



The
British
Psychological
Society

Best Interests

Guidance on determining the best interests of adults who lack the capacity to make a decision (or decisions) for themselves [England and Wales]

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Foreword

In implementing the Mental Capacity Act we have been very keen to provide opportunities for staff, users and carers and their representative bodies and organisations, to supplement the Code of Practice and other Government publications with their own information. Over the last two years we have been able to support bids for events, specialised guidance and small studies into the early impact of the Act that came fully into force in October, 2007.

This publication is one of the projects we were very pleased to be able to support, as understanding best interests is fundamental to understanding the Act. This is an immensely helpful history and guide to best interests decision making. Although it has been developed and produced by the British Psychological Society it will be of use and assistance to all those affected by the Act, not just psychologists.

Paul Gantley

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Introduction

About this guidance

This guidance has been written in order to give additional information and support to people who may have to participate in making decisions on behalf of adults who lack the capacity to do so for themselves. This includes staff working in health or social care (such as doctors, nurses, dentists, psychologists, therapists, social workers, residential and care home managers, care staff, support workers) and carers, families and advocates.

The legal framework for making best interests decisions is defined in the Mental Capacity Act 2005, and further policy guidance is to be found in the Code of Practice to the Mental Capacity Act. This guidance aims to add further to the Code of Practice by looking in more detail at the types of factors that might need to be considered in making a best interests decision, and in considering the process of best interests decision-making.

The aims and objectives of this guidance are as follows:

- to raise awareness of the different ways in which people can make decisions on behalf of those who lack capacity and how these are relevant to the Mental Capacity Act 2005;
- to enable those working with individuals who lack capacity to increase their understanding of what is meant by best interests;
- to enable people who are required to make judgements about best interests, or who are required to participate in best interests meetings, to do this in a structured way. This is in order to ensure that decision-makers consider and weigh all relevant factors in making decisions that are in the best interests of the adult who lacks capacity;
- to provide Chairs of best interests meetings with additional guidance on the process, content and structure of best interests meetings.

The guidance is based on the legal framework of the Act, and on the practical situations faced by those caring for, or making decisions on behalf of, adults who lack capacity. These decisions can vary in complexity and in the significance that they might have on the life of the person. The quality of such decision-making is, however, critical to the effectiveness of the Act in providing an adequate framework for making good decisions when an individual cannot make them for him or herself.

Until this Act, there was no statutory framework for deciding for other people, apart from decisions sanctioned under the Mental Health Act 1983. This meant that many decisions may have been made either without clear and recorded assessments as to capacity or incapacity. It also meant that routine decisions may have been made without appropriate reference to best interests. In some cases, it may have meant that necessary action may not have occurred because of lack of clarity as to what was, or was not, lawful.

This Act brings together the developing case law and policy into a legal framework. It requires that those making decisions for others comply with the statutory requirements, and this, in itself, is a significant change. It will require that carers and professionals:

- ensure that capacity is appropriately assessed – we should not be making decisions on behalf of other people until it is clear that they lack the capacity to do so for themselves, and that this lack of capacity has been properly established;
- follow the process of decision-making for those who lack capacity – we need to follow the process as laid out in Section 4 of the Mental Capacity Act, and the guidance in the Code of Practice which show the important factors that must be looked at;
- enhance decision-making capacity amongst those who may lack it – the Mental Capacity Act requires that we do as much as we can to support and help people make decisions for themselves;

- record the rationale behind any decisions that are made – we need to make sure that the factors we have considered and the judgements we make about best interests can stand up to scrutiny.

It is based on five principles (see www.opsi.gov.uk/acts/acts2005/20050009.htm).

- A presumption of capacity – every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise.

i.e. just because someone has a learning disability, dementia, a mental illness, a brain injury or any other ‘impairment’ or ‘disturbance’ in the way that their mind or brain works, we should not assume that they can’t make decisions for themselves.

- The right for individuals to be supported to make their own decisions – people must be given all appropriate help before anyone concludes that they cannot make their own decisions;

i.e. a judgement that someone can’t make decisions for themselves should not be made until all those involved have given as much help and support as possible to the person, to enable them to make the decision for themselves.

- That individuals must retain the right to make what might be seen as eccentric or unwise decisions;

i.e. even if carers, or other involved people, don’t agree with the decision it does not necessarily mean that the person lacks the capacity to make it for themselves.

- Best Interests – anything done for or on behalf of people without capacity must be in their best interests;

i.e. when we make a decision for someone else, we have to make sure that it is the best one for them

and

- Less restrictive alternative: before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person’s rights and freedom of action. However, the final decision must always allow the original purpose of the decision or act to be achieved.

i.e. there may be different options or choices that can be made. Before the final choice is made all other less restrictive possible options should be considered and wherever possible chosen so that no unnecessary limits are placed on the person’s current or future opportunities, whilst still allowing the original purpose of the decision to be achieved.

This guidance is divided into four sections. **Section 1** looks at the different ways of making decisions for others, and considers the way in which these different approaches are relevant to the Mental Capacity Act. **Section 2** looks at some of the Court cases which have helped develop the law in this area and our understanding of what is meant by best interests. **Section 3** looks at the process of best interests meetings and how to Chair them. **Section 4** goes through some worked examples of how to use the statutory checklist, as required by the Mental Capacity Act.

Section 1: Approaches to making decisions for others

When we make decisions for ourselves, we are usually trying to choose between two or more options. We are trying to decide what is the best course of action for us, given what we know about the situation we are in now, what the future is likely to be and what we know we want. The decision we make will probably be a 'best guess' as to what will give us the best outcome. There are always uncertainties in any choice, so it is very rare that it is absolutely obvious as to what may be the right course of action. As decisions become more complex and more significant in their consequences, then it can become even harder to be sure about what is the right course of action.

When making a decision for ourselves, we would usually weigh up the pros and cons of different choices. Some of these choices may be heavily influenced by our attitudes, values and beliefs. They may also be influenced by our emotional state, or by the views of other people who are important in our lives. Some of our decisions will be unwise or eccentric ones, and we may or may not acknowledge that we have made a mistake. But most people are very reluctant to give up their autonomy and the right to make decisions for themselves.

The legal background

In law, for many centuries, there has been recognition that some people are not able to make decisions for themselves. The means of making decisions on their behalf has changed over time, ranging from *parens patriae* powers (i.e. when the Crown had the authority to act on behalf of children or incompetent adults) through to the Mental Health Act 1959, the Mental Health Act 1983 (when some decision-making powers were removed from statute) and now the Mental Capacity Act 2005. Not all of these powers defined *how* decisions should be made.

It is clear, however, that making a decision on behalf of someone who can't make it for themselves gives the decision-maker a lot of power over the person. The Mental Capacity Act, therefore, seeks to clarify and to define the way decisions are made, in order to ensure that such power is not abused.

Ways of making decisions for others

If it has been decided, following an appropriate assessment of the individual's capacity to make a specific decision, that they are not competent to make it for themselves, then there needs to be a clear and agreed framework for making decisions on their behalf. The framework needs to be ethical and concerned with ensuring that the person's own interests are paramount (as opposed to anyone else's interests). Three main models of making decisions for others have been described – advance decisions, substituted judgement and best interests (Buchanan & Brock, 1998). The Mental Capacity Act allows for elements of all of these, but the over-riding model is that of best interests.

Advance decisions

One method of making decisions for people who lack capacity, is to follow the wishes that they expressed about how they wanted to be treated when they still had the capacity to do so. The Mental Capacity Act (Sections 24 to 26) specifically allows for people to make an advance decision to refuse treatment. It gives the person who lacks capacity the right to refuse treatment, and specifies the way in which the advance decision is to be made and recorded.

There are additional requirements if the advance decision relates to the refusal of life sustaining treatment. The Act does not give people the right to demand treatment, but does give them the right to refuse it. A valid and applicable advance decision over-rides decisions which others might want to make in the best interests of the person who lacks capacity. It is important to note that the provisions *only* refer to a decision made in advance to *refuse* treatment. It does *not* give people the right to demand treatment or any other form of care. The Code of Practice gives more detail as to what makes an advance decision valid.

An advance decision is also not valid if the person has made a lasting power of attorney (LPA) *after* they made the advance decision, and if they have given the donee of the LPA the power to make the decision in question. Anyone (over the age of 18) who has capacity, can choose a person to make decisions for them if they lose the capacity to make decisions for themselves. The person who is chosen is known as the 'donee' and has the authority (if stated in the LPA) to make both medical and welfare decisions. The donee, when making the decision should take account of the person's wishes, but should make the decision using the best interests framework.

The Act also allows for people to make a written statement about their wishes and preferences, in order for these to be used if they lose capacity to make decisions. The statements are not legally binding and do not have the authority of an advance decision to refuse treatment, but should be considered as part of the information needed in making decisions in their best interests.

Substituted judgement

Substituted judgement is a method for making decisions which tries to make the choice that the person themselves would have made, if they had the capacity to do so. It is a method of decision-making used more commonly in the US than in the UK. The US Courts used this method in the case of Karen Quinlan (1976), when it was decided that her father, as the Court-appointed guardian, had the right to make the decision to turn off her life-support machine. Although she had not made any written statement (she was only 21 at the time), she had often expressed the view that she would not want to stay alive if she was in a coma and not going to recover. The Courts decided that her rights to autonomy would be upheld by giving a surrogate the power to make the decision that she would have made.

In another case in the US, substituted judgement was again used as a model of decision-making, although some controversy followed it. This was the case of Joseph Saikewicz. He was a 67-year-old man, with profound learning disabilities, who had spent nearly all his life in a state institution. He was found to be suffering from acute myeloblastic leukaemia, and the issue was whether or not to institute chemotherapy. The Court-appointed guardian recommended that Mr. Saikewicz should not receive treatment, and that he should not be deprived of the right to die. Much of the reasoning behind this was to do with the pain and fear he would experience in the course of treatment, and it was considered that this would be what he would say if he could speak for himself. Mr. Saikewicz died some months later. The criticisms of the decision in this case centred around the fact that it was impossible to try and make the decision that a person, who had never been competent and never expressed a view, would have made.

The use of substituted judgement as a framework for decision-making could, potentially, also lead to abuse. It makes it possible for a decision-maker to state that the wishes or preferences they are expressing are those of the person who lacks capacity, whereas they might, in fact, be the views of the decision-maker instead. They could then decide something which is actually in their interests and not in the interests of the person who lacks capacity.

The Mental Capacity Act requires decision-makers to consider the views and preferences of the person who lacks capacity. However, this is only a part of the decision-making process which should be considered when making the decision. Section 4(6)(a) of the Act makes it clear that it is only one of the factors to be taken into account. The overall framework is that of best interests.

Best interests

'Best interests' is a method for making decisions which aims to be more objective than that of substituted judgement. It requires the decision maker to think what the 'best course of action' is for the person. It should not be the personal views of the decision-maker. Instead it considers both the current and future interests of the person who lacks capacity, weighs them up and decides which course of action is, on balance, the best course of action for them.

The Act does not give a clear definition of best interests, but instead outlines the factors that need to be considered when you are trying to make a decision on behalf of someone else. These factors (known as the statutory checklist and outlined in Section 4 of the Act) try and bring together all the relevant information that will enable you to make the best decision for the person. The statutory checklist consists of the following:

4(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.

4(2) The person making the determination must consider all the relevant circumstances and, in particular, take the following steps.

4(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(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.

4(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.

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.

4(7) He must take into account, if it is practicable and appropriate to consult them, the views of:

- (a) anyone named by the person is 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 power of attorney granted by the person;
- (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).

4(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.

4(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.

4(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.

4(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.

The Code of Practice outlines a scenario (paragraph 5.7) where the decision has to be made as to whether or not an individual should have dental treatment. If we consider this decision in relation to the statutory checklist, it outlines why the decision was made.

Scenario: Whose best interests?

Pedro, a young man with a severe learning disability, lives in a care home. He has dental problems which cause him a lot of pain, but refuses to open his mouth for his teeth to be cleaned.

The staff suggest that it would be a good idea to give Pedro an occasional general anaesthetic so that a dentist can clean his teeth and fill any cavities. His mother is worried about the effects of an anaesthetic, but she hates to see him distressed and suggests instead that he should be given strong painkillers when needed.

While the views of Pedro's mother and carers are important in working out what course of action would be in his best interests, the decision must *not* be based on what would be less stressful for them. Instead, it must focus on Pedro's best interests.

Having talked to others, the dentist tries to find ways of involving Pedro in the decision, with the help of his key worker and an advocate, to try to find out the cause and location of the problem and to explain to him that they are trying to stop the pain. The dentist tries to find out if any other forms of dental care would be better, such as a mouthwash or dental gum.

The dentist concludes that it would be in Pedro's best interests for:

- a proper investigation to be carried out under anaesthetic so that immediate treatment can be provided;
- options for his future dental care to be reviewed by the care team, involving Pedro as far as possible.

What follows suggests how the dentist and those caring for Pedro might have used the statutory checklist to decide what was in his best interests.

The statutory checklist

4(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.*

Pedro has a learning disability, but this does not mean that he should not receive the same treatment as everyone else.

4(2) The person making the determination must consider all the relevant circumstances.

The dentist considered a range of issues when trying to decide what treatment she should give Pedro. These included the amount of pain he is experiencing, the consequences to his health if no dental work is undertaken, the impact on his quality of life if he remains in pain, the distress and fear he experiences when anyone tries to look in his mouth, his future needs for oral health care and the risks of a general anaesthetic.

And, in particular, take the following steps.

4(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.*

The degree of Pedro's learning disability means that it is unlikely that he will gain capacity to make the decision for himself in the future.

4(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.

The dentist consults with others who know Pedro well, to see if there are any ways in which they can involve him in the decision; and if they cannot involve him in the whole decision, can they involve him in some of it.

4(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.

This decision does not relate to a life or death matter.

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).

Pedro has shown, by his behaviour, that he does not want anyone to do anything to his teeth. Although he cannot verbally express a preference, his refusal to co-operate shows that he would prefer that people left him alone.

(b) the beliefs and values that would be likely to influence his decision if he had capacity.

Pedro has never been able to tell people about any beliefs and values.

(c) the other factors that he would be likely to consider if he were able to do so.

The dentist and Pedro's carers have no way of knowing what other factors he might consider.

4(7) He must take into account, if it is practicable and appropriate to consult them, the views of:

(a) anyone named by the person is someone to be consulted on the matter in question or on matters of that kind.

Pedro has not been able to name anyone who should be consulted about the decision.

7(b) anyone engaged in caring for the person or interested in his welfare.

Pedro's mother is clearly interested in his welfare, and therefore must be consulted. The staff who care for him also must be consulted.

7(c) any donee of a power of attorney granted by the person.

Pedro has never had the capacity to make a lasting power of attorney.

7(d) any deputy appointed for the person by the Court.

The Court of Protection has not appointed a deputy to make decisions on Pedro's behalf

as to what would be in the person's best interests and, in particular, as to the matters mentioned in subsection (6).

The dentist must consult as many of the people described as possible, and consider their knowledge of what Pedro would want and what they consider to be in his best interests.

The dentist is the person who is actually responsible for deciding whether or not to treat Pedro. She has an obligation to carry out the steps in the statutory checklist, and those who care for Pedro have an obligation to give her all the information that they can. She had to consider the views of Pedro's mother, who felt that the relief of pain would be of more benefit to Pedro, then subjecting him to the risks of a general anaesthetic. However, the dentist decided that Pedro's current and future best interests would be served by risking the general anaesthetic in order to relieve current pain and be able to carry out future oral health care. The general anaesthetic was likely to be less distressing for Pedro than any other alternatives which would allow for her to examine his mouth and carry out necessary treatment.

If the substituted judgement framework was to be adopted in this case, then it is possible that Pedro would not have received any treatment. It could be said that he was clearly demonstrating his wishes by refusing to open his mouth and that a substitute decision-maker would be doing what Pedro wished by refusing treatment. If the substitute decision-maker was his mother, then again Pedro may not have been treated, as she may not have wished him to have had a general anaesthetic.

The best interests framework, therefore, asks for a range of views and a range of factors to be considered and weighed up. The decision that should be made is one that appears to be, on balance, in the best interests of the person. The fact that the 'standard' is that of the balance of probabilities reflects the reality that is not always immediately obvious what is in their best interests.

Summary

There are three main models for making decisions. The Mental Capacity Act allows for elements of all of them in defining how decisions should be made.

Advance decisions about refusing treatment can be made and are legally binding providing they meet certain conditions. If these conditions are met, then they should be followed, even if they do not appear to be in the best interests of the person who now lacks capacity. A written statement about wishes and preferences does not have the same legal status.

Substituted judgement decisions are included in as much as the known views or wishes of the person when they had capacity have to be considered.

Best interests decisions weigh up a range of factors (including the wishes or preferences of the person, and the views of their families and carers) and decide what is, on balance, the best for the person both now and in the future. Less restrictive options must always be considered.

Section 2: How have the Courts decided on Best Interests?

Initially, the cases that came to Court – where a decision was required on behalf of an adult who lacked capacity – involved judgements about medical treatment. Doctors have always been able to provide medical treatment in an emergency (if the person was unable to consent) under the common law ‘doctrine of necessity’. Additionally, there had been provision for decisions to be made on behalf of incapacitated adults under mental health legislation. However, the Mental Health Act 1983 removed these provisions (unless the person was detained, or unless their property and affairs could be managed under the provisions of Part VII of the Mental Health Act) which meant that there was often no one who could legally make a decision on their behalf.

Medical best interests

The first cases involved the Courts in deciding whether or not a particular treatment was in a person’s medical best interests. In *Re F* [1989]¹ it was determined that the sterilisation of a severely learning disabled woman was in her medical best interests as there was apparently no viable form of contraception available to her and that a pregnancy would be catastrophic to her. It is not clear that a similar decision would be made today, as it may not have met the criteria of best interests being primarily if not exclusively that of medical best interests; but at that time medical best interests dominated legal thinking.

In *Re MB* [1997]² the Court determined that it was in a woman’s best interests to undergo a caesarean section, even though she was refusing it due to a needle phobia. The Court considered that she temporarily lacked capacity due to her extreme fear and that her best interests would be served by giving birth to a baby who was alive and healthy. The judge stated that ‘best interests are not limited to best medical interests’. In this case she was also considering the emotional and welfare consequences to the mother of the potential loss of her child.

Subsequent decisions

There have been a number of cases that are useful in examining how the best interests principle has been expanded to go beyond medical best interests, and which can give some guidance on the range of factors that can be considered. In *Re Y* [1996]³, the Court was asked to decide whether it was in the best interests of a severely learning disabled woman to donate her bone marrow to her seriously ill sister. The woman (Y) lacked the capacity to consent or refuse. The Court considered the following factors in deciding whether it was in her best interests to donate the bone marrow:

- **Benefits:** Y would continue to benefit from contact with her family, consisting of visits to her residential home and involvement in family events outside the home.
- Her mother would continue to be able to visit her. The visits were important to Y, and they might reduce significantly if her sister became more seriously ill.
- Her sister was more likely to recover if she received bone marrow from Y, as opposed to from an unrelated donor. Although her sister’s best interests were not the issue, her survival was in Y’s best interests.
- Her mother and her sister would both be grateful to her, and she would benefit from this gratitude.
- **Disbenefits:** General anaesthesia carries some risks, but this did not appear to be any greater for Y than for anyone else in the population. Y would, in any event, be carefully monitored.
- Any anxieties that Y may have could be managed by a family member going with her to the operating theatre.
- Any pain could be managed by the administration of morphine.

In this case, the social and welfare benefits were considered to outweigh the medical and emotional disbenefits to Y, and permission was granted.

¹ *F v West Berkshire Health Authority* [1989] 2 All ER 545.

² *Re MB (Medical treatment)* [1997] 2 FCR 941.

³ *Re Y (Mental Incapacity: Bone Marrow Transplant)* [1996] 2 FLR 787.

The weighing up of important factors was described formally in *Re A* [2000]⁴. In this case, the mother of a 28-year-old man with Down's syndrome went to the Court of Appeal to try and overturn an earlier judgement that he should not have a vasectomy. She was concerned that, when he moved into Local Authority care, he might have a sexual relationship which would result in the birth of a child. He would not understand the implications of this. Whilst living with her he was under close supervision, but he could be allowed more freedom if the risk of making a woman pregnant was removed. The appeal was refused on the grounds that it was not in A's best interests to undergo a vasectomy. The reasons given by the Court for this were as follows:

- The concept of best interests is not limited to best medical interests, but includes medical, emotional and all other welfare issues.
- Would his freedom be restricted if he retained his fertility (i.e. would he be under closer supervision)? It did not seem that his freedom would be more restricted.
- Would a vasectomy reduce the risk of exploitation or STIs? It would not do so.
- The issue of the impact on his mother, or of any woman who might get pregnant by him, was not relevant in terms of best interests. His best interests were the ones to be considered.
- His relationship with his mother would continue, as his mother would continue to care for him.
- The birth of a child or disapproval of his conduct was unlikely to impinge on him.
- There would be the benefit of foolproof contraception.
- There would be the disbenefit of apprehension, risk and discomfort of the operation.

In the course of this judgement, one of the judges (Thorpe, L.J.) gave some guidance on how to evaluate what is in an individual's best interests. He said that it is 'akin to a welfare appraisal' and that the judge should draw up a balance sheet. The benefits of the procedure should be entered, and then the disbenefits should be entered. The possible gains and losses should be considered, and the likelihood of them occurring. At the end of this process it should be possible to 'strike a balance between the sum of the certain and possible gains against the sum of the certain and possible losses. Obviously only if the account is in relatively significant credit will the judge conclude that the application is likely to advance the best interests of the claimant.'

This makes clear that best interests decisions must be on the basis of weighing up the possible benefits against the possible disadvantages. Medical, emotional, social and welfare benefits and disadvantages should be considered and it is only if the benefits outweigh the disadvantages that the proposed action should be taken.

Serious medical treatment

Best interest decisions can also involve the complex and serious medical treatment of incapacitated adults. In *Re S* [2003]⁵, a hospital trust went to Court to seek a declaration that they should be permitted not to perform a kidney transplant on a severely learning disabled 18-year-old man. He had been admitted to hospital three years earlier, suffering from acute renal failure and had been on haemodialysis ever since. The intention was to continue with the haemodialysis until it was no longer feasible to continue with it, and at that point the doctors would not proceed with either peritoneal dialysis or a kidney transplant, but would instead make provision for palliative care. The reasons for not proceeding with further treatment were based on S's inability to either understand the treatment or, more importantly, co-operate with it. They also believed that he would be distressed by it, as he had been distressed on previous occasions whilst receiving treatment. S's mother opposed the treatment plan, and wished her son to have a kidney transplant. She had offered to donate one of her own kidneys in order that this could occur. S was represented by the Official Solicitor.

The disagreement between the two parties reduced in the course of the hearing. It was agreed that peritoneal dialysis could be given, and that a kidney transplant was not in S's best interests at that point in time. The judge⁶ considered a number of factors in making her judgement. She recognised the fundamental principle sanctity of life, but also stated that it was not absolute. She noted that the duty of

⁴ *Re A (Male sterilisation)* [2000] 1 FLR 549 CA.

⁵ *An Hospital NHS Trust v S* [2003] EWHC 365 (Fam).

⁶ Dame Elizabeth Butler-Sloss, President of the Family Division.

doctors was two-fold – to act in accordance with competent, responsible and relevant medical opinion, and to act in the best interests of their patients. She also noted that when potential life or death decisions were being made and there was disagreement between the family and the clinicians, then it was the Court, not the doctors, who would decide on the best interests of the patient. She reiterated the importance of using the ‘balance sheet’ approach, stating that the advantages and disadvantages of each of the medical options, as well as their viability, should be considered as well as their impact on S’s quality of life. She also supported the view that just because someone could not understand treatment it did not mean that they should not have it. The inability to understand the treatment would have to make it intolerable, before a decision not to treat could be made. She also considered that, with appropriate preparation and support, S’s co-operation could be improved and his distress reduced. She ruled that further medical options should continue if haemodialysis could no longer be sustained, and that a kidney transplant (while not in his best interests at the moment) should not be excluded in the future.

Broadening the scope for the best interests to beyond the medical was reiterated in *Burke v the General Medical Council* [2004]⁷. Mr Burke had cerebellar ataxia which would result in him losing his physical abilities, including the ability to swallow. He sought the right to continue to be fed artificially, and clarification of the circumstances in which Artificial Nutrition and Hydration (ANH) could lawfully be withdrawn. The judge reiterated that medical opinion can never be determinative of what is in a patient’s best interests. He also noted that treatment which placed an intolerable burden on the patient, with little gain in either the length or quality of life, was unlikely to be in the person’s best interests.

Non-medical decisions

The need for decisions (other than in relation to medical treatment) has inevitably come before the Courts. These include contact and residence. It is not always possible or appropriate to take out a guardianship order under the Mental Health Act 1983, and the Courts have, therefore, had to decide what is in the best interests of the person. In *Re F* [2000]⁸ the Court decided that it was in the best interests of an 18-year-old learning disabled woman to be placed by the Local Authority, rather than return home to her mother where she would be at risk of neglect and abuse. Issues relating to her welfare were considered to be of more benefit than any advantages that may be gained by living with her family. In *D-R* [1999]⁹ it was held that a young woman (again with a learning disability) should not have contact with her father, whom she had not seen for some time. It would not be meaningful to her, would confuse her and would cause conflict with other family members.

The ‘balance sheet’ approach was also used in *Re S* [2003]¹⁰. S was removed from her father’s care by the Local Authority following an allegation that her father had hit her. The allegation, as stated, was not upheld in Court. However, it was held that the Court still had to make a determination as to S’s best interests. The judge considered the following points in determining her best interests:

- S’s welfare was the prime concern, and the relative suitability of each party’s plans for her future (i.e. the Local Authority or her father).
- The Local Authority could offer purpose-built accommodation, appropriate staffing, ‘the prospect of more social living amongst people of her own age’, and the opportunity for her family to visit.
- S’s father did not co-operate with the Local Authority.
- S’s father was unable to meet her needs for 24-hour care and to respond appropriately to her challenging behaviour. He was also getting older.
- S had no contact with her siblings.
- S’s father loved his daughter and felt a strong sense of duty towards her.

The judge held that, on balance, S’s best interests would be served by following the Local Authority care plan.

⁷ *R (on the application of Oliver Leslie Burke) and the General Medical Council and the Disability Rights Commission and the Official Solicitor to the Supreme Court* [2004] EWHC 1879 (admin).

⁸ *Re F (Adult: Court’s Jurisdiction)* [2001] Fam 38.

⁹ *Re D-R (Contact: Mentally incapacitated adult)* CA [1999] 2 FCR 49, [1999] 1 FLR 1161, [1999] Fam Law 299.

¹⁰ *Re S (Adult’s lack of capacity: Carer and Residence)* [2003] EWHC 1909 (Fam).

It can be seen, therefore, that a wide range of factors should be considered in determining what is in the best interests of the person. The Courts have given guidance that medical, emotional, social and welfare interests may be relevant and should be entered into the 'balance sheet'.

Acts in relation to care or treatment

Section 5 of the Act allows for more routine, less significant, decisions to be made by carers on behalf of someone who lacks capacity. Prior to the Act, carers could, theoretically, have faced a legal challenge if they, for example, dressed someone or bathed them; or spent money on their behalf without their consent. Any of these actions must still be in the person's best interests, and carers should be able to justify them. If they cannot do this, then they may not be protected from liability. However, it is not necessary to have a formal best interests meeting for each decision – decisions like these, and the reasons for them, could be noted in a care plan. The care plan should also document the assessment of capacity. It is important to note that the protection from liability *only* extends to acts in relation to care or treatment. It also does not provide protection for carers carrying out treatment-related acts for which they do not have the skills.

Section 3: Best Interests meetings

This section considers how to structure and participate in a best interests meeting. It is important to note that there should only be a best interests meeting if the person: (a) has an impairment of, or a disturbance in the functioning of, the mind or brain; and (b) lacks the capacity to make the decision(s) for themselves at this time. This is a two-stage test and we need to be make sure that both have been assessed and evidenced.

The following should be considered in terms of making sure that the meeting is able to make a decision.

Purpose

The meeting should be clear about the nature of the decision to be made. For example, it may be to consider whether or not a specific medical intervention should take place, whether a person should move home, whether specific financial expenditure should occur, etc. If the meeting is being called to make more than one decision, then each of the decisions should be clearly defined and the appropriate people for each decision should be at the meeting.

Preparation

Each of the people attending the meeting needs to come with the relevant information. The information they bring will depend on their relationship to the person. For example, family members may have information about the person's previously expressed wishes and feelings and/or their beliefs and values. They may also have information about how the person is likely to react to whatever decision is reached, or how it might impact upon their relationships with important people in their lives. Family members may also be aware as to whether or not the person has ever expressed clear wishes and preferences, and if they have ever written them down, made an advance decision to refuse treatment, created a Lasting Power of Attorney or whether the Court has appointed a deputy for them). Professional staff will have information about the risks and benefits of specific courses of action. Care staff would have information about the person as they are now.

It is also important to note that everyone attending the meeting will come with their own pre-existing beliefs and attitudes. As far as possible, they should try not to let this influence their decision. They should make a decision that is best for the person, and NOT the decision that they think they would make for themselves.

Process

The process of a best interests meeting might fall into the following stages:

1. Introductions, purpose of the meeting and questions.

Each of the participants needs to say who they are and their relationship to the person. The Chair needs to clarify the decision to be made. They also need to clarify that the decision is one that can be made under the Act* that the options available to the person at the same as those that would be available to someone who did not lack capacity (i.e. they are not being discriminated against); that the person does lack capacity to make the decision for themselves and that all reasonable efforts have been made to enable the person to make the decision for themselves. Section 4(3) to Section 4(5).

2. Gathering information

Each of the participants will be able to bring information that will help in the decision-making. It is at this point in the meeting that you can consider their wishes, feelings, beliefs and values of the person, and other information about the risks, benefits and likely impact of the possible courses of action.

3. Discussion

All the information is brought together, and the benefits and disadvantages of each course of action are noted. It might be useful to write this down (possibly using a flip chart), or another form of contemporaneous record, as this helps with remembering what was said.

*Decisions that cannot be made under the Mental Capacity Act.

4. Summary and evaluation

When all the information has been gathered, discussed and noted, it is useful if the Chair of the meeting summarises the various points and asks the participants to evaluate which is the best course of action and why. It is useful to ask each person individually what they think and to give their reasons.

5. Decision

The participants in the meeting need to decide what, on the balance of probability, is the best decision for the person. There may be some disagreement, but the group should try and reach a consensus decision. It is not good practice to leave the decision in order for it to be made by an individual outside of the meeting. If there is not enough information to make the decision at the meeting, another meeting should be called and all the information should be made available to the participants then.

Decisions that cannot be made under the Mental Capacity Act (S.27 of the Act)

There are some decisions that we are not entitled to take on behalf of someone else (known as excluded decisions). If the meeting has been called to discuss someone's best interests in relation to any of these decisions, then it should not proceed. You cannot decide for somebody else:

- to enter into a marriage or a civil partnership;
- to have sexual relations;
- to a decree of divorce being granted on the basis of two year's separation;
- to dissolving a civil partnership on the basis of two year's separation;
- to a child being placed for adoption by an adoption agency;
- to the making of an adoption order;
- to the discharging of parental responsibilities on matters that do not relate to the child's property;
- to giving consent under the Human Fertilisation and Embryology Act.

These decisions are to do with family and personal relationships, and the best interests framework does not apply.

There are also some decisions which will require a ruling from the Court. They are situations considered to be requiring 'serious medical treatment' and are cases involving the following:

- decisions about the proposed withholding or withdrawal of artificial nutrition and hydration from a person in a permanent vegetative state or a minimally conscious state;
- cases involving organ or bone marrow donation by a person who lacks capacity to consent; and
- cases involving non-therapeutic sterilisation of a person who lacks capacity to consent.

This list is not exhaustive and other situations such as certain terminations of pregnancy, medical procedures for the purpose of donation to another person, having to use a degree of force to restrain the person, experimental or innovative procedures or those raising ethical dilemmas in an area which is untested will also need a ruling from the Court before they can proceed. There may also be other situations where the circumstances and consequences for the patient are serious, and applications to the Court should be considered. (See *Practice Direction E – Applications Relating to Serious Medical Treatment*, Office of the Public Guardian, October, 2007, for full guidance.)

Chairing a Best Interests meeting

The general principles of Chairing any meeting effectively apply to best interests meetings. The meeting itself is only part of the process of making a decision. The stages of the process could be described as:

- preparing for the meeting;
- starting the meeting appropriately (including being on time);
- managing the meeting itself;
- ending the meeting;
- carrying out follow-up action.

Who should Chair the meeting?

The person who has to implement the decision may be the person who calls the meeting. They may not, however, be the most appropriate person to Chair it as they may be required to contribute a lot of information to the meeting. It is likely to be more helpful if the person who Chairs the meeting has both skills and experience in doing this. This is especially important, given that those attending the meeting may not have met together before, or may not be experienced in attending meetings (especially if family members are to attend). It is also possible that the decision is one which will have significant impact on the person who lacks capacity and may also be one which raises opposing viewpoints.

When to have the meeting

The meeting needs to be held at the time the decision needs to be made, while still allowing sufficient time for the decision to be acted upon. This means it should not be so far in advance that circumstances might have changed by the time the decision needs to be acted upon. However, it also means that the meeting should not be unduly delayed because, for example, attempts are being made to enable the person to gain or regain capacity. If the decision can be delayed until they have gained or regained capacity then that should happen. However, it can happen that the meeting is put off in the hope that the person will gain capacity. All those involved need to be clear that this would not place the person at any additional risk.

Preparing for the meeting

The Chair needs to be clear about the purpose of the meeting. They need to confirm, prior to the meeting that an appropriate assessment of capacity has been carried out and that the person does lack the capacity to make the decision under discussion. They need to be clear what decision, or decisions, need to be made; and they also need to ensure that all the relevant people are there. These should include the person responsible for implementing the decision, key staff who currently care for the person, any involved family members and (if they have been appointed) any one named by the person as someone to be consulted and any donee or deputy. If either a donee or deputy has been appointed, they do have authority to make decisions but must still make them in the best interests of the person. As with any other decision maker, they may be required to justify their decision.

The Chair will also need to ensure that there is someone at the meeting who can record the discussion and the decision (together with the reasons for it).

They are responsible for setting the date, time and location of the meeting and asking people to bring along all relevant information that they have which will assist in making the decision. This will include knowledge of what the person themselves might have wanted, any strongly held beliefs they may have had as well as information about the risks and benefits of making the decision or deciding to take no action. All those attending the meeting need to be clear about what the decision is that needs to be made. The agenda, which will structure the meeting, also needs to be sent out.

Possible agenda

A possible agenda and structure could consist of the following:

1. Introductions. It is possible that those attending the meeting will not know each other very well. It might be useful to lay out some 'ground rules', such as listening to each other, treating other people's views with respect, keeping to the point as much as possible and acknowledging that the aim of the meeting is to come to a shared decision that is in the best interests of the person. It might also be appropriate to remind those present that the decision should be made on the basis of what is best for the person and not on the basis of what those present think the person would have wanted or on the basis of what they would want if they were the person for whom the decision was being made. It is probably better not to ask people for their views as to what decision should be made at the start of the meeting, as they may then feel they have to justify and defend it – and this will make it more difficult to use new information or other people's views.

2. Purpose of the meeting. This will serve to clarify the nature of the decision, or decisions, that need to be made. The Chair could also outline the structure that the meeting will take.

3. Review of the requirements of the statutory checklist (including):

- confirmation that it is not an 'excluded decision' (see above);
- confirmation that an assessment of capacity has been carried out and that the person does lack capacity to make the decision;
- confirmation that the options available to the person are not being limited by their age, disability, behaviour, etc.;
- confirmation that efforts have been made to enhance the person's capacity, and to gain a view as to whether or not the person is likely to gain capacity in the future;
- confirmation that amongst those present there is someone who can give information on the nature of the intervention;
- confirmation as to whether or not the decision involves life-sustaining treatment;
- confirmation that amongst those present there is someone who can give information on the person's wishes, feelings, beliefs, values or any other relevant information. If there is not, and it is a serious decision involving health or change of accommodation, then they must confirm whether an Independent Mental Capacity Advocate (IMCA) has been or will need to be instructed. Their views, following meeting and discussion with the person, should be available to the meeting.

This preliminary discussion of the requirements of the statutory checklist will also enable those present to clarify the factors that will be considered in making the decision.

4. Giving information. Those present at a meeting can give information about the relevant factors required in the statutory checklist (i.e. the likely views of the person themselves and the risks and benefits of the proposed intervention, considering medical, emotional, welfare and any other factors that are relevant – examples of these factors will be given in Section 4). You may want to record this information on a flip chart.

5. Discussion. This is the point in the meeting when those present put together all the information and weigh it up as part of coming to the decision. It is important that the Chair encourages all those present to participate, and does not allow any one person or set of views to dominate. It can happen that some people at a best interests meeting think that their role is to persuade others present to fall in with their views. If this is the case, then they are less likely to listen and use the information presented. It may be necessary to tactfully remind them that the best interests meeting is in order to make a decision based on evidence and discussion, and not solely on previously held views.

6. Summary of information and factors to be considered. As Chair, it is your role to summarise the information in terms of the information gathered, and the discussion. It is at this point that having the information visually available on a flip chart, or some other method of recording, is very useful.

7. Deciding on best interests. It might be appropriate to ask each individual what their decision would be and the reasons for it. If there is significant disagreement amongst those of the meeting, it may be appropriate to have further discussion.

It is important for the Chair to remember that not making a decision (i.e. leaving things as they are to run their course) is also a decision, as not acting will also have consequences for the person.

It is also important to remember that the meeting is not authorised to make the decision to carry out the intervention – that is the responsibility of the person who is actually going to be carrying it out. The meeting is there to ensure that the decision is made based on all reasonable and appropriate information. If the decision-maker does not agree with the outcome of the meeting, they cannot be forced to carry out an intervention with which they do not agree. However, they should also not prevent someone else from carrying it out. They are not obliged to follow what the meeting decides – although they would need to be able to give good reasons as to why they thought their decision was more in the best interests of the person who lacked capacity than the decision made by the meeting.

Failure to agree

There are a number of steps the Chair should go through if there is disagreement.

Where the parties to a decision fail to agree on what is in the best interests of an individual, the Code of Practice suggests the following:

Para 5.68 'If someone wants to challenge a decision-maker's conclusions, there are several options:

- *Involve an advocate to act on behalf of the person who lacks capacity to make the decision.*
- *Get a second opinion.*
- *Hold a formal or informal 'best interests' case conference.*
- *Attempt some form of mediation.*
- *Pursue a complaint through the organisation's formal procedures.*

Ultimately, if all other attempts to resolve the dispute have failed, the Court might need to decide what is in the person's best interests. (This refers to the Court of Protection.)

After the meeting

The Chair will be responsible for sending out notes of the meeting, the decisions and their reasons to those attending. Professional staff will be responsible for ensuring that the final notes are entered into the person's records.

If the situation is urgent

There may not always be time to hold a best interests meeting – sometimes urgent action is needed, and the decision-maker has to act. In this case, they should do so – although will still need to be able to justify that their actions are in the person's best interests.

Similarly, it may not always be feasible to hold a formal best interests meeting. In this case, the decision-maker will still need to pay attention to the statutory checklist, but may come to a decision by relevant consultation.

It is also important to ensure that best interests decisions are documented and become part of the person's care plan. Care planning or review meetings are also useful as a means of consultation about what is in a person's best interests.

Section 4: Working through the statutory checklist

This section will work through the statutory checklist with some case examples.

Case Study 1 – Learning disabilities/medical treatment

Mr. J is a 57-year-old man who has a mild learning disability. He displays some features of an autistic spectrum disorder, in that he finds social relationships difficult, has some quite restricted routines (including what and how he eats) and is resistant to change. He has no family, and lives by himself with outreach support going in every day.

Within the last few months, he has been diagnosed with oesophageal cancer. He has been seen by the consultant, who has said that, at this stage of the disease, the only treatment available is palliative. The decision to be made is whether or not, as part of this palliative treatment, a stent should be inserted.

The meeting was attended by the consultant, Mr. J's social worker, his IMCA, three of his support staff, the nurse and speech and language therapist from the community learning disabilities team and a nurse from the palliative care team. All of them had spent time with Mr. J, trying to get to know him and find out what he would want. Mr. J's social worker chaired the meeting. It began by considering the specific questions about: (i) whether all appropriate treatments were being made available to Mr. J; (ii) whether or not capacity could be gained; and (iii) whether Mr. J had been given the opportunity and support to participate in the decision about his treatment.

The statutory checklist

4(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.

Mr. J had been seen by a consultant, who considered the full range of options available to someone at this stage of their disease. Mr. J had no family and an IMCA was instructed for him. The IMCA attended the meetings with the consultant, together with a member of his support staff and a nurse from the learning disabilities team.

4(2) The person making the determination must consider all the relevant circumstances,

The consultant asked that Mr. J's social worker call a meeting of all those involved, in order to bring together all the relevant information. The decision about the stent would be made when this had happened.

The relevant circumstances that needed to be considered were the factors in the statutory checklist and additionally:

The medical consequences of inserting the stent or not inserting it;

How Mr. J was likely to react to either option in terms of distress or other emotional reactions;

What impact either course of treatment was likely to have on his quality of life and welfare.

and, in particular, take the following steps.

4(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.

There was agreement that Mr. J did not have the capacity to make the decision at this point in time. However, many of those present at the meeting thought that with enough time, and if information was presented in a way that he understood, then he might be able to make the decision for himself. The problem was that his condition might deteriorate (and quite quickly) to the point where a decision had to be made as a matter of urgency, and that this could happen before he had gained capacity to make the decision himself.

On this basis, the meeting decided that it could take a decision as to how to act in his best interests as long as they kept monitoring whether or not he had gained capacity to make the decision for himself. If he did not have capacity by the time a decision needed to be made then they would proceed in his best interests. If he did gain capacity, then the decision would be he his. The social worker would be responsible for monitoring this.

4(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.

The support staff and the GP would continue to try to help Mr. J understand what was going on and talk to him about what he would like to happen.

4(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.

Mr. J was terminally ill. However, there was a difference of views as to whether it would be best for Mr. J to undergo any intervention at all. This was because people needed information about whether treatment would alleviate symptoms (it would not cure Mr. J), or whether the treatment itself would be more distressing than no treatment apart from pain relief.

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);

Mr. J's social worker has known him for a long time, and said that he was always found it very difficult when there are changes in his life or his routines. However, he has accepted more support in recent months, and has also changed some of his eating habits when it was suggested to him, and shown that different food would be easier to swallow.

Mr. J has never made any sort of written statement, or verbal statement, about how he would like to be treated should this sort of situation occur. He knows that he has cancer, but has said that he doesn't want to talk about it. This has made it difficult to increase his capacity to make the decision for himself, but people who know him well are still trying to help him understand his illness and the options for treatment.

He has lost weight, and is sometimes sick after eating. He does not talk about this either, nor does he seem to be upset when he is sick.

(b) the beliefs and values that would be likely to influence his decision if he had capacity;

Mr. J has never expressed any views in relation to how people should be treated and helped when they are terminally ill. He does not have any religious faith.

(c) the other factors that he would be likely to consider if he were able to do so.

It is probable that Mr. J would prefer that any decision made would result in the least possible disruption to his routines. This would include staying in his home, with outreach support and nursing care, for as long as possible. This is because he has shown that he finds change very difficult, and also finds it difficult to adjust to a lot of new people.

4(7) He must take into account, if it is practicable and appropriate to consult them, the views of:
(a) anyone named by the person is someone to be consulted on the matter in question or on matters of that kind.;

Mr. J has not been able to name anyone who should be consulted about the decision.

(b) anyone engaged in caring for the person or interested in his welfare;

Mr. J had no family to consult. The staff who care for him must be consulted, as well as his IMCA. His social worker knew him well, as did the nurse from the local community learning disability team; so it was thought to be important to consult them as well.

(c) any donee of a power of attorney granted by the person;

Mr. J has not made a lasting power of attorney.

(d) any deputy appointed for the person by the Court,

The Court of Protection has not appointed a deputy to make decisions on Mr. J's behalf.

as to what would be in the person's best interests and, in particular, as to the matters mentioned in subsection (6).

The consultant consulted as many of the people described as possible, and considered their knowledge of what Mr. J would want and what they consider to be in his best interests.

The people at the meeting looked at the advantages and disadvantages to Mr. J of inserting the stent.

Advantages/benefits of inserting the stent	Disadvantages/disbenefits of inserting the stent
<p>Medical</p> <ul style="list-style-type: none"> ■ There would be reduced risk of aspiration of food. ■ There would be reduced risk of pneumonia following aspiration. ■ Mr. J would have better nutrition and hydration. ■ It would keep the oesophagus open, allowing him to swallow not only food but also saliva. 	<p>Medical</p> <ul style="list-style-type: none"> ■ The operation itself carried a five to 10 per cent risk of death. ■ It could be painful. ■ It could make him feel sick. ■ The stent could become blocked which, although not a medical emergency, could be uncomfortable.
<p>Emotional</p> <p>How Mr. J would be likely to react:</p> <ul style="list-style-type: none"> ■ Mr. J would feel calmer and less frightened, as the current symptoms he was experiencing due to difficulties in swallowing would be reduced. ■ He would still be able to eat and swallow his food, which he enjoyed. ■ He would be less likely to choke, which he would find frightening especially if he was by himself. ■ Mr. J was not worried by hospital visits or admissions, so going into hospital for the operation was unlikely to frighten him. ■ Without the stent, Mr. J's death could be more distressing. 	<p>Emotional</p> <ul style="list-style-type: none"> ■ Mr. J might feel anxious if the stent became blocked, especially if he was not able to immediately tell anyone about it. ■ If it was painful, this would distress him.
<p>Welfare</p> <p>How it would impact on his well-being and quality of life:</p> <ul style="list-style-type: none"> ■ Mr. J would be able to have more choice about what he ate. ■ He would be able to eat food for longer. ■ He would be able to stay in his flat longer, and, therefore, maintain his independence for longer. ■ There would be less disruption to his current routines. 	<p>Welfare</p> <ul style="list-style-type: none"> ■ The stent would require some change in the routine of what Mr. J ate. ■ The stent could impact on Mr. J's quality of life by causing pain and sickness.

When the group felt that all relevant factors have been considered, they were asked individually for their views as to whether it was in Mr J's best interests to have the stent inserted or not. The majority of those present said that when they had arrived at the meeting they had thought that Mr. J should not have the stent. Having had the discussion, they now thought, on balance that he should. They gave their reasons as the risk of aspiration without it, difficulties in nutrition without the stent and that the manner of Mr. J's dying may be more distressing. The IMCA also stressed that it was important continue to try and enhance Mr. J's capacity so that he could make the decision for himself if at all possible.

The support staff were not convinced that Mr. J should have the stent, and felt that nature should take its course. For one of them, she said this was based more on what she felt and less on the basis of the factors that had been considered.

The meeting did reach a consensus. This was that the stent would not be inserted before it became necessary (although it was likely to be necessary within two weeks), that the GP would continue to try and help him make the decision for himself (together with support staff), that plans would be made to increase the support to him in any event, and that if his condition deteriorated and he was becoming distressed, then intervention would be in his best interests. There should be another meeting if this had not happened within one month.

The discussion that happened at the meeting was recorded and placed in the notes.

Case Study 2: Older adults/medical treatment

Ms. M is a 72-year-old woman with a history of schizophrenia. In her early 20s she worked as a hospital cleaner. She lost her job due to her mental illness, and spent many years as an inpatient in a long-stay hospital. When the hospital closed she was discharged and then lived in a series of hostels.

Two years ago her behaviour and her functioning began to deteriorate. She was neglecting herself, not following her usual routines, had become very erratic in her behaviour and threatening and aggressive to those around her. She was seen by her local services and diagnosed with dementia in addition to her chronic schizophrenia. She was placed in a nursing home for people with dementia, but continued to be aggressive and disruptive.

She had developed difficulties in swallowing (it was thought that this may be due to the long-term use of antipsychotic medication) and her speech was also indistinct and hard to understand. She was, however, able to indicate whether she agreed or disagreed with something that was said to her. Her reading and writing skills were limited.

The nursing home tried to implement a diet of soft foods and thickened liquids, but she refused to co-operate and continued to eat ordinary food – especially biscuits and cakes, which she loved. If she was not given them, she would go into the kitchen and take them, or take them from the other residents in the nursing home.

Because of her swallowing difficulties and her insistence on eating the wrong sort of food, she developed aspiration pneumonia. This happened on several occasions, but she became seriously ill with the most recent episode and was admitted to the local acute hospital. Once there, questions were raised regarding her capacity and also what treatment she should receive. There were three options:

1. To provide no active treatment for Ms. M, and to restrict her diet to liquids.
2. To insert a PEG (short for percutaneous endoscopic gastrostomy) tube, and give her all her nourishment through this.
3. To use other methods of feeding her, such as through a drip. (This was a short-term solution.)

Deciding on best interests

Does Ms. M lack capacity to make the decision for herself?

Ms. M was referred by the liaison psychiatrist to the specialist Older Adults service. An initial assessment of capacity to consent to the three options outlined above had been undertaken by the ENT surgeon. His view was that Ms. M lacked capacity for this decision at this time.

Ms. M was also seen by the liaison psychiatrist. He thought it was not clear as to whether or not she did have capacity. She was then seen by the consultant psychiatrist who thought, on the balance of probability, that she did lack capacity. She did, however, appear to express a preference for some form of treatment.

As the three opinions were broadly in agreement, it was judged that Ms. M did lack capacity and that a decision would need to be made in her best interests.

Ms. M had no known relatives. An IMCA was, therefore, instructed as the decision was one which involved serious medical treatment.

The best interests meeting

A best interests meeting took place, involving the ENT consultant, the older adults psychiatrist, the IMCA and Ms. M's social worker. It was convened by the ENT consultant, as Ms. M was under his care, and he was proposing treatment. The meeting considered the requirements as laid down in the statutory checklist (Section 4):

4(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.

Ms. M had long-term, chronic schizophrenia, possible dementia, behaved in an aggressive way and did not co-operate with treatment. Because she did not take care of herself or co-operate, those at the meeting were asked to consider whether it would be in her best interests not to pursue the more invasive treatment of the PEG.

The meeting considered this, and decided that Ms. M's current and past behaviour and history should not be seen as reasons not to treat her.

4(2) The person making the determination must consider all the relevant circumstances and, in particular, take the following steps.

4(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.

Ms. M was considered, on balance, not to be able to make the decision for herself. However, it was possible that she might gain capacity in the future. It was possible that this could happen if her mental state became more stable and if she was able to live in a place where her behaviour could be managed more appropriately. It was thought that this was less likely to happen if she stayed on an acute medical ward.

4(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.

Ms. M had significant communication difficulties, in addition to her mental illness. In the course of trying to assess her capacity it became clear that she found it easier to understand if things were presented to her in clear and simple language. She could not read or write very well, so pictures were also used. She had developed her own simple signs because she knew that people found it hard to understand her when she spoke. It was also important to sit down and face her when speaking to her, as she did not like having to look up at the person who was talking to her. When these methods were used, she was able to agree or disagree with things that were said to her. However, she did not seem to be able to weigh up the pros and cons of any proposed course of action.

4(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.

This decision did relate to life-sustaining treatment. The IMCA raised the issue of whether, by not treating Ms. M's swallowing difficulties with the PEG tube, they could be seen as (even if unconsciously) making the decision that she would die. The ENT surgeon was concerned that Ms. M's lack of co-operation with treatment would make the insertion of the PEG tube impractical. This was disputed by others at the meeting, who felt this was not a sufficient reason not to proceed.

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);

Ms. M had not made an advance decision, or given a clear account of her wishes and preferences. She had not previously put anything in writing. However, in the course of the assessment of her capacity she appeared to indicate that she would have an operation if it would help her to continue to have nourishment.

(b) the beliefs and values that would be likely to influence his decision if he had capacity;

Ms. M had never expressed any views in relation to how people should be treated and helped when they are terminally ill. It was not known at the time whether she had any religious faith.

(c) the other factors that he would be likely to consider if he were able to do so.

It was difficult to determine what other factors Ms. M would take into account. She did not have any family, and she did not have her own home to return to. Because her condition had been deteriorating for a while prior to admission, and because nobody knew her very well, the people at the meeting were not able to be sure about what other factors she would have considered

4(7) *He must take into account, if it is practicable and appropriate to consult them, the views of:*

(a) anyone named by the person is 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;

Ms M had no relatives and had not named anyone who she wanted to be consulted. An IMCA was instructed, and the doctors, nurses and her social worker were otherwise the people involved in the decision.

7(c) any donee of a power of attorney granted by the person;

Ms. M had not made a lasting power of attorney.

7(d) any deputy appointed for the person by the Court;

The Court of Protection had not appointed a deputy to make decisions on Ms. M's behalf

as to what would be in the person's best interests and, in particular, as to the matters mentioned in subsection (6).

The ENT surgeon consulted the IMCA, the social worker and the medical staff involved in Ms. M's care, as to what course of action they considered to be in her best interests. They had to consider what they knew of her own preferences and beliefs, which included her indication (by her behaviour) that she would resist intrusive treatment, that she was likely not to co-operate with treatment and that she appeared to agree to an operation if it would if it would help her take in nourishment.

Relevant circumstances (Section 4(2)) of the checklist

The meeting considered the factors outlined in the statutory checklist and also spent some time considering all the relevant circumstances. These consisted of their knowledge of the medical treatment and its consequences, its likely impact on Ms. M and the way she lived her life and what they thought her preference would be.

Advantages/benefits of inserting the PEG	Disadvantages/disbenefits of inserting the PEG
<p>Medical</p> <ul style="list-style-type: none"> ■ It would reduce the risk of aspiration pneumonia, as she would not need to eat food by mouth. ■ It would provide a long-term method of enabling her to receive nourishment, which would keep her alive. ■ It would remove the need for a naso-gastric tube, which she found distressing and which she kept attempting to pull out. ■ It would enable her to move to a service which could begin to address her mental illness and her behaviour. ■ It would provide an opportunity for medication for her mental illness to take effect. 	<p>Medical</p> <ul style="list-style-type: none"> ■ She might still try to eat by mouth, which could result in aspiration pneumonia from which she could die. ■ She was likely to refuse to co-operate with cleaning the tube, which could result in serious infections that could kill her. ■ The operation itself would present risks to her in her current state of health.
<p>Emotional</p> <ul style="list-style-type: none"> ■ It would reduce the likelihood of aspiration pneumonia, and the consequent distress that this would cause her. 	<p>Emotional</p> <ul style="list-style-type: none"> ■ There was significant risk that she would be very distressed by the insertion of the tube and by the attempts of nursing staff to feed her through it and to clean it. ■ She was likely to become distressed and aggressive if prevented from eating her favourite foods by mouth.
<p>Welfare</p> <ul style="list-style-type: none"> ■ Although unpleasant, insertion of the PEG tube would not be an intolerable burden on her. ■ It would probably lengthen her life. ■ Ms. M had given no indication that she wanted her life to end. 	<p>Welfare</p> <ul style="list-style-type: none"> ■ The PEG tube would mean that she would be unable to engage in one of the things she most enjoyed, which was eating – especially sweet foods and biscuits. ■ She would not be able to live in a hostel, and would need to move to a specialist nursing home which would restrict her opportunities. ■ Her communication difficulties would make it difficult for her to let people know if she was suffering.

The meeting also considered palliative treatment.

Advantages of palliative treatment	Disadvantages of palliative treatment
<ul style="list-style-type: none">■ She would be less distressed, as medication would enable her to stay calm.■ She would be spared the distress and anxiety of the insertion of the tube and the subsequent care that would be required.■ She was already seriously ill and palliative treatment would enable her to have a more peaceful death.	<ul style="list-style-type: none">■ She would die sooner than if the PEG tube was inserted.■ There would be no comprehensive treatment for her mental illness.■ She was unlikely to regain capacity, which would mean that she would not be able to decide for herself what she wanted.

The meeting

Having considered issues of capacity, ensured that Ms. M would not be deprived of treatment because of her mental illness and her behaviour, and judged that she might regain capacity if she received treatment for her mental illness in a more appropriate environment, they then considered the medical, emotional and welfare factors relevant to deciding whether or not the insertion of a PEG tube was in her best interests. They also considered what they knew about her own wishes.

Because of the large amount of information, it was noted on flip charts in order to help those present at the meeting remember it all.

The meeting concluded that there were significant risks attached to the insertion of the PEG tube and that it could result in distress and difficulties for Ms. M. They also agreed that non-insertion would be more likely to result in aspiration pneumonia, and that this would be likely to bring about Ms. M's death.

There was a lot of discussion and some disagreement at the meeting but, in the end, they decided, on balance, that insertion of the PEG tube was in her best interests. They decided that, although Ms. M might not co-operate with the routines necessary for the safe use of the PEG, this should not be seen as sufficient reason not to go ahead. Ms. M was less likely to co-operate whilst a patient on an acute medical ward, and also was not receiving support from nursing staff skilled in working with people with mental illness and dementia.

The discussion that happened at the meeting was recorded and placed in Ms. M's notes.

Case Study 3 – Acute hospital/attempted suicide

Mrs. B, aged 54, was married with two grown-up children. Some years ago she had been diagnosed with breast cancer. This had now returned, and she had secondaries in other organs. She had been given approximately six months to live.

She was admitted to A&E following a paracetamol overdose. The doctor did not assess her capacity. She expressed a wish to die, and the doctor respected this by not treating her. She was instead transferred, as a matter of urgency, to a hospice.

She was seen more or less immediately by a visiting consultant. He was concerned as to whether or not she did have capacity to make this decision, especially as her husband was distraught; saying that she had been depressed because she could see no future for herself and no point in staying alive. Her husband also said that her two daughters agreed with him, and that they were all trying to persuade her that she could enjoy a good quality of life spending her last few months with them.

The consultant assessed her capacity and decided that she lacked capacity to make this decision. She was suffering from a mental disorder, namely depression, which prevented her from being able to use, or weigh, any information about any positive aspects to her remaining life. He did not consider it to be appropriate to detain her under the Mental Health Act at this point in time. He convened a best interests discussion as a matter of urgency, as they were running out of time in which to begin treatment.

4(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.

The doctor in the A&E department could be seen to have made the assumption that, because Mrs. B was terminally ill, it was, therefore, appropriate not to treat her. This may have prevented him from actively considering whether or not she had capacity to refuse treatment for her overdose.

4(2) The person making the determination must consider all the relevant circumstances,

The consultant at the hospice called a meeting as a matter of urgency to bring together all the relevant information.

The relevant circumstances that needed to be considered included a number of factors. These were the factors in the statutory checklist and additionally:

The medical consequences of treating Mrs. B.

How Mrs. B was likely to react in terms of distress or other emotional reactions.

What impact treatment was likely to have on her quality of life and welfare.

and, in particular, take the following steps.

4(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.

The consultant thought that Mrs. B did not have the capacity to make the decision to refuse treatment at this point in time. However, it was thought that she may gain capacity to make decisions regarding her care and treatment in the future, when she had received treatment for her depression. He did not consider it appropriate to detain her under the Mental Health Act. On this basis, the meeting decided that it could take a decision as to how to act in her best interests at this point in time.

4(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.

Mrs. B was informed that there would be a meeting to discuss how to proceed, and she was asked for her views. She responded by saying that there was no point in life, that she was going to die soon anyway.

4(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.

Mrs. B was terminally ill, although it was likely that she could live for some months without distressing pain or discomfort. Not treating her would inevitably bring about her death.

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),

Mrs. B had made no advance decision nor clearly expressed her wishes or preferences. She had put nothing in writing. Her attempted suicide could be understood as her present wish being one to end her life. Her husband said that, in the past, she had always said that if she was in severe pain or distress she would not want continuing treatment (apart from for the pain) and would not want to be resuscitated.

(b) the beliefs and values that would be likely to influence his decision if he had capacity;

Mrs. B was a practising Christian. She was also a strong believer in the importance of family.

(c) the other factors that he would be likely to consider if he were able to do so.

Mrs. B's husband said that he thought his wife would consider the distress that her death would cause her family. He thought that part of her reason for taking an overdose may have been to do with thinking that they would be better off with her dead now, and not having to see her die of cancer.

4(7) He must take into account, if it is practicable and appropriate to consult them, the views of:

(a) anyone named by the person is someone to be consulted on the matter in question or on matters of that kind,

Mrs. B had not named anyone who should be consulted about the decision.

(b) anyone engaged in caring for the person or interested in his welfare;

Mrs. B had a husband and daughters who cared very much about her welfare.

(c) any donee of a power of attorney granted by the person;

Mrs. B had not made a lasting power of attorney.

(d) any deputy appointed for the person by the Court;

The Court of Protection had not appointed a deputy to make decisions on Mrs. B's behalf.

as to what would be in the person's best interests and, in particular, as to the matters mentioned in subsection (6).

Relevant circumstances (Section 4(2) of the checklist)

The meeting considered the factors outlined in the statutory checklist and also spent some time considering all the relevant circumstances.

Other relevant factors

Advantages/benefits of treating her for the overdose	Disadvantages/disbenefits of treating her for the overdose
<p>Medical</p> <ul style="list-style-type: none">■ Treatment would prevent the liver failure (and her subsequent death) which would otherwise occur as a consequence of the overdose.■ Treatment would enable her to be treated for her depression.	<p>Medical</p> <ul style="list-style-type: none">■ She would still be suffering from terminal cancer, from which she would die within approximately six months.
<p>Emotional</p> <ul style="list-style-type: none">■ She would not die from liver failure, which could be extremely distressing for her.■ She would also not experience the distress of her family, as they would be with her if this happened.■ She would gain emotionally from being able to spend additional time with her family, who were very important to her.	<p>Emotional</p> <ul style="list-style-type: none">■ She might be distressed and angry at being prevented from ending her life.■ She would still face the distress of dying from cancer.■ She might feel powerless, in that her wishes were apparently being over-ridden.
<p>Welfare</p> <ul style="list-style-type: none">■ She would be able to spend additional time with her family.■ She could still have a reasonable quality of life for the next few months.■ The manner of her dying could be managed in a more peaceful way.	<p>Welfare</p> <ul style="list-style-type: none">■ She might be angry with her family for insisting that she received treatment for the overdose, which could affect her relationship with them at the end of her life.■ She might consider that the quality of her life over the next few months was unacceptable.

The meeting

The best interests meeting was attended by the consultant from the hospice, a senior nurse and Mrs. B's husband and one of her daughters. It was chaired by the consultant. They then went through the items in the statutory checklist (as described above). They first considered whether she lacked capacity, and decided on the basis of the assessment that she did lack capacity to make the decision to refuse treatment for the overdose. They decided that Mrs. B's terminal illness was not a sufficient reason not to treat her. They considered whether Mrs. B might regain capacity, and decided this was likely to happen if she was treated for depression.

There was a lot of discussion about the pros and cons of treating her for the overdose. They looked at the medical, emotional and welfare factors outlined above. The strong medical opinion was that that not treating her would inevitably bring about her death, and that this would be very distressing for her (as well as for her family).

There was also a lot of discussion about what Mrs. B would want. This was mainly on the basis of information given by the family, and based on things she had said and believed before she became ill and depressed. They also considered the fact that she had tried to kill herself, and that she still felt that life was not worth living.

Because of the large amount of information, it was noted on flip charts in order to help those present at the meeting remember it all.

It was difficult to balance what people thought were in Mrs. B's best interests with what she appeared to want for herself, and with what the family wanted. Their firmly held view was that it would be in Mrs. B's best interests to have the treatment, although it was hard to separate what they wanted (as best for them) from what would objectively be in Mrs. B's best interests. They were very distressed by the possibility of her dying before they had all expected, and in a way which they thought would be unpleasant for her.

The meeting decided that – on balance – it would be better to treat Mrs. B. The balancing factors were the probable distressing nature of death due to liver failure, the possibility of treating Mrs. B for depression and the subsequent quality of time she could then spend with her family.

The discussion that happened at the meeting was recorded and placed in Mrs. B's notes.

Case Study 4 – Moving home

Mr. C is 35-years-old. He has a moderate/severe learning disability and lives with his mother. His father is dead, and he has three siblings who have little contact with him or his mother. He came to the attention of Social Services when neighbours complained to the Council about the rubbish in the garden. Social Services had been aware of Mr. C in the past but he had not been in receipt of any services for nearly 20 years.

Mrs. C (his mother) was unwilling to let social workers into the house. When they did manage to gain entry, they were concerned about the state of the house, about Mrs. C's mental state and about the care that Mr. C was receiving. The house was dirty, and Mrs. C seemed to be very depressed. She had not seen a doctor. Mr. C was not well cared for – his clothes were dirty and he appeared not to have had a bath for some time. There was very little food in the house, and what there was consisted mainly of fizzy drinks and biscuits.

The social workers tried to discuss Mr. C's care with his mother. However, she was not willing to do this. They tried to do this on a number of occasions, and each time Mrs. C. refused to discuss it. She also refused to see her GP in relation to her depression.

Eventually, social services decided that Mr. C should be removed from his home in his own best interests. This followed an assessment of capacity, which showed that he lacked the capacity to make the decision for himself as to where he should live. They therefore convened a best interests meeting.

The best interests meeting

This was attended by his GP, a psychologist who had carried out the capacity assessment, his social worker, the social work team manager, his mother, her solicitor and a representative of the legal department from the Local Authority.

4(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.

The decision must not be based on an assumption that, for example, adults with learning disabilities should be supported to move away from their families.

4(2) The person making the determination must consider all the relevant circumstances and, in particular, take the following steps.

4(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.

The degree of Mr. C's learning disability made it very unlikely that he would gain capacity to make this decision in the future.

4(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.

The psychologist who had assessed him had used a range of methods to make communication more accessible. He had been unable to express a view as to where he should live or who with. He was, however, able to say something about what he currently enjoyed and what he didn't like.

4(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.*

This decision was not related to life-sustaining treatment.

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);*

Mr. C had not written down his wishes or preferences. He was able to express his wishes and asked to choose between two 'concrete' options. He appeared to become anxious when asked to interact with strangers if his mother was not in the room.

(b) *the beliefs and values that would be likely to influence his decision if he had capacity;*

He had not expressed any beliefs or values.

(c) *the other factors that he would be likely to consider if he were able to do so.*

His mother stated that Mr. C would consider her and would want to stay with her.

4(7) *He must take into account, if it is practicable and appropriate to consult them, the views of:*

(a) *anyone named by the person is someone to be consulted on the matter in question or on matters of that kind;*

Mr. C had not named anyone to be consulted.

(b) *anyone engaged in caring for the person or interested in his welfare;*

His mother had the right to be consulted.

(c) *any donee of a power of attorney granted by the person;*

Mr. C had not made a power of attorney

(d) *any deputy appointed for the person by the Court;*

No deputy had been appointed.

as to what would be in the person's best interests and, in particular, as to the matters mentioned in subsection (6).

Other relevant factors

Advantages/benefits of moving away from home	Disadvantages/disbenefits of moving away from home
<p>Medical</p> <ul style="list-style-type: none"> ■ Mr. C would benefit from improved diet and healthier lifestyle. 	<p>Medical</p> <ul style="list-style-type: none"> ■ He might lose his appetite and stop eating, as this had happened once before, many years ago.
<p>Emotional</p> <ul style="list-style-type: none"> ■ Mr. C might be able to make friends. ■ He would be less dependent on his mother. 	<p>Emotional</p> <ul style="list-style-type: none"> ■ Mr. C would be distressed if removed from his mother's care. ■ He might become very anxious, which might impact on his behaviour.
<p>Welfare</p> <ul style="list-style-type: none"> ■ He would be living in good quality accommodation. ■ He would be cared for by skilled staff. ■ He would be treated more as an adult. ■ He would have a more sociable life. ■ He would be able to engage in more adult activities. ■ He could still see his mother. ■ He would be able to make more choices for himself. 	<p>Welfare</p> <ul style="list-style-type: none"> ■ He would be removed from his familiar routines. ■ His behaviour might become challenging. ■ He might not like the people he lived with. ■ He might find it too pressurising to engage in new activities and not enjoy it.

Mrs. C and her solicitor were vehement in their refusal to agree that Mr. C should be removed. They thought that he would be very distressed and unhappy, and would not settle into a new environment. The Local Authority thought that he would settle if it was managed carefully, and that he would be better off in both the short and the long term. Mrs. C said she would seek treatment for her depression.

Those at the meeting were unable to agree about what would be in Mr. C's best interests. A second meeting also failed to resolve the issue, and the decision was then made to refer the case to Court.

Case Study 5: Older adults – residential care

Miss K is an 89-year-old retired head teacher who lives alone, with no living relatives. She attends a day centre five days a week. She cooks light meals for herself and is independent in self-care; a cleaner comes three times a week.

She was admitted to hospital after a fall in the home when she was found after 12 hours by her cleaner lying on the bathroom floor. She refused to use a zimmer frame on the ward stating that she would stick to using a single walking stick, even though this was seen to make her gait poor and increase risk of falls when she moved from sitting to standing, or made sudden moves. In hospital she refused to undergo formal cognitive testing but she was observed to have poor short-term memory and to be disorientated in time and place. A CT scan showed general cortical atrophy.

The team (in the Care of the Elderly ward in the general hospital) was concerned about her going back home where there were stairs (and a stair lift was not feasible). She refused a care alarm and additional carer support, stating that she could manage without these. She stated that she was ready to die. She could move to a ground floor flat or to residential home but she refused to consider either. The team had to decide whether or not it was in her best interests to return home. Liaison psychiatry judged that she lacked capacity to make the decision as to whether she could go back to live in her home as she was not able to identify risks and could not weigh up the different alternatives.

Staff at the day centre felt strongly that she could make her own decisions, but her carer was concerned about the risk of further falls which might leave her disabled.

NB: The decision was about returning home. It was not about what service to offer her if the decision was made for her not to return home.

4(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.

The decision should not be based on an assumption that because Ms. K is old, frail and apparently cognitively impaired, that she will be better off in residential care.

4(2) The person making the determination must consider all the relevant circumstances and, in particular, take the following steps.

In this case, the person making the decision was the care manager.

4(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.

Ms. K currently lacked the capacity to make the decision. The results of the CT scan suggested that the deterioration was significant. The care team had noted that Ms. K found it very difficult to retain new information, and felt that she would not be able to weigh up the options regarding whether or not she should return home, as she was unlikely to be able to retain information about them.

4(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.

Ms. K's primary nurse used written and pictorial materials to try and help her retain and understand the options.

4(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.

This decision was not in relation to life-sustaining treatment.

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);

Ms. K had not made any written statement, but had expressed her views very clearly to her key worker and to staff at the day centre she attended. She did not want to leave her home – she was ready to die, and wanted to die in her own home, with her familiar things about her. Whilst in hospital, she would periodically ask about when she was going home, but did not seem distressed when told that she could not go yet.

(b) the beliefs and values that would be likely to influence his decision if he had capacity;

Ms. K had a strong self-identity as an autonomous person who was used to making difficult decisions on her own. Ms. K had also always been fiercely independent, and was ashamed to ask the 'state' for help. She had managed by herself for her entire life, and this was important to her. She had worked hard to become a Head Teacher, and had said that being dependent was a sign of weakness.

(c) the other factors that he would be likely to consider if he were able to do so.

4(7) He must take into account, if it is practicable and appropriate to consult them, the views of:

(a) anyone named by the person is someone to be consulted on the matter in question or on matters of that kind;

Ms. K had not named anyone to be consulted.

(b) anyone engaged in caring for the person or interested in his welfare;

Her primary nurse and day centre staff should be consulted. Her GP knew her well and should also be involved. As she had no family – and the decision was to do with whether or not she should be placed in a service by the NHS or the Local Authority, an IMCA was instructed.

(c) any donee of a power of attorney granted by the person;

Ms K had not made a power of attorney.

(d) any deputy appointed for the person by the Court;

No deputy had been appointed.

as to what would be in the person's best interests and, in particular, as to the matters mentioned in subsection (6).

Other relevant factors

Advantages/benefits of returning home	Disadvantages/disbenefits of returning home
<p>Medical</p> <ul style="list-style-type: none"> ■ Ms. K might show improvements in her memory, as she would have familiar things around her. ■ She might gain capacity to make decisions for herself. ■ A return to her familiar environment might reduce her general decline, which could also reduce risk of death following an unwanted move. 	<p>Medical</p> <ul style="list-style-type: none"> ■ Ms. K might suffer from serious falls, and any injury that might follow. ■ It was also possible that she might die if she fell and was not discovered in time. ■ Her diet and hygiene might be compromised if she was reluctant to allow help in the house.
<p>Emotional</p> <ul style="list-style-type: none"> ■ Ms. K might feel calmer, as she would not have to deal with so many other people. ■ Her wishes would be followed. ■ She would feel more in control. ■ She would have her memories around her. 	<p>Emotional</p> <ul style="list-style-type: none"> ■ She might become more fearful of falling, and isolate herself. ■ She could become depressed and it would not be noticed easily.
<p>Welfare</p> <ul style="list-style-type: none"> ■ She would be able to maintain some independence for longer. ■ The cleaner and additional staff could continue to check up on her. 	<p>Welfare</p> <ul style="list-style-type: none"> ■ She would have a more limited quality of life, as she would not be able to leave the house without help.

The care manager, the care team in the hospital and the day centre staff discussed Ms. K's future, with the IMCA present. The IMCA had had an opportunity to talk to Ms. K, who, when asked, still said she wanted to go home. She was not able to say how she would deal with the risk of falls – only that she 'could manage'.

Whilst recognising that that there were significant risks attached to letting her go home, the team was reluctant to decide that she could not do so. They felt any move to a new environment would be disruptive, especially if it was against her wishes and might hasten general decline and even her death. There was a marked difference in opinion between hospital staff, who were concerned about risk to her physical health and staff from the day centre and her GP who emphasised her clearly stated wishes and quality of life. However, having considered the factors in the statutory checklist they decided it would not be in her best interests to return home, unless additional care could be provided, primarily to monitor her physical well-being.

The final decision agreed by the team was that she should return home only if she agreed to regular carer visits. It was considered possible that Ms. K would agree the care plan in order to leave hospital but then refuse once back at home. However, she might also regain capacity when she returned home, and it would be essential to have ongoing monitoring of both her safety and her capacity to make decisions about where she would live for herself. On balance, however, the team advised her social worker that they considered it to be in her current best interests to be allowed to return home providing the risk management plan was put into place. If she continued to deteriorate once at home, then a move to residential care should be actively pursued.

Summary

The Mental Capacity Act outlines the process for making decisions on behalf of those who lack capacity to make a decision for themselves. The approach to be used is that of best interests, and there have been a number of Court cases which have shown the factors that should be considered in making a best interests decision.

The Act contains a 'statutory checklist' (Section 4) which tells us the factors which must be considered when making a best interests decision. The Act also provides for staff and/or carers to make routine decisions on behalf of someone who lacks capacity, and also outlines those decisions which can not to be made on behalf of someone who lacks capacity under this Act.

In considering what is in someone's best interests, those making the decision have to consider the factors in the statutory checklist, as well as any other factors or circumstances which might be relevant. These relevant circumstances include the risks and benefits of the decision, including any medical, emotional, social or welfare circumstances which relate to the individual who lacks capacity. Not all decisions will require a best interests meeting, but the person making the decision will still need to consider the factors in the statutory checklist. The person making the decision will need to make sure that there is a record of both the decision that they have made, and the factors that were considered in making it.

If a best interests meeting is necessary, then it needs to be properly organised and Chaired appropriately. The relevant people need to be invited and, if they are not able to attend, need to be able to have any relevant information available to the meeting. The discussion and outcome need to be recorded. The function of the best interests meeting is to be a forum for consultation and advice to the decision-maker.

Appendix

Best Interests meetings: some points to consider

	YES	NO
Has an assessment of capacity been carried out?	<input type="checkbox"/>	<input type="checkbox"/>
Has the assessment shown that the person lacks capacity to make the decision or decisions for themselves?	<input type="checkbox"/>	<input type="checkbox"/>
Is the decision to be made one that is allowed to be made under the Mental Capacity Act (i.e. not an excluded decision or one that requires a Court ruling)?	<input type="checkbox"/>	<input type="checkbox"/>
Has someone been appointed to Chair the Best Interests meeting?	<input type="checkbox"/>	<input type="checkbox"/>
Has someone been appointed to record the Best Interests meeting and the outcome?	<input type="checkbox"/>	<input type="checkbox"/>
Has the Chair ensured that all of those mentioned in the statutory checklist (if appropriate) have either been consulted or invited to the meeting?	<input type="checkbox"/>	<input type="checkbox"/>
Has the Chair sent out an agenda including:		
Introductions	<input type="checkbox"/>	<input type="checkbox"/>
Purpose of the meeting (specifying the decision or decisions)	<input type="checkbox"/>	<input type="checkbox"/>
Review of requirements of the statutory checklist	<input type="checkbox"/>	<input type="checkbox"/>
Giving information	<input type="checkbox"/>	<input type="checkbox"/>
Discussion	<input type="checkbox"/>	<input type="checkbox"/>
Summary of information and factors to be considered	<input type="checkbox"/>	<input type="checkbox"/>
Deciding on best interests	<input type="checkbox"/>	<input type="checkbox"/>
Has the outcome of the meeting been recorded and distributed?	<input type="checkbox"/>	<input type="checkbox"/>

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