



Neutral Citation Number: [2018] EWCA Civ 1067

Case No: 2018/0922

**IN THE COURT OF APPEAL (CIVIL DIVISION)**  
**ON APPEAL FROM THE COURT OF PROTECTION**  
**2018/PI/10770**

Royal Courts of Justice  
Strand, London, WC2A 2LL

Date: 11/05/2018

Before :

**LADY JUSTICE ARDEN**  
**LADY JUSTICE SHARP**  
and  
**LORD JUSTICE PETER JACKSON**

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Between :

<b>PW</b>	<b><u>Appellant</u></b>
<b>- and -</b>	
<b>CHELSEA AND WESTMINSTER HOSPITAL NHS FOUNDATION TRUST</b>	<b><u>(1)</u></b>
<b>RW (by his Litigation Friend the Official Solicitor)</b>	<b><u>(2)</u></b>
<b>PLW</b>	<b><u>(3)</u></b>
<b>MW</b>	<b><u>(4)</u></b>
<b>BW</b>	<b><u>(5)</u></b>
<b>A Clinical Commissioning Group</b>	<b><u>(6)</u></b>
	<b><u>Respondents</u></b>

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**Katie Scott** (instructed by **Capsticks Solicitors**) for the **First and Sixth Respondent**  
**Simon Cridland** (instructed by **RW by his Litigation Friend the Official Solicitor**) for the  
**Second Respondent**  
**Samantha Presland** (instructed by **Appleman Legal**) for the **Applicant**  
The Third, Fourth and Fifth Respondents appeared in person

Hearing dates : 28 April 2018  
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**Approved Judgment**

## **Lady Justice Sharp:**

1. This application for permission to appeal, with the appeal to follow if permission is granted, has been brought on as a matter of urgency at my direction made on 19 April 2018. At that stage I ordered there be a temporary stay of the order of Parker J made on 13 April 2018 pending the determination of the application for permission to appeal. The parties and their representatives have made considerable efforts to prepare the matter for this court at short notice; the applicant's legal team have acted *pro bono*, and we are very grateful to them.
2. The case concerns RW. RW is 77 years old and the father to four sons: the applicant PW, and PLW, BW and MW. RW is currently in the Chelsea and Westminster Hospital (the Hospital). The Clinical Commissioning Group (CCG) for RW's home area was joined to these proceedings on the direction of Parker J on 28 March 2018.
3. There is no transcript available to us of the two judgments given by the judge orally in court on 13 April 2018 and which are the subject of this application; the first of these concerns the judge's determination of RW's best interests pursuant to section 4 of the Mental Capacity Act 2005 (the 2005 Act) and the second, concerns the issue of the scope of the transparency order made by the judge covering the proceedings below.
4. To say the absence of transcripts is regrettable rather understates the position. This is not a criticism of the parties. We are told that PW's legal team were informed that legal aid to cover their conduct of the proceedings had been refused after judgment was delivered on 13 April 2018. This meant there would be no legal aid funding available to pay for transcripts for the purpose of mounting an appeal. In the event, the transcripts were ordered on 21 April 2018 (after directions made by this court that transcripts should be obtained if possible in time for the hearing before us) because the Trust and the Official Solicitor agreed to pay for them. Even so, and despite the nature of this case it has apparently not been possible for the transcripts to be produced in time for this hearing. We have instead, a reasonably full, but not a perfect note of the judgments below, agreed between the parties and approved by the judge; in the circumstances, I have set out rather more of the facts than might otherwise have been necessary.
5. RW has end stage dementia. What this means in general terms is explained by the evidence from his treating consultant, Dr L1, a consultant in acute medicine and elderly care at the Hospital.

“...Dementia is a chronic neurological condition resulting in loss of memory and other mental functions. It is progressive and irreversible and will ultimately lead to death. ‘Advanced’ or ‘end stage’ dementia means dependency in basic activities of daily living, limited or absent verbal communication, failing ability to recognise family and problems with appetite to swallowing. Difficulty swallowing is a sign that a patient is generally near the end of life.

Providing an accurate prognosis in patients with dementia is not possible in individual cases, but there are several symptoms which indicate that the patient is at the end of life stage. The necessity for artificial feeding and the loss of drive to eat and safe swallowing reflex is an indicator that end of life is approaching. Prognosis is usually limited to six months to a year.

Pain is common in patients with advanced dementia and the medical research and guidance literature indicates that this is often under-detected and under-treated. The difficulty with end stage dementia is that patients will have difficulties in communicating that they are in pain. It is therefore very important that such patients receive appropriate palliative care treatment. Palliation is ‘alleviation without cure’. It is not treatment, or withdrawal of treatment, but a reprioritisation aiming to provide comfort, relieve distress, minimise treatment burden and respect autonomy. There is no cure for dementia and, on this definition, all treatment provided for dementia is a form of palliation.”

6. On 6 March 2018 Moor J made a final declaration of incapacity pursuant to section 15 of the 2005 Act (that RW lacks the capacity to make decisions regarding his medical treatment). He also made a transparency order preventing the publication of any material identifying RW or his family or where they lived. By an interim order made on 28 March 2018 Parker J extended the prohibition to include “treating clinicians”.
7. The matter came before Parker J in the Court of Protection on 28 March 2018 for a contested one-day final hearing and comes before this court because there is a disagreement between RW’s sons on the one hand, and the respondent Trust and the Official Solicitor on the other, as to one aspect of RW’s medical treatment at the last stages of his life. This concerns the continued provision of clinically assisted nutrition and hydration (CANH) via a nasogastric (NG) tube, that is, a tube passing through his nose and then into his stomach.
8. Matters relating to RW’s treatment other than the retention of the NG tube were originally contentious, but it is not necessary to refer to them now except briefly. Thus, by the time of the hearing before Parker J on 28 March 2018 the parties were agreed it was in RW’s best interests to be discharged home into the care of his sons; and the CCG were prepared to provide a measure of support if this were to occur (by daily visits by healthcare professionals, Health Care Assistants (HCAs) and District Nurses (DNs) though the CCG have said that HCAs and DN’s would *not* be able to provide NG tube support). There was agreement that a RIG (Radiologically Inserted Gastrostomy) a small flexible tube passed through the skin into the stomach under x-ray guidance, for the provision of CANH was not in RW’s best interests, and there was agreement as to the appropriate “ceiling of care” if RW was discharged home

without a RIG, in respect of the provision of CPR, vasopressor support, inotropic drugs and all types of ventilator support. Whether or not this ceiling of care should include the administration of antibiotics (in circumstances where a RIG had been placed) was contentious at the hearing on 28 March 2018. However Parker J decided it was lawful not to provide antibiotics; nothing now turns on that aspect of her decision, it forms no part of the application for permission to appeal and I need say no more about it. I should add in relation to the RIG that the Trust's fall-back position was that if the court determined CANH should continue to be provided, a RIG was preferable to a NG tube, but that neither was in RW's best interests.

9. Subject to that, and the terms of the transparency order which I deal with at paras 59 onwards, the sole substantive issue Parker J had to determine was whether it was in the best interests of RW to be discharged home with the NG tube in place or to be discharged home for palliative care and oral comfort feeding, having had the NG tube removed before his discharge.

### *Background*

10. Before September 2017, RW had been cared for at home. His principal carer was PW, though his other sons helped. There is no issue but that RW's sons are devoted to him and only want what they consider to be best for him.
11. RW was admitted to K Hospital on 14 September 2017, when a nasogastric tube was inserted. At that stage of his admission he was acutely ill.<sup>1</sup> His sons were dissatisfied with his care there, and in a second hospital to which they transferred him on 28 September 2017.<sup>2</sup> They then transferred him (his second transfer to a third hospital within a matter of days) to the Hospital run by the Trust. Specifically, they brought him to the Accident and Emergency Department of the Hospital on 5 November 2017 and he was admitted on the same day.<sup>3</sup> The NG tube was still in situ.
12. A detailed account of what occurred thereafter is set out in the Position Statement of the Trust for the final hearing on 28 March 2018. It is unnecessary to set out what is said; it is sufficient to say the Position Statement records there were numerous instances where the NG tube was noted to have come out, necessitating chest x-rays for NG re-siting. Various options for RW's treatment on discharge were discussed between the clinical team caring for RW and the family from 23 November 2017 onwards and withdrawal of CANH was first discussed with the family (BW) on 31 January 2018 and with his other sons a few days later. Further, by the end of January 2018 the behaviour of the sons was such that the Trust placed restrictions on them visiting RW (they were allowed to visit individually for up to 30 minutes at a time) and on 16 February 2018 the sons were told by letter that they were permitted to visit RW on an individual basis during normal visiting hours, but were not permitted to remain in his room while personal care was being provided. This was because of aggressive

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<sup>1</sup>On admission he was noted as febrile and tachycardic, hypoxic and hypotensive, was suffering from pneumonia, possible osteomyelitis, had a Grade 4 sacral sore, and a Grade 3 hip pressure sore.

<sup>2</sup> On admission he was noted as suffering from sepsis, acute kidney infection with severe hypernatremia, delirium on background dementia, severe hyoalbuminemia, fluid overload, Grade 4 sacral pressure sore and Grade 3 sore on hip.

<sup>3</sup> On admission he was suffering from a Grade 4 pressure sore on his sacrum, a necrotic ulcer on his left foot, sepsis, aspiration pneumonia, and had a Glasgow Coma Score (GCS) of 4/15.

and confrontational behaviour, in respect of many members of staff but in particular Dr L1, which made it difficult for staff to provide care for RW.

13. The sons raised complaints before us as to the current position with regard to their ability to visit their father, but these are not material for present purposes.
14. RW is now ready for discharge from the Hospital in the sense that he is currently clinically stable and is not suffering from active infection. He has indeed been ready for discharge for some considerable time (since late November 2017) and it appears that but for the disagreement that has arisen as to his medical treatment, this would have occurred.
15. We asked for and have received confirmation from all sides that there has been no material change in RW's medical condition since the matter came before the judge. Though RW's medical notes for the period postdating the judgment below were disclosed by the Trust at PW's request, and then put before us by Ms Presland, it is now accepted that no useful inference can be drawn from them for present purposes, and they take the issues raised by this application no further.
16. The evidence before the judge included witness statements from the brothers (three of whom were acting in person, as they have done before us), from Ms Baker, a solicitor in the Official Solicitor's Healthcare and Welfare team who visited RW in an unarranged visit on 27 March 2018, from Dr LI and from Dr P (a gastroenterologist/nutrition consultant at the Hospital). The evidence also included an Expert Report (the Report) for the Court of Protection from Dr Levy. Dr Levy is the independent medical expert, jointly instructed by the parties. She is a consultant geriatrician and general physician at Hammersmith Hospital; she is the Chair of the British Geriatrics Society special interest group in Ethics and Law and a member of the British Medical Association's core writing group on CANH guidance, currently in preparation. On 28 March, the judge heard oral evidence from Doctor L1 and Dr Levy, and from PW, PLW and MW. She reserved judgment. By the time of the 13 April hearing, the CCG (which makes common cause with the Trust, and is represented before us by Ms Scott who appeared for both parties below) had lodged evidence from its Director of Joint Commissioning in accordance with the judge's earlier direction concerning care plans for RW's care on his discharge from hospital on the different bases argued for by the parties.
17. On 13 April 2018, the judge heard further oral submissions and delivered her judgments granting the Trust's substantive application. She further refused PW (supported by PLW, MW and BW) permission to appeal in respect of both judgments and granted a stay of her order until 4pm on 19 April 2018.
18. As is perhaps obvious from the decision taken by the Trust to impose restrictions on the family's visits to RW, there has been a breakdown of the relationship between the family and the Trust. This was referred to in the written evidence before Parker J, and was mentioned very briefly in her judgment of 13 April 2018. It formed no part of her decision on best interests however, and in my view, albeit it has been the central feature of the submissions of the unrepresented members of the family to this court, it does not advance any aspect of their application for permission to appeal. In this difficult situation Ms Presland understandably concentrated exclusively before the judge, as she did before us, on the core issues concerning RW's best interests; and did

not pursue with the clinicians, though given the opportunity to do so, as the judge recorded in her judgment, the allegations made against them by the family.

*The position of the respondents on best interests*

19. The Trust's position, and that of the Official Solicitor, before the judge was that it is not in RW's best interests for him to be discharged home with the NG tube in place. Dr L1 and Dr Levy were agreed as to RW's medical condition and that continuation of NG tube feeding was neither clinically appropriate, nor in RW's best interests from their perspective as clinicians.
20. By the time of the hearing on 13 April 2018, the judge had evidence from the CCG confirming the position set out in Dr L1's evidence, that in the event that RW was discharged into the community with a NG tube in place, the community team would be unable to provide any care in respect of the CANH and the NG tube.
21. Dr Levy recorded RW's progression at home before his admission to K Hospital, as described to her by the sons. This included that he was largely unintelligible roughly a year before admission to hospital; his mobility declined such that in the weeks prior to admission he was largely confined to bed which is why his pressure areas broke down (a recognised feature of advanced dementia where appropriate pressure care is not given); his executive function became impaired and worsened to the point he required hand feeding, and his oral intake gradually reduced. Dr Levy says this happens for two reasons in dementia. The first is an impaired swallow mechanism which is a neurological impairment reflective of the underlying neurodegeneration. The second is reduced appetite or lack of hunger thought to reflect the neurodegeneration in pathways governing hunger. A combination of these factors leads to people with dementia chewing their food for a long time or pocketing it in their mouth and forgetting to swallow – as was described as happening in RW's case.
22. Dr Levy examined RW on 16 March 2018. She says his current clinical condition is reflective of end stage dementia. Features of this seen by her are: reduced GCS with minimal fluctuation; globally reduced neurological function; no verbal output, no response to commands, no consistently reproducible voluntary motor actions; increased muscle tone and contractures due to inactivity; loss of neurological swallow mechanism and loss of hunger; bed bound and fully dependent for all care including turning in bed; incontinence of bladder and bowels; pressure ulcers (now healed). Other elements of his current physical condition are NG feeding, constipation treated with laxatives, bladder catheterisation and nasal irritation secondary to repeated NG tube insertion.
23. So far as his prognosis is concerned, Dr Levy says dementia is a progressive disease which causes decline in global cognitive and cerebral function. RW's current presentation represents the usual progression of the disease at the end stage. There is no cure and no known therapies to alter the downward trajectory of the illness at this stage. All treatment is symptomatic – that is, to anticipate and manage symptoms. RW would be expected to deteriorate until he dies. This is the usual trajectory of dementia. Given he has vascular dementia he may have more abrupt, step-wise deteriorations. He is at risk of developing infections because of his profound frailty. The presence of a long-term catheter puts him at risk of urinary tract infection; the presence of impaired swallow puts him at risk of aspirating saliva (around 500 mls produced per

day); the presence of a feeding tube puts him at risk of aspirating feed contents; while the NG is sited, frequent episodes of tube dislodgement add to the aspiration risk (since it can lodge in the lung and cause infection or airway collapse). In RW's case, high frequency nursing care, continued feeding and timely antibiotics are likely to have kept him alive for the last several months. Based on her experience and knowledge of RW, her view on his length of life if he continues to receive enteral feeding without complication and with optimal nursing care, is that he may live for months, a year, or possibly longer. If he continues to receive enteral feeding and develops complications of the treatment or any other acute deterioration this may be a terminal event. If RW stops receiving enteral feeding, he is likely to die within weeks.

24. Her assessment of his GCS is "5" in that he opened his eyes to her voice; she was unable to elicit either a motor or verbal response even to pain. There was no facial or physical response to voice. In her oral evidence she put his GCS as "4", she confirmed RW did not demonstrate a response to verbal commands; there was no motor response even to pain and no verbal response. RW's eyes did open when she pushed his hand. She was asked whether such neurodegeneration rendered him less likely to feel pain and indicated she could not say.
25. Dr Levy's opinion is that long term NG feeding in the community for adults with dementia is unusual and very rare. Long term NG feeding in the community "*has a variable evidence base*" and "*there is a paucity of evidence measuring the safety and outcomes.*" Nasal trauma, aspiration of feed, dislodgment and (rarely) intracranial passage of the tube or oesophageal perforation are all associated complications of NG tube use. RW has already suffered the complications of nasal trauma and dislodgment of the tube. It is likely that if RW is discharged with an NG tube in place it would become regularly dislodged requiring his regular return to hospital for its replacement, which would be highly burdensome to him. Being discharged home with an NG tube was not an "*acceptable or appropriate treatment course for RW*". Home NG tube feeding is not considered safe for adults.
26. Dr Levy's evidence on these sensitive topics is nuanced and careful. Amongst other things she says:

"Offering potentially life lengthening treatment in the form of CANH is no different ethically in this scenario than offering other forms of treatment .... Prolonging RW's life, with no recognition of his pain, indignity or suffering and with no potential for recovery from his progressive illness is unjustifiable to my mind and represents a futile, overly-burdensome intervention. RW can't communicate, he can't manoeuvre himself in his bed, he can't swallow more than tiny amounts, he is likely to experience discomfort in his pressure areas from his urinary catheter. I do not think I am projecting my personal view about his quality of life in saying his existence is undignified."
27. Dr L1 says the following; RW is bedbound and unresponsive, except as to pain, and he is unable to communicate. Dr L1's oral evidence was that RW's level of consciousness was significantly impaired with a Glasgow Coma Score (GCS) of "10":

that he reacted by opening his eyes, he did not react to contact, he did not obey instructions and if asked to blink he would not do so.

28. In his written evidence he set out in considerable detail the risks/benefits of various treatment options for RW. In relation to best interests it is his view that there is clinical evidence that contrary to the putative benefit, NG tube feeding is of no clinical benefit to patients such as RW. Feeding by way of NG tube can cause patients discomfort and there is evidence in RW's case that it does so. Long-term use of an NG tube causes nasal erosion and there is evidence of RW starting to suffer from the same. The more the tube is re-sited the higher the risk of aspiration or trauma to the nasal passage. There is a risk of serious harm or death if the tube is misplaced when being re-sited resulting in aspiration pneumonia; and increased pulling on the tube itself increases the risk of aspiration or trauma to the nasal passage when re-siting the same. Other generalised risks associated with use of an NG tube are abdominal cramping, abdominal swelling, diarrhoea, nausea, vomiting and regurgitation of food. *"It is generally accepted that NG tubes do not represent a practical option outside of hospitals."* Tube feeding would not lead to an improvement of RW's condition and *"at best will only prolong his current state"*.
29. Both Doctor L1 and Dr Levy also refer to the following clinical guidance from the National Institute for Health and Care Excellence (NICE) and from the General Medical Council (GMC).
30. Paragraph 1.10.14 of the NICE Guidelines 'Dementia: Supporting People with Dementia and their Carers in Health and Social Care' states that:

"Nutritional support, including artificial (tube) feeding, should be considered if dysphagia [swallowing difficulties] is thought to be a transient phenomenon, but artificial feeding should not generally be used in people with severe dementia for whom dysphagia or disinclination to eat is a manifestation of disease severity."

The relevant GMC guidance ('Treatment and Care towards the end of Life' 2010) is that:

"If a patient is in the end stage of a disease or condition, but you judge that their death is not expected within hours or days, you must provide clinically assisted nutrition or hydration if it would be of overall benefit to them, taking into account the patient's beliefs and values, any previous request for nutrition or hydration by tube or drip and any other views they previously expressed about their care."

31. On behalf of the Official Solicitor, Mr Simon Cridland who appeared below identifies what he describes as a further "dis-benefit" and/or risk of discharge home with the NG tube in place, namely that the CCG would not be able to provide assistance with tube care. Further, notwithstanding the sons' best of intentions, he says it seems unlikely they would be able to watch RW without respite for 24 hours a day. It is



submitted there is good reason to believe that RW's NG tube would continue to become dislodged requiring his return to hospital for its re-siting, just as it has in the hospital environment. This state of affairs would be contrary to his dislike of medical treatment and desire to avoid hospitalisation (although it is noted that his sons do not accept such a concern, drawing a distinction between hospital treatment as an outpatient, such as re-siting of the NG tube, and hospitalisation for a period as an inpatient).

*The family's view*

32. The position of RW's family is very different. In summary, it was (and is) contended that RW's NG tube should remain in situ on his discharge from hospital and that CANH via a NG should be continued once he is home. It is said amongst other things that RW has in fact had the NG tube since mid-September 2017 and has tolerated it well. The family would be able to provide continuous 24-hour a day care for RW which would significantly reduce the risk of the NG tube being displaced by either RW's movement or his fiddling with it. PW has significant experience of feeding with an NG tube, not only feeding with it, but of placement of the tube in a small child, so he is well versed in methods to ensure proper placement. Further PW and his brothers were trained in the use of the NG tube in late 2017. The argument is made that use of an NG tube increases the risk of aspiration pneumonia if it is incorrectly placed. However, without the NG tube the risk of aspiration pneumonia is extremely high, so much so that it would mean almost certain death. PW considers it illogical that the medical advice should be to prefer an option of controlled risk of aspiration to one of an uncontrolled risk of aspiration.
33. We do not have any note of the oral evidence given by the parties. However in setting out the position taken by RW's family, the Official Solicitor's skeleton argument provided the following (and unchallenged) extracts from their evidence as presenting a fair reflection of what they said below.
34. In his witness statement PW says:

“My father is a religious man. He believes in God, angels and spirits. He is a very spiritual man. He brought us all up throughout childhood to believe in God.” “My father is not scared of death and has always been ready for it, whenever that time may come. My father does not believe in quitting. His family motto has always been: ‘As long as we do our best, God will take care of the rest, no matter what, until the bitter end.’” ...“My father has never enjoyed any of his experiences at hospitals throughout his entire life.” ...“My Father disliked his hospital experiences to such an extent; he said he never wanted to go back to a hospital.” ...“My father was so aggrieved by his experiences in hospitals that he told [my] brothers not to call the ambulance if he had another heart attack.”
35. In his oral evidence, PW gave an account as to how his young daughter, who had a progressive neurological disorder from which she later died, had required a NG tube, how PW had been against this, and RW persuaded him that she should have it placed, and that all should be done for her.

36. PLW in his witness statement said:

“I cannot remember a time I did not know my Father wanted to die in his home rather than residential care.” ...“He told me that (i) if something like another heart attack or stroke were to happen he did not want me to call an ambulance or admit him to hospital; (ii) if it was his time to die God would take him; (iii) but, he wanted to die at home, not in some hospital.”

37. In his oral evidence PLW indicated RW was a stoical man who was against taking painkillers, even to the point of having dentistry without local anaesthetic, and that PLW was accordingly against any action that might mean RW’s need for pain relief might be expedited.

38. MW’s witness evidence was:

“My father wants to go home. I know this because, in the past, he repeatedly told me he does not want to die in hospital, and, more recently, he told me he didn’t want to go back to hospital if he had another stroke. My father would want to be fed via a NG tube. I know this because [he] would not trust this hospital to cut him open, and my father does not want to starve.”

39. In their oral evidence PW and PLW confirmed that there had not been discussions with RW when he was less compromised by his dementia as to end of life decisions.

40. The position of the family was therefore that RW should be discharged home with the NG tube in situ in order to continue CANH. In the alternative, RW should be discharged home with palliative care and oral feeding only, but that the NG tube be left in whilst he is in hospital until the moment of discharge to give as much nutrition as possible. PW said he was happy to give an undertaking in either scenario to fully and actively cooperate with those care agencies involved in their father’s care whilst he is at home in the community. Further, PW was concerned that his father was discharged as quickly as possible in light of his father’s clear wish that he would not want to be in hospital in any circumstances. The family were asked during the hearing before us whether this remained their position; Ms Presland for PW, and each of the brothers, specifically confirmed that it did.

### *The Legal Framework*

41. The legal principles that guide decision-making when determining best interests are well known and not now contentious in this application. One of the Grounds of Appeal raised in writing on behalf of PW was to the effect that the approach to best interests might be different if an individual is in a more than minimally conscious state (as RW is); and that in those circumstances, greater weight should be afforded to the principle of the sanctity of life. However this Ground was abandoned during the course of oral argument. What is in issue is not the judge’s approach to the law, but

her appraisal of the evidence and the weight given by her to some of the factors she had to consider. In those circumstances I can deal briefly with the law.

42. Section 4 of the 2005 Act 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."

43. In *Aintree v James* [2014] [2013] UKSC 67; A.C. 591 Baroness Hale said 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."

44. Best interests in this context goes beyond clinical best interests as Baroness Hale explained in *Aintree* at para 39. There she said:

“The most that can be said, therefore, is that in considering the best interests of this particular patient at this particular time, the decision maker must look at his welfare in the widest sense, not just medical but 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.”

45. As to the approach to be taken to P’s wishes and feelings if they are ascertainable, see the observations of Munby J (as he then was) in *ITW v Z* [2009] EWHC 2525 (Fam) in particular at paras 32 and 35; see also the observation made by Hayden J in *Abertawe Bro Morgannwg University Local Health Board v RY & Anor* [2017] EWCOP 2 that the court must try and ascertain P’s wishes and feelings and beliefs and values; but if they are not ascertainable, it is wrong to speculate. Further, whilst the court may find creating a balance sheet to determine best interests to be a useful tool (see *Re A* [2000] 1 FLR 549 at 560) “a balance sheet ...should be a route to judgment and not a substitution for the judgment itself”: per McFarlane LJ in *Re F (A Child (International Relocation Cases))* [2015] EWCA Civ. 882.

46. I should also set out para 62 of the judgment of Charles J in *Briggs (No 2)* [2016] EWCOP 53; we were told the judge read this into her judgment, though its effect does not appear to have been accurately recorded in the Note of Judgment. Charles J said:

“...in my view when the magnetic factors engage the fundamental and intensely personal competing principles of the sanctity of life and of self-determination which an individual with capacity can lawfully resolve and determine by giving or refusing consent to available treatment regimes: (i) the decision-maker and so a judge must be wary of giving weight to what he thinks is prudent or what he would want for himself or his family, or what he thinks most people would or should want; and (ii) if the decision that P would have made, and so their wishes on such an intensely personal issue can be ascertained with sufficient certainty it should generally prevail over the very strong presumption in preserving life.”

47. To this I would only add a brief reference to the Code of Practice to the 2005 Act, to which every decision maker, including the court, has a statutory duty to “have regard”: see section 42 of the 2005 Act. Paragraph 5.31 of the Code provides:

“All reasonable steps which are in the person’s best interests should be taken to prolong their life. There will be a limited number of cases where treatment is futile, overly burdensome to the patient or whether is no prospect of recovery. In circumstances such as these, it may be that an assessment of best interests leads to the conclusion that it would be in the best interests of the patient to withdraw or withhold life sustaining treatment, even if this may result in the person’s death. The decision-maker must make a decision based on the best interest of the person who lacks capacity. They must not be motivated by a desire to bring about the person’s death for whatever reason, even if this is from a sense of compassion. Healthcare and social care staff should also refer to relevant professional guidance when making decisions regarding life sustaining treatment”

48. So far as the approach of the Court of Appeal is concerned it is important to note that if a judge has correctly directed herself as to the law, an appellate court can only interfere if it is satisfied that her decision was wrong; further, that in sensitive and difficult cases of which *Aintree* is an example, and in my opinion this one is as well, an appellate court should be very slow to conclude that the judge below was wrong: see para 42 of *Aintree*,

#### *The Grounds of Appeal*

49. Two central criticisms are made of the judgment below, and the judge’s determination of best interests. First, that the judge failed to appreciate and therefore give any or any adequate weight to RW’s wishes and feeling. These were, contrary to her findings, ascertainable; they pointed to the fact that he was a “fighter”, to the value he ascribed to life and to his desire to “hold fast to it” no matter how “poor” or “vestigial” in nature it was. Secondly, the judge overstated the risk that having the NG tube in place would pose for RW at home and the burden this would place on him, in circumstances where the dedicated care his sons could provide would remove or mitigate that risk. In the result, and in any event, it is submitted the judge’s overall analysis of what was in RW’s best interests failed adequately to address the relevant issues and evidence, and was a flawed one.
50. In my view neither criticism is well-founded. When determining what was in RW’s best interests it is apparent that the judge carefully assessed the evidence and arguments (including those to which I have referred and which are now advanced again on the family’s behalf) within the correct legal framework, having had the benefit, which we have not had, of hearing oral evidence from the family and the clinicians on the matters in issue.
51. With regard to the legal framework, the judge identified the two fundamental principles engaged to be the principles of sanctity of life and the right of self-determination. She observed that the sanctity of life was a strong but not absolute principle. She approached the issue of RW’s welfare, in accordance with the guidance given in *Aintree* at para 39. She further identified the importance of attempting to

ascertain what RW's wishes and feelings would have been. She reminded herself that, in the absence of sufficient evidence, it is wrong to speculate as to what P would have wished or wanted; and she adopted a balance sheet approach whilst at the same time reminding herself that this should be used as route to judgment and was not a substitute for the judgment itself.

52. I have seen nothing supportive of the contention that her appraisal of the evidence to which those principles had to be applied was flawed. The evidence including that which came from RW's sons, was that RW strongly disliked hospitals and would want to return home to die; that he was a religious man with strong spiritual views ("*if it was his time to die God would take him*"), and that he had been in favour of a NG tube when one was indicated for his baby granddaughter. There was however no express indication when he had capacity, as to what he would have wanted in the circumstances that have arisen here. It was not suggested in evidence for example that his spiritual or religious beliefs were such that he would have been opposed to the withdrawal of CANH on such grounds.
53. In the event, the judge concluded the evidence as to RW's wishes, feelings and beliefs did not establish what his beliefs as to the withdrawal of treatment would likely have been. On the material before her, in my judgment, this was a view she was entitled to reach. Thus, whilst she accepted that RW would have wanted to die at home, the judge took the view that what he would have wished for in respect of the continuation of CANH was "*far less clear*" and that without evidence of sufficient quality as to RW's wishes and feelings on the issue, it would be wrong to speculate. It is true there was no evidence that RW held the view that CANH should be withdrawn from him, but this did not preclude a finding by the judge that its continuation was not in his best interests.
54. Equally it seems to me that there is no discernable flaw in the judge's appraisal of the evidence.
55. She gave careful consideration to the risks associated with oral feeding. She had in mind that a risk associated with removal of the tube and palliative care was aspiration through oral feeding and that the same might accelerate RW's demise. However, as the judge said (at para 45 of her judgment) aspiration of food or saliva was also a risk associated with continuation of the NG tube. She also considered the evidence that the presence of the NG tube caused RW discomfort and that he fiddled with it in a way that indicates he wants to remove it (the clinical records showed for example that for a period in February the tube had been pulled out 9 times in 10 days). In that context in my view she was entitled to have regard to oral evidence of both Dr L1 and Dr Levy in response to a question from her, that the insertion and removal of the NG tube was very painful (Dr L1 described how as medical students they practised the placement of NG tubes on one another and the discomfort he experienced, and Dr Levy spoke of her clinical experience that some patients found it so unpleasant they would fail to seek treatment as a consequence).
56. Contrary to the submissions made by the family, it is apparent that the judge did consider the effect of the care they could provide at home on the risk of the NG tube being dislodged or removed. However it was open to her to conclude that the evidence as to how their presence affected such matters (particularly on RW fiddling with his tube when he was in Hospital) was limited; and further, that "*their proposed*

*regime [discharge home with the NG tube in place] is untried and untested and many things could go wrong.”*

57. Taking what she said from the Note of Judgment, the judge in the end determined as follows:

“51. I accept that the brothers are utterly sincere in their proposal to me. That comes across from their presentation in court and their evidence. Their commitment is wholly commendable. However, their proposed regime is untried and untested and many things could go wrong. They accept that if the tube becomes dislodged RW will have to go to hospital. I have heard evidence that RW would not have wanted that bearing in mind his attitude. Hospital visits will be disruptive, and transporting him could be traumatic and disorientating.

52. These questions are secondary. The key question is whether it is in RW’s best interests to have the NG tube at all. I have thought long and hard about that. I have thought about how the plan could in reality work. It is simply not possible to discount the serious risk of pain and suffering and other invasive procedures if NG feeding is continued.

53. The key question is what is the best regime for RW in these circumstances and at the end of his life.

54. I conclude that CANH is no longer justified. Dr L1 says it probably never was justified. There is no question in my mind of a RIG being justified.

55. I accept that palliative treatment is not risk free and there is a real risk of aspiration leading to death, but this is only part of the balancing exercise.

56. I agree with the parties that I am not bound to continue the promulgation of life. The sanctity of life is not absolute. I accept the clinical evidence of Dr L1 and Dr Levy. I have considered the detailed list of benefits as set out in Mr Cridland’s position statement, which I have used as a route to judgment. I have considered, even if I have not cited, every element of that list.

57. I accept that the benefit of continuing to receive CANH via an NG tube can be summarised as the opportunity to live longer.

58. The disbenefits as explained by Dr L1 outweigh those benefits, being the risk of displacement of the tube, the risk of aspiration of food etc., discomfort, and nasal erosion. I find that overall the option of continuing to receive CANH via NG tube is not clinically appropriate and is unsafe. I accept palliation



would make RW as comfortable as possible and ensure his dignity and comfort. He will pass away with palliation in a dignified way...”

58. For my part I am not persuaded she fell into error, even arguably, in arriving at these conclusions. I would accordingly refuse permission to appeal, and lift the stay imposed on the judge’s order.
59. Before leaving this aspect of the case I should add that the applicant faced an additional difficulty, which was not specifically addressed before the judge below but which we raised with the parties during the course of argument.
60. It is common ground that RW’s NG tube would need to be replaced at regular intervals (every 4 to 6 weeks) even if it was not otherwise dislodged or pulled out by RW or displaced during the course of his care. There was however no evidence that any doctor or hospital would be prepared to replace or re-site the tube. This matters because no doctor could be ordered by the court to provide such treatment; and in any event, whether such treatment was clinically indicated would depend on his medical condition at the time (as to which there is an inevitable degree of uncertainty). Ms Scott says the Trust considered it unlikely that the family would bring RW back to the Hospital, given the history, but if that were to occur the Trust could not say whether or not the NG tube would be replaced; all Ms Scott could say was that it would depend on the circumstances. In view of the outcome of this application, the point no longer arises. But it seems to me the practical problems of the family’s preferred option should have been explored in evidence so the court could consider whether the order and outcome contended for by the family was actually achievable in practice or not.

*The Transparency Order: the factual background*

61. Mr Brian Farmer of the Press Association, a very experienced court reporter, was present in court on 28 March 2018 when the transparency order in this case, made on 6 March 2018, was extended to cover the Trust, and he raised some concerns which the judge invited him to put in writing. He did this in an email of 12 April 2018 annexed to the judge’s (second) note of judgement concerning the terms of the transparency order. In that email Mr Farmer said he was particularly concerned about the Trust being anonymised. He stressed that he was not asking to be allowed to identify doctors or nurses or RW. His view was that the right balance in this case would be struck if the press were allowed to name the Trust, and report RW’s age but “an invisibility cloak” was thrown over everyone else (he added, in parenthesis, that he did not have enough information to mount any argument for naming RW, but if the sons were making that argument he may well support them). He made some more general points about the way in which the transparency project was working which may merit some examination, but do not strictly fall within the ambit of this application.
62. In the event, before the parties came into court on 13 April 2018 it was agreed on all sides that the Trust could be named. The contentious issue regarding the transparency order by that stage was whether the family, RW and the clinicians should be named.

63. The family's submissions in short were that RW had led a public life; he had been very involved in various movements such as Families Need Fathers, and had run twice for Parliament. It was said he would want to be named to see an injustice righted, and would have welcomed the publicity. Their position was that Dr L1 should also be named as the "decision-maker".
64. This application was opposed by the Trust and the Official Solicitor. The starting point of the Official Solicitor was that RW should not be named. He was, it was said, a highly vulnerable individual; one of the most vulnerable, who could have no perception in the active stage of his life of the risks to him if when caring for him the family were put under pressure. This was particularly important because the proposal was that RW return home. If any of the family were identified it could lead to the disclosure of the identity of RW; the public could turn up and harass those providing care for him in his home. Further Dr L1 should not be hampered in caring for RW, a point supported by the Trust. In this connection Ms Scott referred to the serious allegations being made by the sons against Dr L1, and Ms Watt of the Trust, and said the clinicians "*should be able to provide care and take actions they genuinely and reasonably believe to be in a patient's best interests...without fear of personal castigation.*"
65. The judge rejected the family's submissions. In relation to Dr L1 she mentioned the allegations made against him by the family. She said it was plain the sons adhered to the allegations and intended to raise them; and took the view she could and should protect Dr L1 from being named as the clinician who gave advice and evidence on the withdrawal of life sustaining treatment in respect of RW. She said if the allegations had been true, they would have been relevant to the determination of best interests, but she had not ruled on them as they were not pursued. She went on to say however: "*I make it clear that on the evidence I heard I was perfectly satisfied as to his professionalism and in person by the measured and objective way in which his evidence was given.*"
66. The judge further accepted the Trust's submission that Dr L1 could not be solely responsible for the medical decision that led to the application coming to court. She recorded Ms Scott's submission that all the public needed to know to be properly informed as to what may be considered to be a controversial decision was the name of the Trust and the independent expert. Further, there was an argument that if the sons were going to make a case against Dr L1 in public, it may be an advantage for him (Dr L1) to be able to rely on her judgment. But she said the Trust could apply to vary the Order, and this was not a reason not to give Dr L1 the protection that he required. "*In the immediate aftermath of a decision, feelings run at their highest.*"
67. In the end, her conclusions were these. Whatever may have been RW's attitude to public life earlier in his life, "*we are in entirely different territory*" and she accepted as Mr Cridland had submitted, that this vulnerable adult should be protected at the end of his life. She said the case of *Westminster City Council v Manuela Sykes* COP123838T to which Mr Farmer referred, was different as the individual in that case was able to articulate her wishes and feelings to be named in public. She decided that the respondents (the sons) must be restrained from identifying themselves to protect the identity of RW and that the transparency order made by Moor J should be continued. She decided the identity of Dr L1 was not to be disclosed and therefore the extension to the transparency order made by her on 28 March 2018 was to be

maintained. She said she was troubled by the very forceful reactions to this decision from the sons (PW and BW had now left the court in some agitation) and how that might impact on Dr L1; she regarded Dr L1 as requiring protection from others who may learn more about his decision and be concerned about it. She said that there was nothing stopping the sons from discussing the facts in this case with the Press on an anonymous basis but that the primary concern was the protection of RW. She regarded the question of his identification as far from fanciful and said that “*Doctors need to be able to get on with their jobs in the interests of other patients.*”

68. The transparency order made below obviously does not govern the approach to be adopted at the hearing of the application for permission to appeal. However, we took the view that in the circumstances, it would be appropriate to maintain the order to cover the hearing before us pending our determination of the issues raised by this part of the application.

### *Discussion*

69. Transparency orders are now the norm in the COP. The standard form of such an order for hearings where the parties attend to resolve a dispute, called “attended hearings” (including serious medical cases) provides that they should be held in public, but with a prohibition on the publication of material identifying P or P’s family. See Part 4 of the COPR 2017 and its associated Practice Direction, PD 4C, in particular para 2.1(a) and (b) and para 2.3 of PD 4C.
70. There is nothing surprising in any of this. The default position reflects the importance attached both to open justice and to the principle that in “*jurisdictions dealing with detention, care and treatment of people with mental disorders and disabilities, the starting point is usually privacy and always anonymity, although either or both may be relaxed.*” Per Baroness Hale in *R(C) v Secretary of State for Justice (Media Lawyers Association intervening)* [2016] UKSC 2 para 26. See also the lucid explanation of the rationale for not identifying P in COP proceedings given by Lord Judge LCJ in *Independent News Media v. A* [2010] EWCA Civ. 343 at paras 18 and 19; and *V v. Associated Newspapers Ltd* [2016] EWCOP 21 at para 91 where Charles J said the default position represented a general conclusion as how best to administer justice but that it would be wrong to approach it as creating a presumption. As Peter Jackson J, as he then was, explained in *The Press Association v. Newcastle upon Tyne Hospitals Foundation Trust* [2014] EWCOP 6 at para 35, the competing interests between on the one hand, the fact that the COP will receive personal information of a private nature arising at around the end of P’s life which P could reasonably presume would not wish to be made public; and the importance of the public having access to information as to how decisions are reached in the COP are “*normally reconciled*” by anonymising P.
71. The extent of the challenge to the transparency order made by Parker J is now only to that part of it which prohibits the identification of RW and therefore, by extension, the identification of his family. Two matters are raised in PW’s Grounds of Appeal: first, that the judge failed to consider RW’s likely views when determining whether his name should be made public; and secondly, access to justice. The latter point concerned the sons’ wish to publicise this case for the purpose of ‘crowd funding’ PW’s appeal, but this is now accepted to be academic as PW’s legal team has continued to act *pro bono*.

72. Contrary to the first ground, it is clear that the judge did consider RW's likely views. The real complaint so it seems to me, is with the judge's assessment of the facts. Such an assessment has to be made before striking the balance between the different rights that are usually engaged in such cases, but which come into particular focus when these matters are contentious (P's right to respect for private life protected by Article 8 of the ECHR and the right to freedom of expression protected by Article 10 of the ECHR). This 'conflict' of rights is of course then resolved in accordance with the approach articulated by Lord Steyn in *In re S (A child)(Identification: Restrictions on Publication)* [2005] 1 AC 593, at 603G. See further *V v. Associated Newspapers Ltd* for a detailed examination of the balancing exercise as undertaken in COP proceedings, where it was said (at para 163) that there may be some cases where the individuals involved can be named.
73. Ms Presland did not address us on the law; instead she shortly re-iterated the points made below with a view to demonstrating that the judge arrived at the wrong result. Supported by the unrepresented litigants, she said that RW would have wanted to be named. She submitted there is no real detriment to RW in taking this course and it would not disrupt his care either at home or in the Hospital were this to occur. Further, there is no indignity in people knowing that RW suffers from dementia, or the medical facts relating to his condition. Mr Farmer, who had been notified of the application for permission to appeal, and who made brief oral representations at our invitation, supported Ms Presland's submissions, subject only to an assumption made by him that if the applicant were to succeed, any order would ensure RW would be identified only after he was 'cocooned' as he put it, at home.
74. The task undertaken by the judge in balancing these different considerations is an evaluative one, akin to the exercise of discretion. This court will not interfere therefore unless the judge erred in principle or reached a conclusion which was plainly wrong, that is, one outside the ambit of conclusions which a judge could reasonably reach: see *Browne v Associated Newspapers Ltd* [2007] 3 WLR 289 at paragraph 45 and *JIH v New Group Newspapers Ltd* at para 26. In this respect I can see no distinction in principle between the Court of Appeal's approach to the balancing exercise undertaken by COP judges at first instance and to those undertaken by first instance judges in other areas of the law where similar rights are engaged. I would be very slow therefore to interfere with an assessment of how the balance is to be struck in such cases, particularly where, as here, the judge has seen and heard from those most closely involved, and will inevitably have a much better feel for the dynamics of such a sensitive and difficult situation.
75. I am not persuaded there are any arguable grounds for interfering in this case. As may be clear from what I have already said, it seems to me that we were in essence merely being invited to substitute our view of how the balance is to be struck for that of the judge, arrived at, as it was, after due and careful consideration.
76. The starting point provided by the rules in the COP is that a hearing (if attended) in a serious medical case should be held in public with a prohibition on the identification of P (the standard order, as was made by Moor J on 6 March 2018). RW lacks capacity; he has an obvious interest in the confidentiality that would normally attach to his medical treatment and to his condition and the detail of it, in the last stages of his life. He is extremely vulnerable and he requires protection. It is of course clear that RW himself has no appreciation of what is going on. As the judge recognised

however that does not mean RW does not have an important interest to be weighed in the scale, as to his own dignity and privacy.

77. I agree with Peter Jackson LJ's further observations made in his judgment in draft, which I have seen, and specifically in this context, those made in relation to reporting restrictions.
78. I quite accept that there are elements of this case that meant the decision to be made here was not an entirely straightforward one. The arguments put by the sons for taking a different course to the usual one for someone *in extremis*, have some weight, because of their knowledge of their father and his general views on life. The judge grasped this however, and distinguished this from RW's views on death, about which she could draw no real conclusion. And it does not follow, as Ms Presland seemed to suggest, that because RW was in the public eye to the extent mentioned (involvement in charity work and standing for Parliament) in his current state, he would wish to be identified as P in these proceedings, with all that this would entail. As the judge put it, "*Whatever may have been RW's attitude to public life earlier in life, we are now in entirely different territory...*". There is also a public interest more generally in withdrawal of medical treatment from people with end stage dementia, particularly when families and clinicians cannot agree. The judge was obviously conscious of this, and there was nothing in her order that prevented either the particular features of RW's care and any wider issues this case may raise from being publicly aired, on an anonymous basis.
79. There were other specific features of the case that also had to be taken into account, in the light of the past difficulties and the legitimate concerns to which these had given rise. One feature, identified by Dr Levy, was the sons' lack of insight, the continued reports from those professionals caring for RW of their confrontational and aggressive behaviour including in the home environment (which they disputed), and their inability to separate out RW's likely wishes and feelings from their own. I should add that these matters were raised by her in a measured way, not to cast doubt on the sons' devotion to their father, of which she was convinced, but because of the impact these features might have on RW's future care. There is no doubt that the sons wish to air their views that their father has been subject to various forms of mistreatment and injustice and to seek publicity to pursue that agenda. These are, as is clear, highly disputed issues and were not pursued before the judge. The real point is however that this case is about RW; it is not about his sons' fight with the Trust. Against this background I do not think the judge (or we) could be sanguine about what would happen if RW were to be identified in the period leading to his death, or that we can be reasonably sure as Ms Presland suggested that this case will not attract much attention; or that if it does, publicity will have no impact on RW's future care (because if the NG tube is removed he will go home, and die peacefully there). That may or may not occur; but it is certainly possible that he may be in a number of different settings in the period to come. Whether that occurs or not, there is it seems to me a real risk that publication of RW's identity could lead to public intrusion into his life which would interfere with the ability of his sons and professional carers to care for him in these final stages of his life.
80. This brings me to the duration of the order. We do not have a copy of the order made on 13 April 2018 as it has yet to be drawn up, and the duration of it is unclear (the earlier transparency orders extended to the period of these proceedings). If my Lord

and my Lady agree, I would propose that the order made prohibiting the identification of RW and his sons should continue during his lifetime. It has not been suggested that it should continue after his death. However that part of the transparency order prohibiting the identification of the individual clinicians in connection with these proceedings should continue until further order. There should in any event be liberty to apply to this court in respect of the terms of the transparency order.

81. I would only wish to add that whatever difficulties there have been in the past, at no stage has anyone doubted the family's love and devotion to RW; this manifested itself in their submissions to us, and in the admirable and moving willingness of these four young men to take on the very considerable responsibility of caring for their father, whatever the outcome of these proceedings.
82. I would therefore refuse the application for permission to appeal on all grounds and, if my Lord and my Lady agree, I would ask counsel in the case to draw up an appropriate order reflecting this judgment, with liberty to apply to this court. In view of the issues raised, I would also give permission for this judgment to be cited in future cases.

**Lord Justice Peter Jackson:**

83. I agree with the reasons and conclusions of Sharp LJ, both as to the best interests decision and the question of reporting restrictions.

*Best interests*

84. Any decision about medical treatment at the end of life, particularly where there is disagreement, requires acutely careful consideration. The decision in the case of RW has received just such consideration from his family, from his medical team at the hospital, from an independent expert of the highest standing, and from Parker J. Now that this court has also looked into the matter closely, I am clear that this application does not cross the threshold for the granting of permission to appeal.
85. Where an individual lacks capacity to make their own decision, the decision must be made in their best interests: MCA 2005 s.1(5). The determination of best interests takes place in accordance with the framework in s.4, set out above. The broad-textured nature of that section allows, indeed encourages, the decision-maker to reach the decision that is right for that individual in that situation.
86. Here, the judge took into account all relevant factors, medical and non-medical, when reaching her conclusion about whether the continued use of an NG tube at home would be in RW's best interests. She gave full weight to the importance to RW of prolonging his life, but she rightly did not treat that as the only consideration. She also weighed the purpose and the burdens of the treatment for him in a situation where his quality of life is extremely poor and where no recovery can be achieved. That is what the law requires: see the MCA Code of Practice [47] above.
87. In relation to medical matters, the judge balanced the risks and was entitled to accept the unanimous professional evidence that maintenance of the tube at home was not an appropriate option.

*Wishes and feelings, beliefs and values*

88. As part of her analysis, the judge also paid careful attention to RW's reasonably ascertainable wishes and feelings, and to the beliefs and values that would be likely to influence his decision if he had capacity, as required by s.4(6)(a) and (b).
89. The Law Commission's recent review of the law relating to Mental Capacity and Deprivation of Liberty Safeguards recommends a legislative addition to s.4(6), so that decision-makers should "*give particular weight to any wishes or feelings ascertained*". In its response on 14 March 2018, the Government accepted this recommendation, noting that the principle of taking account of an individual's wishes and feelings is very important and already represents good practice.
90. In this case, it was common ground that RW would wish to be at home rather than in hospital, though unfortunately the disagreement about his care package has kept him in hospital for months longer than necessary.
91. But RW cannot in his current predicament make known any wishes and feelings about tube feeding for himself in his current condition. Nor had he expressed a view about it in the past. The judge was therefore entitled to conclude that she could not reasonably ascertain his wishes and feelings on that matter.
92. In those circumstances, the judge inquired into RW's beliefs and values. As required by s.4(7), she took into account the views of his sons about his outlook on life and about his welfare. She appreciated that he had always been a public-spirited man of strong opinions, but that did not lead her to conclude that he should in consequence be subjected to unsafe and inappropriate medical treatment.
93. As a society, we rightly treat life as precious, but the ultimate purpose of our existence cannot be to live as long as we possibly can, regardless of suffering and indignity. Even for those who see illness and death as a battle, the true mark of a 'fighter' will sometimes be the courage to accept that treatment can no longer bring benefits.
94. Where a person cannot speak for himself, his family members and carers are often an invaluable source of information about his values and his best interests. At the same time, the illness of a loved one is a harrowing experience for the relatives themselves. It is important that the strength and conviction of their views is not allowed to detract from a steady appreciation of the welfare of the individual concerned.
95. The judge clearly took this approach. I do not accept that she gave inadequate weight to the wishes and feelings, beliefs and values of RW. She carefully considered the views of his sons, but she did not translate these into a requirement for treatment that was medically inappropriate. This was a conclusion she was fully entitled to reach on the evidence before her.

*Two further matters in relation to the best interests decision*

96. The first relates to the original ground of appeal, which read:

"It is contended that above a 'minimally conscious state' the sanctity of life should absolutely prevail regardless of other

balance sheet considerations, unless there is very clear and cogent evidence that P himself would have wished to have CANH withdrawn...”

During the course of the hearing, Ms Presland wisely abandoned this contention. The framework for the assessment of best interests is a universal framework, regardless of diagnosis, and attempts to load the scales in this manner should be firmly resisted.

97. Secondly, I would echo what is said by Sharp LJ at [59-60] above. A court considering a decision of this seriousness must have the realistic treatment options clearly in mind. There is no purpose in deciding whether a particular option is in the best interests of the patient if it is not in fact known to be available. In RW’s case, there is considerable uncertainty as to whether any hospital would re-intubate him after discharge from hospital, and that to my mind was a matter that the judge would have needed to further investigate if she had been minded to conclude that the NG tube should be maintained.

#### *Reporting restrictions*

98. I agree with Sharp LJ that this court is required to review the restrictions that should apply following this application, and also with her conclusion that the balance struck by the judge should not be disturbed. In cases of this nature, the balance between Arts. 8 and 10 will normally be found to tip in favour of protecting the identity of the individual concerned. Individuals and families coming before the Court of Protection in often extreme circumstances should not have the further worry that they are likely to be identified to the public at large.
99. There will be occasional cases (Derek Paravicini, Steven Neary, Manuela Sykes) where individuals are named. Of these, the last is most directly relevant to the situation of RW. Ms Sykes was a campaigner who, before losing capacity, had placed much information about herself and her dementia in the public domain. It is said by RW’s sons that he would want the same, largely so that alleged shortcomings in his treatment at various hospitals could be publicised to the greatest effect. It is said that information about RW could be selected for publication, so as not to expose the indignity of his current condition. I do not find these arguments persuasive. There is no dependable evidence that RW would want his most private information to be identified to the world at large, and any grievances expressed by his sons (which find no support in the judge’s judgment) are theirs, not his. The proposal that there should be a partial embargo, for example on photographs that we have seen of RW in his current condition, risks misinforming, rather than informing the public. I therefore agree with Sharp LJ’s conclusion and her reasons, more fully expressed, as to the continued anonymisation of RW and his family members, and as to the duration of the order.

#### **Lady Justice Arden:**

100. I agree with both judgments.