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Case No: COP13605336

COURT OF PROTECTION

Royal Courts of Justice
Strand, London, WC2A 2LL

Date: 22/05/2020

Before:

MR JUSTICE WILLIAMS

Between:

WARRINGTON AND HALTON HOSPITALS NHS FOUNDATION TRUST

Applicant

-and-

GTI

(by his litigation friend, the Official Solicitor)

Respondent

- -
- -

Mr Adam Fullwood (instructed by **Hill Dickinson**) for the **Applicant**
Ms Bridget Dolan QC (instructed by **the Official Solicitor**) for the **Respondent**

Hearing dates: 22 May 2020

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Approved Judgment

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

....

MR JUSTICE WILLIAMS

The judge has given leave for this version of the judgment to be published. 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.

Covid-19 Protocol: This judgment was handed down by the judge remotely by circulation to the parties' representatives by email and release to Bailii. The date and time for hand-down is deemed to be 13.30PM on 22nd May 2020.

Mr Justice Williams:

Introduction

1. I have today been hearing an application by Warrington and Halton Hospitals NHS Foundation Trust for declarations and orders pursuant to the Mental Capacity Act 2005 in respect of a man who is to be known as GTI,

    a. that he lacks capacity to conduct these proceedings or to consent to medical treatment in relation to the insertion of a percutaneous endoscopic gastrostomy ('PEG') or a radiologically inserted gastrostomy, together with associated ancillary treatment' and
    b. that it is in his best interests to undergo such a procedure
    c. and that the court consents to it on his behalf.

2. The declarations and orders are fully set out in a draft order.

3. Having read and heard the evidence and submissions I made the declarations and orders and gave the necessary consents at the conclusion of the hearing. At that point I gave my brief reasons for acceding to the application and confirmed I would deliver a written judgment later. This is that judgment.

4. The Applicant Trust was represented by Mr Adam Fulwood Counsel. P was represented by Ms Bridget Dolan QC instructed by GTI's litigation friend the Official Solicitor.

5. At the commencement of hearing I approved a transparency order in standard form save for amendments to reflect the remote nature of the hearing necessitated by the Covid pandemic.

Background

6. GTI is now aged 45. He has an established history of schizoaffective disorder which appears to date back to 1997 but is certainly well evidenced from 2006 onwards. It has been controlled with psychotropic medication and he has lived in supported accommodation in the community. In his conversations with the Official Solicitor he described a fairly conventional daily routine for an individual unable to work. Preparing meals, shopping, socialising in the pub, cooking and watching television. However in January 2020, during what appears to have been a paranoid episode, he appears to have stabbed himself in the neck causing significant damage to his recurrent laryngeal nerve. This is the nerve which controls the muscles of the larynx and as a result, following surgery, it became apparent that the neurological damage had affected his swallowing reflex and he is now unable to take food or drink orally without significant risks of aspiration; food and drink passing into the lung. This carries with it the risk of recurrent aspiration pneumonia and physical asphyxia leading to respiratory arrest.

7. Following the operation GTI was an inpatient at Aintree Hospital and initially agreed to the insertion of a PEG. However, on 9 March he was detained under section 2 of the Mental Health Act 1983. The PEG procedure was planned for 11

March 2020 but by then GTI's position had changed and it did not go ahead as there were concerns about its legality.

8. He was discharged on 26 March from Aintree Hospital to Hollins Park Hospital, a mental health unit, with a naso-gastric ('NG') tube in place. He pulled this out within 24-hours of admission to Hollins Park. He was then admitted pursuant to section 17 MHA 1983 to Warrington Hospital where he still remains.

9. Since then numerous attempts have been made to encourage GTI not to interfere with his total parenteral nutrition ('TPN') lines and to agree to the PEG insertion but without success. He has been able on two occasions to drink water from a tap whilst having a shower and obtained a piece of chocolate. He is now supervised permanently by two mental health staff which is plainly highly intrusive.

10. Unfortunately, GTI does not accept that he is unable to eat or drink normally. These seem to be perhaps two of the significant pleasures in his life but he is unable to accept the risks of aspiration or asphyxia. Since the injury he has been fed either by NG tube or directly into his bloodstream by TPN but GTI is resistant to these measures which are in any event only ever contemplated as temporary measures. He has removed several NG tubes and TPN lines inserted to feed him.

11. At the time of the best interests discussion that took place on 20 May GTI had been given 4 bags of TPN over the last nine days, none of which had been finished and completed and so he has had far less than the appropriate nutritional input. Overall it is believed he has had four days' worth of food in the last 51 days. Extracts from the dieticians record of his weight show the following (all in Kg)

10 Feb 93
24 Mar 85.5
2 April 76
11 April 71.5
28 April 72
22 May 66.7

Thus it is apparent that GTI has lost 26.3kg, close to 30% of his body weight.

12. GTI has a fully functioning digestive system and hence the clinical advice is that a PEG tube which delivers food to his stomach and utilises his digestive system is the best way of achieving adequate nutrition.

13. A further complication is that GTI's clozapine medication which has kept his schizoaffective disorder well-controlled has had to be stopped because he has begun to develop agranulocytosis, a well-recognised adverse side effect of clozapine. The development of this side-effect is caused by his deteriorating physical condition associated with the lack of nutrition.

These proceedings

14. It is clear from the evidence of the clinicians that GTI 's ongoing care has been the subject of multidisciplinary collaboration over the last three months. It has become apparent that attempts to deliver nutrition by the nasogastric tube or by TPN have not achieved anything like the delivery of nutrition necessary to sustain GTI 's health. His position has become urgent partly because of the risk to his physical health arising from malnutrition, including sustaining an infection between the 17 and 19 of May but also because of the inability to provide him with the clozapine medication that is essential for the restoration and maintenance of stability of his schizoaffective disorder.

15. At the clinical decision-making meeting which took place on 20 May 2020 the conclusion was reached that the insertion of a PEG was in GTI 's best interests. The decision was then taken to issue proceedings in the Court of Protection in order to seek the court's authorisation for that operation on the basis that GTI lacked capacity to take the decision himself and that the consensus of all present was that it was in GTI's best interests to urgently undergo the insertion of a PEG. The clinical team hoped to carry out the procedure on the afternoon of 22 May.

16. The Official Solicitor was notified of the application on 21 May and instructed counsel. Mr Edwards, a lawyer at the office of the Official Solicitor, spoke to GTI and to GTI 's mother on 21 May.

17. The application has therefore come before me this morning; the 22 of May. I have been provided with position statements by Mr Fulwood on behalf of the NHS Trust and Ms Dolan on behalf of the Official Solicitor. A bundle of documents including

    a. A capacity assessment and witness statement of GTI 's Consultant Psychiatrist
    b. a witness statement from Dr Loo, the Consultant Gastroenterologist responsible for GTI 's treatment,
    c. The minutes of the clinical decision-making meetings.
    d. A witness statement from Mr David Edwards a lawyer at the office of the Official Solicitor who spoke with GTI and his mother on 21 May

18. The Press Association were notified of today's hearing and it has taken place remotely but has been in open court for the purposes of the attendance of the press, albeit when the Daily Cause List was published it was not appreciated that it was a Court of Protection application that would be heard in open court but subject to a transparency order, and so that list wrongly states that it was heard in chambers.

19. All the parties and witnesses attended remotely by Zoom. GTI had told the Official Solicitor that he did not want to participate in the hearing. The same was also true of GTI's mother. In the course of the hearing I heard oral evidence from both Dr Loo and Dr Mercadillo.

The parties' positions: a summary

20. The NHS Trust submitted that

    a. the evidence as to capacity clearly established through the recent assessment of Dr Mercadillo that GTI lacked capacity to make a decision in relation to the insertion of the PEG and to conduct proceedings, and

    b. the evidence from Dr Loo established that without the insertion of a PEG, GTI's condition would deteriorate as a result of malnutrition, leading potentially to his collapse and death. Although the insertion of a PEG was not without its risks, in particular should GTI remove it or interfere with it thereafter, there was no other viable means to deliver nutrition to GTI now. Although the insertion of a PEG would not prevent GTI from taking food or drink by mouth that risk existed regardless of what other form of nutrition delivery was adopted.

21. On behalf of the Official Solicitor Ms Dolan summarises the Official Solicitor's position

    '[GTI] does not wish to have a PEG inserted, he wishes to feed himself orally instead. The Official Solicitor is however, at present, in agreement that the proposed PEG is in GTI's best interests, and supports the application made.

    Ms Dolan noted that the evidence as to capacity had not been quite as straightforward on examination as in some cases. The view of the NHS Trust's Deputy Medical Director, Dr Robinson, and other references to GTI having capacity engendered some uncertainty. However, review of the totality of the records and in particular the opinion of GTI's treating consultant made clear that he did lack capacity. In relation to the best interests the position was clear-cut; without delivery of nutrition through the PEG there was a growing risk that GTI might die, possibly within the next 2 to 3 weeks.

22. It is clear from the evidence that since early March GTI has stated that he does not want a PEG inserted. In his telephone conversation with Mr Edwards yesterday he repeated this. He views it as intrusive and clearly holds a strong belief that he could if given the opportunity eat and drink normally. He expressed the view that imposing the procedure on him was reminiscent of the behaviour of dictators and was not the sort of thing that was acceptable.

23. GTI 's mother did not want to take a position which set her against GTI 's wishes. She hoped that ultimately the court would take responsibility

The Substantive Application: Legal Framework

24. The Mental Capacity Act 2005 sets out the statutory scheme in respect of individuals aged over 16 who lack capacity. Section 15 gives the court the power to make Declarations as to whether a person lacks capacity to make a specified decision and the lawfulness or otherwise of any act done or to be done in relation to that person. Section 16 gives the court the power to make an order and make the decision on a person's behalf. Section 48 gives the court discretion to make an

order on an interim basis and in particular if it is in the person's best interests to make the order without delay.

25. Section 2(1) of the Act provides that a person lacks capacity if,

    'at the material time he is unable to make a decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.'

    It does not matter whether the impairment or disturbance is permanent or temporary. The determination of whether a person lacks capacity is to be made on the balance of probabilities.

26. Section 3 provides that a person is unable to make a decision for himself if he is unable

    a. to understand the information relevant to the decision,
    b. To retain that information,
    c. To use a way that information as part of the process of making the decision or
    d. To communicate his decision (whether by talking, using sign language or any other means).

    The section goes on further to provide that a person is not to be regarded as unable to understand information relevant to a decision if he is able to understand an explanation given in a way appropriate to his circumstances. It also provides that a person who is able to retain information relevant to a decision for a short period of time does not prevent him from being regarded as able to make the decision. Information relevant to a decision includes information about the reasonably foreseeable consequences of deciding one way or another or failing to make the decision.

27. Section 1 of the Act sets out the principles applicable under the Act. Sub-section (5) provides that

    '*An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made in his best interests.*

28. Section 4 of the Act deals with 'Best interests'

    (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) any donee 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.

29. The courts have emphasised in a variety of contexts that 'best interests' (or welfare) can be a very broad concept.

    a. *Re G* (*Education*: *Religious Upbringing*) [2012] EWCA Civ 1233, 2013 1 FLR 677.

    b. *Re A (A Child)* 2016 EWCA 759.

    c. *An NHS Trust v MB & Anor* [2006] EWHC 507 (Fam).

    d. *Re G (TJ)* [2010] EWHC 3005 (COP).

    e. *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, [2014] AC 591.

Legal Principles on Best Interests

30. In *Aintree University Hospital NHS Trust v James* [2013] UKSC 67, the Supreme Court considered the first case to come before it under the MCA. Baroness Hale, giving the judgment of the court, stated at paragraph [22]:

    '[22] Hence the focus is on whether it is in the patient's best interests to give the treatment rather than whether it is in his best interests to withhold or withdraw it. If the treatment is not in his best interests, the court will not be able to give its consent on his behalf and it will follow that it will be lawful to withhold or withdraw it. Indeed, it will follow that it will not be lawful to give it. It also follows that (provided of course they have acted reasonably and without negligence) the clinical team will not be in breach of any duty toward the patient if they withhold or withdraw it.'

    '[39] The most that can be said, therefore, is that in considering the best interests of this particular patient at this particular time, decision-makers 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 towards the treatment is or would be likely to be; and they must consult others who are looking after him or are interested in his welfare, in particular for their view of what his attitude would be.'

31. At [44-45] it is said that the purpose of the best interests test is to consider matters from the patient's point of view.

32. Whilst the application of the law relating to giving, withholding or withdrawing medical treatment quires sensitivity and care, it is now clear and well-established. In *Re A (A Child*) 2016 EWCA 759, the Court of Appeal said:

    In considering the balancing exercise to be conducted:

    "'1. The decision must be objective; not what the judge might make for him or herself, for themselves or a child;

> *2. Best interest considerations cannot be mathematically weighed and include all considerations, which include (non-exhaustively), medical, emotional, sensory (pleasure, pain and suffering) and instinctive (the human instinct to survive) considerations;*
>
> *3. There is considerable weight or a strong presumption for the prolongation of life but it is not absolute;*
>
> *4. … account must be taken of the pain and suffering and quality of life, and the pain and suffering involved in proposed treatment against a recognition that even very severely handicapped people find a quality of life rewarding.*
>
> *5. Cases are all fact specific."'*

33. The weight to be attributed to P's wishes and feelings will differ depending on such matters as how frequently they are expressed, how consistent the views are, the complexity of the decision and how close to the borderline of capacity the person is. (See [35] *RM, ITW v Z* [2009] EWHC 2525(COP) [2011] 1WLR 344). In *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67 the Supreme Court made it clear that the court below had been wrong to focus on what "the reasonable patient" would decide, and emphasised that the patient's own wishes and feeling must be properly considered: "the things which were important to him… should be taken into account because they are a component in making the choice which is right for him as an individual human being."

34. Several cases after *Aintree* have considered weight to be placed on the wishes and feelings of an incapable adult in the best interests' assessment. In *M v N (by her litigation friend, the OS), Bury Clinical Commissioning Group* [2015] EWCOP 9 Hayden J (paras. 28, 30):

> *".....where the wishes, views and feelings of P can be ascertained with reasonable confidence, they are always to be afforded great respect. That said, they will rarely, if ever, be determinative of P's 'best interests'. Respecting individual autonomy does not always require P's wishes to be afforded predominant weight. Sometimes it will be right to do so, sometimes it will not. The factors that fall to be considered in this intensely complex process are infinitely variable e.g. the nature of the contemplated treatment, how intrusive such treatment might be and crucially what the outcome of that treatment maybe for the individual patient. Into that complex matrix the appropriate weight to be given to P's wishes will vary. What must be stressed is the obligation imposed by statute to inquire into these matters and for the decision maker fully to consider them. Finally, I would observe that an assessment of P's wishes, views and attitudes are not to be confined within the narrow parameters of what P may have said. Strong feelings are often expressed non-verbally, sometimes in contradistinction to what is actually said. Evaluating the wider canvass may involve deriving an understanding of P's views from what he may have done in the past in circumstances which may cast light on the strength of his views on the*

contemplated treatment. Mr Patel, counsel acting on behalf of M, has pointed to recent case law which he submits, and I agree, has emphasised the importance of giving proper weight to P's wishes, feelings, beliefs and values see Wye Valley NHS Trust v B.

35. The Court must take account of paragraphs 5.31 – 5.35 of the Code of Practice when making decisions about life-sustaining treatment:

"5.29 A special factor in the checklist applies to decisions about treatment which is necessary to keep the person alive ('life-sustaining treatment') and this is set out in section 4(5) of the Act. The fundamental rule is that anyone who is deciding whether or not life-sustaining treatment is in the best interests of someone who lacks capacity to consent to or refuse such treatment must not be motivated by a desire to bring about the person's death. 5.30 Whether a treatment is 'life-sustaining' depends not only on the type of treatment, but also on the particular circumstances in which it may be prescribed. For example, in some situations giving antibiotics may be life-sustaining, whereas in other circumstances antibiotics are used to treat a non-life- threatening condition. It is up to the doctor or healthcare professional providing treatment to assess whether the treatment is life-sustaining in each particular situation. 5.31 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 where there 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 interests 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. 5.32 As with all decisions, before deciding to withdraw or withhold life-sustaining treatment, the decision-maker must consider the range of treatment options available to work out what would be in the person's best interests. All the factors in the best interests checklist should be considered, and in particular, the decision-maker should consider any statements that the person has previously made about their wishes and feelings about life-sustaining treatment. Importantly, section 4(5) cannot be interpreted to mean that doctors are under an obligation to provide, or to continue to provide, life-sustaining treatment where that treatment is not in the best interests of the person, even where the person's death is foreseen. Doctors must apply the best interests' checklist and use their professional skills to decide whether life-sustaining treatment is in the person's best interests. If the doctor's assessment is disputed, and there is no other way of resolving the dispute, ultimately the Court of Protection may be asked to decide what is in the person's best interests. 5.34 Where a person has made a written statement in advance that requests particular medical treatments, such as artificial nutrition and hydration (ANH), these requests should be taken into account by the treating doctor in the same way as requests made by a patient who has the capacity to make such decisions. Like anyone else involved in making this decision, the doctor must weigh written statements alongside all other relevant factors to decide whether it is in the best

interests of the patient to provide or continue life-sustaining treatment. 5.35 If someone has made an advance decision to refuse life-sustaining treatment, specific rules apply. More information about these can be found in chapter 9 and in paragraph 5.45 below. 5.36 As mentioned in paragraph 5.33 above, where there is any doubt about the patient's best interests, an application should be made to the Court of Protection for a decision as to whether withholding or withdrawing life-sustaining treatment is in the patient's best interests."

36. Therefore, a host of matters must all go into the balance when the judge seeks to arrive at his objective assessment of whether **this** treatment is in **this** patient's best interests. In particular I must consider GTI's views including any views he might have expressed when he had capacity.

The Evidence and Discussion

37. Section 2 MCA imposes a 'diagnostic threshold' which in this case is addressed by Dr Mercadillo. GTI has an established diagnosis of schizoaffective disorder the records showing this back until 2006 if not earlier in 1997. In the course of his current presentation he has shown cognitive impairment in the form of motivation, mental processing and attention.

38. She emphasised that the deterioration in his bloods which had resulted in the withdrawal of clozapine was significant and that the restoration of his white blood cells and neutrophils which would hopefully result from better nutrition would allow the resumption of clozapine which would then assist in restoring his capacity.

39. Dr Mercadillo identifies matters caused by the schizoaffective disorder which render GTI unable to make a decision for himself.

    a. He cannot understand the physical health consequences of his decision not to have a source of nutrients; he is convinced that he can eat and drink normally. When he is presented with evidence of repeated fluoroscopy tests he denies that they are his. He cannot understand that the route of food and drink to his stomach cannot be opened as normal due to the laceration of one of the nerves in his neck
    b. he was unable to retain the information that his lungs would be affected if he aspirates food and drink
    c. he is unable to weigh relevant information as he disbelieves what medical staff say apparently as a result of delusional beliefs about medical staff being against him or a rigid interpretation of material in a literal rather than a balanced or weighted fashion. He believes that modern medicine will save him even if he does face an infection and that he can survive as long as is needed until he is able to take food and drink by mouth.

40. She said in evidence that although GTI had said he did not want to undergo the procedure that his character was such that she thought it likely he would accept that it had been undertaken and that if it were explained to him by the court in a straightforward and factual way he would probably understand why it had been imposed upon him. She thought there was a risk of him not accepting it but the

balance of her opinion was that he would 'knuckle under'. He was being supported this afternoon by those best known to him and in particular by a nurse who he got on well with.

41. This assessment accords with the views expressed by those who assessed GTI for detention under section 2 MHA on 9 March 2020 and those who assessed him on 19 March for his detention under section 3 MHA. Both recorded that he lacked insight into his condition and lacked capacity to decide about his care and treatment. The 9 March assessment noted concrete thinking and his view that he could swallow water and so did not need to receive CANH.

42. GTI's discussion with Mr Edwards also demonstrated his lack of insight into the consequences of the neurological damage to the nerves in his larynx. He appears not to accept that food and drink will go directly into his lungs and, in any event, if they did that he would cough them up. He did not seem to appreciate there was any risk at all.

43. There is material which shows others have thought GTI may have capacity, including the Aintree Hospital staff, although no details of how that conclusion was reached emerge from the records. On 6 May the Deputy Medical Director at Warrington expressed the view that GTI had capacity although this was not apparently following a full capacity assessment. An independent capacity assessment was then sought from Dr Graham Barton. He concluded that GTI does not understand the risks or the gravity of the situation and that therefore he did not think he had capacity

44. Between the 17 and 20 of May GTI appears to have been delirious although this improved following the provision of antibiotic medication. He was recorded as having hallucinations and persecutory ideation on the 18 and 19 of May.

45. I am satisfied on the basis of the medical evidence that GTI currently lacks capacity to take a decision for himself. The overwhelming weight of the evidence supports the conclusion that GTI is either unable to understand the information about the risks or his inability to take food or drink by mouth or that he is unable to use or weigh that information. These functional deficits are a consequence of his schizoaffective disorder; perhaps in part because the persecutory nature of the disorder leads him to question the reliability of the medical advice or perhaps in part is because of concrete thinking which prevents him considering alternatives to his own formulation of his situation. There is no means by which he could currently be enabled to make a decision save perhaps by authorising the treatment in order to restore proper nutrition and thus enable the resumption of the administration of enteral clozapine. On the evidence currently available it is possible to say that the current lack of capacity is likely to endure for some months if not years if his previous history of adapting to necessary change is an indicator

Medical Evidence on PEG

46. Dr Loo is a Consultant Gastroenterologist based at the NHS Trust. He says that following surgery at Aintree Hospital GTI was found to have an unsafe swallow and was thought to have oropharyngeal dysphagia secondary to neck trauma. He

gave evidence that the Aintree Hospital is the regional ENT centre and that the notes made clear that they envisaged no future role for surgery for GTI. Thus it would appear that further surgery to correct the neurological damage is not a possibility. He went on to explain that swallow assessments had concluded that it was unsafe for GTI to eat food or fluids of any consistencies. Those tests included therapists giving GTI foods of different consistency to try to eat and observing his ability so to do. However, they also included a video fluoroscopic examination on two occasions which supported the swallow tests. Dr Loo said that this did not mean that GTI could not swallow small amounts of liquid or food and it might be that references to him drinking tap water whilst taking a shower or occasionally managing to get hold of some chocolate were examples of him having been able to consume some drink or food by mouth. However, Dr Loo emphasised these were self-reports by GTI and Dr Mercadillo expressed reservations about how much GTI might have consumed without the knowledge of staff. She pointed out that he had been subject to four person supervision reducing to three and now two and so his ability to consume anything covertly was very limited indeed. However Dr Loo in particular emphasised that being able to consume small amounts of water or a piece of chocolate carried with them the risk of aspiration or choking and the fact that GTI may have successfully consumed some was of no assistance in determining whether he could safely consume sufficient nutrition to keep himself alive and well.

47. The evidence of Dr Loo, but also supported by the multidisciplinary team who have been involved in GTI's care, was that providing nutrition by a nasogastric tube was not feasible as GTI had removed it on occasions. Nor was TPN feasible on a medium to long term basis as it was administered via a cannula which was itself painful and carried with it risks of infection. The TPN tube had come out either as a result of GTI removing it or for other reasons.

48. The only viable means of delivering sufficient nutrition to maintain GTI 's health was the insertion of a PEG. He accepted that this carried with it risks both in relation to the operation under general anaesthetic and in the aftermath. In particular given GTI's antipathy to the procedure there was a risk that he might pull out the PEG tube which for the first two weeks would be a 15 to 20 cm silicon tube emerging from just below his breastbone. Pulling it out would risk trauma to the perforation including enlarging it. However, the tube is designed to be capable of removal without further operation. If discovered within an hour or so the tube could be reinserted without further operation. He thought they would attempt this having committed themselves to feeding by PEG as being in GTI's best interests. After roughly a week to two weeks the tube could be replaced by a shorter tube more in the nature of a button which would be less intrusive. He accepted that if GTI reacted badly that might require physical restraint or medical sedation to stop him pulling out the PEG and whilst he could not contemplate this in the long term he did consider that it might be justified in the short-term to enable sufficient nutrition to be delivered to improve GTI's health and to allow the re-administration of clozapine. If those could both occur GTI's attitude to the PEG and his toleration of it might improve thus reducing the need for consideration of restraint or sedation.

49. In his statement Dr Loo helpfully set out a table setting out the benefits and risks of each of the alternatives. He set out in some detail the nature of the procedure and its aftermath.

50. The medical evidence establishes that the neurological damage to the nerves in GTI's neck have damaged his swallowing reflex to such an extent that food and drink are highly likely to be aspired into the lungs rather than swallowed into the stomach. Corrective surgery is not an option. Aspiration of food or drink into the lungs carries with it the risk of recurrent pneumonia which even if treated may be life-threatening. Furthermore, aspiration of food or drink into the lungs may cause asphyxia and respiratory arrest again potentially life-threatening. Although GTI may not accept them the conclusions of the clinicians are fully supported by the evidence. The ability to occasionally swallow a chunk of chocolate or a mouthful of water does not detract from the general conclusion that normal eating and drinking are not possible and carry grave risks to GTI's health.

51. At present GTI is receiving very little in the way of nutrition. The reduction in his weight from 93kg to 66.7kg is a compelling indicator of the inability to provide GTI with the nutrition he needs by other means. Four full days of nutrition in the last 51 is plainly inadequate. An incomplete administration of four days TPN in the last nine is also clearly inadequate. The continuation of these attempts to deliver nutrition are clearly not going to deliver a level of nutrition that is consistent with GTI's health needs. It hardly needed to be said by Dr Loo, but perhaps is worth emphasising, ultimately if GTI continues to receive so little nutrition his health will eventually collapse and he may die. The lack of nutrition has also led to the development of clozapine driven agranulocytosis and thus the best form of medication that can be provided for the schizoaffective disorder is now only capable of administration in doses which are inadequate to restore or maintain stability of his schizoaffective disorder. The malnutrition has also recently led to GTI developing an infection.

52. I am therefore satisfied that GTI cannot safely eat or drink via his mouth. If he does so the risks of pneumonia or asphyxia are significant and the potential consequences life-threatening. It of course remains the case that GTI may try to eat or drink whether a PEG is inserted or not. Whilst under close supervision this will be difficult but it is hoped that GTI will be discharged back to his supported accommodation and he will then be able to eat or drink. Unless he accepts the dangers associated with so doing he will be at risk. However, the hope is that when his condition improves and his mental health stabilises again he will come to accept the need for the PEG and indeed the need to avoid eating and drinking. Dr Mercadillo was cautiously optimistic given her knowledge of GTI's character and history to date. It is clear that the continuation of the delivery of nutrition by the means pursued since the operation in January is not likely to achieve its intended purpose or to maintain an adequate level of nutrition to GTI. It is likely that his malnutrition will worsen and eventually he will collapse. His ability to covertly take occasional drinks of water whilst in the shower or the occasional covert piece of chocolate may put off the deterioration but that seems inevitable.

53. The insertion of a PEG tube if successful is a less intrusive and painful means of maintaining nutrition than an NG tube or TPN. Dr Loo said that many patients do

not require even analgesia after the operation and if they do it is low level. He anticipated that GTI would be able to administer his own PEG feeds via three or four bolus each day rather than overnight pump administration. He would receive ongoing support both from the mental health and the nutrition teams if he returned to his supported accommodation.

54. The insertion of a PEG tube is a surgical procedure under general anaesthetic and hence is not without risk including those associated with general anaesthesia, poor wound healing, bleeding and infection. There is some risk of perforation of the stomach. Following the insertion of the PEG there are risks arising in relation to P attempting to remove the PEG which include tissue damage and peritonitis. This risk must be a real one given his expressed views both in opposition to the insertion of a PEG and his belief that he can obtain nutrition naturally but also in relation to his views that to do something against his will was reminiscent of Nazi Germany. If he feels that his personal autonomy has been grossly violated that might encourage him to seek to remove the PEG.

P's Wishes

55. When GTI was interviewed by Mr Edwards (amongst others) the following passages are of particular note:

    a. When asked what he thought if the doctors were right about that risk? GTI stated "I would agree and have a PEG put in; but I don't think they are right. It is invasive treatment, I don't think we need it anymore, there are better ways of doing things, or there should be."
    b. "I need to start eating and drinking properly and get back to my regular life".
    c. When asked what his previous life was like GTI stated: "It was good; I do like a drink, I usually get up between 9-10, have breakfast, have a shower, catch up with the daily news. I live on my own, I don't work because of the schizophrenia, supposedly ... Walk into town, have a coffee, go to the pub, have a pint; I generally have a good life, I talk to people at the pub; there are some weird people, you have to be careful who you talk to in pubs. I start making plans to make my tea, do some shopping if I need to; the usual stuff really. Watch TV, sometimes have a bottle of wine, in bed by 10. I would like a partner, but the good ones are very hard to find."
    d. "If you can't live life, it's not worth living. It is taking away two of your senses, your sense of taste and your sense of smell; and those are more important than your other senses... All I want is a drink of liquid and a sandwich; what's wrong with it?"

56. It is clear that eating and drinking are a significant part of GTI's daily life; that is hardly surprising. They are central to most people's daily lives but perhaps assume a greater importance when there is less in the landscape to divert one's attention. Work, children, partners, hobbies might all provide a distraction, but for GTI not only are food and drink important in themselves but they also feature in his daily routines in terms of his visit to the pub and to purchase food. However, Dr Mercadillo described his other interests including cars and music and cautioned against placing too much emphasis on daily routines linked to food and drink.

57. It is clear that GTI does not want to die. His actions in January 2020 do not appear to have been an attempt at suicide although he used that expression in conversation with the Official Solicitor. They appear to have been an action which was entirely out of character. Therefore, on the basis that he wishes to live, the insertion of a PEG would appear to be the only means by which this could be achieved with minimal risk and with the possibility of discharge from hospital and some sort of return to normality. NG or TPN are not consistent it seems with a return to living in the community. Although the insertion of a PEG will not prevent him orally consuming food or drink the combination of a resumption of greater stability in his mental health together with provision of support in the community may reduce that risk.

Conclusion

58. As I have outlined above it is clear in my judgement that the medical and other evidence establishes that GTI meets the diagnostic and functional criteria to conclude that he lacks capacity to take the decision in relation to the PEG procedure.

59. Drawing all of the various threads together in relation to whether it is in his best interests I conclude that it is. I say that because

    a. the medical evidence makes it clear that GTI cannot receive adequate nutrition through eating or drinking nor by any alternative means.
    b. If he does not receive adequate nutrition his decline will continue his malnutrition will worsen and he is at risk of dying from starvation.
    c. The evidence demonstrates that GTI does not wish to die but that he derives pleasure from his life; not just eating and drinking but various aspects including socialising and his interests in cars and music.
    d. In order to restore his mental health he needs to be able to resume taking clozapine which he will only be able to do if his physical health recovers such that his body is able to handle its administration without the risk of agranulocytosis
    e. although his mother does not wish to oppose GTI's expressed wishes I feel confident that she wishes him to improving his physical and mental health and that the idea of him dying of malnutrition/starvation would be profoundly distressing for her which he would not want her to suffer.

60. Clearly there are risks associated with undertaking the PEG. These include the risks associated with operations under general anaesthetic but also the subsequent risks of GTI seeking to remove the PEG. I'm also particularly conscious of the insult to GTI's personal autonomy of imposing a medical procedure on him against his wishes. Although I am satisfied that he lacks capacity to make the decision it is he who has to live with it not I. I take seriously what he said to Mr Edwards, not only the fact of the PEG being intrusive, but more importantly, that the state overriding his wishes and imposing a medical procedure on him would be experienced by him as a gross insult to his personal autonomy and dictatorial. How would I feel were that to be done to me I ask rhetorically. Of course, it is almost impossible to provide an answer given that the situation GTI finds himself in is beyond my ability to truly understand. If I were to suggest that I might feel angry and violated I doubt that it

does justice to GTI's position. However there is another side to this from GTI's perspective I think. I do note though that GTI said his mother means the world to him. I also see that he speaks positively about his life prior to his injury. He enjoyed socialising and would like to expand his circle of friends. He aspired to meeting a partner. He emerges as an intelligent and articulate man who has much to live for. I do not believe that he wishes to continue on a slow decline towards malnutrition, starvation and death. I do not believe he would dream of putting his mother through that appalling process. I believe he would wish to resume as good a life as was possible given the cards life has dealt him. That appears to have been his attitude before and the evidence of those who have been involved with him for some years appears to support the likelihood of him adapting and making the best of his situation again. Thus, whilst I accept that in approving the carrying out of this procedure I am overriding his wishes, I believe that in the short, medium and long term it is the best course for him and I hope that at some point in the future he might (even if only to himself) see that was so.

61. The Court of Protection exists to take decisions such as this. It not the decision of the hospital or any of the members of staff, nor that of GTI or his family or of the Official Solicitor. Ultimately the state has delegated the making of decisions such as this to the judges of the Court of Protection and it is we who bear responsibility for these decisions. Although it is never easy to make a decision which is contrary to a person's own wishes I am satisfied that the evidence in this case clearly establishes that it is in GTI's best interests to undergo the PEG procedure and that he lacks capacity to take the decision himself.

62. I will therefore make the declarations and orders sought.