Neutral Citation Number: **[2014] EWCOP 4**

Case No: COP 12483664

COURT OF PROTECTION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 22/05/2014

Before :

MR JUSTICE HAYDEN

- -

Between :

SHEFFIELD TEACHING HOSPITALS NHS FOUNDATION TRUST	**Applicant**
- and -	
	1ST Respondent
TH (BY HIS LITIGATION FRIEND THE OFFICIAL SOLICITOR)	
	2ND Respondent

-and-

TR

- -
- -

Mr Spencer (instructed by **Sheffield Teaching Hospitals NHS Foundation Trust**) for the **Applicant**
Miss Roberts QC (instructed by **The Official Solicitor**) for the **1st Respondent**
TR the 2nd Respondent in person

Hearing dates: 14th & 15th May 2014

- -

Judgment

This judgment was delivered in private. The judge has given leave for this version of the judgment to be published on condition that (irrespective of what is contained in the judgment) in any published version of the judgment the anonymity of the incapacitated person and members of their family must be strictly preserved. All persons, including representatives of the media, must ensure that this condition is strictly complied with. Failure to do so will be a contempt of court.

Mr Justice Hayden :

1. On the 14th May 2014 I granted declarations in respect of TH, a 52 year old man presently in a minimally conscious state at what has been described as the lower end

of the spectrum of that condition (i.e. a very profound disorder of consciousness). There is no doubt TH lacks capacity to litigate in these proceedings and also lacks the capacity to give or withhold consent to his medical treatment. I have considered the papers and also heard oral evidence from Dr Gary Dennis, Consultant Neurologist at the Sheffield Teaching Hospital's NHS Trust, Senior Nurse Cliffe who works in the neurology department, Professor Barnes, Honorary Professor of neurological rehabilitation at Newcastle University, TR, TH's ex-wife and long term partner and GM TH's friend of many years.

2. In relation to withdrawal of nutirition and hydration I am persuaded that the correct course is to adjourn this issue to provide for a structured clinical assessment to evaluate whether there is evidence that TH's primary neurological pathways are sufficiently intact to permit any evidence of awareness to be detected and fully to assess, over a set period of time, TH's general awareness, responsiveness and capacity to experience pain. The National Clinical Guidelines have been drawn to my attention in some detail and Professor Barnes has highlighted the benefits of a standard assessment tool, for example the Sensory Modality Assessment and Rehabilitation Technique (SMART) and the Wessex Head Injury Matrix (WHIM).

3. Both Professor Barnes and Dr Dennis are clear that most features of those modality assessments are an every day aspect of instinctive medical care given by the team at the Hallamshire Hospital. Nonetheless both agree there is much to be gained by formalising that assessment and collating the clinical data in order to obtain the clearest picture of TH's prolonged disorder of consciousness.

4. I note that Baker J also found this to be an important strategy in *Re M (Adult Patient) (Minimally conscious state: withdrawal of treatment) 2012 1WLR 1653*. At 259 Baker J observed:

> *"It is therefore of the utmost importance that every step should be taken to diagnose the patient's true condition before any application is made to the court. Professor Turner-Stokes said in evidence that she was 'reasonably confident that future guidelines will state that, before making any decision concerning the withholding of ANH there should be formal testing in the form of the SMART diagnostic test coupled with WHIM tests carried out over a period of time. In future therefore, no such application for an order authorising the withdrawal of ANH from a patient in a vegetative state or a minimally conscious state should be made unless:*
>
> > *(1) a SMART assessment (or similarly validated equivalent) has been carried out to provide a diagnosis of a patient's disorder of consciousness and*
> >
> > *(2) in the case of a patient thereby diagnosed as being in a minimally conscious state a series of WHIM assessments have been carried out over time with a view to tracking a patients progress and recovery (if any) through the minimally conscious state. If an assessment scale becomes validated in the medical literature for tracking a person's recovery through the minimally conscious state, this assessment may alternatively be used in the place of the WHIM."*

Professor Turner-Stokes remarks were prescient the 'future guidelines' became the NICE guidelines to which I have already referred.

5. The Trust here initially sought authority to provide, in the exercise of its clinical discretion, life sustaining treatment, including the discretion to decide whether TH should receive cardiac or respiratory resuscitation on a ventilator should he suffer

arrest. Ultimately authority to resuscitate was not pursued. I have been impressed by the way in which Dr Dennis and his team have listened so carefully to TH's partner and to Professor Barnes in refining and honing their clinical plans.

6. Professor Barnes has for the last 28 years of his career focused entirely on the rehabilitation of people with severe and complex disabilities, particularly brain injury, spinal injury, stroke, multiple sclerosis, cerebral palsy and muscle spasticity and pain. He has a particular interest in 'life expectancy'. He is well recognised at national and indeed international level in his field. He has been President of the British Society for Rehabilitation Medicine and is the founder President of the World Federation for Neuro-rehabilitation. In addition he is an author of over a hundred journal articles in his field as well as many review articles. He is the author of the definitive text books on undergraduate and post graduate neurological rehabilitation and has significant experience in the management of rehabilitation and other health services.

7. In his very helpful report dated the 29th April he concluded that it would be likely that if TH suffered a cardio respiratory arrest then that would indicate progression of his underlying and already severe neurological disability. In those circumstances Professor Barnes considered that it would not be in TH's best interest to proceed with resuscitation on collapse. He noted that a DNAR (Do Not Attempt Ressucitation) order is now in place and that such an order is both reasonable and in his view in TH's best interest. Understandably nobody has sought to dissuade me that this properly represents TH's best interest and I endorse that decision.

8. The medium term objective is to transfer TH's care from the hospital to a specialist nursing home. TR opposed that. Though she is full of respect and genuine admiration for TH's treating clinical team she believes that TH would loathe his present situation. She tells me that **he** would find it a violation of **his** dignity. Without the advantage of lawyers acting on her behalf her 'proposals' are instinctive rather than structured. She says that she wishes TH to be returned to her care and to look after him along with his mate 'Spud**'**. (I don't think I have ever been given this man's full name). As the hearing evolved it became clear that what TR really wanted to do was to ensure that TH's voice was heard in this court room with her as the conduit for it. TH would not want his present situation she says, he wishes to die, preferably as quickly and as painlessly as possible. That these are his wishes she has no doubt. For her part she told me she was 'not ready to let him go', but she would be failing him, she thought, if she did not communicate what she was confident were his views to this court. I will say more concerning the issue of TH's wishes below but I propose to preface those observations by setting out something of the background to this case.

9. TH was admitted to the Northern General Hospital in Sheffield on the 11th February of this year. At that point, as Professor Barnes has emphasised in evidence to me and indeed in his report, he had a reduced Glasgow coma score of just 3 out of 15 which is the lowest possible score, indicative of a very severe depression of consciousness. TH was also noted to have jerking movements to the right side of the body with deviation of the eye to the right. That, it was considered, indicated epileptic activity. This seizure activity was terminated in the casualty department but he was then transferred to the Intensive Care Unit where he was intubated due to his persisting depression of consciousness. His general health revealed a background of known alcohol excess and his seizure was thought to be due to alcohol withdrawal and

hyponatremia. That is a condition characterised by a very low serum sodium which in turn can cause neurological damage and is associated with excessive alcohol consumption.

10. Though there was some small improvement, TH remained confused when transferred on to the ward. However, on the 22nd February he had a further episode which was probably, in Professor Barnes's view, a 'generalised tonic clonic seizure' which required intravenous treatment. The following day there was a further episode associated with high temperature and these difficulties continued with a further reduction of serum sodium. It was at that point, due to what was recognised to be an increasingly complex and serious condition, a referral was made to the neurological department at the Hallamshire Hospital. It is pertinent to record that prior to this admission TH had a pre existing serious neurological disability called Central Pontin Myelinolysis. That condition is characterised by degeneration of the brain stem / pontin region and is again often, though not exclusively, associated with alcoholism. To add to this complex picture TH was also known to have Wernicke-korsakkoff syndrome. That is characterised by visual problems, unsteady gate, mental changes such as memory loss and occasional behavioural issues, again associated with alcoholism.

11. Professor Barnes noted that TH has 'decompensated alcoholic liver damage' and that the records show a 'proximal myopathy in the arms' by which I understand the upper part of the arm is weak. TH had been chair bound and incontinent and had marked ataxia. He also had pressure sores as a result of his wheelchair bound status. Suffice to say that even prior to this admission therefore, TH's condition had become debilitating.

12. The Hallamshire Hospital was able to bring the epilepsy under control and the low sodium level was, as I understand Professor Barnes's evidence, entirely corrected. The neurological status however has shown no signs of recovery and there is consensus between Dr Dennis and Professor Barnes that TH remains under a serious neurological disability.

13. In a letter filed in these proceedings, dated 2nd April, Dr Gary Dennis noted that whilst TH's acute medical problems have in fact improved his current clinical state in fact appears worse than prior to his admission to hospital. 'He is unable to communicate in a comprehensible manner either verbally or non verbally. He does not understand even the simplest of commands. Further EEG's have excluded the possibility that the present condition is due to underlying continuous epileptic activity. Whilst the speech and language therapy team feel TH is able to swallow soft food stuff the consensus is that 'TH's understanding of a need to eat is severely compromised and he therefore does not initiate feeding. When he is fed by nursing staff he tends to spit out food thereby not sustaining sufficient calorie intake to maintain his weight'. He is presently fed by his naso gastric tube and there have been occasions, now some weeks ago, when he tried to pull the tube out. TH is incontinent of both urine and faeces and has a urinary catheter**.** I have been told by Nurse Cliffe and by TR that TH wears an adult size nappy.

14. As Professor Barnes's evidence was not disputed, no party had required him to give evidence. Bearing in mind TR was not represented I took the view that the serious decisions contemplated in this case really required the assistance of Professor Barnes

in evidence. Evidence on issues of this importance could not, in my view, be taken over the telephone or by video link unless it was unavoidable and although the question of Professor Barnes' attendance was only raised in the afternoon of the 13th May he agreed to attend and was here by 10.30am in London on the 14th having travelled down from Newcastle on very short notice. I am extremely grateful to him, it shows precisely, if I may say so, the level of commitment which has been the hallmark of his very distinguished career.

15. In his evidence Professor Barnes was asked about the possibility of any improvement. He did not entirely discount it as a possibility, but as he readily acknowledged, "improvement" in these circumstances could only mean a relatively small increase in the level of consciousness. There is no "cure" and MR scans, he told me, showed that the brain has suffered catastrophic damage from which it will not recover. As he put it in his report, TH's condition is "permanent and irreversible".

16. He emphasised that there were treatment options available for complications such as further derangement of serum sodium or recurrence of active epilepsy, but the treatment would be for the complications rather than the underlying condition itself.

17. Asked specifically about TH's rehabilitative potential, Professor Barnes observed in his report:

> "Regrettably, I do not consider that TH has rehabilitative potential. He is being assessed by therapy services on the ward and his lack of communication precludes any meaningful learning that would be required to undergo a period of rehabilitation. He needs passive therapy in a sense of stretching exercises for the limbs and good quality nursing care. The nursing care would include appropriate management of his feeding, catheter, pressure areas, etc. However this is nursing care rather than rehabilitation."

18. It is this view that reinforces the hospital's analysis that the medium term future for TH lies in a specialist nursing home.

Antibiotic Therapy

19. Whether treatment for TH by antibiotics was in TH's best interest, said Professor Barnes, was "a very difficult" question. However there emerged a broad consensus during the course of the hearing. One in which TR and GM also had little difficulty in supporting. The policy to be pursued is easy to state. The reality will require a judgment call which I have no doubt will, at times, be less than clear cut.

20. The consensus was that relatively "minor infections" such as urinary tract infections, inflammations caused by infection of some sort, should be treatable by a short course of antibiotics in order to maintain TH's general comfort. This could equally apply to relatively "mild" chest infection. Thus, all supported the view expressed in Professor Barnes' report that it was in TH's best interest for mild/minor infections to be treated with a course of antibiotics.

21. However, of course some mild infections will potentially become serious when untreated and lead to overwhelming infections such as pneumonia or septicaemia. Such overwhelming infections, it was recognised, are less readily treatable and will often require a period of time in an intensive care unit for respiratory support as well as intravenous antibiotics. Moreover, such overwhelming infection would probably indicate, in Dr Dennis' and Professor Barnes' view, a natural progression of TH's condition. Both ultimately concluded that if overwhelming infection occurred, then it would not be in TH's best interest for that to be treated with antibiotic therapy.

22. As Professor Barnes indicated, it is "a matter of clinical judgment whether an infection is mild or overwhelming". In clinical terms, however, he considered the distinction would usually be reasonably clear. But in order to assist the treating team, he proffered the suggestion that if an infection is so severe that TH requires intensive care, respiratory support or cardiovascular inotropic support, then such infection should not be treated, but if the infection is milder such as not to require that kind of level of support, then the infection should be treated.

Nutrition and Hydration

23. The real question in the case is whether it is in TH's best interest to receive nutrition, hydration and medication. Despite the range of clinical difficulties that I have set out, Dr Dennis nonetheless considered that at 52, TH had "the strength of a man of his age", and considered that life expectancy might be at the more positive end of the spectrum. As head of the clinical team he sees TH regularly, and I place considerable emphasis on his view. It can, of course, only be speculative, but he sees the possibility of TH living for 12/18 months, possibly longer.

24. Professor Barnes is much more pessimistic. He considered the prognosis for TH to be grave. He puts it in these terms:

> "My estimate of the worst case scenario is that TH could die within the next few days/weeks as a result of complications of his neurological condition. A likely possibility is overwhelming infection giving rise to pneumonia/septicaemia. The possibility of renal failure also needs to be considered. It is also quite possible that he could have cardiopulmonary arrest as a result of the brain damage in the pontine region. The best case scenario would be that TH does not develop such complications and is able to live for several more months or even a year or so. This is a possibility as long as he receives good quality nursing care. I have seen many individuals who in similar advance state of neurological disability who with good quality nursing care and appropriate treatment of complications have managed to live for many months/years in a similar disabled state. On the balance of probabilities I consider that his actual prognosis is nearer the worst case scenario than the best case scenario."

25. I pause there to interpolate that the best case scenario or the worse case scenario rather depends on the individual's perspective of TH's best interests.

26. I repeat, the real issue in the case is whether it is in TH's best interest to receive nutrition and hydration or whether he should quite simply be permitted to bring his life to an end in the manner and timescales of his choice.

27. Professor Barnes says very cautiously that 'at the present time' he thinks it is in TH's best interest to receive nutrition and hydration. Dr Dennis said in evidence that he would not consider it unethical to treat TH only by hydration and pain relief if the court considered that to be in TH's best interest. He had not, at that stage, heard from Professor Barnes. Presented with that factual scenario, Professor Barnes unhesitatingly discounted it. The withdrawal of nutrition, with the continuation of hydration, would, he said, merely prolong the process.

28. Whether TH experiences pain has been very difficult to identify. The SMART/WHIM assessment will better inform us, but I note that I have come, at this stage, to a very similar conclusion, on the evidence I have heard, to that which Baker J arrived at in *Re: M (Super)*. Namely, that there is some evidence that TH feels some pain or discomfort, but his capacity for feeling pain is plainly very much reduced. I have been told of an occasion when, as a consequence of a blocked catheter, TH had a litre and a quarter of urine drained. Dr Dennis was surprised to find such a build up of urine without any striking visible pain prior to its release.

29. The degree of accuracy to which I have already been informed of TH's capacity to experience pain is a tribute to the high quality of care that he is receiving, as everybody has acknowledged. I have heard that Dr Dennis periodically tests TH's capacity for pain by the use of conventional methods, all of which to date have in fact showed no response. Nonetheless, the structured assessment contemplated by SMART will give the best possible picture, and this case should move forward on nothing less than the best evidence that is available.

30. Whether withdrawal of hydration and nutrition will, in the long term, be in TH's best interest remains yet to be seen. I have no doubt that the Trust will approach this with an open mind and a preparedness to be reflective and to reconsider in the way that they have already shown themselves able to do, and which I have certainly found extremely impressive and helpful.

31. I return to the issue of TH's wishes. Mr Spencer, counsel on behalf of the Trust, identified the issue at this hearing in his position statement.

> "The key issue for the court to determine is whether TH has actually made an advance statement that binds his clinicians and carers. Put simply is it in TH's best interest for him to be treated and cared for in hospital and/or nursing home or should he be permitted to return home to die."

32. The advance statement to which Mr Spencer refers is that contemplated by Section 24 of the Mental Capacity Act 2005:

> ***24 Advance decisions to refuse treatment: general*** *(1)"Advance decision" means a decision made by a person ("P"), after he has reached 18 and when he has capacity to do so, that if—*
>
> *(a)at a later time and in such circumstances as he may specify, a specified treatment is proposed to be carried out or continued by a person providing health care for him, and*

(b)at that time he lacks capacity to consent to the carrying out or continuation of the treatment, the specified treatment is not to be carried out or continued.

(2)For the purposes of subsection (1)(a), a decision may be regarded as specifying a treatment or circumstances even though expressed in layman's terms.

(3)P may withdraw or alter an advance decision at any time when he has capacity to do so.

(4)A withdrawal (including a partial withdrawal) need not be in writing.

(5)An alteration of an advance decision need not be in writing (unless section 25(5) applies in relation to the decision resulting from the alteration).

33. The validity and applicability of advance decisions, compliant with Section 24, is set out in Section 25 which provides:

25 Validity and applicability of advance decisions *(1)An advance decision does not affect the liability which a person may incur for carrying out or continuing a treatment in relation to P unless the decision is at the material time—*

(a)valid, and

(b)applicable to the treatment.

(2)An advance decision is not valid if P—

(a)has withdrawn the decision at a time when he had capacity to do so,

(b)has, under a lasting power of attorney created after the advance decision was made, conferred authority on the donee (or, if more than one, any of them) to give or refuse consent to the treatment to which the advance decision relates, or

(c)has done anything else clearly inconsistent with the advance decision remaining his fixed decision.

(3)An advance decision is not applicable to the treatment in question if at the material time P has capacity to give or refuse consent to it.

(4)An advance decision is not applicable to the treatment in question if—

(a)that treatment is not the treatment specified in the advance decision,

(b)any circumstances specified in the advance decision are absent, or

(c)there are reasonable grounds for believing that circumstances exist which P did not anticipate at the time of the advance decision and which would have affected his decision had he anticipated them.

(5)An advance decision is not applicable to life-sustaining treatment unless—

(a)the decision is verified by a statement by P to the effect that it is to apply to that treatment even if life is at risk, and

(b)the decision and statement comply with subsection (6).

(6)A decision or statement complies with this subsection only if—

(a)it is in writing,

(b)it is signed by P or by another person in P's presence and by P's direction,

(c)the signature is made or acknowledged by P in the presence of a witness, and

(d)the witness signs it, or acknowledges his signature, in P's presence.

(7)The existence of any lasting power of attorney other than one of a description mentioned in subsection (2)(b) does not prevent the advance decision from being regarded as valid and applicable."

34. Section 26 sets out the statutory consequences and effect of an advance decision:

> ***26 Effect of advance decisions***
> *(1)If P has made an advance decision which is—*
>
> *(a)valid, and*
>
> *(b)applicable to a treatment,*
>
> *the decision has effect as if he had made it, and had had capacity to make it, at the time when the question arises whether the treatment should be carried out or continued.*
>
> *(2)A person does not incur liability for carrying out or continuing the treatment unless, at the time, he is satisfied that an advance decision exists which is valid and applicable to the treatment.*
>
> *(3)A person does not incur liability for the consequences of withholding or withdrawing a treatment from P if, at the time, he reasonably believes that an advance decision exists which is valid and applicable to the treatment.*
>
> *(4)The court may make a declaration as to whether an advance decision—*
>
> *(a)exists;*
>
> *(b)is valid;*
>
> *(c)is applicable to a treatment.*
>
> *(5)Nothing in an apparent advance decision stops a person—*
>
> *(a)providing life-sustaining treatment, or*
>
> *(b)doing any act he reasonably believes to be necessary to prevent a serious deterioration in P's condition,*
>
> *while a decision as respects any relevant issue is sought from the court.*

35. It is clear therefore that an advance decision which meets the criteria has the effect of being valid and applicable as if TH had made it and had made it when of full capacity at the time when the question arises as to whether the treatment should be carried out or continued.

36. The issues involved in determining 'best interests' in medical cases have relatively recently been considered in the Supreme Court in *Aintree University Hospital NHS Foundation Trust v James* [2013] 3 WLR 1299. There Baroness Hale, with whom the other Supreme Court Justices agreed, emphasised the following:

    i) *The MCA is concerned with enabling the court to do for the patient what he could do for himself if of full capacity, but goes no further (see paragraph 18);*

    ii) *The fundamental question is whether it is lawful to give the treatment (see paragraph 20) and the focus is whether it is in the patient's best interest to give the treatment rather than on whether it is in the best interest to withhold or withdraw it (see paragraph 21);*

    iii) *The MCA emphasises the need to see the patient as an individual with his own values, likes and dislikes, and to consider his best interest in an holistic way.*

37. As Baroness Hale emphasises, the Mental Capacity Act code provides some guidance about life sustaining treatment at paragraphs 5.31-33. At paragraph 40 Baroness Hale also emphasised that whilst it was correct to consider whether the proposed treatments would be futile in the strict sense of being ineffective or of no benefit to the patient, the medical effects of the treatment was only one part of a much broader equation.

> *"40. In my view, therefore, Peter Jackson J was correct in his approach. Given the genesis of the concepts used in the Code of Practice, he was correct to consider whether the proposed treatments would be futile in the sense of being ineffective or being of no benefit to the patient. Two of the treatments had been tried before and had worked. He was also correct to say that "recovery does not mean a return to full health, but the resumption of a quality of life which Mr James would regard as worthwhile". He clearly did consider that the treatments in question were very burdensome. But he considered that those burdens had to be weighed against the benefits of a continued existence. He was also correct to see the assessment of the medical effects of the treatment as only part of the equation. Regard had to be had to the patient's welfare in the widest sense, and great weight to be given to Mr James' family life which was "of the closest and most meaningful kind"."*

38. In this court room TR and GM have transported TH from his hospital bed, in his minimally conscious condition, and their obvious love and affection for him has brought his character and personality to this court. They have communicated not merely his words and wishes, but also his feelings, too frequently conflated as the same concept, but in truth entirely different. There is no doubt at all that there was never a conversation in which TR and TH contemplated the kind of specific treatment that is now being debated here, and as such the stringent requirements of Section 24 are not met. There is no advance decision to refuse treatment here.

39. I have had the advantage here of listening to or reading the evidence of individuals who have populated TH's life for most of his adulthood. TH's friendships are enduring, faithful and lifelong. It says a great deal about him that he can inspire such friendship and, to my mind, it particularly qualifies these individuals to convey to me TH's own authentic voice.

40. None of these witnesses portray TH as a hero. With a lifelong dependency on alcohol and obvious "demons" in his past (as TR refers to them), he is manifestly a flawed man. He has always been, as TR put it, "a bit cookie". He is deeply suspicious of authority and of the reach of the State. He dislikes tactility, and though he and TR were plainly "soul mates", he would never, she told me, "hold her hand in the street". When he was unable to move around he refused to allow social workers to come into his house to bath him. TR told me he asked her to help him. Though the marriage had broken down and though it was no longer incumbent upon her to help, she did so she told me because she knew he could not face the indignity of being bathed by outsiders.

41. Another of TH's friends, "Fordie", told me in his statement that TH was at his best "unsupervised", as he put it. "Not being happy with authority figures of any description! Company and freedom to play his Slade tracks were the most important features in TH enjoying his life", he said. All who knew him knew that that dislike of authority and of outsiders very much extended to hospitals and "medics of any description however well meaning", said his friend Phil. Phil considered his present situation would be pure torture for TH despite what he (Phil) recognised to be the excellent ward staff.

42. TH was a talented drummer. All his friends say that when, through his Ataxia, he was no longer able to play, the life force seemed to simply drain out of him. Every day for as long as anybody can remember, he practiced, striving for perfection, and occasionally agreeing reluctantly to public performances in respect of which I am told he was extremely self critical.

43. Phil cautioned himself about "slipping into the past tense". When talking about TH I think many professionals have at times had to issue similar cautions to themselves in this case. Phil told me TH had a wicked sense of humour, and a keen intellect, which he seemed to have liked to hide. "I don't think he'd like to remain as he is and certainly not in hospital" said Phil.

44. JM and RM met TH during the late 80s when he was a drummer in a band. It was obvious to JM from the very beginning that TH didn't follow what she saw as "the normal conventions of life", by which she meant 'job, house, wife, kids etc'. He intended "to live life his way. Often finding solace in alcohol". She said that over the years TH has made it absolutely clear that he has an "intense dislike of hospitals". If he was ever admitted she said he would "escape" at the earliest opportunity, usually to the detriment of his health, mental and physical. He was, she said, fiercely independent. He hated to rely on anybody. 'When he was ill in a home he made it very clear that was no real life nor an existence he would want'.

45. She also noted that TH was a very private, non-tactile person. She said the thought of being dependent on other people to clean and feed him, he would find "abhorrent". She concluded her sensitive comments and her insightful remarks with this passage:

> "There are no winners in this situation at all. All I can say is that I believe with all my body and soul that TH would find the situation he was in a living hell, and if we cared anything for him, we would let him go and find peace."

46. What I find to be striking from this evidence is its complete lack of any tendency towards the judgmental. These are individuals who do not necessarily share TH's views . One or two plainly do not. All, however, are clear that this is a situation that he would find unendurable and an affront to his dignity.

47. It is, of course, TR who knows TH best of all. They were together for 20 years. She described him as a pretty unique person, highly intelligent, very creative, with a wonderful sense of humour, with real care and empathy for and towards others. He loved his music. He played drums all his life. He had many friends and she said on the surface TH appeared sociable and full of confidence. He drank alcohol, she said, all his life to help him cope with self confidence and self esteem. But getting to know the real TH was to uncover a troubled, complex person, she said, which she attributed to his childhood. "He disliked the constraints of society around him. Drinking was an escape from his demons". He never liked hospitals. She told me he was particularly affected when his mother was transferred to a nursing home. He took himself to bed, unable to cope with her situation and overwhelmed by grief.

48. It was that period, in TR's view, that led to an increase in alcohol and also to use of cannabis which in turn caused mental health problems, she felt. He rebuffed professional help, wishing to be left on his own to deal with things his way. Following a fall in 2012, TH was diagnosed with Ataxia she said, which impacted upon his independence and ability to play the drums. He felt unable to play the drums and never did again as his coordination was effected in his arms and legs, and he no longer had feeling in his feet.

49. TR described that loss as tremendous for TH. She tried to encourage him to start drumming again to build up his strength in his arms and legs, but he refused steadfastly. Drumming, she said, was his life, and from that point he became less interested in the world around him. He hated the fact that he had to rely on people, especially to get his beer. He declined to attend the Ataxia clinic. He refused to cook. He lost his appetite. He was frightened to eat as he couldn't keep it down. Though he could drink, he refused the 'build up' drinks as TR called them. A piece of evidence which I think illuminates his own feelings about his situation. Self hygiene became more difficult. He was devastated at the thought of "strangers" coming to bath him, and pleaded with TR to continue. He said he wanted to have some dignity left.

50. He declined all support. He wished for no intervention from outside services. He was frustrated and angry with his disabilities. As he was never going to improve, he would rather die young and drink to the end he said. He expressed it uncompromisingly. "My brain is fucked, I am fucked and I want to drink as it's the only thing I enjoy."

51. At Hallamshire Hospital he does not and cannot communicate with anybody at all, as the experts have told us.

52. TR confirmed the medical view that it is now sometime since TH communicated at all. When he last spoke he appeared to be mentioning an old school friend his noises, for that is all they are, were peppered with occasional expletives. TR thought that TH 'has fear in his eyes and looked frightened'. GM agreed with that description. She told me in evidence that she was not ready for TH 'to go' but she was not here for herself, she knew what TH wanted and she would be letting him down if she failed to communicate that to me.

53. If ever a court heard a holistic account of a man's character, life, talents and priorities it is this court in this case. Each of the witnesses has contributed to the overall picture and I include in that the treating clinicians, whose view of TH seems to me to accord very much with that communicated by his friends. I am left in no doubt at all that TH would wish to determine what remains of his life in his own way not least because that is the strategy he has always both expressed and adopted. I have no doubt that he would wish to leave the hospital and go to the home of his ex-wife and his mate's Spud and end his days quietly there and with dignity as he sees it. Privacy, personal autonomy and dignity have not only been features of TH's life, they have been the creed by which he has lived it. He may not have prepared a document that complies with the criteria of section 24, giving advance directions to refuse treatment but he has in so many oblique and tangential ways over so many years communicated his views so uncompromisingly and indeed bluntly that none of his friends are left in any doubt what he would want in his present situation. I have given this judgment at this stage so that I can record my findings in relation to TH's views. Mr Spencer on behalf of the Trust does not argue against this analysis, he agrees that nobody having listened to the evidence in this case could be in any real doubt what TH would want.

54. What weight I give those views and how they balance against the available medical options for TH's future now awaits the conclusions of the structured SMART assessment and indeed any other information that comes to light in the interim but it is important to record my findings at this stage in order that they may provide a clear factual matrix in future analysis.

55. I must record that the Official Solicitor's lawyers appear not to share my analysis of the cogency and strength of TH's wishes regarding his treatment. I confess that I have found this surprising. If I may say so, they have not absorbed the full force of Baroness Hale's judgment in *Aintree* and the emphasis placed on a 'holistic' evaluation when assessing both 'wishes and feelings' and 'best interests'. They have, in my view, whilst providing great assistance to this court in ensuring that it has the best available medical evidence before it, focused in a rather concrete manner on individual sentences or remarks. To regard the evidence I have heard as merely indicating that TH does not like hospitals as was submitted, simply does not do justice to the subtlety, ambit and integrity of the evidence which, in my judgment, has clearly illuminated TH's wishes and feelings in the way I have set out.

56. I reiterate that whatever the ultimate weight to be given to TH's views it is important to be rigorous and scrupulous in seeking them out. In due course the clarity, cogency and force that they are found to have will have a direct impact on the weight they are to be given. 'Wishes' and 'best interests' should never be conflated, they are entirely separate matters which may ultimately weigh on different sides of the balance sheet.