IN THE HIGH COURT OF JUSTICE
COURT OF PROTECTION
[2021] EWCOP 39

No. COP 13718293

Royal Courts of Justice
Strand
London, WC2A 2LL

Friday, 30 April 2021

IN THE MATTER OF **THE MENTAL CAPACITY ACT 2005**
A N D
IN THE MATTER OF **ZA**

Before:

MR JUSTICE COHEN

B E T W E E N :

AN NHS FOUNDATION TRUST — Applicant

- and -

ZA
(by her litigation friend, the Official Solicitor) — Respondent

ANONYMISATION APPLIES

MS H. MULHOLLAND appeared on behalf of the Applicant.

MS E. SUTTON appeared on behalf of the Respondent.

J U D G M E N T
(**via Microsoft Teams**)

MR JUSTICE COHEN:

1 This case concerns ZA, a 53 year old lady from the North of England. The court has been asked to make decisions as to her best interests in circumstances where all who have seen her, whether the treating team or experts, agree that she does not have capacity.

2 The particular issue before the court is whether ZA should have an above the knee amputation of her right leg.

The History.

3 ZA was diagnosed with chronic schizophrenia in 1982 for which she received anti-psychotic medication. The chronology reveals that she has not been hospitalised for her psychiatric condition since 1997 and, instead, has received intermittent support from her Community Mental Health Team. She lives at home with her husband and their now adult son.

4 In 2002 she was diagnosed with type 2 diabetes and since then has suffered from various associated symptoms including moderate to severe eye conditions, and kidney complications.

5 In 2013 diabetic foot ulcers, and chronic osteomyelitis (infection of the bone) were first diagnosed. It is the combination of ZA's physical and psychological conditions which have made this case so difficult for those who treat her, for her family and for the court.

6 In 2011 a mini mental state examination disclosed a mild cognitive impairment, and tests have confirmed that ZA has suffered and suffers from an ever increasing cognitive impairment.

7 The relationship between the cognitive impairment, schizophrenia and the episodes of delirium with which ZA was first diagnosed in 2016, is an issue which is highly complicated and to which I will return.

8 Section 3 of the Mental Capacity Act 2005 reads as follows:

> "**Inability to make decisions**
>
> (1) For the purposes of section 2, 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 or weigh 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).

9 In this case, the decision that has to be taken, as I have mentioned, relates to her right leg, and whether it should be removed by amputation. ZA has consistently expressed her opposition to this course and so the court has to consider whether she has the capacity to make the decision in the light of the provisions of section 3 of the Act.

10 To assist in the process, I have heard from five doctors: Dr A is ZA's consultant diabetologist and physician. Dr B is her consultant vascular surgeon. Mr Scurr is the expert consultant vascular surgeon, instructed by the Official Solicitor. Dr C is ZA's treating consultant psychiatrist. Dr O'Donovan is the expert consultant psychiatrist instructed by the Official Solicitor. In these proceedings ZA is represented by the Official Solicitor, and both the Official Solicitor and the Hospital Trust have instructed counsel, for whose help and assistance I am very grateful.

11 Before the hearing began, I spoke to ZA at her request and, after the doctors had given their evidence, I heard from ZA's husband and son. The proceedings have been heard in public, with the exception of the evidence of the family members, which I heard in private.

ZA's Medical History.

12 Since 2016, ZA has had repeated infections in her legs and feet and, depending on how one defines the reason for her hospital admission, she has had either 11 or 13 admissions with diabetic foot ulcers. Since June 2020 I calculate that she has only spent a total of some seven weeks at home, and she has been in hospital continuously since October 2020.

13 It was during her first admission in connection with her ulcers, in August 2016, that she was diagnosed with delirium, secondary to residual infection. Most of the admissions to which I have referred have related to her right leg rather than ZA's left leg. In November 2016 the treating team recommended a below the knee amputation of the right leg due to the extent of the osteomyelitis, but ZA refused, and was deemed to have the capacity so to do.

14 In April 2018, ZA again refused an amputation and, although there is no detailed evidence of a capacity assessment set out in her notes, it is implicit that she was considered to have had capacity to make the decision. In October 2018 the second and third toes of ZA's left foot were amputated. It appears that she was deemed non-capacitous and the operation was carried out as an emergency/necessity without court authorisation and, presumably, without consent. It was reported that she struggled to cope with the loss of toes, at least for a while, obviously a much less significant operation than that which is now proposed.

15 In January 2019, ZA was reviewed in the High Risk Diabetic Foot Clinic, after a long hospital admission, and was assessed to have capacity to make decisions regarding her footcare. In October 2019, during the course of an eight week admission, for right foot osteomyelitis and left foot early osteomyelitis, the question of amputation of ZA's right foot was again discussed. ZA refused to proceed with it. She was deemed to lack capacity to make the decision at this time, and a best interests process was followed. At the best interests meeting, taking place at the end of that month, ZA's husband relayed ZA's wishes, stating: "ZA does not want amputation, and if she is going to die let it happen as we are all going to die." ZA's son observed that his mother had been "strongly against amputation." It was agreed that the procedure would be delayed and that ZA would be reassessed in the community.

16 In August 2020, ZA was deemed to have capacity to make decisions regarding her medical care at that time when refusing amputation, this being in the context of bleeding ulceration of the diabetic right foot. In October 2020, the concerns were raised by the district nurses about ZA's right foot. The paramedics attended and considered that ZA had capacity to make her decision to refuse to attend hospital. The District Nursing Team disagreed and contacted Psychiatric Services.

17 Thus it was that in January 2019 and in August 2020, ZA was considered to have capacity and the treating team felt bound by her decision not to have an amputation, whilst in October 2019 she was considered to lack capacity.

18 The August 2020 consideration is particularly relevant for two reasons. First, the diagnosis of capacity was made by a consultant in acute medicine and, secondly, by that time her foot was described as "completely collapsed".

19 Since November 2020, the treating team, including the consultant psychiatrist, and Dr O'Donovan have all concluded ZA does not have capacity; this is a unanimous medical view that is put to me, and it has not been disputed by either counsel.

20 The doctors reach their view about capacity as a result of frequent discussions with ZA which demonstrate that her ability to understand is severely compromised, especially around (i) the nature of the operation that is proposed, (ii) the risk of death if she does not have the operation and, with it, (iii) what death actually means. It is common ground between all the doctors that ZA has a significant cognitive impairment. Whether this is the consequence of her schizophrenia or her poorly controlled diabetes and recurrent infections giving rise to delirium. is in issue, but that her cognitive abilities are severely impaired is agreed. Much of the information given to ZA is either not understood or not believed.

21 I did not, of course, conduct any medical examination myself, but I did speak remotely to ZA at her request before the case began. She was sitting in a comfy chair in hospital with a laptop in front of her so that I could see her and she could see me in my courtroom in London. To me, as to the doctors, she made it very clear that she did not want her foot amputated. To everyone to whom she talks about it, it is her “foot” that might be amputated rather than her “leg”. She is of the view that her foot is getting better and that there is no infection or, if there is, that all that she needs is antibiotics.

22 In fact, the medical evidence is very clear. Her foot is no longer connected by the ankle to her leg bones. The bone has entirely eroded and the foot lies at an angle to where it should be, and is held to the leg only by flesh and tissue. It is accurately described as a 'flail' foot. The underside of the foot is open and leaking from the ulcer residue.

23 ZA is not getting better. She may feel that she is getting better because the degeneration of the foot has destroyed the nerve endings so that the foot gives her no pain. Her understanding of death is limited. By that I do not mean that she cannot engage in a philosophical discussion about death at a basic level. She seems not to understand what death means to human existence. Rather, she says that she has been told that she will die if she does not have the operation, but she does not seem to believe it. She says to the doctors that she would like to go on living but she would rather die than lose her leg. To me she described, when asked about death, that she would not be able to marry again and would need new shoes.

24 All the doctors agree that her cognitive impairment does not permit her to understand, retain, and weigh the information to be able to give an informed decision. I agree, and find that she does lack capacity and, accordingly, the decision as to whether or not the amputation should take place falls to the court to make, applying the test of her best interests.

The Views of the Doctors

25 Surgically, alone, the doctors agree that the decision would be straightforward:

(i) This lady would be best served, looking at the issue in a vacuum, by an above the knee amputation. It would remove the infected bone and flesh. The doctors are clear and unanimous that a below the knee amputation would be counterproductive because ZA will not be able to use a prosthesis because of her cognitive impairment, and the result of a below the knee amputation would be to leave the knee muscles in a state of contraction which would cause pain and be likely to necessitate an above the knee operation. It would be of no benefit to ZA to leave her with a knee she cannot use.

(ii) If she does not have surgery, the probability is that she will die within six to 12 months from sepsis which will overwhelm her. On that Doctors A, B and Mr Scurr concur. If she does have the surgery Dr B and Mr Scurr agree that she will be likely to live for somewhere in the bracket of 5-10 years. Dr A, the one of the three of them who is not the vascular surgeon, promoted the idea that she would live for 20 years.

(iii) I agree with the evidence of the vascular surgeons. They explained convincingly why this lady's other problems will mean that her life expectancy is significantly diminished. Above all, those problems are the complications of her uncontrolled diabetes, and her non-compliance with medication. I was given statistics for the long term survival of those with diabetes, namely that after limb amputations only one-third remain living after three years. In addition, there is a strong likelihood of ulcers appearing at a fresh site, in particular the left leg, and the other complications of diabetes, as I have mentioned, will remain significant.

26 The advice of Dr A is that the amputation is necessary and he supports it as being in ZA's best interests, albeit that he worries about the effect of it upon her mental health. Dr B says that, while surgically it would be best for her, he opposes the operation as the impact on the quality of ZA's life, physical and mental, would be significant and would impose too great a burden on those who would care for ZA. Mr Scurr agrees that, medically, it would be best for her but can go no further than that and says that the balancing between the different aspects of this case is very difficult. Dr C, having listened to all the evidence, says it is simply too finely balanced for her to call as to what is in ZA's best interests. Dr O'Donovan considers ZA's distress may be relatively short-lived and that without the operation her mental and physical health will continue to deteriorate and therefore she should have the operation.

27 The Hospital Trust ask me to make the order for the amputation as being in ZA's best interests. The Official Solicitor, acting for ZA, asks me to order that it would be lawful for her not to have the operation.

The Arguments in favour of Amputation

28 I accept that the treatment will prolong ZA's life, albeit not for as long as Dr A has suggested. Antibiotics have not succeeded in removing the infection, and the only way of doing so is by removing the infected bones.

29 It may be that the removal of the infection will remove or reduce ZA's symptoms of delirium. On this issue the psychiatrists are not at one as to whether it would remove the delirium, and whether the delirium does or does not exacerbate her cognitive impairment. The difficulty in opinion in this area is exacerbated by the fact that delirium and the positive symptoms of schizophrenia which ZA experiences, are very hard, if not impossible, to distinguish. To put it another way the symptoms of delirium can mimic psychotic or schizophrenic symptoms. It is for that reason that I use the word "may" in the context of removing the delirium.

30 The surgery is supported, with reservation, by ZA's husband and son. They want ZA to live, but they are concerned about how she would feel about it and about them were she to think that she has had an operation that she does not want with their connivance. But all those factors that I have mentioned on balance would point towards her having the operation rather than not.

The Arguments against Amputation

31 First, ZA has made it clear throughout the period, since 2016 when the issue first arose, that she does not want the amputation. I accept that there are uncertainties about the depth of the investigation into her understanding of the issues and, indeed, about her understanding of the issues, but I am not prepared to do other than work on the basis that the many professionals who describe ZA as having capacity did so after proper consideration. As I say, ZA's views have been very consistent, and I refer also to the recent periods when she is deemed not to have capacity because they evidence that her views have not changed.

32 In November 2020, when she was assessed to lack capacity, she was described as being "very emphatic" that she didn't want the amputation. On 23 November it is reported by Dr C that ZA became very distressed saying that she would "rather die with her foot in dignity than have the amputation." In March 2021 ZA told Dr O'Donovan that if her foot was amputated "then it's not worth living." To the Official Solicitor, on 4 April 2021, she said: "If I die, I die, we all die sometime, it's not like I am young." When asked about the choice of having her leg taken but living for many years, or keeping her leg but dying sooner, she said: "I'd die sooner. I don't want to be in a wheelchair, I'm not that person. It doesn't matter though because I won't die any sooner anyway, and if I do then I do, but I'll be around for years to come."

33 On 17 April, just before this hearing began, ZA again told the Official Solicitor, when informed that she might only have a few months to live at home absent the amputation, and asked whether this worried her, she said: "No, because it will be a natural death and at least I'll be in one piece" and that "It's up to God what happens next. It's a terrible thing to lose a leg, I would not like to live longer with one leg." And only in the course of the last few days she has indicated to her son, again, that she does not want the amputation. So her wishes, both when capacitous and when non-capacitous, are clear and unambiguous.

34 Secondly, it follows inevitably that a decision to amputate will be against her wishes and, in my judgment, is likely to be significantly distressing to her. I do not accept the view of Dr O'Donovan that because of ZA's cognitive impairment it might soon cease to be an issue to her as she would forget. In my judgment, she is likely to be profoundly distressed. To ZA it would not be the loss of a valueless limb. She uses her stump to hobble around her room holding on to the furniture. I accept, of course, that she should not be doing this, and her ability to do it might not endure, but at the moment she has some mobility, albeit putting herself at risk of a fall. She values her mobility. Not only, therefore, would she lose her

mobility with an amputation, but the loss of the limb would be constantly in her mind. I do not agree that because of her cognitive impairment somehow the loss would not lodge in her mind.

35 Thirdly, the impact on the quality of life would not be negligible. Without a limb, dressing, toileting and moving in and out of a chair or bed will be more difficult. She will lose some of her independence and will be more dependent on others.

36 Fourthly, there is real anxiety about what the impact of an operation will be on her relationship with her husband and son. Will she feel that they have colluded with the hospital to permit an operation that she did not want?

37 Lastly, in the list of reasons why the operation would not be in her interest, is the psychological distress and potential deterioration to her mental health that there might be. On that, Dr C and Dr O'Donovan were agreed. Dr C emphasises that the operation is "very likely to impact negatively on her psychological wellbeing". Dr O'Donovan advises that, given her persistent and strongly held views in regard to amputation over a number of years, the emotional and psychological impact that this will have on ZA should not be underestimated, and later in her report writes: "There is a significant chance that she will develop depression or a relapse of her psychotic illness following this procedure." Dr O'Donovan went on to advise that one should under estimate the risk of this leading to suicidal thoughts, albeit, she says, that her ability to complete an act might make it very difficult to achieve.

Discussion

38 Four points were raised upon which I do not place great weight. First, that all surgery comes with a risk. The risk of surgery in this case is far less than the risk of no operation. Secondly, the burden which Mr B said will be placed on carers; that was for him an influential point, but it seems to me not to be of weight if it is not an anxiety to ZA's husband and son. Their concern is not for themselves, it is for their wife and mother, as the case may be. In saying that, I do not overlook the burden that will be taken on by them, which will be considerable.

39 Thirdly, I do not place any weight on the argument that ZA might not be able to return to the home that she knows however much she would like to, and, indeed, it is agreed she would, because the occupational therapy team might say that the home is unsuitable and that the family should be rehoused. I say that because (i) it does not seem to me to help determine the issue before me because it will arise whichever course I take; and (ii) it seems to me very speculative and, from what I have read, there sems no obvious reason why the home should fail any inspection.

40 Fourthly, religion does not feature in the considerations that have been presented to me in this case. Although there has been mention of whether or not the operation would or would not meet the tenets of her faith, in fact, no one has argued in this hearing that it is a factor which should influence my thinking in any way.

41 In considering best interests I have to follow the criteria set out in s.4 of the Mental Capacity Act. Under subsection (6), I must consider, so far as reasonably ascertainable, ZA's past and present wishes and feelings, and, in particular, any relevant written statement made by her when she had capacity. I do not have any written statement from her, but her past and present wishes and feelings are made very clear to me that she does not want the operation.

I do not think that subsections (6)(b) and (c) add very much, if anything, to the tests I have to consider. But, under subsection (7) I must take into account, if it is practicable and appropriate to consult them, the views of anyone engaged in caring for ZA, or interested in her welfare and, of course, that is above all her husband and her son. They both want her to be happy and to live for as long as possible. They say that she will be pleased to come back to home, and it would be difficult for her without a leg, if that were the court's decision, but they will do everything they can to help her, whatever the outcome of this case is.

42 This case is different from other reported cases that counsel have come across, in that in this case there are known to be ZA's longstanding capacitous wishes which have been clearly expressed, unlike, for example *The Pennine Acute Hospitals NHS Trust v TM* [2021] EWCOP 8 where there was a persistent and misguided belief by the patient that he would improve without surgery and that, it was found, diminished the weight that otherwise might be given to his consistently expressed wishes. But, in that case there were not the presence of persistent capacitous wishes which exists in this case. ZA had made a clear decision before she lost capacity and although (a) her capacity has now left her, and (b) her leg has become less useful than it was before 2020 she is entitled to have respect given to her wishes, formed as they were when she did have capacity. They remain important to her now and they are not to be discounted just because she lacks capacity. That is not to say that her wishes are decisive.

43 I recognise that there is a strong presumption that it is in the best interests for a person to stay alive, but this is not an absolute (see *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67, particularly at paras. 35 to 39). The principle of the continuation of life carries great weight, but there are cases where the best interests are served as, for example in *Briggs* [2017] 4 WLR 37, where Charles J held that for some the best interests are served by giving effect to what a patient wants and wanted for herself. Best interests is a holistic test.

44 This case is not about someone choosing to die. It is about someone who wishes to take her chances and enjoy what she perceives as the best standard of living, independence and dignity, even if it is for a shorter period.

45 I have to put myself in ZA's position and in this case, which is in many respects finely balanced, I take the view that enforcing treatment upon ZA would not be in her best interests, and I hope that I have explained my reasons for coming to that conclusion.

46 I conclude by saying something about the prescription of antibiotics, which has been raised as an issue. In my judgment, it is not necessary for me to rule at this stage whether or not ZA should be discharged upon antibiotics. The thrust of medical opinion is that ZA should be discharged without them, and that they should be kept back in reserve until they are really needed and thought that they might work. I am content to endorse that that would be in her best interests to the extent that my approval is thought to be helpful or necessary.

CERTIFICATE

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