

Appendix 1 – practical guidance for best interests decision-making

Decisions for adults who lack the capacity to consent to medical treatment in England and Wales are governed by the Mental Capacity Act 2005 (MCA). The MCA specifies that any act done, or decision made, for a patient who lacks capacity, and does not have a valid and applicable advance decision to refuse treatment (ADRT), must be done or made in his or her best interests. This means that a decision-maker must consider all relevant circumstances, including any wishes, feelings, beliefs and values of the patient. The MCA requires that the decision should be that which, objectively, is in the best interests of the patient. The best interests test is therefore not, formally, what is called a ‘substituted judgment’ test (i.e. a ‘what the person would have done test’). However, the courts have held that in the context of decisions about life-sustaining treatment, where it is clear what decision the patient would have taken had they had capacity, then this will almost invariably give the answer as to what is in their best interests.⁶⁶

The MCA deliberately avoids defining best interests, and instead sets out a process to be followed when making a decision. In some cases, this process will be reasonably straightforward. In making more serious decisions about life-sustaining treatment, such as clinically assisted nutrition and hydration (CANH), it will be more extensive and formal. This section provides some practical guidance and tips for best interests decision-making.

Is a best interests decision required?

A best interests decision is not required if the patient has made a valid and applicable advance decision to refuse treatment (ADRT), which applies in the patient’s clinical situation. Here the patient has already decided to decline treatment, and that decision must be respected. If there is any doubt about the capacity of the patient at the time of making the ADRT, or about its validity or applicability, legal advice should be sought and the Court of Protection may be asked to decide.

If the patient has made a lasting power of attorney (LPA) appointing a health and welfare attorney with the power to consent to, or refuse, life-sustaining treatment, and the LPA has been registered with the Office of the Public Guardian, the health and welfare attorney is the lawful decision-maker and is required to act in the patient’s best interests. If there is genuine doubt that the attorney is acting in the best interests of the patient, this should be resolved as soon as possible. The Court of Protection should be asked to decide if that doubt or disagreement persists.

Where there is no ADRT or health and welfare attorney, the decision-maker will be the person with overall responsibility for the patient’s care, usually the consultant or GP, who must make a decision based on the best interests of the patient.

Who should be consulted as part of best interests decision-making?

The Mental Capacity Act sets out who should, where practicable and appropriate, be consulted as part of the assessment of best interests. This includes:

- anyone named by the individual as someone to be consulted on such matters;
- anyone engaged in caring for the patient or interested in his or her welfare; and
- any court-appointed deputy.

Where there is nobody that fits into the above categories, an Independent Mental Capacity Advocate (IMCA) must be consulted.

66 *Salford Royal NHS Foundation Trust v Mrs P*[2017] EWCOP 23. <https://www.bailii.org/ew/cases/EWCOP/2017/23.html>

The second of the categories above is potentially very broad and open to interpretation. How extensive this consultation should be will depend on what is 'practicable and appropriate' in the individual circumstances and should be proportionate to the consequences of the decision being made. So, for example, if a patient is in the end-stage of a degenerative neurological condition and is known to be approaching the end of their life, consultation with a smaller group of people may be appropriate. Where someone has suffered a sudden-onset brain injury, but is otherwise healthy, more consultation will be needed. The nature, and complexity, of the family relationships may also be relevant factors in this decision. The person responsible for making the decision should ultimately decide how wide this consultation should be, but should take account of the views of other members of the healthcare team in reaching that decision. The decision of who to consult must not be influenced by a desire to achieve agreement on a particular course of action.

For the most significant decisions, it is important to ensure that attempts are made to identify all relevant people to be consulted about whether CANH would be in the patient's best interests. Those consulted usually include family members and could also include friends, colleagues etc., who have known the patient well and may be aware of their views and values. In some cases a neighbour or close friend may have been more involved in the patient's day-to-day life and have a clearer view of the patient's wishes than family members, and so it is important to look beyond the immediate family to gain as much information as possible to feed into the decision-making process. Identifying those who can contribute this information – and ensuring that a range of views is heard – can be difficult. Some strategies that have proved helpful are:

- asking those who are closest to the patient whether there are other family members, friends, carers, colleagues or associates who may have information about the patient to contribute to the best interests assessment;
- asking those who have provided information if they are aware of any other people who hold, or might hold, a different view to their own – it is important that these people are consulted; and
- identifying those who visit the patient to assess whether they should be consulted.

If a decision is made specifically not to consult with a particular individual, the reasons for this should be recorded in the medical notes.

*'I want to make it clear that his wife was a great support to him and she stayed with him in the hospital. She was there for him on a daily basis for some three years. She found the situation extremely difficult and, eventually, she came to the conclusion that she had to move on with her life. I am told she has not seen Christopher for some 19 to 20 years. Their marriage broke down and a decree absolute has been pronounced [and ...] in those circumstances, I take the clear view that it was not necessary to inform her of this application.'*⁶⁷

Mr Justice Moor, Re CL

Best interests discussions should also involve all members of the care team. The views of care staff at all levels can be relevant and helpful in assessing what the patient would judge to be in his or her best interests, particularly those who have spent a considerable period of time with the patient and those close to them. Those responsible for commissioning healthcare for the patient should also be consulted.

⁶⁷ *Abertawe Bro Morgannwg University Local Health Board v CL* [2017] EWCOP 31. 6. www.bailii.org/ew/cases/EWCOP/2017/31.html

If the patient has no family or other person able to represent their views or, for whatever reason, it is not considered appropriate to consult those who are close to the patient, an Independent Mental Capacity Advocate (IMCA) must be instructed. Even where there are family members and/or others available and positively engaged in the discussion, where the resource is available, it can also be helpful to involve an independent advocate (who may be an IMCA or other experienced advocate) to help with decision-making. An advocate can, for example, help to identify others who need to be consulted and help with the collection of information to be taken into account in the best interests assessments. Some families have reported finding it helpful to have an advocate to help them to navigate their way through the system and to ensure that the patient's views and likely wishes are heard.

Whilst, in the vast majority of cases, those consulted want what is best for the patient, not all family relationships are straightforward; there may be some cases where the views presented are not focused on the best interests of the patient. This may simply be because those consulted find it hard to separate their own views and preferences from those of the patient. They may, for example, have religious views that the patient did not share (or they may lack or oppose the religious views which the patient held) which, subconsciously, influence the information they provide; or there may be financial considerations or concerns which influence their views about either continuing or stopping CANH. Health professionals need to be conscious of the possibility that relatives may have ulterior motives for the views they express.

*'In many cases I have found family and friends to be, as I have set out above, the only real conduit through which P's wishes can be communicated. In this case RY's 'voice' has remained resistantly silent [...] I have felt unable to rely on CP's account of her father's wishes for a number of reasons. I do not doubt that she loves him dearly, even though I suspect that their relationship has not always been equitable. I also consider that she has a strong faith. She told me that her wishes were indistinguishable from those she has advanced as her father's i.e. even a wholly compromised life, punctuated by pain, would be better than no life. It is also quite plain that she has not accepted the medical evidence and that her belief both in her father's present abilities and future prognosis is very unrealistic.'*⁶⁸

Mr Justice Hayden, Re RY

Seeking views from a number of different people and seeking examples or evidence to back up statements made, or views expressed, is a good way of testing the information provided and ensuring that decisions are focused on what is in the best interests of the patient, not in the best interests of others.

68 Abertawe Bro Morgannwg University Local Health Board v RY & Anor [2017] EWCOP 2, 34-38. <http://www.bailii.org/ew/cases/EWCOP/2017/2.html>

Box 10: Practical guidance on who should be consulted about best interests – key points:

1. When making best interests decisions, decision-makers should as far as 'practicable and appropriate' consult with:
 - anyone named by the individual as someone to be consulted on such matters;
 - anyone engaged in caring for the patient or interested in his or her welfare; and
 - any court-appointed deputy.
2. The consultation should include family, friends, colleagues, neighbours etc. who have relevant information about the patient, his or her wishes, feelings, beliefs and values, that could help to inform the decision of whether CANH would be in the patient's best interests.
3. The scope and extent of this consultation will depend on the individual circumstances and should be proportionate to the consequences of the decision to be made; the nature and complexity of family relationships will also be a relevant factor. The decision of who to consult must not be influenced by a desire to achieve agreement on a particular course of action.
4. Best interests discussions should involve all members of the healthcare team, particularly those who have spent some considerable time with the patient and those close to them. Those responsible for commissioning healthcare for the patient should also be consulted.
5. If there is no family, or other person to represent the patient, or there is nobody it is appropriate to consult, an IMCA must be appointed.
6. Health professionals need to be conscious of the possibility that those consulted may find it hard to separate their own views and preferences – such as religious or non-religious beliefs or financial interests – from those of the patient, or may have ulterior motives for the views they express. Seeking views from a range of people and asking for examples or supporting evidence for the views expressed helps to ensure that decisions are focused on the patient.

Initiating best interests discussions

Discussions about treatment options, and whether treatment that is possible is in the best interests of the patient, are a standard part of good-quality care and form part of an ongoing dialogue with those close to patients who lack capacity to give consent. Where CANH is provided, it should be reviewed as a standard part of future care-planning. When discussions take place and decisions are made about other interventions, such as providing antibiotics, or CPR, CANH should also feature in the discussion.

The concept of best interests should be introduced at an early stage of the patient's treatment and care, with an initial discussion about the views, beliefs, wishes, feelings and values of the patient. This may not be the point at which a decision about how to proceed is made, but the concept of best interests and an initial discussion about the patient's beliefs, wishes, feelings and views in relation to CANH can begin very early on. Clinicians should make clear what the nature and purpose of this discussion is, and at what stage decisions will be made.

Discussions about whether it is in the patient's best interests to receive or to continue to receive CANH can be challenging and complex, and require sensitivity. This is particularly so where the patient has been receiving CANH for a long time and it is the primary form of life-sustaining treatment being provided. If nothing has changed clinically, some family members will wonder why this question is being raised now. Health professionals can find it particularly challenging to initiate these conversations, lest those close to the patient interpret this as the healthcare team 'giving up' on the patient. As the provision of CANH can only be justified if it is in the best interests of the patient, however, it is crucial that these discussions take place.

A change in condition, prognosis, or care setting can prompt a discussion about whether continuing CANH will be in a patient's best interests. In some cases, the prompt for a discussion about best interests may come from a question from the patient's family – but the responsibility for initiating best interests discussions should not fall to them. The senior clinician should ensure that discussions about best interests in relation to CANH take place on a regular basis.

Best interests meetings

Where decisions are complex, or are likely to have serious consequences for the patient (as is the case with decisions about CANH), it is good practice to convene formal best interests meetings to share and exchange information and to discuss how the patient's best interests can be met. This is not a requirement of the Mental Capacity Act but is a good way of making important decisions and can also help health professionals to demonstrate that the proper process has been followed. As has been made clear throughout this document, best interests decision-making is part of a process rather than a single determinative event. Best interests meetings, therefore, should be viewed as one step in that process – in reality, discussions about what is in the best interests of a patient should begin before this point. It is usually the responsibility of the decision-maker to initiate best interests meetings but they should also be set up when requested by those close to the patient. All parties have the same goal: to determine the best interests of the patient. It is, therefore, in everyone's interest that these meetings are as productive as possible, with everyone feeling they have had the opportunity to have their information and views heard and considered.

Careful planning can maximise the effectiveness of best interests meetings: allowing sufficient time, a quiet space, ensuring that the numbers are manageable and that those close to the patient do not feel intimidated, 'outnumbered', or overwhelmed by the clinical staff. Family members should be encouraged to attend with someone who will be able to support them.

In the meeting itself, someone should be designated to chair the meeting and facilitate discussion. In many cases, this will be the decision-maker themselves, but in some circumstances it may be deemed more appropriate to have some separation between the decision-maker and the chair or facilitator. Whoever is responsible for chairing or facilitating the meeting should ensure that everyone is clear about:

- the purpose of the meeting;
- the decisions that need to be made;
- who is responsible for making the decisions;
- when they will be made; and
- when participants will be informed.

They should also be conscious of the risk of inadvertent pressure or coercion, where the treating team all agree on a decision and those close to the patient find it difficult to question, challenge or disagree, and ensure that everyone has the opportunity to share their views.

A detailed record should be kept of all best interests meetings, summarising the information exchanged and clearly documenting any decisions reached. Notes should be circulated to all parties present, who should be given the opportunity to dispute any points of factual accuracy before they are finalised. In addition, it may be helpful to make a digital recording of formal best interests meetings and share a copy with all relevant parties. This enables family members to listen again to the information in their own time and enables those who could not attend to hear at first hand what was said; it also ensures that a full and accurate record of the meeting is available to all parties.

Box 11: Practical guidance about best interests meetings – key points:

1. Best interests meetings are not required by the MCA but are a good way of making important decisions and for health professionals to demonstrate that the appropriate process has been followed.
2. They are usually convened by the decision-maker but should also be set up when requested by those close to the patient.
3. In order to maximise the effectiveness of best interests meetings, sufficient time and a quiet space should be provided and steps should be taken to help those close to the patient to contribute effectively and to ensure they do not feel overwhelmed by the clinical staff.
4. A detailed note of the meeting should be circulated to all those in attendance to check its accuracy before it is finalised; it may also be helpful to make a digital recording to be shared with all relevant parties.

Assessing best interests

Section 4 of the MCA sets out a checklist of common factors which should be considered when making a decision about best interests. This checklist is not exhaustive, and there may be additional factors which should be taken into consideration.

Mental Capacity Act 2005, section 4

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).

The type of information to be considered**Clinical information**

Unless the patient had previously indicated that information is not to be shared with others, it is reasonable to assume he or she would want relevant information shared with those who may be asked to contribute to the decision-making process.

In discussions with those close to the patient, the clinical team should therefore:

- explain, in simple terms, the patient's clinical condition, diagnosis and prognosis including the level of uncertainty surrounding this information;
- provide realistic information about what the future holds for the patient, including the long-term care options available;
- avoid making general statements about the likely extent of the patient's disability but, instead, focus on specific activities and interests that might be important to this particular person, such as the extent to which they will be able to interact and/or communicate with others or gain pleasure from activities such as listening to music or watching television;

- provide accurate information about what they should expect following the withdrawal of CANH; and
- explain how the withdrawal of CANH would be managed and the end-of-life care that would be provided.

Information about the patient

The role of those close to the patient is to provide the decision-maker with information about the patient. This might include:

- the nature and length of their relationship with the individual;
- a description of what the patient was like before becoming ill – work, hobbies, likes, dislikes, what was important to them etc.;
- any examples of things the patient said or did that might indicate the view that they are likely to have of their current situation;
- anything relevant the patient wrote down – in a diary, letters, on social media or in e-mails, for example;
- any religious, spiritual or ethical beliefs the patient held and how these might impact on the decision;
- aspects of the patient's personality that might be relevant to the decision; and
- whether they believe the patient would want CANH provided/continued and their rationale for that assessment.⁶⁹

Ideally, a decision-maker should accumulate enough information so that he or she knows sufficient about the patient to form a clear view as to what the patient would have wanted for him or herself if they had the capacity to make the decision.

'The purpose of the best interests test is to consider matters from the patient's point of view. That is not to say that his wishes must prevail, any more than those of a fully capable patient must prevail. We cannot always have what we want. Nor will it always be possible to ascertain what an incapable patient's wishes are. Even if it is possible to determine what his views were in the past, they might well have changed in the light of the stresses and strains of his current predicament. In this case, the highest it could be put was, as counsel had agreed, that 'It was likely that Mr James would want treatment up to the point where it became hopeless'. But insofar as it is possible to ascertain the patient's wishes and feelings, his beliefs and values or the things which were important to him, it is those which should be taken into account because they are a component in making the choice which is right for him as an individual human being.'⁷⁰

Lady Hale, *Aintree v James*

69 The need to be satisfied that a suitably clear indication can be gleaned from such information was stressed by Mr Justice Baker in *W v M*[2011] EWHC 2443 (Fam) 107.

70 Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67. 39. <http://www.bailii.org/uk/cases/UKSC/2013/67.html>

What types of information have the courts taken into consideration in decisions about CANH?

'Prior to his injury he told his cousin that he did not agree that people should be assisted to die, and that a life was no less valuable or worth living if a person was chronically disabled or ill. P was a deeply religious man. He strongly believed that life was sacred given by God and could only be taken away by God. As a Sunni Muslim he believed that suffering was a component of predestination and someone else should not play an assisting role in shortening life merely because of the subjective quality of that life. It is against the tenet of his faith to do anything to shorten a life... All these matters point strongly towards P wishing to ensure that life preserving treatment should continue whatever may befall him.'⁷¹

Mr Justice Newton, *St George's Healthcare NHS Trust v P*, 2015

'Mrs N, all agreed, 'lived to shop'. She loved clothes, she was extremely attentive to her appearance. M told me her mother never left the house without 'her hair and nails being immaculate... [she] kept the family home immaculately clean; she was as obsessive about its appearance as she was regarding her own presentation... It would be easy to criticize these occupations as shallow; it would require discounting her feistiness, her pride and her commitment to her children...'

'I am left with little doubt that Mrs N would have been appalled to contemplate the early pain, increasing dependency and remorseless degeneration that has now characterised her life for so long.'⁷²

Mr Justice Hayden, *M v Mrs N*, 2015

'I acknowledge that there is no evidence that Mr Briggs ever specifically addressed that best case scenario but, in my view, if he was able to do so, he would be horrified by that prospect for himself and his family. This is because he would consider that that he and they would have to lead lives in which because of his very limited cognitive and physical abilities he could not take an active and meaningful part in anything that they had previously enjoyed and valued as individuals and had hoped and expected to enjoy together during and after the childhood of his daughter. In my opinion his views, values and beliefs about how life should be lived would cause him to conclude that for him such a life was intolerable.'

'As a risk taker and a man of courage I consider that he would not take a different view based on the possibilities that as a result of the ending of his CANH alone, or together with the treatment of his PSH and dystonia, would cause him pain and him and others distress. In my view, he would consider that his family would take comfort from knowing that this arose from what he wanted.'⁷³

Mr Justice Charles, *Briggs v Briggs*, 2016

'The views which PL expressed to her family and friends about the prospects of being dependent on life support, or receiving artificial assistance in order to survive, are clear. She simply would not want this...'

SL told me he recalls a conversation with his mother in which she had told him expressly that she would not wish to be 'kept alive artificially'. By that time she had had first-hand experience of the death of a good friend who had passed away in a local hospice. She told him: 'If I can't have a full life, I just want to go.'⁷⁴

Mr Justice Cobb, *PL v Sutton Clinical Commissioning Group*, 2017

71 *St George's Healthcare NHS Trust v P*[2015] EWCOP 42. 38. <https://www.bailii.org/ew/cases/EWCOP/2015/42.html>

72 *M v Mrs N*[2015] EWCOP 76. 53-60. <https://www.bailii.org/ew/cases/EWCOP/2015/76.html>.

73 *Briggs v Briggs* [2016] EWCOP 53. 119-120. <https://www.bailii.org/ew/cases/EWCOP/2016/53.html>

74 *PL v Sutton Clinical Commissioning Group* [2017] EWCOP 22. 38-39. <https://www.bailii.org/ew/cases/EWCOP/2017/22.html>

'Mrs P was headstrong, frequently combative, effervescent with ideas and projects... Her partner Z told me how he missed sitting up with Mrs P late into the night, drinking whilst he, largely unsuccessfully (he told me) tried to change her opinions on the political issues of the day...'

'... she was immensely private about her own health. She never, for example, took her medication in front of people. One of her sisters told me how she would always take her medication discretely [sic] in the bedroom. She would not talk about her health issues... All agreed that her insistence on privacy was a feature of Mrs P's determination to present a strong face to the world...'

'Q told me in evidence that there had been a number of occasions when her mother had made it clear to her that she would not have wanted to prolong her life through medical treatment. Her religious beliefs, which changed and developed throughout her life, left her with a sense of consolation that she would be reunited with people dear to her after death. She told Q that she was not afraid of dying. Given that she and her mother were in regular email correspondence Q was confident that some of these views might have been expressed in her undeleted emails from her mother. Accordingly, she began a search. She told me that this was extensive and took her a long time. She found an email dated 13 May 2013. Following some superficial domestic exchanges is the following, which I record in full:

'Did you see that thing on dementia? Made me think of Dad and what a travesty of life his last years were and all the sadder as he had such incredible talent. You know I miss Mum everyday and still talk to her but it is a comfort that she went quickly and I am still haunted by how he ended up... Get the pillow ready if I get that way!... Love Mum'

'... The context of this email seems to me to be significant. It was written by Mrs P having watched a television programme about dementia. This triggered her recollection of her father's death which it is agreed remained a source of great sadness to her. The communication does not therefore exist in a vacuum but in the specific context of her view of life without consciousness or thought. That she identifies, as 'a travesty'. Moreover, so confident was Q that her mother would have expressed this view in writing at some point that she trawled three years of undiscarded emails before finding it. This to my mind gives great credibility to Q's assertion that this was an issue that Mrs P had mentioned with some regularity. It is in this context that I find it to be a powerful indicator of Mrs P's own wishes. Reinforcing this are her own actions, concealing her health issues and deliberately not informing her family about them.'⁷⁵

Mr Justice Hayden, Salford Royal NHS Foundation Trust v Mrs P, 2017

More detailed information about these cases, and how they have influenced the development of the law in this area can be found in [Appendix 4](#).

Written statements about the patient

It can be difficult for those close to the patient to articulate all of the information required in a short space of time in a face-to-face meeting and it is often more productive to ask those who are providing information to do so in writing, to be submitted as part of the best interests process. Taking this approach allows those providing information to produce the statement at their own pace and allows decision-makers to seek views from a much wider group of people than would be possible if all the information was provided orally at a best interests meeting. It also means that there is an accurate record of the statements in the authors' own words rather than the information being paraphrased by the individual taking notes of the discussion.

75 Salford Royal NHS Foundation Trust v Mrs P [2017 EWHC EWCOP 23. 30; 35-37. <https://www.bailii.org/ew/cases/EWCOP/2017/23.html>

Some health professionals also find it helpful to provide their contribution to the best interests assessments as a written statement, to allow family members to take it away to read and digest in their own time.

Box 12: Practical guidance about the information to be considered in best interest assessments – key points

1. The clinical team should provide accurate and factual information, in a way those close to the patient can understand, expressed as practical examples of what the patient may be able to experience, do or achieve, rather than general statements about levels of disability.
2. Those close to the patient should provide information about the patient as a person, what he or she was like before the injury, interests, beliefs, feelings, values and anything the patient said, did or wrote down that might be relevant to the decision.
3. It can be helpful to ask those who know the patient – family, friends, colleagues etc. – to provide written statements about the patient, including whether they think the patient would want CANH to be provided and why they think that.

Using the information

All of the information and evidence provided about the patient's past and present wishes, feelings, beliefs and values, including the balance of current positive and negative experiences, should be carefully assessed in relation to the most realistic prognostic evidence available.

The decision needed is whether the information provided about the patient, combined with the clinical information about the patient's likely prognosis, would provide clear evidence to rebut the strong presumption that it will be in the patient's best interests to prolong his or her life.

The amount and strength of evidence required to rebut that presumption will depend on the individual circumstances of each case. In every case the benefits and harms must be weighed up in the light of what is known about the patient's likely wishes.

Assessing best interests in relation to CANH can be complex, involving the balancing and weighing of a range of divergent and competing factors – both clinical and personal. The courts have promoted a 'balance-sheet approach' to this task which some clinicians also find helpful as a tool for decision-making.⁷⁶ This approach is where the potential benefits and risks of each option are set out side by side. This exercise is not a numerical one and it is the weight of the arguments, rather than the number on each side, which assists in identifying what is in the patient's best interests. As part of this process any 'factors of magnetic importance' should be identified; these are factors that might have a decisive influence on the outcome. The balance sheet does not provide 'the answer'; but it is a way of ensuring that all relevant factors have been carefully considered and of demonstrating how the decision has been reached.

'In determining where the best interests lies, it is helpful to draw up a balance sheet of the various factors... In doing so, however, the court must bear in mind the warning given by McFarlane LJ in *Re F* (A Child) (International Relocation Cases) which, although, as the title of the case shows, given in a different context, applies to the judicial use of balance sheets generally:

'Whilst I entirely agree that some form of balance sheet may be of assistance to judges, its use should be no more than an aide memoire of the key factors and how they match up against each other. If a balance sheet is used it should be a route to judgment and not a substitution for the judgment itself. A key step in any welfare evaluation is the attribution of weight, or lack of it, to each of the relevant considerations; one danger that may arise from setting out all the relevant factors in tabular format, is that the attribution of weight may be lost, with all elements of the table having equal value as in a map without contours.'⁷⁷

Mr Justice Baker, Re D

The 'balance-sheet approach' to decision-making was first alluded to by the Law Lords in *Bland* where, at the same time, they also held that such an approach would be inappropriate in that case: as he was in VS, continuing treatment had no therapeutic benefit and was therefore 'futile'.⁷⁸

The BMA has always taken the view that a balance-sheet approach should be applied across all categories of patients,⁷⁹ and considers that this follows from the approach of the Supreme Court in *Aintree v James*. Even for patients who are in VS, there may be benefits to put in the 'benefits side' of the balance sheet: for example, if a patient believed strongly in the principle of sanctity of life and in there being intrinsic value in being alive this should be given serious consideration in making a decision on whether to prolong his or her life. It will always be a decision about what is in the best interests of that individual patient, and not a blanket approach to particular categories or groups of patients.

⁷⁷ *Re D* [2017] EWCOP 15. 40. <https://www.bailii.org/ew/cases/EWCOP/2017/15.html>.

⁷⁸ *Airedale NHS Trust v Bland* [1993] AC 789. 868. <https://www.bailii.org/uk/cases/UKHL/1993/17.html>.

⁷⁹ British Medical Association (2007) *Withholding and Withdrawing Life-prolonging Medical Treatment: Guidance for Decision Making*. 3rd Ed. Blackwell Publishing: London. 62.

Box 13: Practical guidance about using the information to assess best interests – key points:

1. The decision that needs to be made is whether the information provided about the patient, combined with the clinical information about the patient's likely prognosis, would provide clear evidence to rebut the strong presumption that it will be in the patient's best interests to prolong his or her life.
2. A 'balance-sheet approach' can help to ensure that all relevant factors have been carefully considered and to demonstrate how the decision has been reached.
3. This exercise is not a numerical one and it is the weight of the arguments, rather than the number on each side, which assists in identifying what is in the patient's best interests.

Whilst the decision must be focused on what is right for the individual patient, there is scope to consider the effect of the decision on other people, such as family members, to the extent that the individual him or herself would have been likely to consider that factor if he or she were able to do so.

'I start with the assumption that an instinct for life beats strongly in all human beings. However, I am entirely satisfied that Mrs N would have found her circumstances to be profoundly humiliating and that she would have been acutely alert to the distress caused to her family, which she would very much have wanted to avoid.'⁸⁰ (Emphasis Mr Justice Hayden's own).

Mr Justice Hayden in *Re Mrs N*

The Mental Capacity Act places significant emphasis on identifying the patient's prior and current wishes, feelings and beliefs as part of any best interests assessment. In some cases, this will not be problematic. There may be times, however, where a person's prior, capacitous wishes, feelings and beliefs are, or appear to be, in conflict with their current behaviour. Similarly, it may not always be easy to identify consistent or reliable wishes, feelings and beliefs. The emphasis is on decision-makers taking all reasonable and appropriate steps to identify the choice that is right for the individual. The greater the uncertainty about the correct decision, the greater the degree of scrutiny that will need to be applied including, in some cases, seeking legal advice or applying to the Court of Protection.

'...it is not correct to assume that because a P, and others in an equivalent position, demonstrate contentment and happiness that their present wishes or feelings are that they wish to, and so if they had capacity to do so they would now consent to life-sustaining treatment.'⁸¹

Mr Justice Charles, *Briggs v Briggs*

80 *Re Mrs N* [2015] EWCOP 70, 71. <http://www.bailii.org/ew/cases/EWCOP/2015/76.html>.

81 *Briggs v Briggs* [2016] EWCOP 53, 52. <https://www.bailii.org/ew/cases/EWCOP/2016/53.html>

Patients who have never had capacity

Where the patient has never had capacity, a similar process needs to be followed to enable the decision-maker to gain an accurate picture of the patient, as a person, including any likes or dislikes and to gain an understanding of his or her life, even though not all of the information will be available. The decision about whether to provide, or continue to provide, life-sustaining treatment in patients who have never had capacity to make decisions also depends on the patient's best interests.

This issue has not been considered in the courts in relation to adults, but in cases involving young children, the courts have made clear that: 'the starting point is to consider the matter from the assumed position of the patient' and that 'the paramount consideration is best interests'.⁸²

'There is a strong presumption in favour of taking all steps to preserve life because the individual human instinct to survive is strong and must be presumed to be strong in the patient. The presumption however is not irrebuttable. It may be outweighed if the pleasures and the quality of life are sufficiently small and the pain and suffering and other burdens are sufficiently great.'⁸³

*Mr Justice MacDonald, *Kings College Healthcare NHS Trust v Thomas and Haastrup**

There will be some adult patients who have never had capacity, but who have still been able to express wishes and feelings. These should be taken into consideration as part of best interests decision-making in the same way as for patients who have lost capacity. Where the patient has never been able to express wishes and feelings, it is likely to be more difficult to assess best interests with any degree of certainty and so these cases are more likely to require court review.

Recording best interests decisions

The GMC requires that doctors keep an accurate record of decisions about a patient's treatment and care and of who was consulted in relation to those decisions.⁸⁴ The MCA Code of Practice also requires that a detailed record should be kept of all best interests decisions made and how they were reached. In addition to the decision itself, the record should include:

- how the decision about the patient's best interests was reached;
- what the reasons for reaching the decision were;
- who was consulted to help work out best interests; and
- what particular factors were taken into account.⁸⁵

A model proforma is attached as [Appendix 2](#), which provides a way of ensuring that a thorough best interests assessment has been undertaken and documenting the process. Once completed, the form and accompanying information (including any written submissions made by those close to the patient and the agreed minutes, or digital recording, of all best interests meetings) should be included as part of the medical record.

⁸² Kings College NHS Foundation Trust v Haastrup [2018] EWHC 127 (Fam). 69. <http://www.bailii.org/ew/cases/EWHC/Fam/2018/127.html>

⁸³ Kings College NHS Foundation Trust v Haastrup [2018] EWHC 127 (Fam). 69. <http://www.bailii.org/ew/cases/EWHC/Fam/2018/127.html>

⁸⁴ General Medical Council (2010) *Treatment and care towards the end of life: good practice in decision making*. GMC: London. Para 75.

⁸⁵ Mental Capacity Act 2005 Code of Practice, para 5.15.