

Neutral Citation Number: [2022] EWCOP 26

Case No: 13920979/FD22P00024

<u>COURT OF PROTECTION</u> <u>INHERENT JURISDICTION OF THE HIGH COURT</u>

Royal Courts of Justice Strand, London, WC2A 2LL

Date: 24/06/2022

Before :

SIR JONATHAN COHEN

Between :

A MENTAL HEALTH NHS TRUST

-and-

BG (by her Accredited Legal Representative SB) <u>First</u> <u>Respondent</u>

Applicant

-and-

FG

<u>Second</u> <u>Respondent</u>

-and-

IG

<u>Third</u> <u>Respondent</u>

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Ms N Kohn (instructed by Bevan Brittan LLP) for the Applicant Mr S Elgueta (instructed by Begum & Co Solicitors) for the First Respondent The Second and Third Respondents appeared in person

Hearing dates: 23 May 2022

Judgment Approved

This judgment was delivered in private. The judge has given leave for this version of the judgment to be published on condition that (irrespective of what is contained in the judgment)

in any published version of the judgment the anonymity of the incapacitated person and members of their family must be strictly preserved. All persons, including representatives of the media, must ensure that this condition is strictly complied with. Failure to do so will be a contempt of court.

Sir Jonathan Cohen:

Introduction

- 1. On 23 May 2022 I announced that I acceded to the application of the Mental Health Trust in this case and declared and ordered that (in summary):
 - i) BG lacked capacity to conduct these proceedings and/or to make decisions about her care and treatment including nutrition and hydration;
 - ii) It was lawful and in BG's best interests for no further treatment to be provided to her against her wishes and for her to be discharged home from hospital notwithstanding her admission pursuant to section 3 Mental Health Act 1983;
 - iii) It was lawful and in her best interests for her not to receive any artificial nutrition and hydration against her wishes nor to receive any medication or treatment against her wishes;
 - iv) It was lawful and in BG's best interests for her to receive the palliative care plan and not to be provided with any invasive or life-saving interventions against her wishes.
- 2. The application was supported by BG, her parents and by the independent psychiatrist instructed by the Official Solicitor, called upon to assist the court in circumstances to which I shall return.
- 3. I reserved my judgment which I now give.

The History

- 4. BG is the much-loved daughter of her parents who are also parties to these proceedings. She is now 19 years old.
- 5. BG and her parents are all highly intelligent and have made a major contribution to the hearings that I have conducted by both their written and oral submissions. I wish at the outset of this judgment to pay tribute to their dignity and articulateness, to their compassion for one another and their wisdom. There is no doubt of the love that the parents hold for their child or that she holds for them.
- 6. From a very early age BG has been exceptionally sensitive and has struggled with regulating her emotions and dealing with the ordinary events of everyday life that others take in their stride. She took the weight of the world on her shoulders, and she was exceptionally anguished and distressed by, for example:
 - i) The recounting of historical events in which people had suffered;

- ii) Accounts of suffering of animals or seeing roadkill;
- iii) World events, whether they show the plight of humans or animals.

All these events would lead her to become overwhelmed and inconsolable with distress.

- 7. BG's emotional awareness of the suffering of others completely overwhelmed her. She felt the pain of everyone and everything and was unable to regulate her own emotions.
- 8. BG first came into contact with mental health services aged 8. Her increased anxiety had led her to have not only the frequent overwhelming experiences to which I have already referred, but she became unable to sleep in her own bed and developed fears of terrorism, burglars and family death, for example, without any personal experience of the same. She had two courses of cognitive behavioural therapy, one when aged 10 and one when aged 13.
- 9. BG's depression is estimated to have started when she was 14 years old and her suicidal and self-harm behaviours started soon afterwards. At that time she was completely dependent on her mother. In December 2017 self-harm by cutting commenced.
- 10. In February 2018 BG was formally diagnosed with anorexia nervosa.
- 11. Since early 2018 BG has been under the continuous care of psychiatric services.
- 12. In 2018 BG completed a very wide range of eating disorder-focussed therapy sessions. These lasted over a period of some 6 months and during them BG maintained a healthy weight but made it clear that she was only eating so that people knew that she needed help for her other problems, these being depression and emotional dysregulation. She was tearful every day, unable to go to school and did not see the point in living. In November 2018 BG's self-harm had increased to the extent that she needed help from a specialist community team from the Mental Health Trust.
- 13. BG has been an inpatient in hospital almost continually for some 3 years. She was admitted to a medical paediatric ward in one hospital, a private adolescent psychiatric eating disorder ward in a different hospital and 4 other units thereafter. The only prolonged period that she was considered able to be at home was between December 2020 and early April 2021. Since then she has remained at hospital (with episodes of leave home) until the date of my decision, initially under Section 2 MHA and then Section 3. By the time of her admission BG was very agitated, self-harming including banging her head, punching herself and cutting, culminating in her ingesting bleach.
- 14. In early 2022 BG had 9 sessions of electro-convulsive therapy (ECT) before it was discontinued after producing no improvement. At the time that the matter came before me on the first occasion on 6 May BG's medication and treatment regime was summarised as follows:

- i) Her nutrition was delivered twice per day via nasogastric (NG) tube and under restraint on all occasions. The nutrition maintained her weight at approximately Body Mass Index (BMI) 15 but her agitation and resistance to feeds worsened progressively during the second half of 2021.
- ii) BG drank sugar free squash or water but declined any oral intake which might contain calories.
- iii) She was prescribed 12 different medications.
- iv) She received weekly psychological support, with little or any effect.
- 15. BG had by then received over 1,000 NG feeds under restraint during her various hospital admissions. This has caused her immense distress. She has to be restrained by no fewer than 4 staff members as she struggled against it so much. I have no doubt that it was also highly distressing for those having to administer the feeds.
- 16. The applicants has diagnosed BG as suffering from:
 - i) Anorexia nervosa
 - ii) Mixed personality disorder
 - iii) Mixed anxiety and depression
 - iv) Chronic fatigue
 - v) Fibromyalgia
- 17. BG accepted the above diagnoses except mixed personality disorder which she disputed, and she additionally added unremitting widespread physical pain.

Expert Evidence

- 18. Dr Z is a consultant psychiatrist in eating disorders employed by the applicant trust. She has provided 4 statements to the court. It is very much to her credit that despite having to oversee and implement a course of treatment to which BG is strongly opposed, she has retained the trust and confidence of BG and her parents. In her brief oral evidence, she impressed as an exceptionally competent and caring doctor.
- 19. I was, however, concerned when the matter came before me on 6 May that Dr Z's evidence was the only medical evidence before the court. I understand that this issue was raised before Cobb J when directions were given on 26 April 2022, but the matter was felt to be of such urgency that whilst a second opinion report would be admitted in evidence if obtained in time, the case needed to be determined quickly.
- 20. I was concerned about this lack of evidence for a number of reasons:
 - i) The court was being asked to make a decision which would lead inevitably to BG's death on the advice of just one doctor, albeit that she was reflecting a team view;

- ii) That doctor was in a therapeutic relationship with her patient which inevitably impacts on her independence;
- iii) Only a short time before Dr Z had been seeking the advice of a second opinion doctor but had been unable to obtain that opinion in time for the hearing. It seemed to me that if that second opinion was desirable then, it remained desirable.
- iv) Although the matter was plainly urgent, the necessity of making the right decision on the best evidence was paramount and the relatively short period of time, then thought to be about 5 weeks, seemed to me to be justified.
- 21. In accordance with the practice note issued by the Official Solicitor (OS) on 3 February 2021 I invited the OS to conduct enquiries under the Harbin v Masterman procedure. The OS had already indicated to me in advance of my order that she was willing to take on this role. A hearing date was set for 9 June 2022 by which time a report from Doctor Tyrone Glover, a consultant psychiatrist with a specialism in eating disorder psychiatry, was to have been available.
- 22. Present at court at the hearing on 6 May was BG and her parents. It was clear that they were very disappointed that the matter could not be concluded on that day.
- 23. A combination of events made it essential that the hearing was brought forward and I accordingly interrupted a case that I was conducting on circuit to sit early in the morning on 23 May to hear the case.

The Nature of the Medical Evidence

- 24. There was next to no disagreement between Dr Z and Dr Glover. Dr Z described BG presenting as "intensely consumed by pain (physical and emotional)". She reported that BG expressed a deep desire to die and to be allowed to die by the withdrawal of her nutrition so that she can slowly die in her mother's arms in her bed.
- 25. BG experiences internal voices of a derogatory nature. Their messages reinforce her worthlessness. She is unable to talk about anything else and there are no methods to provide her with any alleviation or respite. She has an intense belief and drive to convince others of her emotional torment and pain.
- 26. Dr Z says most of BG's beliefs are driven and stem from "her low self-esteem a sense of worthlessness and not deserving anything, a lack of identity, a lack of secure attachment, the long periods of time which she has spent in psychiatric institutions, and a belief against the world not being a safe place which causes her pain and is against her."
- 27. Dr Z concluded that the Mental Health Trust had exhausted all treatment options that might alleviate her various disorders.
- 28. Dr Z opined that BG did not have capacity to make decisions about her case and treatment, including nutrition and hydration. BG's beliefs and her using and weighing in the balance the relevant information about care and treatment were dominated by her desire not to experience pain and she saw her death as the only escape. All of

BG's views and beliefs had an underlying theme of not deserving anything except punishment and that she is bad. BG's belief was that she takes up too much space; she is contaminated by nutrition and she experiences this in her body as pain and burning under her skin which progresses all over. Her experience of receiving nutrition added to her belief of being bad and worthless and deserving of negative things.

- 29. Dr Z's view was that BG's belief systems enabled her only to make one-sided decisions. She was unable to accept that a higher body weight and nutritional state could help nourish her brain and may help with some of her symptoms of anxiety and depression. She could not accept that the use of medication could assist with her symptoms. Her fixed and immovable beliefs about herself and nutrition and her preoccupation with death overrode her ability to apply (use and weigh) the relevant information. Accordingly, Dr Z was of the view that BG lacked capacity to make decisions about her treatment.
- 30. Whilst it is possible for a patient to lack capacity to make the relevant decisions but have capacity to conduct proceedings, this would be very rare. BG was able to understand the nature of proceedings but she was unable, in Dr Z's view, to weigh in the balance the relevant information about the issues the court has to determine. Likewise, she was unable to weigh in the balance any legal advice about her care and treatment.
- 31. Dr Glover's views about BG's psychiatric condition were very similar to those of Dr Z. He agreed "wholeheartedly with Dr Z's carefully considered conclusion that BG lacked capacity in the relevant domains".
- 32. He said that there is clear evidence that BG is suffering from very severe, unremitting forms of mixed anxiety and depression and anorexia nervosa. He agreed entirely with Dr Z's diagnosis with the exception of that of personality disorder, on which he felt he could not express a view having not interviewed BG, her parents or her clinician. He had not done so, not just because of the abbreviated time available to him to prepare his report, but because to do so would have been likely only to increase BG's distress.
- 33. BG had instructed her own solicitor in whom she had confidence. Cobb J had approved her solicitor's appointment as her litigation friend.
- 34. At the hearing on 6 May both BG and her parents argued strongly and cogently that BG did have capacity. They pointed out that BG only went along with her treatment regime over a very prolonged and distressing period so that she could prove that she did have capacity and had had the opportunity to weigh up and consider all the options that were open to her by way of treatment. She had read widely about and researched her conditions and understood all their dimensions.
- 35. It is not necessary to go further into the issue of capacity because sadly on 17 May 2022 BG was rushed into hospital. At the time of the hearing on 23 May all parties agreed that BG did not have capacity.
- 36. It accordingly follows that I have to make a determination as to what was in BG's best interests applying the tests set out at Section 4 Mental Capacity Act 2005.

Best Interests

37. Section 4 (6) of the MCA:

(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.

- 38. BG has made it completely clear over a prolonged period of time that she would wish to take her own decision and exercise her own autonomy over her body. Her very clear decision is that she wishes to be discharged from hospital, to go home and determine for herself, what if any nutrition or hydration she takes.
- 39. This is not a sudden decision. It has been a long and deeply held wish of hers. I have had the obligation and privilege of reading her diary over many weeks. It is a harrowing read, setting out her suffering and how it should be resolved.
- 40. Section 4 (7) MCA:

(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).

- 41. BG's parents have provided written statements and I have heard from BG's mother. I found what she had to say exceptionally thoughtful in these impossibly difficult circumstances. She and her husband believed it to be in BG's best interests that her wishes should be respected and treatment withdrawn. They did not rule out the possibility that once released back home and "from the torture of NG feeding BG might feel a little differently and might wish to try drinking a little supplement".
- 42. She emphasised that from BG's point of view there were two points of

"paramount importance going forwards: she wants to have the absolute autonomy to be allowed to decide for herself what medical treatment she will accept or decline and the knowledge that her voice and her rights will be respected. She is exhausted from being in so much intolerable pain for so long, and she would like to be sure that any palliative care plan guarantees pain relief such that she is not obliged to suffer further than absolutely unavoidable".

- 43. Dr Z came to the same conclusion. She advised that the continuation of an active treatment plan, including the current medication and nutrition, had a poor prognosis and was likely only to worsen BG's mood and suicidality.
- 44. There was nothing more that could be done in her view to achieve an improvement in BG's mental state. Everything that could be tried had been tried.
- 45. Over the past 4 years, BG had been treated in institutions/hospitals and her development and life in general had been focussed around illness. Outside of her family she has no external relationships nor engaged in any activities which could help in building identity beyond illness or even give opportunities for distraction.
- 46. A widely drawn best interests meeting had concluded that it was in BG's best interests for active treatment to be discontinued. The level of suffering that BG had experienced, her desire to be allowed to die, her family's agreement with her wishes and feelings, and the poor prognosis following the exhaustion of all treatment options led to that conclusion. The negative aspects of treatment appear to outweigh any potential benefits which would ostensibly be only to preserve her life which is not something that she wishes for.
- 47. Dr Glover agreed. In his opinion "medical treatment so far, no matter its wellintentioned nature, has not in any way helped BG's suffering to reduce. It is very reasonable to claim, and I suspect that Dr Z would agree, that it has added further pain. It must be in her best interests now for this to stop".

Discussion

- 48. This case is quite unlike any that I have come across and although similar in some respects, it is also markedly different to <u>A Local Authority v E [2012] EWHC 1639</u> (<u>COP</u>). The distinction lies above all in the fact of the agreement between experts that there is nothing more that can be done to help BG.
- 49. The law contains the strong presumption that all steps will be taken to preserve human life unless the circumstances are exceptional. However, the principle is not absolute and may yield to other considerations: <u>Airedale NHS Trust v Bland</u> [1993] AC 789:

"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"

50. To be asked to make an order which will be likely to lead to the death of a sentient, highly intelligent and thoughtful individual who, if otherwise able and minded, might accept treatment which could assist her is as grave a decision as can be made. It has of course weighed heavily for a long period with BG, her parents and Dr Z, and now me. Simply because all the evidence points one way does not extinguish the burden. But, in the tragic and deeply distressing circumstances of this case, I am in no doubt that it is in BG's best interests that I made the various declarations.

Reporting Restrictions (RRO)

- 51. BG is very sensitive and proactive in accessing what is written about her. She was deeply distressed to be able to find a reference to her case in a tweet that was published. There was nothing in the tweet that would have identified to BG or anyone else that the matter referred to her except the case number. I make it clear that I am not criticising the author of the tweet.
- 52. On 6 May I continued a blanket reporting restrictions order made by Cobb J, but included a recital in the order that I had made no substantive order at that hearing.
- 53. The Mental Health Trust, BG and her parents have all sought to persuade me that I should continue the RRO. Regardless of the wording and the restrictions that I might impose on it, they argued that BG would be likely to find any report about herself and that would cause only greater anxiety and distress. No formulation of words would stop that distress.
- 54. In the few days or weeks that were likely to be left of BG's life, her parents urged me not to take any step that might reduce its quality, such as it was.
- 55. Mr Brian Farmer on behalf of the press urged me otherwise. He reminds me that the Court of Protection sit in public. How, he posed, could it be justified for the court to take a decision that will almost inevitably lead to someone's death without the public being allowed to know that such a decision had been taken.
- 56. This case raises once again the balancing act between Article 8 ECHR, the right to private life, and Article 10, the right to freedom of expression.
- 57. I have considered the matter anxiously. I was persuaded by Mr Farmer that it would not be proper for a decision of this gravity to be made in secrecy, particularly in circumstances when the duration of BG's life was uncertain. Accordingly, on 23 May when announcing my decision I authorised publication in these terms:

"The court today has been dealing with an application by a Mental Health Trust seeking orders permitting the ceasing of artificial nutrition and hydration to a young person suffering from a very complex condition including a severe eating disorder. The inevitable result will be that the young person will die unless he/she chooses otherwise. The application is supported by the young person and the immediate family and the independent expert instructed by the Official Solicitor. I have allowed the application and will, in a reserved judgment, give my reasons in this very difficult case. I will reconsider the issue of further publication after I have handed down my reserved judgment. In the meantime, there is to be no additional reporting or identification of the Mental Health Trust, the Acute Trust, the young person, their family or the treating doctors or the geographical location in which any of the above are situated."

58. I shall consider any further applications that are made including in respect of this judgment after I have handed it down.

Postscript

- 59. The Mental Health Trust has at my request kindly kept me informed of BG's progress. She returned home on the afternoon of the hearing. She was very pleased to be there.
- 60. She has completed working through a list of tasks that she has set herself to do. She has ceased taking any oral nutrition and is now extremely weak. She is having daily contact with the palliative care team.

Further Postscript

61. I have been informed that BG passed away on 23 July 2022. That she remained living for as long as she did, was a matter of surprise to the treating team and of great distress to BG. Her last days were spent in a hospice.