpful to anyone.

7. Before I explain my reasons for my decision there are two matters I should mention at the outset. This case was listed to be heard before me in court in Nottingham. But with the onset of the national COVID-19 medical emergency it became clear to me that a traditional physical courtroom trial was likely to be extremely risky to the participants and therefore was unacceptable. Therefore, I decided with the agreement of all participants, at a telephone case management conference on the day before the start of the trial, that the hearing would be by Skype. The organiser and manager of the virtual hearing was Mr Matt Nichols of DAC Beachcroft in Bristol, the solicitors for the GP. I am very grateful for his extremely assiduous work in ensuring that the hearing proceeded almost without a hitch. I am also grateful to all the lawyers and other participants who cooperated so fully so as to enable the hearing to function. There were 17 continuously active participants at the hearing and in addition 11 witnesses were heard. Further, two journalists observed the proceedings. The participants and witnesses were scattered all over the country from Northumberland to Cornwall, Sussex to Lancashire. The only slight problem was that a few of the recording files became corrupted by virtue of their size. The lesson is that a sequence of recordings should be made, none exceeding about 30 minutes. In the current national crisis, it must be expected that hearings will be conducted remotely in this way as a matter of routine practice.

8. The second preliminary matter is to record that SJ's counsel, Mr Peter Mant, and his instructing solicitor, Ms Kate Jackson, appeared pro bono. That was a major philanthropic act by them. The issues were complex and challenging and the case they formulated and presented was done with eloquence skill and erudition. I am very grateful to them.

9. For the purposes of the hearing I was provided with an ebundle made available via ShareFile containing 929 pages of evidence. Each party furnished comprehensive position statements. I heard 11 witnesses as follows:

   i) SJ (from Nottingham)

   ii) The GP (from the Midlands)

   iii) Professor W, Consultant and Professor in Neurological Rehabilitation (from Oxford)

   iv) Dr H, Consultant in Rehabilitation Medicine (from Kent)

   v) PC, Care Home Manager (from the Midlands)

   vi) MA, Lead Nurse (from the Midlands)

   vii) SH, Activities Co-ordinator (from the Midlands)

   viii) RM, Senior Care Support Worker (from the Midlands)

   ix) Dr G, Consultant Neuropsychiatrist (from Northumberland)

x) BR, Dietician (from the Midlands)

xi) Dr P, Palliative Care Consultant (from the Midlands).

10. The case was heard over three days.

11. In addition to the statutory provisions mentioned above the following parts of section 4 of the 2005 Act are centrally relevant when assessing AF's best interests:

i) Subsection 6, which provides

> "[The decision maker] 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."

ii) Subsection 7, which provides so far as is relevant:

> "[The decision maker] must take into account, if it is practicable and appropriate to consult them, the views of …
>
> (b) anyone engaged in caring for the person or interested in his welfare …"

12. I was also referred to numerous authorities including decisions of the House of Lords, the Supreme Court, and the European Court of Human Rights in Strasbourg.

13. These provisions and authorities clearly establish a number of simple propositions which guide the evaluative judgment which I must make as to AF's best interests. This exercise is quintessentially an evaluation rather than an exercise of discretion.

14. The propositions are:

i) When assessing best interests, the exercise is first and foremost to consider matters from the point of view of the protected party: *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67 at [45].

ii) Welfare must be assessed in the widest sense, not merely medical but social and psychological also: ibid at [39].

iii) While there is a strong presumption in favour of the preservation of life this can in an appropriate case yield to the need to respect personal autonomy and dignity of the protected person and his right to self-determination: ibid at [35]. The strong presumption in favour of the preservation of life reflects the

categorical terms of article 2 of the Convention, both in its mandatory and prohibitory aspects, as well as the terms of section 4 (5) of the 2005 Act.

15. Mr Mant places great weight on what he would describe as the golden seam running through the legislation namely the right of AF to self-determination and to have his autonomy respected. As he put it, it is the right of the past capacitous AF to determine the fate of the present incapacitous AF. His submissions came close to saying that this was in effect the determining factor. The other counsel do not dispute the relevance of this principle but do not agree that decisive weight is to be attributed to it. It is one of a number of factors to be put into the mix when making the holistic best interests evaluation. Of, at least, equal merit or importance is the principle of preservation of human life, as well as the fact that while AF's present life is markedly diminished compared to his life before his stroke, it is still a life which has intrinsic quality and from which he appears to derive appreciable pleasure.

16. A very important consideration when judging AF's present quality of life is to keep at the forefront of one's thinking that it would be fallacious to seek to judge the processes of his mind by the standards of a capacitous mind. All the expert witnesses agreed with me that the workings of a grossly incapacitated mind is a largely undiscovered country. It would be a grave mistake to assume that AF repines and that he makes relativistic judgments about the plight in which he finds himself. As Dr G rightly stated: "it is very difficult to know his subjective views since the stroke". What is known is that he derives simple physical and emotional pleasures from his quotidian existence.

17. AF was born in Ireland and is now in his seventies. He came to this country in the 1960s and obtained employment in the NHS, where he worked until his retirement. He was married; his wife died from cancer after a short illness. They had two daughters, SJ and K, who was disabled. By dint of loving care from her parents, K survived longer than expected and died in her teens.

18. AF is described by his family as a strong and fiercely independent man. His experiences in the NHS meant that he was familiar with disease and death. He stated on many occasions to those close to him that he would not want to be kept alive as a "body in a bed". This language is reminiscent of the description of Tony Bland by Lord Goff as a "living corpse". In her first statement SJ said this:

> "Working in a hospital for 30 years, he saw sickness and death. Death doesn't scare my Dad. What scared him was loss of dignity. He saw some of the worst situations people can be in and he would talk about that and say, "you shouldn't always keep people alive".
>
> I honestly thought that my Dad had done something about it. He said it so many times, that he didn't want to be kept alive, that I can't believe he didn't write that down. When my disabled sister, K, was alive, he told me he had an envelope taped to the bottom of the chest of drawers with his will, and the name of the Home he wanted her to go to, and the names of the staff he employed to help look after her, and even the name of a van to be available as a taxi for me - honest to God, that's

> how organised he was. I can't believe that he did all that for my sister, and he did it for my Mum when she was dying with cancer, but he didn't do it for himself. I'm so angry with him about that. How could he not have done it for himself?!
>
> He would never want to be just a body in a bed. I heard his passion about this, and now we're living it. Everything that he used to say for all those years about the people in the hospital, now we're living it. And I'm failing him, because he would want to be just let go."

19. In her second statement she said this:

> "Because my dad worked in hospital, he would often talk about the fact that it is cruel to keep people in a bed for so long if they can't do anything for themselves. He would often say it was not how it should be, being "a body in a bed" and that he wouldn't want to be that way. He spoke about the indignity of being in such a situation. He was a very dignified man. He would make remarks such as 'just put me in a corner by the range with a gun and I'll sort it out meself'. His wishes and feelings about this could not have been clearer."

20. As SJ recognises it would have been open to AF to have written down an advance decision under sections 24 and 25 of the Act of 2005. But he did not. The evidence was that following the death of his wife he consulted the solicitor in Ireland who was dealing with the probate of her will about the possibility of making a living will, but that he never followed it up. However, given his expressed wishes I doubt very much, had he written such an advance decision, it would have covered anything other than a descent into a vegetative or minimally conscious state. As I will explain, AF is sentient, cognitively active, emotionally aware and possessed of motor functions, albeit grossly impaired physically and mentally. I find it impossible to conceive that he would ever have written an advance decision mandating being starved to death were he to find himself in his present position.

21. Similarly, I find it impossible to construe the statements that he made, which have been so clearly recorded by SJ and other family members, as being applicable to his current condition.

22. I record that in none of the cases that were cited to me was the protected party enjoying anything like the degree of functionality as that presently enjoyed by AF. They were all either vegetative, minimally conscious or in an equivalently parlous position.

23. I now record the expressions of his wishes and feelings in the immediate aftermath of the stroke on 5 May 2016.

    i) Up to 12 May 2016 AF ate and drank voluntarily. However, on that day he started to refuse food and was saying that he wanted to die. He was however dysphagic and extremely confused.

ii) On 19 May 2016 the decision was taken that he did not have capacity and that it was in his interests for him to be fed through a nasogastric tube. Attempts were made to insert the tube, but AF resisted stating that he wished to die. It is common ground that insertion of a nasogastric tube is extremely unpleasant and painful.

iii) On 21 May 2016 the tube was successfully inserted. There is a record that AF turned to his daughter and said "this is wrong".

iv) Notwithstanding that he was made to wear mittens in order to prevent the tube being removed there is a record that on 23 May 2016 AF removed the tube.

v) On 24 May 2016 the tube was reinserted with a bridle to prevent removal. Nevertheless, on 1 June 2016 AF managed to pull it out and was very distressed when staff endeavoured to reintroduce it.

vi) On 7 June 2016 the PEG was inserted under sedation. It is recorded that he continued to state that he wished to die. On 2 July 2016 he resisted feeding via the PEG.

vii) On 8 July 2016 AF is recorded as having refused feeding and stating that he wished to die and to be with his wife and daughter, both of whom had died, as explained above.

viii) On 15 July 2016 AF told the psychiatrist, Dr C, that he wished to die but he also told him that he wished to live.

ix) On 25 July 2016 AF told the IMCA that he wanted to die because of the stroke. He was in tears when he said this. He said, "I long to be dead".

24. On 3 August 2016 AF was discharged from hospital to the care home where he has remained ever since. Although there are records that for a while he resisted PEG feeding it is apparent that his resistance has reduced over time and he now cooperates by lifting his top for the PEG to be connected. The PEG feed is pump driven and operates overnight for 12 hours.

25. What was AF's capacity during this period? Dr H told me, and I accept, that he would have lost capacity to make a decision about his treatment approximately halfway between 5 and 19 May 2016. That would have been the watershed. He had definitely lost capacity when the first attempt to insert the nasogastric tube was made on 19 May 2016, and he had lost yet further capacity on each subsequent date. His rate of decline thereafter to his present position would have been approximately linear.

26. Therefore, virtually all of the expressions of wishing to die were made by AF after he had lost capacity. Now, it is true that the court must take into account wishes expressed by an incapacitated person. This is not controversial. However, what weight the court gives to such wishes must equally take into account that they are expressed by somebody who has lost capacity and, as I have stated above, the workings of an incapacitated mind are a largely undiscovered country. Undoubtedly, at this time AF was most upset at the cruel hand that fate had dealt him. However, I cannot accept

that he then expressed a fully rational and considered view that he wished to take the ultimate fatal step.

27. AF's present existence is obviously limited but it is clear that he derives pleasure in a number of respects from physical and emotional stimuli. I summarise the evidence which I have heard:

    i) Notwithstanding that he is presumably full up by virtue of the PEG feed, and therefore not hungry, he does enjoy certain foods. He enjoys in very modest amounts spicy food from time to time. He enjoys doughnuts, chips, toast and cake, again intermittently. Although he does not drink daily he likes coffee and hot chocolate. There is agreement that of itself the amount that he ingests orally would not be enough to sustain his life.

    ii) He enjoys receiving a wash of his back.

    iii) He enjoys animals. One of the carers had an old labrador called Y, now sadly put to sleep. He would be very pleased when Y lay on his bed and he could hold him and feel his wet nose. I have seen a photograph of AF holding Y on his bed; AF is beaming. I have also seen a photograph of AF beaming when a small Shetland pony was brought into his room.

    iv) He enjoys the company of children. PC brought her grandchild in to meet AF. AF described him as beautiful and asked if he could hug him. PC was stunned by this. Other children have been brought to meet AF; he has much enjoyed their company.

    v) AF enjoys listening to music from a visiting musician. I have seen a most affecting video of the musician playing Irish Eyes with AF plainly enraptured and marking the beat with his hand.

    vi) AF enjoys listening to an Irish radio station on a digital radio. He enjoys watching television and especially watching the Irish rugby team.

    vii) I was told by SH, the activities coordinator, that she had read AF poetry from an anthology belonging to her father. She read him poems by the war poets, Rupert Brooke, Siegfried Sassoon and Wilfred Owen. She told me that these "really hit the spot". He became emotional and his eyes filled with tears. She asked: "should I stop?" He shook his head. She asked: "Should I carry on?" He nodded.

    viii) Although his verbal communication is limited it is not non-existent. He is normally monosyllabic, but occasionally full sentences are formed. He also communicates well non-verbally. RM told me that he is a very good communicator either by eye contact or gestures.

    ix) AF will not let anyone into his mouth, not even the visiting dentist. It may be that he is suffering from mouth ulcers which may account for his reluctance to eat. That aside, there is no obvious source of any pain, and AF does not display any signs of pain.

28. AF's GP who knows him well was clear that the proposal would inevitably lead to AF's death. He was very strongly opposed to it. He was of the view that not only would it be unethical but also arguably unlawful.

29. Professor W was of the opinion that were AF to be set on the proposed path there would be a "large probability" that it would lead to his death. Nonetheless, he was of the opinion that it was in his best interests that he should be so directed. His evidence was that only one possible conclusion can be drawn from the totality of the evidence available concerning his past wishes and other personal factors, and that is that AF did not wish CANH to be initiated or continued, and that he would still not wish CANH to continue. In his opinion the totality of AF's behaviour is of a man who "does not want to be here" but who does not wish to expose himself to more pain or distress by active resistance and does not wish to distress those who care for him by being antisocial or uncooperative.

30. I do not agree with this view which is as much ethical as it is medical. In writing Dr H appeared to be of the same opinion as Professor W although when he was faced with the awful consequences of the proposal under cross-examination he appeared to shrink from that view, stating that in such circumstances he would not agree with Professor W's view and that it was in any event not a medical question. Dr G gave compelling evidence about the possible psychiatric disorders from which AF may be suffering. She was of the opinion were he to be set on the path proposed death would be "overwhelmingly likely". She was clear that the proposal would be directly contrary to his best interests. The dietician, BR, was less sure that the proposed path would inevitably lead to death. This was a "very difficult question" the answer to which was "we just do not know". This led me to observe, as I had earlier, that if this were the case then what is being proposed is a macabre experiment. The palliative care consultant, Dr P stated that in the present national medical emergency it would be impossible to provide palliative support for AF either in his current home or in a hospice. That is an additional reason for refusing the proposal.

31. I revert to the specific matters in section 4(6) and (7):

    i) I have fully considered AF's past wishes. Before the stroke AF did not make a relevant written statement. His oral statements to his family cannot be construed as being applicable to anything more than a descent to a vegetative or minimally conscious or equivalent state. They cannot be construed as being applied to his present condition. Following the stroke AF's statements were made at a time when he crossed the boundary into incapacity and cannot be construed as a rational and considered wish for self-destruction.

    ii) I find it virtually impossible to answer the hypothetical and counterfactual question of what AF's beliefs and values would be if he had capacity today. In that event of course there would not be a case in the Court of Protection. I think it unlikely that if he were granted a brief window of lucidity, he would reach the conclusion that he would be better off dead rather than to continue with the limited life that he presently enjoys. He would recognise that he is not in the grips of a terminal illness leading inevitably to an unpleasant and painful death. I do not think that were he granted that brief window of lucidity he would ask to be taken at once to Dignitas.

iii) I do not consider that there are any other factors that he would be likely to consider if he were able to do so.

iv) The views of SJ have been clearly set out above. I have taken full account of them. The views of the GP and the carers at the care home are that it is unthinkable that AF should be in effect starved to death. They would not be prepared to participate in such a process which would mean that AF would have to move elsewhere. Even if that were possible at the present time, and it is not, such a move would inevitably cause disturbance and distress to AF.

32. I have reached the very clear conclusion that it would be categorically contrary to AF's interests for him to be set on the path that will lead to his inevitable death from starvation. This may be a diminished life, but it is a life nonetheless which has, as I have said, intrinsic quality and from which AF derives pleasure and satisfaction.

33. For these reasons I conclude that it would be in AF's best interests for CANH to continue.

34. That concludes this judgment.