Mental Capacity Act 2005

Draft Code of Practice

Contents of the Code of Practice

Chapter 1 - The Scope and Purpose of the Code of Practice to the Mental Capacity Act

Introduction

1.1 The Mental Capacity Act 2005 (the Act) provides the framework for acting and making decisions on behalf of individuals who lack the mental capacity to do these acts or make these decisions for themselves. Everyone working with and/or caring for adults who lack capacity, whether they are dealing with everyday matters or life-changing events in the lives of people who lack capacity, must comply with the Act.

1.2 In a day-to-day context, mental capacity includes making decisions or taking actions affecting daily life – when to get up, what to wear, what to eat, whether to go to the doctor when feeling ill etc. In a legal context, it refers to a person's ability to do something, including making a decision, which may have legal consequences for the person lacking capacity, or for other people.

1.3 The legal framework provided in the Act is supported by this Code of Practice, which provides guidance and information to those acting under the terms of the legislation. The Code has statutory force, which means that certain categories of people have a legal duty to have regard to it, of which further details are provided below. However, the Code is not an exhaustive guide and will be complemented by specialist information for professionals, literature for family carers and other carers and basic information of interest to the general public.

1.4 The Act and therefore this Code applies to all persons habitually resident or present in England and Wales. However, it will also be possible for the Court of Protection to consider cases, which involve persons who live outside these jurisdictions.

The role of the Code

1.5 The Code provides guidance to all those working with and/or caring for adults who lack capacity, including family members, professionals and carers. It describes their responsibilities when acting or making decisions with, or on behalf of, individuals who lack the capacity to do these things themselves. In particular, it focuses on those who will have a duty of care to a person lacking capacity and explains how the legal rules set out in legislation will work in practice. As noted above, however, relevant information for those affected by the Act will also be provided in other formats suitable for their audience.

1.6 The Code also provides information on how to obtain more detailed guidance from other sources, where this is particularly relevant. A list of contact details is provided in Annex A and further information appears in the footnotes to each chapter. References made and any links provided to material or organisations do not form part of the Code and do not attract the same legal status. Signposts to further information are provided for assistance only and references made should not suggest that the Department for Constitutional Affairs endorse such material.

Status of the Code

1.7 Section 42 of the Act sets out the purpose of the Code of Practice, which is to provide guidance for specific people in specific circumstances.

1.8 Section 43 sets out procedures for the preparation of and consultation about drafts of the Code of Practice, and for parliamentary consideration.

1.9 Section 42, subsections (4) and (5), set out categories of people who are placed under a duty 'to have regard' to the Code and gives further information about the status of the Code. The following categories of people are under a duty to have regard to the Code when acting in relation to a person who lacks capacity:

- People working in a professional capacity (for example, a doctor who is assessing a person's capacity to make a particular decision or a social worker who is arranging for a person lacking capacity to move into a supported living arrangement);
- People who are receiving payment for work in acting in relation to the person without capacity (for example, a care assistant working in a residential care home for people with learning disabilities);
- Anyone who is an attorney of a Lasting Power of Attorney (LPA) (see chapter 6);
- Anyone who is a deputy appointed by the Court of Protection (see chapter 7);
- Anyone acting as an Independent Mental Capacity Advocate (see chapter 11);
- Anyone carrying out research approved in accordance with the Act (see chapter 10).

1.10 These categories of people must be able to demonstrate that they are familiar (in broad terms) with relevant parts of the Code or with the guidance produced on particular parts of the Code. If they have not followed the relevant guidance contained in the Code then they will be expected to give reasons why they have departed from it.

1.11 Other people, who are not placed under this legal duty, will still be expected to follow the guidance in the Code. The Act applies to e*veryone* who looks after, or cares for, someone who lacks capacity, including carers or family carers and the Code will help them to understand the Act and apply it.

1.12 Failure to comply with the Code can be used in evidence before a court or tribunal in any civil or criminal proceedings, if relevant (section 42(5)). This applies, not only to those categories of people who have a duty to have regard to the Code, but also to those who are not under such a duty. This is because carers or family carers still have an obligation to act in accordance with the principles of the Act and in the best interests of a person lacking capacity. It is therefore important that anyone working with or caring for a person who lacks capacity should become familiar with the Code.

Scenarios used in the Code

1.13 The Code includes many boxes within the text in which there are scenarios, using imaginary characters and situations. These are intended to help illustrate what is meant in the main text. The scenarios should not in any way be taken as templates for decisions that need to be made in similar situations. They have no legal status.

References in the Code

1.14 Throughout the Code, the Mental Capacity Act 2005 is referred to as 'the Act' and any sections quoted refer to this Act unless otherwise stated. Where reference is made to provisions from other legislation, the full title of the relevant Act will be set out, for example 'Mental Health Act 1983'.

Alternative Formats

1.15 The Code has been published as an easy-read summary, an audio version, and is also available in Welsh.

Chapter 2 - The Mental Capacity Act: Statutory Principles

Introduction

2.1 This chapter provides a general introduction to the Mental Capacity Act 2005 (the Act). **Part 1** of this chapter provides a brief overview of the main provisions of the Act and explains the implications of the Act for people with capacity problems, their families, carers and professionals who work with them. **Part 2** provides a commentary on the statutory principles that underline the provisions of the Act and govern how it is to be interpreted and implemented.

Part 1: Outline of the Act

2.2 The Mental Capacity Act sets out a framework for acting and making decisions on behalf of adults aged 16 years and over who lack the mental capacity to act or make such decisions for themselves. It sets out principles and mechanisms for making personal welfare decisions, health care decisions and financial decisions affecting people without the capacity to make their own decisions.

2.3 The Act's starting point is to confirm in legislation the assumption that adults have full legal capacity to make their own decisions unless it is shown that they do not. It also includes provisions to ensure that people are given all appropriate help and support to enable them to make their own decisions or to maximise their participation in any decision-making process. The Act is intended to assist and support people who might lack capacity and to discourage those who care for them from being overly restrictive or controlling. But the Act also aims to provide an appropriate balance between an individual's right to autonomy and self-determination with the right to safeguards and protection from harm where that person lacks capacity to make decisions to protect him/herself.

What changes does the Act introduce?

2.4 Many of the provisions in the Act are based upon existing common law principles (i.e. principles that have been established through decisions made by courts in individual cases). The Code seeks to clarify and improve upon these existing principles and build upon current good practice, which has derived from them. The underlying philosophy of the Act is to ensure that individuals who lack capacity are the focus of any decisions made, or actions taken, on their behalf. The interests of the person who lacks capacity should prevail; not the views or convenience of those caring for that person.

2.5 The Act's key provisions are designed to:

- Set out five guiding principles to underpin the Act's fundamental concepts and to govern its implementation (see Part 2 of this chapter);
- Provide a definition of those who lack decision-making capacity and set out a single clear test for assessing whether a person lacks capacity to take a particular decision at a particular time (see chapter 3);

- Establish a checklist for determining what is in the 'best interests' of a person lacking capacity as the criterion for taking actions or decisions on that person's behalf (see chapter 4);
- Clarify the law when acts in connection with the care or treatment of people lacking capacity to consent are carried out in their best interests, without formal procedures or court intervention, but with clear restrictions and limitations (see chapter 5);
- Extend the provisions which enable people to plan for future lack of capacity by making Lasting Powers of Attorney (LPAs) covering health and welfare decisions as well as financial affairs, with improved safeguards against abuse and exploitation (see chapter 6);
- Provide for a decision to be made, or a decision-maker (deputy) to be appointed, by a new specialist Court of Protection in cases where there is no other way of resolving a matter affecting a person lacking capacity (see chapters 7 and 14);
- Make statutory rules, with clear safeguards for people, whilst they still have capacity, who choose to make an advance decision to refuse medical treatment (see chapter 8);
- Provide for the appointment of Independent Mental Capacity Advocates to support and represent people without capacity who have no-one to speak for them, when decisions need to be made about serious medical treatment or a change in care home or hospital accommodation (see chapter 9);
- Set out specific parameters, safeguards and controls for research involving, or in relation to, people lacking capacity (see chapter 10);
- Provide mechanisms to protect people lacking capacity from abuse or exploitation by creating a new public office – the Public Guardian – to oversee attorneys and deputies and to act as a single point of contact for referring allegations of abuse to other relevant agencies. The Act also introduces a new criminal offence of ill-treatment or wilful neglect of a person lacking capacity (see chapter 13);
- The Code also clarifies how the Act relates to other laws affecting people lacking capacity, such as those affecting children and young people (see chapter 11), the provisions of mental health legislation (see chapter 12) and the legal requirements concerning access to information (see chapter 15).

What acts and decisions does the Act cover?

2.6 The Act covers a wide range of decisions made, or actions taken, on behalf of people lacking capacity, whether they relate to day-to-day matters or represent major life-changing events. These include matters in connection with the personal welfare of people lacking capacity, their health care and medical treatment and the management of their property and financial affairs. Actions or decisions may range from choosing what to wear or what to buy when doing the weekly shopping, to carrying out a routine dental check-up, or deciding whether the person should move into residential care or undergo a major surgical operation.

What acts and decisions are not covered?

2.7 There are certain decisions, which can never be made on behalf of a person who lacks capacity to make those decisions, either because they are so personal to the individual concerned or because they are governed by other legislation. Sections 27-29 and 62 set out the specific decisions which can never be made or acts which can never be done under the Act, whether by family members, carers, attorneys or the Court of Protection. These include:

- Decisions concerning family relationships - including consent to marriage or civil partnership, sexual relationships, divorce, placing a child for adoption, taking over parental responsibility for a child, or consent to fertility treatment;
- Decisions to give, or to consent to, treatment for mental disorder of people who are liable for detention and treatment under the Mental Health Act 1983 (further guidance is given in chapter 12);
- Decisions on voting or casting a vote at an election or a referendum on behalf of a person lacking capacity to vote.

2.8 In relation to acts, section 62 makes clear that nothing in the Act has an effect on the law concerning unlawful killing or assisting suicide, (for further details in relation to acts see chapter 5).

Who is affected by the Act?

2.9 The provisions for decision-making or taking action under the Act will affect adults over 16 years who lack capacity to make their own decisions as a result of an impairment of, or a disturbance in the functioning of, the mind or brain. An assessment of capacity will therefore be of fundamental importance to all people whose capacity may be questioned. Guidance on defining and assessing capacity is given in chapter 3.

2.10 The Act sets out fundamental legal rules that apply to everyone working with and/or caring for adults who lack capacity, including family members, professionals and other carers. The rules also apply to people appointed in a formal capacity to act as an attorney or deputy for a person lacking capacity. The Act provides mechanisms for resolving disputes or difficulties which are important for all family members, carers and professionals using the Act, as well as for people who are considered to lack capacity themselves.

Part 2: The Statutory Principles

2.11 Section 1 of the Act sets out five key principles, designed to emphasise the fundamental concepts and underlying 'ethos' of the Act and to provide a 'benchmark' for decision-makers and carers acting under the Act's provisions. The statutory principles can be summarised as follows:

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

- 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;
- Individuals must retain the right to make what might be seen as eccentric or unwise decisions;
- Best interests – anything done for or on behalf of people without capacity must be in their best interests; and
- Least restrictive alternative – anything done for or on behalf of people without capacity should be the least restrictive of their basic rights and freedoms.

2.12 The message conveyed by these principles is that the Act is intended to be enabling and supportive of people lacking capacity, not restricting or controlling of their lives. The Act aims not only to protect people who lack capacity, but also to maximise their autonomy and ability to participate in decision-making.

2.13 The statutory principles apply to all actions and decisions taken under the Act. Following the principles and applying them to the Act's framework for decision-making will help to ensure not only that appropriate action is taken in individual cases, but also to point the way to solutions in difficult or uncertain situations. The five principles are described in more detail below.

- **The presumption of capacity: 'A person must be assumed to have capacity unless it is established that he lacks capacity.' (s.1(2))**

2.14 A fundamental principle of the common law is that every adult has the right to make his/her own decisions and is assumed to have capacity to do so unless it is proved otherwise. The Act now sets out clearly in statute that individuals have the right to make choices and decisions for themselves (the right to autonomy), unless it has been shown that they lack capacity to make these particular choices and decisions themselves.

2.15 A person's decision-making capacity is the pivotal issue that determines whether or not his/her right to make decisions must be respected – balancing the right to autonomy and self-determination against the right to safeguards and protection from harm where that person lacks capacity to make decisions to protect him/herself. The starting point, however, is always to assume that the individual does have capacity until there is proof that the person lacks the capacity to make the decision in question.

Mrs A has been diagnosed as being in the early stages of dementia and her son is worried that she is becoming confused about money. She knows her pension is paid into the bank every month but cannot always remember which bills she has to pay or how to pay them. Her son must first assume she has capacity to manage her affairs and look at each financial decision as it has to be made, giving his mother the help and support she may need to make these decisions for herself. As a start, he offers to help make arrangements to pay the bills by direct debit and explains to her what this means. Mrs A agrees this would be helpful and signs the relevant forms because she is able to understand what she is doing. He goes shopping with her and sees she is quite capable of finding the goods she needs and making sure she gets the correct change when paying for them. But when it comes to deciding how to get the best returns from

her investments, Mrs A gets confused about the different options, no matter how they are explained to her, even though she had been able to make such decisions in the past. Her son concludes that at this time she has capacity to deal with everyday financial matters but not more complex affairs. He therefore suggests that she should make an appointment to see her solicitor to discuss the possibility of making a Lasting Power of Attorney while she still has capacity to do so.

2.16 Some people may need help or support to be able to make a decision or to communicate their decision, but the need for help and support does not automatically mean they cannot make that decision until it is proved they lack the capacity to do so. The Act's definitions of people who lack capacity and the inability to make a decision are explained in more detail in chapter 3.

- **Maximising decision-making capacity: 'A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.' (s. 1(3))**

2.17 The second of the Act's key principles clarifies that a person should not be treated as unable to make a decision until everything possible – or practicable – has been done to help the person make his/her own decision. This is linked to the presumption of capacity. Individuals who have an illness or disability that might affect their ability to make decisions for themselves should be enabled and encouraged to take as many decisions for themselves as they can. The aim is to ensure that people who can make decisions for themselves, but may need help and support to do so, are not automatically labelled as lacking the capacity to make these decisions and therefore subject to unnecessary interventions.

2.18 There are many ways in which people can be given help and support to enable them to make their own decisions, and these will vary depending on the decision to be made, the time-scale for making the decision and the individual circumstances of the person needing to make it. The practicable steps to be taken might include using different means of communication, providing information in an accessible form, or treating an underlying medical condition to enable the person to regain capacity.

2.19 Chapter 3 gives more detailed information on the ways in which people can be helped and enabled to make decisions for themselves. The following steps should be considered amongst others:

- Try to minimise anxiety or stress by making the person feel at ease. Choose the best location where the person feels most comfortable and the time of day when s/he is most alert;
- If the person is likely to regain capacity, wait to see if this occurs (unless the decision is urgent). If the cause of the lack of capacity can be treated, it may be possible to delay the decision until treatment has taken place;
- If there are communication or language problems, consider using a speech therapist or interpreter, or consult family members on the best methods of communication;
- Be aware of any cultural, ethnic or religious factors which may have a bearing on the person's way of thinking, behaviour or communication

- Consider whether or not a friend or family member should be present to help reduce anxiety. But in some cases the presence of others may be intrusive.

2.20 Anyone involved in assisting and supporting a person with capacity problems should be careful not to use excessive persuasion or 'undue influence', which might have the effect of making the person reach a decision s/he might not otherwise have made.[1] Behaving in a manner which is overbearing or dominating, or seeks to influence the person's decision, is quite different from providing appropriate advice and support.

- **Unwise decisions: 'A person is not to be treated as unable to make a decision merely because he makes an unwise decision.' (s. 1(4))**

2.21 This principle again underpins the right to autonomy and reflects the fact that each one of us is an individual with our own values, beliefs, preferences and attitude to risk, which may not be the same as those of other people. Thus, even if a person makes a decision which others, including family, friends or professional advisers, regard as unwise, unusual or irrational, this does not necessarily mean that the person lacks capacity to make that decision.

A person with mental health problems smokes cigarettes and continues to do so even though he has a severe chest condition. Smoking might generally be regarded as an unwise thing to do for someone with his condition. Doctors have explained to him the risks of continuing to smoke with his condition and have advised him to give up. He should not be assumed to lack capacity to decide whether to smoke or not simply because medical advice and general opinion might be that it would be unwise for a person with his particular condition to smoke.

2.22 There may however be a cause for concern if an individual repeatedly makes unwise decisions, which will place him/her at a significant risk of harm or serious exploitation. Concern may also be triggered if a person makes a particular decision, which defies all notions of rationality or is markedly out of character. In these situations, it would be relevant to look at the person's past decisions and choices. While such situations should not automatically lead to the conclusion that capacity is lacking, they might raise doubts about capacity and indicate the need for further investigation. For example, such a decision might indicate that the person is suggestible or susceptible to undue influence, or it could suggest a lack of understanding or the need for more information about the nature or likely consequences of decision in question.

An elderly woman with vascular dementia spends nearly £500 on fresh fish from a door-to-door salesman. She is very fond of fish but there is far too much to fit into her freezer. Before the onset of dementia, she was always very thrifty and careful with her money and would never have dreamt of buying such a quantity of expensive fish or spending this amount in one go. This decision alone may not automatically mean she now lacks capacity to manage all aspects of her finances, but her son makes further enquiries and discovers she has also overpaid her cleaner on several occasions, (something she has never done in the past). He decides it is time to use the registered Lasting Power of Attorney previously made by his mother giving

[1] Undue influence in relation to consent to medical treatment was considered in *Re T (Adult: Refusal of Treatment)* [1992] 4 All E R 649, 662.

him authority to manage her financial affairs.

- **Best interests: 'An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.' (s. 1(5))**

2.23 The principle of acting or making decisions in the best interests of a person who lacks capacity is a well-established common-law principle and the concept has been developed by the courts[2]. Section 1(5) enshrines this principle in statute as the overriding principle that must guide all actions taken or decisions made under the Act on behalf of someone lacking capacity.

2.24 It is not possible for statute to give a single all-encompassing definition of 'best interests' because what will be in a person's best interests will depend on that particular individual and his/her personal circumstances. However, the Act (in section 4) sets out a checklist of steps that must be taken in order to decide what is in a person's best interests each time an act or decision is being taken on behalf of an individual who lacks capacity. Chapter 4 provides more detailed guidance on best interests and factors to be taken into account when deciding what will be in the person's best interests.

- **Least 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.' (s. 1(6))**

2.25 The final principle confirms that before any action is taken, or decision made, on behalf of a person lacking capacity, thought must be given as to whether it is possible to decide or act in a way that would interfere less with the person's rights and freedoms. This is known as choosing the 'least restrictive alternative' and includes considering whether there is a need to act or make a decision at all.

2.26 Where there is more than one course of action or a choice of decisions to be made, it is important to explore all possible options or alternatives and to consider which option would be least restrictive of the person's future choices or would allow them the most freedom. However, the purpose for which the act or decision is needed must always be remembered, and other options considered only so long as the desired purpose can still be achieved.

A young man with profound learning disabilities also has epileptic seizures and frequently injures himself when in the throes of a fit. His carers can usually take action to protect his head if they see the first signs of seizure, but this means he has to be constantly observed. He gets frustrated by not having any space and privacy. Various options are considered, such as leaving him alone in the hope that any injuries will not be serious, confining him to a room with soft furnishings where he does not have to be observed, or providing him with protective headgear. A protective helmet is tried and while he doesn't like it at first, it soon becomes clear that it allows him more freedom to move around and he gets used to wearing it.

[2] See for example *Re MB (Medical Treatment)* [1997] 2 FLR 426, CA; *Re A (Male Sterilisation)* [2000] 1 FLR 549; *Re S (Sterilisation: Patient's Best Interests)* [2000] 2 FLR 389; *Re F (Adult Patient: Sterilisation)* [2001] Fam 15

2.27 While this principle requires the 'least restrictive alternative' to be considered, any action taken or decision made must be in the person's best interests. Therefore an option may be chosen which is not the least restrictive alternative, so long as that option is in the person's best interests. In practice, the process of choosing the least restrictive option and deciding whether a particular action or decision is in the person's best interests will be intermingled. But it is important to remember that both these key principles of the Act must be applied each time a decision or action may need to be taken on behalf of a person lacking capacity.

Chapter 3 – Capacity to make a decision

Introduction

3.1 This chapter deals with the provisions in the Act about capacity and lack of capacity and provides guidance on assessing capacity. **Part 1** explains the concept of capacity and what it means to lack capacity to make a decision. It also describes the two-stage test of capacity set out in the Act. **Part 2** suggests a range of practical steps that can be taken to help individuals to make decisions or improve their ability to participate as fully as possible in decisions affecting them. **Part 3** describes the processes involved in assessing capacity and sets out the circumstances when professionals should be involved. **Part 4** provides a summary of the factors that are discussed in this chapter and might be applied in practice. It should be noted however, that the summary is for quick reference only and should not be relied upon in isolation of the information contained in the chapter itself.

Part 1: What is mental capacity?

3.2 In a day-to-day context, mental capacity means the ability to make decisions or take actions affecting daily life – when to get up, what to wear, what to eat, whether to go to the doctor when feeling ill etc. In a legal context, it refers to a person's ability to do something, including making a decision, which may have legal consequences for the person themselves or for other people.

3.3 Following the Act's first key principle (s.1(1) – see chapter 1) the starting-point should be to assume that the person has capacity to make the decision in question (the *presumption of capacity*). Some people may need help or support to be able to make a decision or communicate a decision (see Part 2 below), but the need for help and support does not automatically mean that they cannot make that decision.

3.4 In legal proceedings, the burden of proof will fall on any person who asserts that another person lacks capacity. The person making the assertion will have to show, on the balance of probabilities, that the individual lacks capacity - that it is more likely than not that the person lacks capacity to make the decision in question.

Defining lack of capacity

3.5 Section 2 of the Act sets out the Act's definition of a person who lacks capacity. Section 3 sets out the test for assessing whether a person is unable to make a particular decision and therefore lacks capacity. In applying these together, the Act requires a '*functional approach'* when deciding whether a person lacks decision-making capacity – this means that capacity is decision-specific and must therefore be assessed in relation to the particular decision, at the time the decision needs to be made, and not the person's ability to make decisions generally.

3.6 Section 2(1) defines a person who lacks capacity as follows:

> "For the purposes of this Act, a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation

to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain."

3.7 Section 2(2) clarifies that it does not matter whether the impairment or disturbance is permanent or temporary. A person can lack decision-making capacity even if the loss of capacity is partial or temporary or if his/her capacity fluctuates (see paragraphs 3.24-3.25 below). In particular, a person may lack capacity in relation to one matter but not in relation to others.

Qualifying age

3.8 Section 2(5) makes it clear that the Act generally only applies to people lacking capacity who are aged 16 years and over. The implications of the Act for children and young people, in particular those aged 17-18 years, are described in chapter 11.

The two-stage test of capacity

3.9 In order to decide whether an individual has capacity to make a particular decision, a two-stage test must be applied:

- Is there an impairment of, or disturbance in the functioning of, the person's mind or brain? If so,
- Is the impairment or disturbance sufficient that the person lacks the capacity to make that particular decision?

Stage 1: Impairment or disturbance

3.10 First, before deciding whether a person lacks decision-making capacity under the Act, it is necessary to show that the inability to make a decision is caused by "an impairment of, or a disturbance in the functioning of, the mind or brain", i.e. some form of mental disability. This is sometimes referred to as a 'diagnostic threshold' for a finding of a lack of capacity. If there is no such impairment or disturbance, the individual cannot lack capacity within the meaning of the Act.

> Mr B is 48 and has lived in a London suburb with his wife and two children for the past 20 years, while working in a City bank. He decides to leave his job and wants to spend a year travelling. He feels his children are now old enough to fend for themselves and wants more adventure in his life. His wife is shocked that her reliable and cautious husband could make such a decision and is worried about their future financial security. She persuades him to talk things over with their family doctor. The doctor can find no indication that Mr B is suffering from the effects of stress, any mental illness, such as depression, or any other impairment of, or disturbance in the functioning of, his mind or brain. Therefore, there appears to be no reason to doubt Mr B's capacity to make each of these decisions.

3.11 The impairment or disturbance may occur in a wide range of situations. Examples include people who are affected by the symptoms of alcohol or drug misuse, delirium, or following head injury, as well as the more obvious categories of mental illness, dementia, learning disabilities or the long-term effects of brain damage. It may also include people with grave physical

conditions, who may experience confusion, drowsiness or loss of consciousness as a result of their illness or treatment.

Principle of equal consideration

3.12 Section 2(3) makes it clear that a finding of lack of capacity cannot be made merely on the basis of a person's age or appearance, or from unjustified assumptions based on the person's condition or any aspect of his/her behaviour. This has been referred to as a 'principle of equal consideration' to ensure that people with capacity problems are treated no less favourably than anyone else. Preconceptions about whether someone has capacity to make a decision just by looking at them or by making prejudicial assumptions about their abilities must play no part in the assessment of capacity. Each person and each decision must be considered on its own merits.

3.13 "Appearance" is a deliberately broad term and may include visible medical problems, disfiguring or other disabilities, features associated with Down's syndrome, skin colour or mode of dress (including religious dress). A person's "condition" also covers a range of factors, including physical disabilities, learning difficulties, age-related illness or temporary conditions (such as drunkenness or unconsciousness). It should not be assumed that an individual's appearance or condition in itself will affect the person's capacity to make decisions. Similarly, forms of behaviour (such as talking too loudly, talking to oneself or avoiding eye contact), cannot on their own be used to justify an assumption of a lack of capacity.

Stage 2: Inability to make a decision

3.14 If stage 1 of the test of capacity is met, the second stage requires it to be shown that the impairment or disturbance causes the person to be unable to make the decision in question. Section 3 of the Act sets out the test for determining whether a person is unable to make a decision for him/herself and therefore lacks capacity. This is a 'functional' test, focussing on how the decision is made, rather than the outcome or consequences of the decision. Section 3(1) provides that a person is unable to make a decision if s/he is unable:

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

(a) Understand the information relevant to the decision

3.15 Before assessing a person's *understanding of information relevant to the decision*, every effort must first be made to provide that information and explain it to the person in a way that is most appropriate for that individual and will assist his/her understanding. Relevant information will include the particular nature of the decision in question, the purpose for which the decision is needed and the likely effects of making or not making the decision.

3.16 The need to present and explain the information in a way that is appropriate to the person's circumstances is specified in section 3(2). This requires that suitable support be provided, so that an explanation of the relevant information can be given in a way that is appropriate to meet the person's individual needs, using the most effective means of communication (such as simple language, signing, visual aids, Makaton or any other means) to assist the person's understanding. Cursory or inadequate explanations are not acceptable. Some practical steps are set out in Part 2 of this chapter, suggesting ways of providing help and support to enable someone to make a decision – those suggestions may also be helpful in finding ways of explaining information in a way the person can understand.

3.17 Some examples are as follows. A person with a learning disability may need to have information read to him/her and perhaps illustrated by pictures, so that s/he has an alternative way of understanding what happens, and can stop the reader for clarification if the explanation uses jargon s/he does not understand. A person with anxiety or depression may find it difficult to reach a decision about treatment under pressure in a group meeting with professionals, and may prefer to read the relevant documents in private and come to a conclusion alone, asking for specific help where necessary. Someone who has an acquired brain injury may need information to be explained several times and in different ways, reinforced by leaflets, illustrations, notices and posters.

3.18 Section 3(4) stipulates that the information relevant to a decision includes information about the likely consequences of deciding one way or another or of making no decision at all. The explanation of what is proposed, and any possible consequences, should be given in broad terms and simple language (or whatever method of communication the person requires). It will not always be necessary to explain all the minutiae. However, the more serious the consequences of the decision, the greater the degree of understanding required[3].

Mr C has learning disabilities and now requires medication for heart problems. He has been advised by his GP to have a blood test to check his medication levels. He has had injections before and is anxious about what a blood test will entail. First the GP provides him with a leaflet explaining the purpose of the test, the procedure to be carried out, the risks involved both in having or not having the test, and that it is his right to decide whether or not to consent to having the test. Mr C finds reading difficult, so his carer reads it out to him, and then asks him to give an account of the information in his own words. Mr C can't remember much and gets confused. The GP gives Mr C a booklet where the information is explained in simpler language and each part is accompanied by photographs or drawings. The GP asks the carer to go through the booklet with Mr C a few times over the next few days. When he returns to the surgery, Mr C is able to pick out the equipment the GP needs to carry out the blood test. He is also able to tell the GP that, despite his fear of having a needle put in his arm, he would rather have the test so the best level of medication for him can be determined

[3] *Re T (Adult: Refusal of Treatment)* [1992] 4 All E R, 649

(b) Retain the information relevant to the decision

3.19 The person must be able to *retain the information* for long enough to use it in order to make a choice or an effective decision. Section 3(3) stipulates that the ability to retain information for a short period only should not automatically disqualify the person from making the decision – it will depend on what is necessary for the decision in question. Aids, such as notebooks, photographs, videos and voice recorders, may also be used to assist retention and recording of information.

(c) Use or weigh the information as part of the process of making the decision

3.20 This has been described in the courts as the ability to weigh all relevant information in the balance as part of the process of making a decision and then use that information to arrive at a choice.[4] There are cases where the person concerned can understand the information but where the effects of a mental impairment or disturbance prevent him/her using the information or taking it into account, or cause the person to make decisions which are inevitable, regardless of the information and his/her understanding of it.

3.21 For example, a person suffering from anorexia may be able to understand rationally the consequences of not eating, but lack the capacity to weigh those consequences against the desire not to eat and will decide not to eat regardless of whether s/he feels hungry, the time of day etc. Certain types of pathology seen after catastrophic brain damage, such as a massive stroke, can cause people, who are able to understand and absorb information, to take decisions or to act impulsively, regardless of the information available or their understanding of it.

(d) Unable to communicate the decision (whether by talking, using sign language or any other means

3.22 The final criterion that would indicate an inability to make a decision is the fact that the person is *unable to communicate the decision* by any possible means. Very few people will fall within this criterion. In particular, it will affect those with the very rare condition known as 'locked-in syndrome' or in other circumstances where it is impossible to tell, one way or the other, whether the person is capable of making a decision or not.

3.23 Before concluding that someone is totally unable to communicate and therefore lacks capacity, strenuous efforts must first be made to assist and facilitate communication. Part 2 of this chapter provides pointers to aid communication with people with specific disabilities or cognitive problems. In addition, it is very likely in cases of this sort that professionals with specialised skills in verbal and non-verbal communication will be required. Communication by simple muscle movements, such as blinking an eye, or squeezing a hand, to indicate "yes" or "no," can be sufficient to indicate that the person has the ability to communicate and therefore may have capacity.[5]

[4] See for example *Re MB* [1997] 2 FLR 426; *R v Collins and Ashworth Hospital Authority ex parte Brady* [2001] 58 BMLR 173

[5] *Re AK (Adult Patient) (Medical Treatment: Consent)* [2001] 1 FLR 129

Additional issues surrounding capacity

Fluctuating capacity

3.24 Some people may at times be quite capable of making their own decisions and running their own lives, but have a mental health problem or other condition which affects their decision-making abilities, and therefore their capacity, during acute phases. For example, someone with a bi-polar illness may spend money unwisely and get into debt during a hyper-manic phase, which they may regret later when they become more lucid. A person with a psychotic illness may have delusions affecting their judgement, which may disappear after treatment. Temporary factors may also affect someone's ability to make decisions, such as acute illness, severe pain, the effect of medication, or distress caused by bereavement or a sudden shock.

3.25 In cases of fluctuating or temporary lack of capacity, as in any other case, an assessment must be made of the person's capacity to make a particular decision at the time that the decision has to be made. It may be possible to put off the decision until such time as the person has recovered and regained capacity to make his/her own decision (see also chapter 4 on 'Best Interests'). It should also be remembered that many people with capacity problems, such as those with learning disabilities, are often able to learn new skills and abilities throughout their lives so assessments of their capacity to make certain decisions may need to be made and reviewed periodically.

'On-going' lack of capacity

3.26 Although as a general rule capacity should be assessed in relation to a particular decision or a specific issue, there may be circumstances where a person has an on-going condition, which affects his/her capacity to make a type of decision or a range of inter-related or sequential decisions. One decision on its own may make sense but the combination of decisions can indicate that a person may lack capacity.

3.27 As with fluctuating conditions, capacity should be reviewed over a period of time since, with experience and support, people can improve their decision-making capabilities. In particular, someone with an on-going condition may become able to make some, if not all decisions. However, it is important that measures are put in place to protect the person from repeatedly making inappropriate decisions that put him/her at risk or may result in preventable suffering or disadvantage (see also paragraphs 2.21 – 2.22 on 'Unwise decisions').

A young man sustained a head injury during an accident at work. In the personal injury litigation that followed he was awarded a significant amount of damages intended to cover the costs of the care he would need as a result of the head injury. An application was made to the Court of Protection to appoint a deputy to manage his financial affairs. The young man objected to the proposed appointment saying that he was capable of managing his own money and affairs and that as he was now a multi-millionaire, he should be able to spend his money as he wished. He presented the court with a list of what he intended to do with his damages award; this included fully-staffed luxury properties and holiday villas in several countries, cars with chauffeurs, jewellery and various other items for himself and his family. Although he

could afford a number of these luxuries, he could not afford all of them and also be able to cover his care needs for the coming decades. The court judged that whilst the young man had capacity to make day-to-day financial decisions, he did not have capacity to make significant investment decisions. As he lacked the capacity to manage the amount of money involved, the court therefore made an order appointing a deputy to make such decisions.

Existing common law tests of capacity

3.28 The definition and two-stage test of capacity set out in the Act are expressed to apply "for the purposes of this Act". Schedule 6 also makes consequential amendments to existing statutes in order to ensure that the definition and two-stage test of capacity is used, as appropriate, in relation to other proceedings. For example, this will ensure that inability to act as a juror is assessed according to a person's capacity to do the very specific tasks involved in acting as a juror.

3.29 There are also several *common law* tests of capacity arising from judgments in court cases which set out specific legal tests in case law.[6] Examples are as follows:

- Capacity to make a will[7];
- Capacity to make a gift[8];
- Contractual capacity[9];
- Capacity to litigate[10];
- Capacity to enter into marriage[11].

3.30 The Act's new definition of capacity is intended to build on the terms of existing common law tests. As cases come before the court, it is likely that judges will consider the new statutory definition and they may use it to develop common law rules in particular cases.

Part 2: Helping individuals to make their own decisions

3.31 One of the Act's key statutory principles is that a person is not to be treated as unable to make a decision unless all practicable steps to help him/her to do so have been taken without success (see chapter 2). Section 3(2) expands on that principle by requiring support to be provided that is appropriate to the person's condition and to meet his/her individual needs before they can be regarded as unable to make a decision (see paragraphs 3.15-3.17 above). This part suggests a range of practical steps that can be taken to help individuals to make decisions or improve their ability to participate as fully as possible in decisions affecting them.

Steps to help someone make a decision

3.32 There are several ways in which people can be helped and supported to enable them to make their own decisions. These will vary depending on the

[6] For details, see British Medical Association & Law Society, *Assessment of Mental Capacity: Guidance for Doctors and Lawyers* (Second edition) (London: BMJ Books, 2004)
[7] *Banks v Goodfellow* (1870) LR 5 QB 549
[8] *Re Beaney (deceased)* [1978] 2 All ER 595
[9] *Boughton v Knight* (1873) LR 3 PD 64
[10] *Masterman-Lister v Brutton & Co and Jewell & Home Counties Dairies* [2003] 3 All ER 162 (CA)
[11] *Sheffield City Council v E & S* [2005] 1 FLR 965

decision to be made, the time-scale for making the decision and the individual circumstances of the person wishing to make it.

3.33 The Act applies to a wide variety of people with a range of conditions that may affect their decision-making capacity. Different methods will apply when seeking to give appropriate explanations, help and support to a person with learning disabilities, for example, compared to those that will help to stimulate memory recall and recognition in a person with dementia. In the following paragraphs, some pointers are given in order to prompt consideration of all relevant factors. Only some of these will be relevant or appropriate in any particular situation and the examples are not exhaustive.

i. Providing all relevant information

3.34 The provision of relevant information is essential for any type of decision-making, no matter how simple the decision or capable the decision-maker. If people are asked what they want to have for breakfast on a particular day, they need to know what food is available before making that decision. If the decision concerns consent to medical treatment, the doctor will need to explain fully what is involved in the proposed course of treatment and the consequences of consenting to or refusing this treatment.

3.35 All practicable steps must be taken to help the person to make a decision for him/herself. This includes providing all information relevant to the decision in question in a way the particular individual can understand. It is important to choose the means of communication that is easiest and most appropriate for the person concerned. Consideration may be given to the following:

Relevant information

- Take time to explain anything you think might be relevant or might help the person make the decision in question;
- Try not to burden the person with more detail than is required – this may be confusing. A simple explanation in broad terms may be sufficient for the decision to be made, provided it does not omit key information;
- Describe any foreseeable consequences of making the decision, or of not making any decision at all; what are the risks and benefits?
- Explain the effects the decision might have on the person him/herself and on others, particularly those who have a close relationship with the person or are involved in caring for him/her;
- If there is a choice, give the same information in a balanced way on any alternative options.

Communication: general points to consider

- Consult family members, carers or whoever knows the person well on the best methods of communication (for example, using pictures or signing) with the person concerned. They may also know if there is someone with whom the person can most easily communicate and also the best times for doing this;
- Use simple language and where appropriate use pictures and objects rather than words or as illustrations;

- Speak at the right volume and speed with appropriate vocabulary and sentence structure;
- Enlist the help of others who know and are trusted by the person, such as relatives, friends, GP, social worker, religious or community leaders;
- Be aware of any cultural, ethnic or religious factors which may have a bearing on the person's way of thinking, behaviour or communication;
- Consider whether the services of an independent advocate might be helpful in assisting communication.

Communication: aids for people with specific communication or cognitive problems

- Use any aids which might be helpful, such as pictures, photographs, pointing boards or other signalling tools, symbols and objects, videos or tapes;
- Find out what the person is used to – for example Makaton or some way of communicating that is only known to those who are close to them;
- If the person has hearing difficulties, consider using appropriate visual aids or sign language;
- Consider using any appropriate mechanical devices such as voice synthesisers or other computer equipment;
- In extreme cases of communication difficulties, consider other forms of professional help, such as an expert in clinical neuropsychology.

ii. Making the person feel at ease

3.36 Most people find it easier to make decisions if they are in an environment where they feel at ease or if the location is relevant to the decision in question. It is also important to recognise that some people are more alert or able to pay attention at different times of day. Some people may benefit from having support from a family member or friend, but others may find this intrusive. The following pointers may be helpful in considering what may be possible and appropriate in each situation:

Location

- Where possible, choose the best location where the person feels most at ease – usually, people will feel more comfortable in their own home than in, say, a doctor's surgery or a lawyer's office;
- Consider whether it may be easier to make the decision in a different location more relevant to that decision – for example a decision about consenting to treatment in hospital may be made easier by a visit to hospital to see what is involved;
- Choose a quiet location where interruptions are unlikely. Try to eliminate any background noise or distractions, such as the television or radio, or people talking.

Timing

- If possible, try to choose the best time of day when the person is most alert – some people are better in the mornings, others are more lively in the afternoon or early evening;
- If the person's capacity is likely to improve, for whatever reason (for example, after treatment for depression or a psychotic episode) wherever possible wait until it has done so. Clearly this may not be possible if the decision is urgent;
- Some medication could affect capacity (e.g. medication which causes drowsiness or affects memory). Consider delaying the decision until any negative effects of medication have subsided;
- Take one decision at a time – be careful to avoid tiring or confusing the person;
- Don't rush – allow time for reflection or clarification where possible and appropriate;
- Be prepared to abandon the first attempt and try at other times.

Support from other people

- Consider whether the person might benefit from having another person present. In some cases the presence of a relative or friend can provide helpful support and reduce anxiety;
- Be aware that in other cases, the presence of others might be intrusive and could increase anxiety, or might influence the person's ability to make a free choice.

iii. Enabling decision-making

3.37 Having done everything practicable to provide all relevant information and to create the best possible environment for decision-making, there are other techniques and support mechanisms, which may be useful in helping people to make decisions. Illustrative examples are given below.

- Many people find it helpful to be able to talk things over with people they trust or who have been in a similar situation or faced similar dilemmas. For example, people with learning difficulties may benefit from the help of a designated support worker or being part of a support network with their peers;
- When someone is in an acute state of distress, e.g. following bereavement, or where there are long-standing issues influencing someone's understanding, decision-making may be delayed to give the individual the opportunity to undertake a recognised psychological therapy;
- It may be helpful for the person to have assistance from an advocate who is independent of the family or other agencies involved in the person's care. An independent advocate could help the person express wishes and aspirations and make real choices (see chapters 9 & 14);
- Some voluntary organisations and charities have produced publications, tapes and other materials to help people who need support to make decisions, or those who provide support. Some of this material is designed to help people with specific conditions, such as Alzheimer's disease or profound learning disability.

Part 3: Assessment of capacity

3.38 The assessment of capacity is of fundamental importance to everyone affected by the provisions of this Act. By making an assessment that an individual lacks capacity to make a decision, the person's right to take that decision may be denied. Alternatively, a different assessment could permit a person lacking capacity to do something, or carry on doing something, whereby serious prejudice could result to that person. It is therefore important that anyone called upon to assess another person's capacity must understand what they are being asked to do and be prepared to justify their findings.

3.39 In most cases, assessing capacity is relatively straightforward and this part of the Code provides some general guidance for those involved. However, it is impossible to cover in any detail the full range of circumstances in which assessments of capacity may be required. In more complex cases (see paragraphs 3.51-3.54 below), reference may need to be made to more detailed professional guidance.[12] After someone has made an assessment that an individual lacks decision-making capacity with respect to a particular matter that person may then perform acts in respect of the care or treatment, and in the best interests of, the person lacking capacity (see chapter 5).

When should capacity be assessed?

3.40 According to the principles of the Act (see chapter 1), the starting point should be the presumption of capacity. Doubts as to a person's capacity may arise for a number of reasons, either because of the person's behaviour or circumstances, or through concerns raised by someone else, but any such doubts must be considered specifically in relation to the particular decision that needs to be made. The following questions should first be considered:

- Does the person have all the relevant information needed to make the decision in question? If there is a choice, has information been given on any alternatives?
- Could the information be explained or presented in a way that is easier for the person to understand?
- Are there particular times of day when the person's understanding is better or particular locations where they may feel more at ease? Can the decision be put off until the circumstances are right for the person concerned?
- Can anyone else help or support the person to make choices or express a view, such as an independent advocate or someone to assist communication?

3.41 Part 2 of this chapter (above) describes various steps which can be taken to address these questions. If all appropriate steps have been taken without success, an assessment of the person's capacity to make the decision in question should be made.

[12] See for example, British Medical Association & Law Society, *Assessment of Mental Capacity: Guidance for Doctors and Lawyers* (Second edition) (London: BMJ Books, 2004); British Psychological Society, *Guidelines on assessing capacity* (forthcoming)

Who assesses capacity?

3.42 The person who is required to assess an individual's capacity will be the person who wishes to take some action in connection with the person's care or treatment or who is contemplating making a decision on the person's behalf. It will therefore depend on the particular circumstances and the decision to be made. For most day-to-day actions or decisions, the carer most directly involved with the person at the time assesses his/her capacity to make the decision in question. In most circumstances, it is sufficient for the person assessing capacity to hold a reasonable belief (see paragraph 3.45 below) that the person lacks capacity.

> Ms D suffered brain damage in a road accident and is unable to speak. She is cared for at home by her family who at first thought she was unable to make any decisions, but soon discovered that she was able to express her choices by pointing at the clothes she wants to wear or selecting the types of food she prefers. She is also able to indicate by her behaviour that she enjoys attending the day centre but she refuses to go swimming and her carers have assessed her as capable of making these decisions. Ms D needs further hospital treatment but she gets very distressed when away from home. Her mother feels that this should be taken as an indication that Ms D is refusing consent to the treatment in question, but her father thinks she lacks capacity to refuse consent to potentially beneficial treatment. The clinician who is proposing the treatment will have to assess Ms D's capacity.

3.43 Where consent to medical treatment or examination is required, the doctor proposing the treatment must decide whether the patient has capacity to consent and should record the assessment process and findings in the person's healthcare record (see paragraph 3.60 below). Where a legal transaction is involved, such as making a will or a power of attorney, the solicitor handling the transaction will need to assess whether the client has capacity to give instructions – this requires the solicitor to assess whether the client has the required capacity to satisfy the relevant legal test, perhaps assisted by an opinion from a doctor.

3.44 The more serious the decision, the more formal the assessment of capacity may need to be (see paragraphs 3.51-3.54 below). For example a professional, such as a psychiatrist or psychologist, may be asked for an opinion to assist with the assessment. A professional opinion may help to justify a finding about capacity, but the decision as to whether someone has or lacks capacity must be taken by the potential decision-maker or person taking the action, and not the professional who is merely there to advise. Ultimately, if a person's decision-making capacity is disputed, it is a question for the court to decide (see paragraphs 3.62-3.63 below).

Reasonable belief of lack of capacity

3.45 Family carers and other carers are not expected to be experts in assessing capacity, and it is therefore sufficient for them, amongst others using the Act, to hold a 'reasonable belief' that another person lacks capacity in order to receive statutory protection from liability. This means that they will be expected to have reasonable grounds for believing that the person lacks capacity to make the decision or consent to the act in question, at that particular time. Formal processes are rarely required unless the assessment

is challenged, for example by the person whose capacity is being assessed or by another family member. In such circumstances, the assessor must be able to point to objective reasons as to why they believe the person lacks capacity.

How is capacity assessed?

3.46 Where there are doubts about capacity, it is important that people are assessed when they are at their highest level of functioning for the decision in question because this is the only realistic way of determining what they may or may not be capable of doing. Many of the practical steps suggested above to enable decision-making (see Part 2) will also be helpful in creating the best environment for capacity to be assessed. Once this has been done, *the two-stage test of capacity* described above (see paragraphs 3.9-3.23) must then be applied, i.e.:

- Is there an impairment of or disturbance in the functioning of the person's mind or brain? If so,
- Is the impairment or disturbance sufficient that the person lacks the capacity to make that particular decision?

3.47 In many cases, it will be, or may seem obvious whether there is any impairment or disturbance, which could affect the person's decision-making capacity. For example, there may have been a previous diagnosis of a mental illness or disability, or recognisable symptoms to indicate the recurrence of illness or the disabling effects of a head injury. Any assumptions should however be revisited and reviewed. In other cases, such as dementia, the onset of debilitating illness is gradual and the point at which capacity is affected (or is potentially affected) is hard to define. During the period when capacity is borderline, a medical opinion may be required.

> Mr E is 87 years old and has lived alone since his wife died 3 years ago. He is supported by his daughter, who visits every evening, and a home carer who comes for an hour each morning to help him get up. Mr E has little short-term memory and is often confused about the time of day, so he forgets to eat. He also neglects his personal hygiene but usually agrees to have a bath when his daughter persuades him. She would like him to move to residential care, but having discussed it with him, she feels satisfied that he understands the risks involved in staying at home and is capable of deciding to take those risks. Two months later, Mr E has a fall and breaks his leg. While being treated in hospital, he becomes more confused and depressed. Although he says he wants to go home, at this point in time his daughter feels he cannot understand the consequences or weigh up the risks of doing so. She takes steps to involve relevant professionals in assessing his capacity to make this decision.

3.48 People should not be considered to lack capacity simply on the basis that they have a particular diagnosis or condition, but this must be shown to affect their ability to make a decision at the time the decision needs to be made. The following questions should be considered:

- Does the person have a general understanding of what the decision is and why s/he is being asked to make it?

- Does the person have a general understanding of the consequences of making, or not making, this decision?
- Is the person able to understand and weigh up the information relevant to the decision, and use it as part of the process of arriving at a decision?

In borderline cases, or where there is any element of doubt, the person doing the assessment must be able to show, on the balance of probabilities, that it is more likely than not that the answer to the above questions is 'No'.

3.49 The following pointers may also be relevant in carrying out an assessment of capacity:

- Anyone assessing someone else's capacity should ensure that they themselves understand fully the nature and effect of the decision or action relating to the assessment. Where appropriate, they may need access to relevant documents and background information, such as details of the extent or complexity of the person's finances where capacity to manage his/her affairs is being assessed, (see chapter 15 for further details);
- Family members, friends and those close to the person may be able to provide valuable background information, including about the person's past behaviour, values and wishes prior to the assessment. But care must be taken to avoid their personal views from influencing the assessment;
- All the information relevant to the decision should again be explained to the person in broad terms and simple language, using the most appropriate means of communication;
- After a reasonable time span, the person should be able to paraphrase roughly the explanation s/he was given a few minutes earlier;
- Generally, questions which are susceptible to the answer 'yes' or 'no' should be avoided (e.g. Did you understand what I just said?) since they are rarely sufficient for assessing the person's capacity. However, in cases where there are major communication difficulties, there may be no alternative to positive or negative responses, but such responses may need to be reinforced by asking the questions in different ways;
- Do not be misled by the person's preserved social skills or mistake such skills as proof of the person's capacity to make a particular decision;
- Consider whether the test should be repeated to ensure reliability.

3.50 In relation to more formal assessments of capacity to make serious or complex decisions (see below), the following may be relevant:

- For certain decisions (such as capacity to make a will) it is important to be aware of the requirements of the legal tests for assessing this particular type of capacity;
- Although medical or psychometric tests may be valuable tools for establishing whether someone has a mental impairment or disturbance in the functioning of mind or brain and for assessing cognitive skills, the requirements of the legal test of capacity must still be fulfilled.

When should professionals be involved?

3.51 The majority of decisions made on behalf of people lacking capacity will be day-to-day decisions and as such, those caring for them on a daily basis will be able to assess their capacity to make these decisions. However, certain more complex or major decisions may require the involvement of different people in order to assess capacity. In many cases all that may be needed is an opinion from the person's GP or family doctor. Where the person has been diagnosed with a particular condition or disorder, it may be more appropriate to seek an opinion from a specialist, such as a consultant psychiatrist or psychologist who has extensive clinical experience of the disorder and is familiar with caring for patients with that condition. In other cases, a multi-disciplinary approach is best, using the skills and expertise of different professionals.

3.52 Doctors or other experts should never express an opinion without first conducting a proper examination and assessment of the person's capacity to make the decision in question and applying the appropriate test of capacity. Family members and other carers may be able to provide important background information, but care must be taken to avoid influencing the assessment. It is a matter of good practice that details of the assessment and any conclusions are recorded in the relevant professional records (see paragraph 3.60 below).

3.53 In some cases it is a requirement of the law that a formal assessment of capacity be carried out. These include the following situations:

- Where a doctor or other expert witness certifies that in their professional opinion a person who has signed a legal document (such as a will) has capacity to do so but whose capacity could be challenged;[13]
- To establish that a particular person who is or likely to be involved in litigation requires the assistance of the Official Solicitor or other litigation friend;[14]
- Where the Court of Protection is required to make a decision as to whether a person has or lacks capacity in relation to a particular matter;
- Where the court is required to make a decision as to a person's capacity;[15]
- Where there may be legal consequences of a finding of capacity – for example in a settlement of damages following a claim for personal injury;
- Where legal proceedings are contemplated (for example, divorce proceedings) and there is doubt about the person's capacity to instruct a solicitor or take part in the proceedings.

3.54 In other cases, a judgement will need to be made as to whether it is appropriate or necessary to involve a doctor or other expert in assessing the person. Any of the following factors might indicate the need for professional involvement:

[13] *Kenward v Adams,* The Times, 29 November 1975.
[14] Civil Procedure Rules 1998, r 21.1
[15] *Masterman-Lister v Brutton & Co and Jewell & Home Counties Dairies* [2002] EWCA Civ 1889, CA at 54

- The gravity of the decision or its consequences;
- Where the person concerned disputes a finding of a lack of capacity;
- Where there is disagreement between family members, carers and/or professionals as to the person's capacity;
- Where the person concerned is expressing different views to different people, perhaps through trying to please each one or tell them what s/he thinks they want to hear;
- Where the person's capacity to make a particular decision may be subject to challenge, either at the time the decision is made or in the future – for example a person's testamentary capacity may be challenged after his/her death by someone seeking to contest the will;
- Where the person concerned is repeatedly making decisions that put him/her at risk or could result in preventable suffering or damage.

Confidentiality

3.55 Carrying out an assessment of capacity requires the sharing of information about the personal circumstances of the person being assessed. Yet doctors, lawyers and other professionals are bound by a duty of confidentiality towards their clients, imposed through their professional ethical codes and reinforced by law. As a general principle, personal information may only be disclosed with the client's consent, even to close relatives or 'next of kin'. However, there are circumstances when disclosure is permitted in the absence of consent[16].

3.56 It is important that information concerning the person being assessed which is directly relevant to the decision in question is made available to ensure that an accurate and focused assessment can take place. Every effort must first be made to obtain the person's consent to disclosure by providing a full explanation as to why this is necessary and the risks and consequences involved. If the person is unable to consent, disclosure of such information as is necessary to properly assess capacity may still be permitted. Chapter 15 contains greater detail on the ways in which people who care for or otherwise deal with people lacking capacity, can access information.

Refusal to be assessed

3.57 There may be circumstances in which a person whose capacity is in doubt refuses to undergo an assessment of capacity or refuses to be examined by a doctor. It will usually be possible to persuade someone to agree to an assessment if the consequences of refusal are carefully explained. For example, it could be explained to a person wishing to make a will that the will could be challenged and held to be invalid after their death, while evidence of their capacity to make a will could prevent this from happening.

3.58 If the person lacks capacity to consent to or refuse the actual assessment itself, it will normally be possible for an assessment to proceed so long as the person is compliant and this is considered to be in the person's best interests (see chapter 4). However, in the face of an outright refusal, in most circumstances no one can be forced to undergo an assessment of capacity unless required to do so by a court in legal proceedings. Even then, entry to a person's home cannot be forced and a refusal to open the door to the

[16] For example the circumstances discussed in *W v Egdell and others* [1990] 1 All ER 835 at 848; *S v Plymouth City Council and C* , [2002] EWCA Civ 388) at 49

doctor may be the end of the matter. Where there are serious concerns about the person's mental health, forcing an entry and making an assessment under mental health legislation may be warranted, so long as the statutory grounds are fulfilled. (However, a refusal to be assessed is in no way sufficient grounds for an assessment under the Mental Health Act 1983 – see chapter 12).

Recording assessments of capacity

3.59 Where assessments of capacity relate to day-to-day decisions and caring actions, no formal assessment procedures or recorded documentation will be required. However, if the carer's assessment is challenged, they must be able to point to the grounds, which justified a reasonable belief of lack of capacity (see paragraphs 3.62-3.63 below).

Professional records

3.60 Where professionals are involved, it is a matter of good practice that a proper assessment of capacity is made and the findings of that assessment are recorded in the relevant professional records. This includes, for example:

- An assessment of a person's capacity to consent to medical treatment made by the doctor proposing the treatment and recorded in the patient's clinical notes;
- An assessment of a person's capacity to instruct a solicitor to carry out a legal transaction (where necessary supported by a medical opinion) made by the solicitor and recorded on the client's file.

Formal reports or certificates of capacity

3.61 In some cases, a more detailed report or certificate of capacity may be required, for example:

- For use in court or other legal proceedings;
- As required by Regulations or Orders made under the Act (*as yet not finalised and subject to separate consultation);*
- As required under the Court of Protection Rules *(as yet not finalised and subject to separate consultation).*

How can a finding of lack of capacity be challenged?

3.62 There are likely to be occasions when someone may wish to challenge the results of an assessment of capacity. For example, certain individuals may feel they have been wrongly assessed as lacking capacity to make a decision they believe they are capable of making, or alternatively someone else may wish to challenge a finding of a lack of capacity on their behalf.

3.63 The first step in challenging a finding of lack of capacity is to raise the matter with the person who carried out the assessment. If the individual who allegedly lacks capacity is making the challenge, it may be helpful to have support from family, friends, or an independent advocate for example. The assessor should be asked to give reasons why they believe the individual lacks capacity to make the decision in question and to point to objective evidence to justify that belief. They will need to show they have taken into

account the principles of the Mental Capacity Act (see chapter 2) and, in the case of attorneys, deputies or those acting in a professional capacity, the guidance set out in this chapter. In some cases, it may be possible to seek a second opinion from an independent professional or other expert in assessing capacity. Ultimately, an application can be made to the Court of Protection for a ruling on whether or not a person has capacity in relation to the particular matter or decision in question[17] (see chapter 7).

Part 4: Summary of factors: Supporting decision-making and assessing capacity

3.64 The following provides a summary of the information contained within the chapter, listing key factors which should be taken into account when seeking to support individuals to make their own decisions or when assessing their capacity to do so. The summary should not be relied upon in isolation and reference should be made to the detail contained within the chapter.

The presumption of capacity:

1. Every adult should be assumed to have capacity to make a decision unless it is proved that s/he lacks capacity.

The principle of equal consideration:

2. An assumption about someone's capacity cannot be made merely on the basis of the person's age or appearance, condition or aspect of his/her behaviour.

Supporting decision-making:

3. Does the person have all the relevant information needed to make the decision in question? If there is a choice, has information been given on any alternatives?

4. Could the information be explained or presented in a way that is easier for the person to understand?

5. Are there particular times of day when the person's understanding is better or particular locations where they may feel more at ease? Can the decision be put off until the circumstances are right for the person concerned?

6. Can anyone else help or support the person to make choices or express a view, such as a relative, an independent advocate or someone to assist communication?

If all attempts to help the person make the decision have failed:

7. Is there reason to believe that the person has an impairment of, or a disturbance in the functioning of, his/her mind or brain (e.g. a previous diagnosis of a mental disability or disorder, other recognisable symptoms or disabling conditions)? It

[17] See for example *Re B (Consent to Treatment: Capacity)* [2002] 1 FLR 1090; *Masterman-Lister v Brutton & Co,* [2003] 3 All E R 162

doesn't matter whether the condition is temporary or permanent.

8. If so, has that impairment or disturbance made the person unable to make the decision?

Inability to make a decision:

9. Does the person have a general understanding of what the decision is and why s/he is being asked to make it?
10. Does the person have a general understanding of the consequences of making, or not making, this decision?
11. Is the person able to understand, retain, use and weigh up the information relevant to this decision as part of the process of making a decision?
12. Can the person communicate his/her decision (whether by talking, using sign language or any other means)?

For more complex or serious decisions:

13. Consider the need for a more thorough assessment of capacity, for example by involving a doctor or other professional.

Chapter 4 - Best Interests

Introduction

4.1 Where a person lacks capacity to make a particular decision, the Act allows people to have powers in certain circumstances (for example, if they have powers as an attorney under an LPA or a court-appointed deputy) to make decisions on behalf of the person who lacks capacity. If a person does not have power to make decisions on behalf of a person who lacks capacity, they may receive protection from liability in performing an act in connection with the care or treatment of that person (or a person whom they reasonably believe lacks capacity). One of the key principles of the Act is that any act done, or any decision made, for or on behalf of a person who lacks capacity must be done, or made, in that person's *best interests*.

4.2 **Part 1** of this chapter explains the concept of best interests and when the best interests' principle must be applied. **Part 2** describes the factors that must be considered when trying to decide what is in someone's best interests and explains how determinations on best interests may be made. **Part 3** considers some problems that may arise when determining the best interests of a person lacking capacity. The key steps involved in determining best interests are summarised in **Part 4** at the end of the chapter.

Part 1: The best interests principle

4.3 The principle of acting in the best interests of a person who lacks capacity has become well established in the common law and the concept has been developed by the courts in cases relating to adults lacking capacity, mainly those concerned with the provision of medical treatment.[18] Section 1(5) of the Act enshrines this principle in statute as the overriding principle that must guide all actions done for or decisions made on behalf of someone lacking capacity to make such decisions, with the exceptions of the research and advance decisions provisions of the Act. The principle applies to anyone using the Act's provisions, including family carers and other carers, professionals, attorneys, deputies and the Court of Protection. The intention is to provide some consistency in how decisions are made on behalf of people lacking capacity to make their own decisions.

4.4 Given the wide range of decisions and actions covered by the Act and the varied circumstances of the people affected by its provisions, the term 'best interests' is not defined in the Act. However, section 4 explains how to determine the best interests of a person who lacks capacity. This section sets out the common factors that must always be taken into account by anyone who needs to decide what is in the best interests of an individual who lacks capacity in any particular situation (see Part 2 below).

4.5 It is important to recognise that consideration of a person's best interests is only relevant when a person lacks, or is believed to lack, capacity to make the decision in question (or where an attorney is acting for a donor who still has capacity under a Lasting Power of Attorney for property and affairs). The Act's first key principle (see chapter 1) confirms that people must be assumed to

[18] See for example *Re A (Male Sterilisation)* [2000] 1 FLR 549; *Re S (Sterilisation: Patient's Best Interests)* [2000] 2 FLR 389; *Re F (Adult Patient: Sterilisation)* [2001] Fam 15

have capacity to make a decision unless it is established that they lack it. People with capacity are able to decide for themselves what they want to do, and may even choose an option which others consider to be unwise or not in their best interests. That is their prerogative as competent and autonomous adults. However, where someone lacks capacity in relation to a particular matter, any decisions and actions taken on that person's behalf must be in his/her best interests.

4.6 It is important to place the focus firmly on the person lacking capacity in order to make an objective assessment as to what might be in that person's best interests. Priority should be given to identifying all those issues most relevant to the individual who lacks capacity since it is that person's best interests that are pertinent, not those of the decision-maker or other person. In deciding what is objectively the best course of action for that person, the decision-maker must take into account all the factors it would be reasonable to consider, not just those s/he personally thinks are important. For example, if a decision-maker imposed his/her personal views as if s/he were the individual who lacked capacity, s/he would not be acting in the best interests of the person who lacked capacity.

A young man with a severe learning disability lives in a care home. He has frequent dental problems causing him a lot of pain when he may become aggressive and violent. He refuses to allow the staff to clean his teeth and bites anyone who attempts to open his mouth. The staff have suggested that the best solution would be to remove all his teeth, as this would solve all their problems in one go. His mother hates to see him distressed and thinks he should be given no dental treatment, other than strong painkillers when needed. While the views of his mother and carers are important in deciding what course of action would be in his best interests, what would be more convenient or less stressful for them is irrelevant. The dentist must take account of all the factors in the best interests checklist to make an objective assessment about the young man's best interests as well as what would be the least restrictive option for him.

Who is the 'decision-maker'?

4.7 Reference is made in this chapter, and in other parts of the Code, to the 'decision-maker' as a shorthand term for the person who is deciding whether to take action in connection with the care or treatment of an adult who lacks capacity or who is contemplating making a decision on that person's behalf. Who is the decision-maker will therefore depend on the particular circumstances and the decision to be made.

4.8 For most day-to-day actions or decisions, the decision-maker will be the carer most directly involved with the person at the time. Where the decision involves the provision of medical treatment, the doctor proposing the treatment is the decision-maker. Where nursing care is provided, the nurse is the decision-maker. An attorney acting under a Lasting Power of Attorney or a deputy acting under a court order will be the decision-maker, so long as they are acting within the scope of their authority.

4.9 Whoever is the decision-maker in any particular case must first determine what decision or action would be in the best interests of the person lacking capacity. Part 2 of this chapter describes the processes involved in

determining best interests, including the consultations that the decision-maker must carry out before reaching a conclusion about best interests.

Part 2: Determining best interests – the statutory checklist

4.10 Section 4 of the Act sets out steps that must be taken to determine what might be in the best interests of a person who lacks capacity. The law cannot give a definitive account of what is in a person's best interests, or what *all* the factors that need to be taken into account to make that determination might be, since this will vary with each individual person and his/her particular circumstances. Instead, the Act sets out a checklist of common factors which must *always* be taken into account in any situation where a decision is being made or an act is being done for a person lacking capacity (an explanation of each of the factors is given in paragraphs 4.12-4.46 below). The particular factors in the checklist can be broadly summarised as follows:

- Equal consideration and non-discrimination;
- Considering all relevant circumstances;
- Regaining capacity;
- Permitting and encouraging participation;
- Special considerations for life-sustaining treatment;
- The person's wishes and feelings, beliefs and values;
- The views of other people.

4.11 It is important to remember that the checklist does not define best interests nor give an exhaustive list of factors to be taken into account. Rather it refers to factors that must always be considered in determining what is in a person's best interests. Not all the factors in the checklist will be relevant to all types of decisions or actions, but they must still be considered if only to be disregarded as irrelevant to that particular situation.

Equal consideration and non-discrimination

4.12 One particular factor that will always be relevant has been called the 'principle of equal consideration', intended to ensure that people with capacity problems are not subject to discrimination or treated any less favourably than anyone else. Section 4(1) begins with a clear statement that a determination of someone's best interests must not be based merely on the person's age or appearance, or any condition or aspect of his/her behaviour which might lead others to make unjustified assumptions about what might be in the person's best interests. Preconceptions about someone's best interests formed just by looking at them or by making prejudicial assumptions about their quality of life or circumstances must play no part in the determination of best interests. There can be no shortcuts in determining best interests and a proper and objective assessment must be carried out on every occasion.

4.13 "Appearance" is a deliberately broad term and may include visible medical problems, disfiguring or other disabilities, features associated with Down's syndrome, skin colour or mode of dress (including religious dress). A person's "condition" also covers a range of factors, including physical disabilities, learning difficulties, age-related illness or temporary conditions (such as drunkenness or unconsciousness). Decisions about best interests must not be based on any preconceived ideas or negative assumptions arising from the person's age, appearance or condition, nor from forms of

behaviour (such as talking too loudly or laughing inappropriately), which may make others feel uncomfortable.

> An elderly man with dementia is beginning to neglect his appearance and personal hygiene. His daughter is his personal welfare attorney and assumes it would be best for him to move into a care home, since the staff would be able to help him wash and dress smartly. However, it cannot be assumed that such a move would be in his best interests simply on the basis of his age, condition and appearance. All other factors in the best interests' checklist must be considered before a determination is made including consideration of his own past and present wishes, and the views of persons involved in his care.

Considering all relevant circumstances

4.14 A determination of a person's best interests involves identifying those issues most relevant to the individual who lacks capacity in the context of the decision in question. The statutory checklist sets out the minimum necessary considerations but all other matters relevant in the particular situation must also be taken into account. Section 4(2) therefore requires the person making the determination to consider "all the relevant circumstances" as well as following the steps set out in the checklist.

4.15 It is recognised that the decision-maker may not be in a position to make exhaustive enquiries to investigate every issue which may have some relevance to the person lacking capacity or the decision in question. Relevant circumstances are defined in section 4(11) as those:

> "(a) of which the person making the determination is aware, and
> (b) which it would be reasonable to regard as relevant."

4.16 The relevant circumstances will necessarily vary from case to case. For example, when making a decision about major medical treatment, a doctor would need to consider the clinical needs of the patient, together with the potential benefits and burdens of the treatment on the person's health and life expectancy. For example, in giving judgment in a case concerning a possible kidney transplant, the President of the Family Division said that, when considering the best interests of a patient, it is the duty of the court "to assess the advantages and disadvantages of the various treatments and management options, the viability of each such option and the likely effect each would have on the patient's best interests and, I would add, his enjoyment of life."[19] However, it would not be reasonable to consider issues such as life expectancy when deciding whether it would be in someone's best interests to be given medication for a minor problem.

4.17 Similar considerations apply where a financial decision needs to be made on behalf of a person lacking capacity. For example, if a person had received a substantial sum of money as compensation for an accident resulting in brain injury, the decision-maker would have to consider all the circumstances when making decisions about how the money is spent. For example, s/he would need to think about whether it would be in the best interests of the person lacking capacity to purchase a new property that could be easily adapted to

[19] *An Hospital NHS Trust v S* [2003] EWHC 365 (Fam), paragraph 47

the person's needs. Alternatively, it might be in the person's best interests to stay in the same accommodation and invest the money for future care, if perhaps his/her condition may improve and care needs change over the next couple of years. However, it may be unreasonable to base a decision about best interests on the possibility of recovery if the person's prognosis is unknown.

Regaining capacity

4.18 The second of the Act's key principles is that before a person is found to lack capacity to make a decision, all practicable steps must be taken to help the person make that decision (see chapter 2). In keeping with this approach, when looking at best interests, section 4(3) requires the decision-maker to consider whether the individual concerned is likely to regain the capacity to make that particular decision in the future and if so, when that is likely to be. It may be possible to put off the decision until the person can make it him/herself. This delay may allow further time for additional steps to be taken to restore the person's capacity or to provide support and assistance to enable the person to make the decision.

4.19 Even if the decision cannot be put off, how the decision is made is likely to be influenced by whether the person will always lack capacity for this and/or other decisions or is likely to regain capacity at some point.

Mr F has suffered a stroke leaving him severely disabled and unable to communicate. Within days he has shown signs of improvement, so with intensive treatment there is hope he will recover in time. He has always looked after the family finances, so Mrs F suddenly discovers she has no access to his personal bank account to provide the family with money to live on or pay the bills. The decision cannot be put off, so an application is made to the Court of Protection for an interim order providing Mrs F with the authority she needs to access Mr F's money to support the family. A decision about longer-term arrangements can be delayed until the extent of Mr F's recovery is known.

4.20 Some factors which may indicate that a person may regain capacity include the following:

- The cause of the lack of capacity can be treated, either by medication or some other form of treatment or therapy;
- The lack of capacity may decrease in time (for example where caused by the effects of medication or alcohol, or following a sudden shock);
- People may learn new skills or be subject to new experiences which increase their capacity to make certain decisions (for example, a young adult with learning disabilities who leaves his/her parental home to live in supported accommodation and gains new skills as a result);
- The person may have a condition which causes capacity to fluctuate (such as some forms of mental illness) so it may be possible to arrange for the decision to be made during a lucid interval;
- A person previously unable to communicate may learn a new form of communication.

Permitting and encouraging participation

4.21 The next step in considering a person's best interests is to ensure that the person is involved in the decision-making process to the fullest possible extent. The fact that the person lacks capacity does not mean that s/he can be cut out or ignored. It is important always to consult the person on the particular decision to be made and to try to seek their views. This will involve taking time to explain what is happening and why a decision needs to be made, and using all possible means to permit and encourage the maximum involvement and participation or to help the person improve his/her ability to participate.

4.22 This factor in the best interests checklist, set out in section 4(4), builds on the Act's provisions which aim to ensure that people are given all appropriate help and support to enable them to make their own decisions or to maximise their participation in any decision-making process. These include the principle set out in section 1(3). Detailed guidance is given in chapter 3 (Part 2) suggesting practical steps to assist and enable decision-making which may be also be helpful in encouraging greater participation. For example, when explaining the issues involved in a particular decision, it may help to use simple language, perhaps illustrated with pictures or photographs, or to choose a time and location where the person feels most relaxed and at ease. Alternatively, more sophisticated forms of communication support may be required.

4.23 Even if the person lacks capacity to make the decision in question, s/he may have views on matters affecting the decision, and on what outcome would be preferred. It may fall to other people to communicate with the person to establish their views, but the decision-maker must be satisfied that all reasonable efforts have been made to help the person participate before s/he goes on to determine what is in the person's best interests. For example, a trusted relative or friend, or an independent advocate may be able to help the person to express wishes or aspirations or to indicate a choice between different options.

> The parents of a young woman with learning difficulties are going through a bitter divorce and are arguing about who should continue to care for their daughter. She cannot understand what is happening but attempts are made to see if she can give some indication of where she would prefer to live. An independent advocate is appointed to work with her to help her understand the situation and to find out her likes and dislikes and matters which are important to her. With the independent advocate's help, she is able to participate in decisions about her future care.

Special considerations for life-sustaining treatment

4.24 A specific factor in the best interests checklist relates to decisions concerning the provision of life-sustaining treatment. Section 4(5) clarifies that in determining whether life-sustaining treatment is in the best interests of someone who lacks capacity, the person making the determination must not be motivated by a desire to bring about the individual's death. Life-sustaining treatment is defined (in section 4(10)) as treatment which a person providing health care regards as necessary to sustain life.

4.25 Whether a treatment is 'life sustaining' depends not only on the type of treatment, but also on the particular circumstances in which it may be prescribed. For example, in some situations giving antibiotics may be life-sustaining, whereas in other circumstances antibiotics are used to treat a non-life-threatening condition. The important factor here is that providing treatment to the person is necessary to sustain life. It is for the doctor to assess whether a treatment is life sustaining in each particular situation.

4.26 Doctors must give special consideration to written statements that ask for life-sustaining treatment, such as artificial nutrition and hydration (ANH). Wherever possible, all steps should be taken to prolong life. However, in exceptional cases, or where the patient is close to death, the provision of ANH may cause great suffering and loss of dignity. Doctors must take account of the patient's wishes as set out in the written statement but weigh these carefully against all other relevant factors in deciding whether it is in the best interests of the patient to provide or continue ANH. Doctors sometimes must apply to the Court of Protection if they want to withhold or withdraw life-sustaining treatment where there is doubt about the patient's best interests (see chapter 7).

4.27 However, there will be some limited number of cases, for example in the final stages of terminal illness, where treatment is futile or where there is no prospect of recovery. In such circumstances, it may be in the best interests of the patient to withdraw or withhold treatment. All the factors in the best interests checklist must be considered, but the person determining best interests must not be motivated in any way by the desire to bring about the person's death.

4.28 For example, in a situation where someone is in the final stages of a terminal illness, with only a few days left to live, it might well cross the mind of someone who cares for that person that "he is suffering so much, it would be better for him to be dead". The law cannot stop the carer from *thinking* such thoughts – whether out of compassion, or from more sinister motives. What section 4(5) does is to forbid the decision-maker from being motivated by any such desire to bring about the death of the person lacking capacity in his/her assessment of what is in that person's best interests. It makes clear that whatever the decision-maker might personally want for the person lacking capacity cannot interfere with a best interests assessment as to whether treatment for the person lacking capacity should proceed. The decision-maker must consider the range of treatment options available and, having followed at a minimum all the steps in the best interests' checklist, determine the patient's objective best interests in respect of those treatments.

4.29 Importantly, section 4(5) cannot be interpreted to mean that doctors are under an obligation to provide, or to continue to provide, life-sustaining treatment where that treatment is not in the best interests of the person. Doctors must apply the best interests' checklist and use their professional skills to decide whether the provision of such treatment is in the person's best interests. If the doctor's assessment is disputed, and there is no other way of resolving the dispute, ultimately the Court of Protection may be asked to decide what is in the person's best interests (see Part 3 below).

The person's wishes and feelings, beliefs and values

4.30 A particularly important element of the best interests checklist is the consideration, so far as these can reasonably be ascertained, of:

> '(a) the person's past and present wishes and feelings (and in particular, any relevant written statements 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.'

4.31 Section 4(6) places the focus firmly on the person lacking capacity, and requires (so far as is reasonably ascertainable) consideration of the issues most important to him/her and what s/he would have wanted. It also reflects the need to make all reasonable efforts to find out whether the person has expressed any relevant views in the past, whether verbally, in writing or through behaviour or habits, as well as trying to seek his/her current views.

4.32 However, it is important to recognise that the person's wishes, feelings or other views will not automatically control the outcome of a best interests assessment. The "best interests" principle is a fundamental principle, requiring what is best for the person in the particular circumstances, which may not necessarily accord with the person's views. In some cases, *past* wishes and feelings may conflict with *current* wishes and feelings. While neither past nor present wishes can determine the decision which is now to be made, both are important and must be weighed against each other and considered alongside other factors in the best interests checklist.

Reasonably ascertainable

4.33 The extent to which it is possible to ascertain the person's past and present views will depend on the individual circumstances and, in particular, on the amount of time available. Only what is "reasonably ascertainable" must be considered. What may be reasonably ascertainable in an emergency will differ from what can be found out in a non-urgent situation. But even in an emergency, there may still be an opportunity to try to communicate with the person.

Past and present wishes and feelings

4.34 People who cannot express their current wishes and feelings in words or other conventional ways may still express their wishes and feelings through their behaviour. Expressions of pleasure or distress and their emotional responses will also be relevant in deciding what is in their best interests. Where the person is able to express any wishes and feelings, it is important to ensure as far as possible that these are the person's true wishes and have not been influenced by others. An independent advocate could provide support to enable the person to indicate their views without the risk of being influenced by others involved in the decision.

Written statements

4.35 Specific reference is made in section 4(6)(a) to any written statements made by the person before losing capacity. People can express a wide range of preferences for the future in a written form, such as the type of medical treatment they would wish to receive in the event of future illness, where they would prefer to live, or how they wish to be cared for, for example. Where such statements exist, the decision-maker must consider them carefully. Should a best interests decision be made that departs from the person's preferences as set out in writing in advance, the decision-maker should record the reasons for that departure and be prepared to justify them if challenged.

4.36 Where a person has made a written statement in advance requesting particular medical treatments, these requests should be taken into account by the treating doctor in the same way as requests made by a competent patient. This information will help the doctor decide what form of treatment is in the person's best interests. However, doctors may not have to comply with the wishes set out in a written statement if, in their professional judgment, the treatment would be clinically unnecessary or inappropriate and not in the person's best interests.

4.37 It is important to note the distinction between a written statement expressing treatment preferences, as opposed to a statement which constitutes an advance decision to refuse specified treatment within the meaning of section 24 of the Act, which has a different status in law. The former type of advance statement must be taken into account under section 4(6)(a), as described above, when determining the best interests of the person who made the statement but who now lacks capacity. However, an advance decision to refuse treatment which meets the legal requirements set out in the Act must be respected, and the specified treatment must not be given or continued, when the person who made the advance decision no longer has capacity to consent to treatment – this type of advance decision is discussed separately in chapter 8.

Beliefs and values

4.38 Of equal importance are the person's beliefs and values. We are all influenced by our values and beliefs in making decisions. This factor may be of particular significance for people who lack capacity, for example because of a progressive illness such as dementia. Values and beliefs may be indicated by the person's cultural background, or known past behaviour or expressions, such as religious or political conviction. Some people may have set out their values and beliefs in a written statement made while they still had capacity.

> A young woman with a history of political activity sustains serious brain damage during a car accident. The court appoints her father as deputy to invest the compensation she received. As the decision-maker he is obliged to take into account the views of others before deciding how to invest the money. He talks to her friends from college who tell him more about her political beliefs. This persuades him that choosing the option favoured by the bank's financial adviser would not be in her overall best interests, as although it gives the highest return, the fund includes bonds and shares from specific multi-national companies that he knows she disapproved of.

Instead he employs an ethical investment advisor to choose appropriate companies in line with her beliefs.

Other factors the person would be likely to consider

4.39 When making a decision, people with capacity will take account of a range of factors including the consequences of the decision for themselves and the effects of the decision on other people, particularly family members or close friends. Section 4(6)(c) of the Act allows for similar factors to be taken into account in relation to a decision made on behalf of a person who lacks capacity. Consideration must be given to any of the factors the person would consider if able to do so. This might include, for example, altruistic motives and concern for others, as well as duties and obligations towards dependants or future beneficiaries or as a responsible citizen.

Decisions involving benefits to others

4.40 The Act allows for acts the primary purpose of which would be to benefit a third party, provided that those acts are in the best interests of the person lacking capacity. The interpretation of best interests is broader than the person's medical best interests. A particular example might be a decision to take a sample of blood from a person lacking capacity to consent, where the sample is to be used for genetic testing for familial cancer, for the possible benefit of another family member rather than for the direct benefit of the person lacking capacity. The courts have held that the possible wider benefits to a person lacking capacity, arising for example from emotional support from close relationships, are important factors in determining the person's own best interests.[20]

4.41 Another situation might be to allow HIV testing to be carried out if there was a needle stick injury to a healthcare worker involved in the person's care. However, the decision maker would have to be satisfied that it was in the best interests of the person lacking capacity irrespective of the concerns relating to the healthcare worker. Consideration would then have to be given as to whether the results of the test could be disclosed to the healthcare worker and to those advising on the need for HIV post-exposure prophylaxis.[21]

The views of other people

4.42 For the first time, the Mental Capacity Act establishes the right for family members, partners, carers and other relevant people to be consulted on decisions affecting a person who lacks capacity to make those decisions and what might be in that person's best interests. People with a right to be consulted include:

- Anyone named by the person lacking capacity as someone to be consulted;
- Anyone engaged in caring for the person or interested in the person's welfare;

[20] See for example *Re Y (Mental Incapacity: Bone marrow transplant)* [1996] 2 FLR 787*; Re A (Male Sterilisation)* [2000] 1 FLR 549

[21] The duties of confidentiality, obligations under the Data Protection Act 1998 and the prohibition on disclosure contained in the NHS (Venereal Disease) Regulations 1974 and the NHS Trusts and Primary Care Trusts (Sexually Transmitted Diseases) Directions 2000 will need to be considered.

- Any attorney appointed by the person under a Lasting Power of Attorney;
- Any deputy appointed by the Court of Protection.

4.43 In considering a person's best interests it will be important to consult with all relevant people. It will be particularly important to consult those who are closest to the person concerned at the relevant time and who know the person well. This is likely to include family carers and other close relatives and in particular spouses or partners of the person lacking capacity as well as anyone previously named by the person. Where relevant, other family members or friends who are concerned about the person's welfare should also be consulted.

4.44 The Act requires such consultation to take place, but only if it is "practicable and appropriate" in the particular circumstances where a decision needs to be made. This is not intended to give absolute discretion to the decision-maker about whom to consult, rather decision-makers will need to show they have thought carefully about whom to consult and be prepared to explain why a consultation that they declined to carry out was either impracticable or inappropriate. It will always be appropriate to give careful consideration to the views of family carers engaged in caring for the person lacking capacity, wherever it is practicable and appropriate to do so. It is good practice for the decision-maker to have a clear record of their reasons if they consider that it is not practicable or appropriate for family carers or others engaged in caring for the person lacking capacity, attorneys, deputies or any named persons to be consulted. This will assist in them being able to demonstrate that they have acted in the best interests of the person lacking capacity. Where it is practicable and appropriate to consult such persons the person making the best interests determination must take their views into account. Where professionals are involved in determining best interests, it would also be good practice to record reasons why a particular decision is thought to be in the best interests of a person lacking capacity, in particular where the decision conflicts with the views of those consulted, such as family carers or those close to the person concerned.

4.45 The consultation is concerned with two matters –

- First, what the people consulted consider to be in the person's best interests on the matter in question, and
- Secondly, whether they can provide any information on the wishes, feelings, values or beliefs of the person lacking capacity.

If prior to losing capacity, the person concerned has nominated someone whom s/he would like to be consulted, the named person is more likely to have that information. People who are close to the person lacking capacity, in particular family members, partners and other carers are likely to know the person best. They may also be able to assist with communication or interpret signs, which give an indication of the person's present wishes and feelings. The people consulted may have different but equally valid views of what may be in the person's best interests (conflicting views are dealt with further in paragraphs 4.55-4.61 below). Such views should also be taken into account and weighed against the person's own views and other factors relevant to the decision in question.

A young woman with severe congenital brain damage is cared for at home by her parents and attends a day centre a couple of days each week. The day centre staff are proposing to take some of the service users on holiday. While the parents agree that it would be good for their daughter to go away on holiday, they know that she gets very distressed and anxious if she is surrounded by strangers who don't know how to communicate with her. They also know that she will only eat certain kinds of food. They discuss their concerns with the staff and it is agreed that the care assistant with whom she has a good relationship will accompany the young woman on holiday, and will also make sure that her food needs are met.

4.46 Any attorney appointed by the person under a Lasting Power of Attorney, and any court-appointed deputy, should be consulted whenever the person's best interests are being considered, if practicable and appropriate. Even if the LPA is only concerned with financial affairs, the attorney may have some knowledge about the person's wishes and feelings which are relevant to his/her best interests and could affect personal or healthcare decisions (see chapter 6).

A young woman with severe learning disabilities lives with her parents and attends the local training centre three days a week. Staff at the centre notice that she is becoming very friendly with a male trainee and appears to enjoy his attentions. However, the staff are concerned as to whether she has capacity to enter into a sexual relationship with the young man. They discuss the issue with her parents, who are anxious to protect their daughter but do not want to deny her the chance of a relationship that she might enjoy and benefit from. A case conference is arranged, involving the young woman, her parents, her key worker and other professionals involved in her care. It is agreed that it is in the young woman's best interests that she be supported in continuing with the relationship. A care plan is developed, with the full involvement of her parents, to provide education and support for the young woman to help her understand what is involved in allowing the friendship to develop into a sexual relationship.

Confidentiality

4.47 The requirement for consultation must be balanced against the right to confidentiality of the person lacking capacity. That right should be protected so that consultation only takes place where relevant and with people whom it is appropriate to consult. For example, it is unlikely to be appropriate to consult anyone whom the person had previously indicated should not be involved. However, there may be occasions where it is in the person's best interests for specific information to be disclosed (see chapter 15). If professionals are involved in the determination of best interests, they will also need to comply with their own duties of confidentiality in accordance with their professional codes of conduct.

Duty to apply the best interests principle

4.48 The principle set out in section 1(5) confirms that any act done, or any decision made, on behalf of a person lacking capacity must be done in his/her best interests. Section 4(8) confirms that the best interests principle, and the duties to be carried out in determining best interests, also apply in certain

circumstances where the person concerned may not in fact lack capacity in relation to the act or decision in question. The specified situations are:

- Where an attorney is acting under a Lasting Power of Attorney (for example, in relation to financial matters while the donor still has capacity);
- Where someone exercising powers under the Act "reasonably believes" that the person lacks capacity.

4.49 The second situation reflects the position that it is sufficient for carers and other decision-makers to "reasonably believe" that the person lacks capacity to make the decision or consent to the action in question (see chapter 3).

Reasonable belief as to best interests

4.50 The need to determine the best interests of a person lacking capacity, and to act in accordance with them, applies in relation to all decisions made or actions taken under the Act, extending from informal decisions to court based powers. Where there is a need for a court decision, the court may clearly require formal documentary evidence, including from those with relevant professional expertise (for example in psychiatry and/or social work) as to what course of action might be in the person's best interests. However, in many day-to-day situations, such formality is neither required nor appropriate and in emergency cases may not be possible.

4.51 Where the court is not involved, section 4(9) provides protection to a person who acts or makes a decision in the reasonable belief that they are doing so in the best interests of the person who lacks capacity. Family carers and other carers, professionals, attorneys and deputies, can only be expected to have *reasonable grounds for believing* that what they are doing or deciding is in the best interests of the person concerned. This does not mean that decision-makers can merely impose their own views. Rather, they must be able to point to objective reasons to demonstrate why they believe they are acting in the person's best interests. They must consider all relevant circumstances and apply all elements of the checklist.

4.52 It may be shown subsequently that someone was mistaken in his/her opinion of best interests and that the actual decision or action taken was not the best thing for the person lacking capacity. Coming to an incorrect conclusion does not necessarily mean that the decision-maker would not receive protection.. S/he does, however, have to be able to show that it was reasonable, in the particular circumstances which applied at the time, to believe that the action taken or the decision made was in the person's best interests.

A woman is knocked unconscious after being mugged and is rushed to hospital by ambulance. She has sustained head injuries and a stab wound and has lost a lot of blood so the casualty doctor arranges an urgent blood transfusion, believing this to be necessary to save her life and therefore in her best interests. When her relatives are finally contacted, they say the woman's beliefs meant that she would have refused all blood products. There was no prior indication of who she was, or what her beliefs were, as her handbag had been stolen. The doctor therefore had reasonable grounds for believing that his action was in his patient's best interests and so was justified in taking that action. If, however, a document had been available that confirmed her religion and her refusal of blood products, the doctor would not have been acting in her

best interests in failing to take that into account when deciding what treatment to give.

Part 3: Problems in determining best interests

4.53 The purpose of the best interests' principle and the statutory checklist is to ensure that when decisions are taken or acts done for those lacking capacity, the outcome is the best one available for the person concerned. The variety of factors in the checklist provides scope for considerable flexibility to enable appropriate results to be arrived at in individual cases.

4.54 Such flexibility is needed to ensure that primacy is given to the best interests of the person lacking capacity. It would therefore be impossible to weigh the various factors in the checklist in any order of priority or importance since these will vary according to individual circumstances. In the majority of cases, the determination of the person's best interests will be straightforward. However, more complex decisions, such as decisions surrounding major medical treatment or a change of residence, will require a balancing exercise of the pros and cons and of all other relevant factors, when deciding what is in the person's best interests.

Dealing with competing or conflicting concerns

4.55 When trying to determine the best interests of a person lacking capacity, a decision-maker may be faced with competing or conflicting concerns. For example, family members, partners and carers may disagree between themselves about what is in the best interests of the person lacking capacity or may have different memories as to the previously expressed views of the person concerned. Or, for example, family carers may disagree with a professional's view about the person's care or treatment needs.

4.56 The decision-maker will need to find a way of balancing these concerns or deciding between them. The first approach should be to try to seek a consensus between everyone involved – including the person who may lack capacity so far as s/he is able to participate and anyone who has been involved in the consultations. However, it is important to remember that reaching a consensus will not in itself determine the best interests of the person lacking capacity. It is important that everyone focuses on what would be best for the person who lacks capacity, and strives to reach agreement about the best solution.

Some time ago, Mr G made a Lasting Power of Attorney appointing his son and daughter as joint attorneys to manage his finances. He now has Alzheimer's Disease and has moved into private residential care. The LPA has been registered and a decision needs to be made about Mr G's house, a country cottage which has important associations for all the family. His son wants to sell it and invest the money for Mr G's future care. His daughter wants to keep the property, at least for the present, as she and other relatives spend holidays there and often arrange for Mr G to visit and spend time in his old home. She also thinks he would have wanted to keep the cottage for as long as possible so it can continue to be used and enjoyed by family members. After efforts are made to seek Mr G's views, the family meets to discuss all the issues involved. After hearing other family views, the attorneys agree that it would be in their father's best interests to keep the

property for so long as he is able to enjoy visiting it.

Family, partners and carers who are consulted

4.57 Where those consulted continue to hold differing views about the person's wishes and feelings, or what might be in his/her best interests, the decision-maker will need to weigh the contribution of different parties. This will depend entirely upon the circumstances of each case, the carers involved and their relationship with the person who lacks capacity. In some situations, the close relationship with family carers will show to the decision maker that they have a particular insight into how to interpret the person's wishes and feelings, which can assist the decision maker in reaching their decision. In such circumstances family carers and others close to the person concerned can often be the best people to help establish the views of the person who lacks capacity.

4.58 At the same time, paid carers and voluntary sector support workers may have more specialist knowledge about up-to-date care options or treatments, and some may also have known the person for many years. It is possible that anyone consulted (including family members) may have conflicts of interest; this should not rule out their contribution, but decision-makers should always ensure that these do not impact on determining what is best for the person who lacks capacity. In weighing up the different contributions of different people, the decision-maker should consider how long the person being consulted has known the person lacking capacity, and what their relationship is.

Resolving disputes about best interests

4.59 If consensus is not possible, it is up to the person charged with making the decision or carrying out the act in question to reach a conclusion about the best interests of the person who lacks capacity, having considered all relevant circumstances and worked though the statutory checklist.

4.60 Ultimately, the question of what is in the best interests of a person lacking capacity may be one for the court to decide. If consensus cannot be reached or if someone wishes to challenge a determination about best interests made by a decision-maker, there are a number of options that could be explored, including:

- Involving an advocate who is independent of all the parties involved in the decision to act on behalf of the person lacking capacity (see paragraph 4.62 below);
- Getting a second opinion (for example, concerning the need for medical treatment);
- Holding a formal or informal case conference;
- Attempting some form of mediation (although reaching a consensus will not determine best interests of the person lacking capacity).

4.61 Guidance on the various dispute resolution methods which may be available is given in chapter 14. Finally, if all other attempts to resolve the situation fail, an application may be made to the Court of Protection for a ruling on what particular decision or course of action is in the person's best interests. The

application procedures and the powers of the Court of Protection are explained in chapter 7.

Independent advocacy

4.62 Reference has been made in this chapter to the potentially useful role of independent advocacy services in providing a focus on the views and wishes of a person who may lack capacity in the determination of their best interests. The availability of advocacy services for those who do not qualify for an Independent Mental Capacity Advocate (IMCA) cannot be guaranteed. However, the following situations might indicate that the involvement of an independent advocate could assist the determination of best interests:

- Where the person lacking capacity has no close family or friends to take an interest in his/her welfare, and the decision to be made is not one which qualifies the person for the support of an IMCA (see chapter 9);
- Where family members are in dispute or disagree about the person's best interests;
- Where the person lacking capacity is already in contact with an independent advocate.

Part 4: Summary of key steps for determining best interests

4.63 The following provides a summary of the information contained within this chapter, listing key factors which should be taken into account in determining the best interests of a person lacking capacity. The summary should not be relied upon in isolation and reference should be made to the detail contained within the chapter.

- Don't make assumptions about someone's best interests merely on the basis of the person's age or appearance, condition or aspect of his/her behaviour.

- Try to identify all the issues and circumstances relating to the decision in question which are most relevant to the person who lacks capacity.

- Consider whether the person is likely to regain capacity (e.g. after receiving medical treatment). If so, can the decision wait until then?

- Do whatever is possible to permit and encourage the person to participate, or to improve his/her ability to participate, as fully as possible in making the decision.

- If the decision concerns the provision or withdrawal of life-sustaining treatment, you must not be motivated by a desire to bring about the person's death. Don't make assumptions about the person's quality of life.

- Try to find out the views of the person lacking capacity, including:

  – The person's past and present wishes and feelings – both his/her current views and whether the person has expressed

any relevant views in the past, either verbally, in writing or through behaviour or habits
- Any beliefs and values (e.g. religious, cultural or moral) that would be likely to influence the decision in question
- Any other factors the person would be likely to consider if able to do so

- Consult other people, if it is practicable and appropriate to do so, for their views about the person's best interests and to see if they have any information about the person's wishes, feelings, beliefs or values. But be aware of the person's right to confidentiality – not everyone needs to know everything. In particular, try to consult:

  - Anyone previously named by the person lacking capacity as someone to be consulted
  - Carers, close relatives or friends who take an interest in the person's welfare
  - Any attorney of a Lasting Power of Attorney made by the person
  - Any deputy appointed by the Court of Protection to make decisions for the person

  or,

  - For decisions about major medical treatment or a change of residence and where there is no-one who fits into any of the above categories, an IMCA (See chapter 9)

- Weigh up all of the above factors in order to determine what decision or course of action is in the person's best interests.

Chapter 5 - Acts in connection with care or treatment

Introduction

5.1 Section 5 of the Act makes provision for carers (both family members and paid carers) and health and social care professionals, amongst others, to receive statutory protection from liability for certain acts performed in connection with the personal care, healthcare or treatment of a person lacking capacity to consent to those acts. These provisions are intended to give legal backing, in the form of protection from liability, for acts considered to be in the best interests of someone who lacks capacity.

5.2 **Part 1** of this chapter describes the provisions in section 5 and explains how they operate in practice. **Part 2** describes the restrictions and limitations on the protection from liability offered by section 5. **Part 3** explains the circumstances in which a carer, acting without formal authority, can buy goods or organise necessary services for a person lacking capacity, and arrange for these to be paid for out of the person's money.

Part 1: Protection for acts done for people who lack capacity

5.3 Every day, millions of acts are done to and for people who lack capacity either to care for themselves or to consent to someone else caring for them. Examples might be actions such as helping individuals to wash, dress, eat or attend to their personal hygiene, taking them to see the doctor or dentist, or helping them buy food or have gas and electricity supplied to their home. Sometimes, carers and professionals have to take serious steps to preserve or improve a person's health, such as surgery or the administration of powerful medication, even where the patient lacks capacity to consent to it.

5.4 According to basic legal principles, many of these actions, particularly those which involve touching a person or interfering with their property, could be unlawful. People have the right to freedom from interference with their body or their possessions unless they give permission for that interference. A problem arises when people lack capacity to give that permission or consent to having things done to or for them. For example, if a person lacks the necessary capacity to dress him/herself and a carer dresses the person, the carer is potentially committing trespass to that person in touching him/her without consent (even if the action did not involve any violence or harm the person in any way). Or if a neighbour enters the house of a person lacking capacity in order to do housework etc, they could be trespassing on the person's property.

5.5 The purpose of the provisions discussed in this chapter is to ensure that when people need to perform such acts and they follow the principles of the Act (see chapter 2), they will be protected from liability for committing acts which could otherwise amount to civil wrongs or crimes, such as trespass or assault for example.[22] By offering protection from liability, the Act enables caring actions to take place in the absence of consent. Such actions can be performed as if the person concerned had capacity and had given consent. There is no need to obtain any formal powers or authority to act.

[22] The provisions of section 5 are based on the common law 'doctrine of necessity' as set out in *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1

5.6 Unlike the formal decision-making powers provided under the Act for attorneys and deputies (see chapters 6 and 7), section 5 does not provide carers or professionals with any specific powers or authority to make decisions on behalf of people lacking capacity to make their own decisions. Rather, section 5 potentially provides them with protection from any liability for their actions, so long as they can show that the act was in the best interests of the person lacking capacity and carried out in accordance with the principles set out in section 1 of the Act.

What type of acts would potentially attract protection from liability?

5.7 Section 5(1) sets out the circumstances in which protection from liability for acts done to or for people who lack capacity may be available. The types of acts which may attract protection from liability under section 5 (referred to as 'section 5 acts') are those carried out *in connection with the care or treatment* of a person who is believed to lack capacity in relation to the matter in question. The category is intentionally wide, the key issue simply being whether the act has a connection with the "care" or "treatment" of the person lacking capacity to consent to it. The Act does not define these terms, which should be given their ordinary meaning. Section 64(1) makes clear that treatment includes a diagnostic or other procedure.

5.8 As a general rule, a 'section 5 act' is one where consent (either explicit or implied) would normally be required from a person of full capacity for the particular act to be carried out. Examples (but not an exhaustive list) are as follows:

Acts in connection with personal care may include –

- Acts of physical assistance with washing, dressing or attending to personal hygiene;
- Help with eating and drinking;
- Help with mobility (such as putting someone in a car to take them to see their doctor or to participate in social or leisure activities);
- Doing the shopping or buying essential goods;
- Acts performed in relation to household services (such as gas and electricity supplies, housework, repairs or maintenance);
- Acts performed in relation to domiciliary or other services required for the person's care (such as homecare or meals on wheels);
- Acts performed in relation to other community care services (such as day care, residential accommodation or nursing care) – but see also paragraphs 5.11-5.15 below;
- Acts associated with a change of residence (including moving property and clearing the former home).

Acts in connection with healthcare and treatment may include –

- Diagnostic examinations and tests;
- Medical and dental treatment provided by health professionals;
- Admission to hospital for assessment or treatment (except for people who are liable to be detained under the Mental Health Act 1983 (see chapter 12)) – but see also paragraphs 5.16 and 5.45-5.49 below;
- Nursing care (whether in hospital or in the community);
- Any other necessary medical procedures or therapies (such as the taking of blood or other bodily samples, physiotherapy or chiropody);

- Emergency procedures (such as cardiopulmonary resuscitation);
- Significant medical treatment (such as major surgery or some forms of life-sustaining treatment) – but see also paragraphs 5.16-5.19 below.

5.9 Any such act may attract protection from liability under section 5, but only in circumstances where the person concerned is believed to lack capacity and the act is considered to be in the person's best interests and carried out in accordance with the Act's principles (see paragraph 5.24 onwards).

5.10 Some section 5 acts may cause major life changes with significant consequences for the person concerned. Those requiring particularly careful consideration are described in the following paragraphs.

A change of residence

5.11 People who lack capacity to make decisions relating to their own care rely on others to care for them. It may be possible for care to be provided in their own homes, but in some cases, this may involve a change of residence, either a move to live with relatives or into a care home or nursing home.

5.12 Generally such a move would require the person's formal consent if they had capacity to give, or refuse, it. But for those who lack capacity to consent, a careful determination must be made in each individual case as to whether such a move is in the person's best interests, taking account of all the factors in the best interests checklist (see chapter 4), including the person's past and present wishes and feelings and the views of other relevant people. This will include family members and others concerned with the person's welfare, anyone previously named by the person as someone to be consulted, and any attorney or deputy. Where there is no-one who fits into any of the above categories, and it is an NHS body or local authority which is proposing to arrange the accommodation, and the proposed stay exceeds 8 weeks in relation to a care home or 28 days in relation to a hospital, an Independent Mental Capacity Advocate (IMCA), must be involved to represent the person lacking capacity and provide information which may be relevant in determining the person's best interests (see chapter 9).

5.13 In particular, thought must be given to whether there is any other choice that would be less restrictive of the person's rights and freedom of action. If the proposed move to a hospital or care home would have the effect of depriving the person of their liberty, the protection for such acts that are in the best interests of the person who lacks capacity afforded by section 5 will not be available. Instead, an order authorising the deprivation of liberty will be required from the Court of Protection (see paragraphs 5.45 to 5.49 below).

5.14 In some cases, there may be no alternative way of providing the care the person needs, other than a change of residence. So long as the Act's principles and the requirements for determining best interests have been complied with, actions involved in moving the person to different accommodation may lawfully be carried out under the protection offered by section 5. While the decision in itself to move someone cannot be protected under section 5, acts resulting from that decision may be protected.

5.15 However, in cases where there are serious disputes between family members, or between the local authority responsible for the placement in a

care home and the person's carers, or where there is a risk that the circumstances of the person's stay in the hospital or care home may amount to a deprivation of liberty (and there is no specific authorisation for this in place - see Part 2 below) an application should be made to the Court of Protection for an order as to where it is in the best interests of the person lacking capacity to live.

Healthcare and treatment decisions

5.16 Section 5 also allows action to be taken to ensure a person lacking capacity to consent receives necessary medical treatment. This could involve taking the person to hospital for out-patient treatment or arranging for admission to hospital (including informal admission for treatment for mental disorder). Even if the person concerned was not compliant with the treatment or admission to hospital, such action may be still attract protection from liability under section 5, although the circumstances in which force or restraint could be used are limited by the restrictions set out in section 6 (see Part 2 below).

5.17 Particular consideration will need to be given to actions in relation to major healthcare and treatment decisions. In each case, a careful determination of best interests and consideration of the least restrictive option must be carried out (in the same way as described in paragraphs 5.12-5.13 above - with appropriate consultation with persons engaged in caring for the person who lacks capacity or interested in their welfare, and including where relevant an IMCA), before any such act can attract protection from liability under section 5. (See chapter 9 for more details on the IMCA service.)

5.18 Before the Act came into force, the courts decided that some decisions relating to the provision of medical treatment were so serious that each case should be brought before the court so that a declaration could be made that the proposed action was lawful.[23] It is anticipated that the following cases should continue to be brought before a court namely:

- The proposed withholding or withdrawal of artificial nutrition and hydration (ANH) from patients in a permanent vegetative state (PVS);
- Cases involving organ or bone marrow donation by a person lacking capacity to consent;
- The proposed non-therapeutic sterilisation of a person lacking capacity to consent to this (e.g. for contraceptive purposes);
- Some termination of pregnancy cases; and
- Other cases where there is a doubt or dispute about whether a particular treatment will be in a person's best interests.

5.19 The final category of 'other cases' likely to be referred to the court include those involving ethical dilemmas in untested areas (such as innovative treatments for variant CJD) or where there are otherwise irresolvable conflicts between professionals, or between professionals and family members. More details on the need to refer to the court for decisions in respect of serious health care and treatment decisions can be found in chapter 7.

[23] The procedures resulting from those court judgments are set out in Practice Note *(Official Solicitor: Declaratory Proceedings: Medical and welfare decisions for adults who lack capacity)* [2001] 2 FLR 158

Who can take action?

5.20 Section 5 of the Act refers to a person who "does an act in connection with the care or treatment of another person". The section can apply to any person and the likelihood is that a number of people may be performing acts that will attract protection from liability under section 5 at any particular time. There is no question of one person having a statutory power to the exclusion of all others. The provisions in section 5 do not confer any special powers on anyone to make substitute decisions or to give substitute consent. Nor do they specify *who* has the authority to act in a particular instance. Section 5 allows carers and healthcare professionals caring for a person who lacks capacity to be able to carry out those caring obligations without incurring liability.

5.21 For example, carers may provide personal care for an individual lacking capacity, including any necessary assistance with washing, dressing, toileting or eating. Such carers could be family carers who look after a relative who lacks capacity at home, paid carers providing domiciliary homecare services or care assistants working in a care home or nursing home where the person lives. Section 5 may also cover the acts of care assistants in a day centre if a person lacking capacity needs assistance with personal care while attending the centre. It may also cover acts performed by nurses providing nursing and personal care in hospitals or in the community.

> On any one day, an older person with early onset dementia who lives at home may have help with breakfast from a family member in the morning, the dressing of a pressure sore by a district nurse in the afternoon and be taken to the park by a friend later in the day. Each of these individuals, provided they have taken reasonable steps to see if the person lacks capacity to consent to the action they propose to take, and they are acting in the person's best interests, would be protected from any liability in relation to the act performed under section 5 of the Act.

5.22 Also in connection with a person's care, a carer may have to deal with some financial matters, for example using the money of the person lacking capacity to pay for necessary goods or services, such as buying food, paying the electricity bill or paying for home care services. These issues are discussed further in Part 3 of this chapter.

5.23 Where the act involves the provision of medical treatment, the doctor responsible for the patient's care and treatment is the person 'doing the act', although some aspects of the treatment may be delegated to other members of the clinical team to carry out the necessary acts under section 5.

The steps required for people to be protected from liability for their actions

5.24 A step-by-step approach may be helpful for anyone wishing to take action in connection with the care or treatment of another person in order to benefit from protection from liability offered by section 5.

5.25 First, reasonable steps must be taken to ascertain whether the person concerned has capacity in relation to the matter in question (see paragraphs

5.28-5.31 below and chapter 3) – if the person has capacity, his/her consent to the action will be required to provide protection from liability.

5.26 Secondly, consideration must be given to the principles of the Act set out in section 1 (see chapter 2). These include:

- The presumption that a person has capacity unless it is proved otherwise;
- All practicable steps must be taken to help the person understand what act is proposed and to enable the person to make or participate in any decisions relating to it;
- An unwise decision must not automatically be assumed to indicate a lack of capacity;
- Considering whether a less restrictive option is available.

5.27 Thirdly, where there are reasonable grounds for believing that the person lacks capacity in relation to the matter, the person doing the act must then consider whether there are reasonable grounds for believing that it will be in the person's best interests for the act to be done (see chapter 4). All relevant circumstances must be considered, and the best interests checklist followed.

What is "reasonable"?

5.28 As explained in chapter 3, the Act requires a functional approach when deciding whether a person lacks capacity – this means that capacity must be assessed in relation to the particular decision at the time it is needed. In day-to-day situations, the carer attending to personal care needs must consider whether the person has capacity in relation to the matter in question. For example, a carer helping a person to dress should consider whether that person can consent to being helped by explaining what options there are (i.e. getting dressed or staying in night-clothes) and the consequences (for example, being able to go out or having to stay in all day; being cold etc.). A carer wanting to help someone to wash must consider whether that person has capacity to consent, having explained the options (e.g. a bath or a shower).

5.29 Carers acting informally are not expected to be experts in assessing capacity, but they must be able to show that they have taken *reasonable steps* to find out and therefore have *reasonable grounds for believing* the person lacks capacity in relation to that particular matter. Formal assessment processes are rarely required, although in some circumstances professional practice may require this for example in respect of capacity to consent to medical treatment. However, anyone wishing attract protection from liability for an act under section 5 must be able to point to some objective evidence leading to a belief that the person concerned lacks capacity to consent to the act in question. If their belief is challenged, they will be protected from liability so long as they can point to the steps taken to find out whether the person has capacity and the grounds which justified a belief of lack of capacity.

5.30 Similarly, carers, relatives and others who are acting informally can only be expected to have *reasonable grounds for believing* that what they are doing is in the best interests of the person concerned. This means that family carers or other carers should not merely impose their own views; rather they must be able to demonstrate that they have considered all relevant circumstances

when deciding what is in the person's best interests. If their determination of best interests is challenged, they will be protected if they can show that it was reasonable, in all the circumstances of that particular case, for them to believe that the action they took was in the person's best interests.

5.31 Where professionals are involved, their professional skills will be taken into account in deciding what would be considered "reasonable". For example, doctors assessing a person's capacity to consent to medical treatment would be expected to demonstrate a higher level of skill than a lay person, by recording in the person's healthcare record the steps taken in the assessment process and the reasons for their findings. In determining what treatments should be offered, professionals must apply normal clinical and professional standards. They must then decide whether the proposed treatment is in the best interests of the person who lacks capacity, taking all relevant circumstances into account, including the elements of the best interests checklist (see chapter 4).

Emergency situations

5.32 There may be circumstances where it is necessary to give emergency medical treatment in order to save the life or prevent serious harm to a person who lacks capacity to consent to such treatment. What will be 'reasonable steps' in such circumstances in making best interests determinations will be different to non-urgent situations. In emergencies, it might be reasonable for urgent treatment to be given without delay.

No protection in cases of negligence

5.33 Section 5 operates in conjunction with other provisions of the law. Professionals and others have duties of care which, if breached, give rise to liability in the tort of negligence. The Act states explicitly that section 5 does not provide a defence to negligence, whether in carrying out a particular act or by failing to act where necessary. So, section 5 may provide a doctor with protection against liability in the tort of battery if the doctor carries out an operation which is in a person's best interests, even though the person lacks capacity to consent. If, however, the doctor then performs the operation in a negligent fashion then there will still be liability in the tort of negligence. So, the person who lacks capacity is in the same position as a person who (with capacity) had consented to the operation.

> A surgeon carried out a lumpectomy operation on a young woman who lacked capacity to consent to the operation, having established that this would be in her best interests. Following the operation, she suffered serious complications and it was discovered that the surgeon had not followed proper procedures during the operation causing her some permanent damage. While the surgeon was protected from liability for performing the act of the lumpectomy operation, as this was in the young woman's best interests, he would still be liable in any claim for damages resulting from his clinical negligence in the way he had performed the operation.

Effect of an advance decision to refuse treatment

5.34 When providing healthcare or treatment for a person lacking capacity to consent to those medical procedures, health professionals must act in accordance with any advance decision to refuse treatment made by that person with capacity, so long as the advance decision is both valid and applicable to the proposed treatment.

5.35 Where a health professional is satisfied that an advance decision as defined in the Act exists and is valid and applicable in the circumstances which have arisen, then section 5 does not give protection from liability for any treatment provided which is contrary to the person's instructions in the advance decision. However, treatment providers would be protected from liability under section 26(2) of the Act if they were unaware of an advance decision or were not satisfied that an advance decision exists which is both valid and applicable to the particular treatment (Further guidance on advance decisions is given in chapter 8).

Part 2: Limitations on section 5 acts

5.36 Section 6 imposes two important limitations on acts which can be carried out with protection from liability under section 5 (as described in the first part of this chapter):

- No protection is offered to people who restrain a person lacking capacity in order to carry out any act in connection with the care or treatment or to force that person to comply with the act, unless certain conditions are met (see below);
- No-one is authorised by section 5 to do an act which conflicts with a decision made by an attorney acting under a Lasting Power of Attorney or a deputy appointed by the court (see paragraphs 5.50-5.51).

The use of restraint

5.37 As a general rule, any act that is intended to restrain a person lacking capacity will not attract protection from liability. However, section 6 specifies certain strict conditions, which if satisfied, will serve to provide protection from liability for someone who uses restraint to prevent harm to a person who lacks capacity to protect him/herself. Any restraint used must be proportionate to the likelihood and seriousness of the harm.

What is restraint?

5.38 Restraint is defined in section 6(4). Someone is said to restrain a person lacking capacity if s/he:

- Uses, or threatens to use, force to do an act which the person resists, or

- Restricts the liberty of movement of someone who lacks capacity, whether or not the person resists.

5.39 Therefore, any threat of force or use of actual physical force or violence will not attract protection from liability under section 5 unless the conditions set out in section 6 are met.

The conditions which may justify the use of restraint

5.40 Since the Act has the best interests of people who lack capacity as one of its key principles, the use, or threat, of any sort of force or restriction of liberty is generally not permitted. However, the practicalities of caring for and providing protection for people who lack capacity are also recognised. A line needs to be drawn between justifiable protection of people who may lack capacity on the one hand and unjustifiable force or coercion on the other. The Act draws this line by setting out two conditions which, if satisfied, may provide protection from liability to carers and others who need to use restraint:

- The first condition is that the person taking action must reasonably believe that it is *necessary* to do an act which involves restraint in order to *prevent harm* to the person lacking capacity;
- The second condition is that the act is a *proportionate response* (in terms of both the degree and the duration of the restraint) to the likelihood of the person suffering harm and to the seriousness of that harm.

When might restraint be "necessary"?

5.41 The onus is on the person doing the act to identify objective reasons to justify his/her belief that restraint is necessary, i.e. that the person being cared for is likely to suffer harm unless some sort of physical intervention or other restraining action is taken. The restraining act must be necessary in order to avert harm – not simply to enable the carer or professional to do something more quickly or easily. Where restraint is necessary to prevent the person from coming to any harm, only the minimum of force or other type of restraint may be used and for the shortest possible duration.

An elderly man with dementia has been prescribed medication for a heart condition, which requires his blood pressure to be monitored regularly, and occasional blood tests to be carried out. He does not like being "messed about with" and also is unable to keep still for long enough for the tests to be done. Both his GP and the district nurse are concerned that his medication may cause harm if it is not prescribed at the correct level and balanced against other drugs he has been prescribed. After trying, without success, all possible means to explain to the man what is happening and why, the nurse asks her colleagues to hold him still just for long enough for the tests to be carried out. In doing so, they are acting in his best interests (and the test is necessary to prevent harm to the man), acting proportionately in response to the likelihood and seriousness of harm and would be protected from liability in restraining him in this way.

What is "harm"?

5.42 The Act does not define "harm" since it is likely to vary according to the individual circumstances of the person lacking capacity. For example, a person who lacks capacity to understand the dangers of cars, may run into a busy road without warning, unaware of the danger; a person who lacks capacity to remember where s/he lives may wander away from home and be unable to find the way back; a person who lacks capacity to manage financial decisions may run up huge debts through spending money excessively when going through a manic phase or may be at risk of self-harm when depressed. In many cases, the risk of harm can be prevented by common sense measures (such as locking away poisonous chemicals or removing obstacles) as well as care planning for people being cared for by health or social services authorities, taking account of any risk assessments. However, it is impossible to eliminate all risk, and if a risk arises then a proportionate response is required to prevent harm occurring.

What is a "proportionate response"?

5.43 The scale and nature of any form of restraint must be a *proportionate response* to the likelihood of the person who may lack capacity suffering harm and to the seriousness of that harm. The means of restraint should be the minimum necessary to achieve the desired outcome, using the minimum force or least intrusive intervention and for the shortest possible time. For example, a carer may need to keep hold of the arm of a person who lacks capacity to understand the dangers of roads while crossing a road but it would not be a proportionate response to stop the person going outdoors at all. It may be appropriate to have a secure lock on a door leading to a busy main road, but it would not be a proportionate response to lock someone in a bedroom all the time because they have a tendency to wander out onto the road.

5.44 Special care is needed when dealing with people who have particularly challenging behaviour. Reference should be made to guidance issued by the Department of Health and Department for Education and Skills on the use of restrictive physical interventions for people with learning disability and autistic spectrum disorder in health, education and social care settings[24]. In Wales, the relevant guidance is the Welsh Assembly Government's 'Framework for Restrictive Physical Intervention Policy and Practice.'

A young man who lacks capacity to control his behaviour sometimes gets distressed in his college class and hits the wall in frustration. Sometimes he hurts himself. Staff are concerned about how to tackle this. They don't want to take him out of the class because although it sometimes upsets him, he says he enjoys it, is keen to get on the bus in the morning, and is learning new skills. They have tried having a support worker sit with him in class, but he still gets upset. The support worker could try to hold him back but thinks this would be inappropriately invasive, even though it would prevent him from hurting himself in the short term. Instead staff decide to give the man a

[24] DH and DfES, *Guidance for restrictive physical interventions: How to provide safe services for people with learning disabilities and autistic spectrum disorder* (2002), available at http://www.dh.gov.uk/assetRoot/04/06/84/61/04068461.pdf

specially designed protective arm cuff for a few weeks whilst they work with him to find ways of managing his emotions without harming himself. This means he can carry on coming to the class.

Actions that amount to deprivation of liberty

5.45 The provisions in section 5 provide a potential defence for any necessary and proportionate restriction of a person's liberty – so long as the conditions set out above are met. They do not permit actions which go so far as to *deprive someone of his/her liberty.* Actions amounting to a deprivation of liberty for which there is no other lawful authority (for example, under mental health legislation) will only be lawful if authorised by the Court of Protection.

5.46 Section 6(5) expressly confirms that someone carrying out an act under section 5 will do more than "merely restrain" a person lacking capacity if s/he deprives that person of liberty within the meaning of Article 5(1) of the European Convention on Human Rights. This section applies not only to public authorities covered by the Human Rights Act 1998 but to anyone carrying out acts in connection with care or treatment under section 5. Therefore the defence against liability provided by section 5 is not available to anyone whose actions result in a deprivation of liberty of a person lacking capacity. Nor can an attorney or deputy authorise such a deprivation of liberty without recourse to the court.

5.47 The difference between restriction of liberty and deprivation of liberty is complex. In a number of recent cases, the European Court of Human Rights said that the distinction was "one of degree or intensity, not one of nature or substance".[25] There must therefore be particular factors in the specific situation of the person concerned which provide the "degree" or "intensity" to result in a deprivation of liberty. The factors might relate, for example, to the type of care being provided, how long the situation lasts, its effects and the way in which the particular circumstances came about.

5.48 In *HL v UK*, the European Court said that "the key factor in the present case [is] that the health care professionals treating and managing the applicant exercised complete and effective control over his care and movements". They found "the concrete situation was that the applicant was under continuous supervision and control and was not free to leave."[26]

5.49 The Department of Health has issued guidance on the distinction between restriction and deprivation of liberty, and the steps that may be taken by local authorities and NHS bodies to avoid situations, which may involve depriving people of their liberty[27]. In Wales, the Welsh Assembly Government has also issued guidance in respect of these issues[28]. If it is concluded that it is not possible to provide appropriate care in a way, which does not amount to deprivation of liberty of a person lacking capacity, then:

[25] *HL v The United Kingdom* (Application no, 45508/99). Judgement 5th October 2004, paragraph 89

[26] Ibid, paragraph 91

[27] Department of Health, *Advice on the decision of the European Court of Human Rights in the case of HL v UK (the "Bournewood" case)* Gateway Ref 4269, (10 December 2004), available at http://www.dh.gov.uk/assetRoot/04/09/79/92/04097992.pdf

[28] Welsh Health circular WHC (2005) 005 advice on the decision of the European Court of Human Rights in the case of HL v UK (the Bournewood case)

- Where treatment for mental disorder is required, consideration should be given to using the formal powers of detention under the Mental Health Act 1983 (see chapter 12);
- In all other cases, or where the grounds for detention are not met, an application should be made to the Court of Protection for an order as to what action should be taken in the person's best interests (see chapter 7).

The Code will be updated to reflect further legislative safeguards made in response to the case of HL v UK (commonly known as the Bournewood judgment).

Effect of formal decision-making powers

5.50 Section 5 provides protection from liability to carers and professionals in circumstances where no formal powers are required. However, where formal decision-making powers already exist, for example under a Lasting Power of Attorney (see chapter 6), or through an order appointing a deputy made by the Court of Protection (see chapter 7), these powers will take precedence. This is because provided that an attorney or a deputy acts within the scope of his/her powers, s/he can provide consent on behalf of the person who lacks capacity, so it is no longer necessary to act in the absence of consent. Anyone acting contrary to a decision of an attorney or a deputy acting within the scope of his/her powers will not therefore have protection from liability.

5.51 There may be occasions when carers or health professionals feel that an attorney or deputy is acting outside the scope of his/her authority, or contrary to the best interests of the person lacking capacity. An application to the Court of Protection may be necessary if the problem cannot be resolved. Section 6(6) clarifies that life-sustaining treatment, or treatment necessary to prevent a serious deterioration in the person's condition, can be given pending a ruling from the court.

Part 3: Paying for goods, services and other expenditure

5.52 It is recognised that people who care for others who lack capacity often have to spend money on their behalf in order to provide that care. For example, carers may arrange for milk to be delivered or for a chiropodist to call to provide a service to the person at home. More costly arrangements might be for house repairs or organising a holiday. Where it is appropriate for carers to arrange such matters, and so long as the arrangements made are in the best interests of the person lacking capacity, the carers' actions are likely to be protected from liability under section 5. The following paragraphs explain the legal obligations for payment and the circumstances in which any expenditure incurred by carers in making necessary arrangements can be reclaimed from a person lacking capacity.

Who pays for necessary goods and services?

5.53 In general, a contract entered into by a person who lacks capacity to make the contract is voidable if the other person knows, or must be taken to have known, of the lack of capacity. However, the Sale of Goods Act 1979 modified this rule when applied to contracts for 'necessaries'. A person who lacks capacity who agrees to pay for necessary goods is legally obliged to pay a

reasonable price for them. Similar common law rules also apply to essential services. These rules are now brought together under section 7 of the Act. This clarifies that the person lacking capacity to enter the contract for necessaries must pay a reasonable price for both the supply of necessary goods and the provision of necessary services.

What is necessary?

5.54 Section 7(2) sets out the definition of "necessary", which means suitable to the person's condition in life (i.e. his/her place in society, rather than any mental or physical condition) and his/her actual requirements at the time when the goods are supplied or the services are provided. Thus, while food, drink and clothing are necessary for everyone, the actual requirements for the type of food or the style or amount of clothing will vary according to the person's individual circumstances or "condition in life". The aim is to ensure that people can enjoy a similar standard of living and way of life as they experienced before lacking capacity. For example, if a person who now lacks capacity had always bought expensive designer clothes, s/he should be able to have them replaced with similar quality clothes as necessary goods. However such clothes would not be necessary for a person who usually wore cheap jeans and T-shirts.

5.55 Goods will not be necessary if the person's existing supply is sufficient. So, for instance, one pair of shoes (or possibly two pairs) bought for a person lacking capacity to buy them for him/herself would be considered necessary, but a dozen pairs would probably not be necessary.

Arranging for payment to be made

5.56 As explained above, the legal responsibility for paying for necessary goods and services lies with the person for whom they are supplied, even though that person lacks the capacity to contract for them. Where that person also lacks the capacity to arrange for such expenditure, section 5 and section 8 of the Act operate together to allow a carer who arranges for goods and services also to arrange settlement of the bill.

5.57 Section 5 requires the carer to have taken steps to ascertain the person's capacity and if s/he lacks capacity, to decide what goods or services would be in the person's best interests (see Part 1 above). Section 8 then confirms that the carer can lawfully deal with payment for those goods and services in one of three ways:

- If neither the person lacking capacity nor the carer who has arranged for the goods or services can produce the necessary funds, then the carer may promise that the person who may lack capacity will pay (i.e. the carer may pledge the credit of the person who lacks capacity). Of course, it may be that a supplier will not be happy with such a promise, in which case formal steps will be required (see paragraphs 5.60-5.61 below);
- If the person lacking capacity has cash in his/her possession, then the carer may use that money to pay for goods or services (e.g. to pay the milkman or the hairdresser);
- The carer may choose to pay for the goods or services with his/her own money and is then entitled to be reimbursed or otherwise

indemnified from the money of the person lacking capacity. Again, this may involve using cash in the person's possession, or running up an IOU. (However, such an arrangement is unlikely to be appropriate for paid carers who may be prevented by their contracts of employment from using their own money or handling their client's money.) Formal steps would be required before carers could gain access to any money held by a third party such as a bank or building society (see paragraphs 5.59-5.62 below).

5.58 As a matter of good practice, carers should keep bills, receipts and other proof of payment when paying for goods and services on someone else's behalf. In particular, these may be needed when claiming reimbursement since anyone dealing with the person's finances should be keeping proper records or accounts (see below).

Access to income or bank accounts etc

5.59 The intention of these provisions is to make it possible for ordinary but necessary goods and services to be provided for people who lack the capacity to organise and pay for them. However, section 8 does not give any authorisation to a carer to gain access to income or assets, or to sell property, belonging to the person who lacks capacity. A distinction is drawn between the use of available cash already in the possession of the person lacking capacity on the one hand and the removal of money from a bank account or selling valuable items of property on the other.

5.60 Where the assets of a person lacking capacity to manage them are held in a bank or building society account or are invested, specific authority (in the form of a Lasting Power of Attorney, a deputyship or a single order of the Court of Protection) will generally be required before the bank or building society can give access to them to anyone other than the legal owner. Formal authorisation is also required before any valuable items of property can be sold.

During some very severe storms, several tiles were blown off the roof of the house owned by a man with Alzheimer's disease and it is clear to his family that urgent repairs are needed to make the roof watertight. He lacks capacity to make arrangements for the work to be done and also lacks capacity to make a claim on his insurance. The repairs are likely to be costly because scaffolding has to be erected. His son decides to go ahead with organising the repairs and agrees to pay the cost himself since his father does not have the appropriate sum of cash in his possession. The son could then apply to the Court of Protection for authority to make the insurance claim on his father's behalf and for him to be reimbursed from his father's bank account to cover the cost of the repairs.

5.61 In some cases, formal arrangements may already have been made giving someone lawful control over finances and property belonging to a person lacking capacity. For example, a property and affairs attorney may have been appointed under a Lasting Power of Attorney (see chapter 6) or a deputy appointed by the Court of Protection to make financial decisions on behalf of a person lacking capacity (see chapter 7). Alternatively, someone (usually a carer) may have been appointed under Social Security Regulations to act as 'appointee' to claim benefits for a person lacking capacity to make his/her own claim and to use the money on the person's behalf. However, an

appointee has no authority to deal with other assets or separate or non-benefit savings.

5.62 Section 6(6) makes clear that an informal carer cannot make arrangements for goods or services to be supplied to a person lacking capacity if this conflicts with a decision made by someone who has formal powers over the person's money and property. Where there is no conflict, the carer may ask for reimbursement of any expenditure from any attorney, a deputy or where relevant, an appointee.

Chapter 6 - Lasting Powers of Attorney

Introduction

6.1 This chapter describes the main provisions in the Act relating to Lasting Powers of Attorney (LPAs) and provides basic guidance on their practical implications. The Office of the Public Guardian will provide additional guidance for both donors (those making LPAs) and attorneys (referred to in the Act as donees but generally referred to in the Code as attorneys), for example on the procedures involved in making an LPA and the registration process for LPAs.

6.2 **Part 1** of this chapter explains what is meant by a Lasting Power of Attorney (LPA), describes the types of decisions that donors can delegate to their attorneys and sets out the circumstances in which an LPA can and cannot be used. **Part 2** sets out the duties and responsibilities of attorneys and describes the standards of conduct expected of attorneys. It also explains the actions which can be taken against an attorney who fails to meet appropriate standards. **Part 3** briefly considers the transitional arrangements which will apply to Enduring Powers of Attorney (EPAs) created before the implementation of this Act.

Part 1: What is a Lasting Power of Attorney?

6.3 A power of attorney is a legal document by which one person (the donor) gives another person or persons (the attorney(s) or donee(s)) the authority to act as the donor's agent(s) on his/her behalf. Any decision made by an attorney acting within the scope of his/her authority under a power of attorney can be treated as if made by the donor him/herself. Prior to the introduction of the Enduring Powers of Attorney Act 1985, every power of attorney automatically became invalid once the donor lacked capacity to make his/her own decisions. That Act, however, introduced the Enduring Power of Attorney (EPA) - a particular type of power of attorney that allowed the attorney(s) to continue to act on behalf of the donor in relation to property and financial affairs even after the donor ceased to have capacity.

6.4 The Mental Capacity Act introduces a new form of power of attorney, a Lasting Power of Attorney (LPA), to replace EPAs and to extend the areas in which donors can authorise others to make decisions on their behalf in the event that they lack capacity. In addition to property and financial affairs, donors can now also appoint attorneys to make decisions concerning their personal welfare when they may lack capacity to do so, including healthcare and consent to medical treatment. Different attorneys may be appointed to take different types of decisions.

6.5 LPAs relating to decisions about property and financial affairs (referred to as 'property and affairs LPAs' or sometimes 'financial LPAs') can be used both before and after the donor loses capacity, according to the donor's wishes. However, personal welfare LPAs (including those relating to healthcare decisions) can only be used when the donor lacks capacity to make a particular personal welfare decision. To be valid, an LPA must be correctly executed in the prescribed form and it must be registered with the Public Guardian before it can be used. The different types of LPAs are described in more detail in paragraphs 6.12-6.28 below.

Creating a Lasting Power of Attorney

6.6 Many people, while they have capacity, may wish to plan for a future time when they lack capacity. Making a Lasting Power of Attorney enables people to appoint their chosen representative(s) to take decisions on their behalf when they lack capacity. Such advance planning also enables donors of LPAs to give appropriate instructions and information to their chosen attorneys so that they are able to carry out the donor's wishes.

6.7 An LPA is a legal instrument authorising the attorney to make important decisions affecting the livelihood, property, health or personal welfare of the donor. Attorneys also have the power to act on any decisions they make (section 64(2)). Careful thought must therefore be given when making an LPA, both in choosing the right person as attorney (someone who is trustworthy, competent and reliable – see also paragraphs 6.34-6.38 below) and in following the correct procedures to ensure the LPA is valid.

6.8 Section 9 of the Act defines an LPA and specifies the requirements and procedures that must be followed in order to create a valid LPA. These requirements are set out in section 10 and Schedule 1 of the Act. Only adults aged 18 or over who have the capacity to do so may make an LPA. The LPA instrument must include a certificate, completed by an independent third party,[29] confirming that in the opinion of the third party the donor understands the purpose of the LPA and that neither fraud nor undue pressure was used to persuade the donor to make the LPA.

6.9 In all cases, the LPA must be registered with the Public Guardian before it can be used. An application to register the LPA can be made either by the donor, while s/he still has capacity to do so, or by an attorney, at any time before the LPA needs to be used.

Acting under a Lasting Power of Attorney

6.10 Of particular importance is section 9(4) which specifies that, when acting under an LPA, attorneys are subject to the provisions of the Act and in particular, section 1 - *the principles* and section 4 - *best interests* and any conditions or restrictions specified in the instrument. Guidance is given in chapter 2 on the application of the Act's principles, which include:

- The presumption that the donor has capacity to make his/her own decisions unless it is proved otherwise;
- All practicable steps must be taken to help the donor make his/her own decisions or to permit and encourage the donor to participate as fully as possible in any decisions affecting him/her;
- An unwise decision must not automatically be assumed to indicate a lack of capacity;
- Anything done for or on behalf of the donor must be in his/her best interests;
- Anything done for or on behalf of the donor should be the least restrictive of his/her basic rights and freedoms.

[29] Details of who may be a certificate provider are available from the OPG

6.11 In considering whether the donor has capacity to make a particular decision, attorneys should refer to the guidance in chapter 3 on the definition and assessment of capacity. In particular, assessments of capacity or best interests should not be based merely on the donor's age or appearance, or from unjustified assumptions based on his/her condition or behaviour. When deciding what is in the donor's best interests, it will be important for attorneys to have regard to the guidance in chapter 4. In particular, they must consider the donor's past and present views on the matter in question, and where appropriate, consult with relatives, carers and others who may be involved in caring for or have an interest in the donor's welfare. The duties and responsibilities of attorneys are described further in Part 2 of this chapter.

A long-time member of the Green Party appoints his solicitor as his attorney under a financial LPA. While he has confidence in his solicitor to manage his affairs efficiently, he stipulates in the LPA that any investments made on his behalf must be ethical investments in companies, which operate in a socially and environmentally responsible manner.

Lasting Powers of Attorney: Decision-making powers

(1) Personal welfare LPAs

6.12 A personal welfare LPA enables donors to appoint an attorney (or attorneys) to make decisions about their personal welfare (including healthcare and medical treatment) which they would normally make for themselves, but may lack capacity to do so in the future. Donors can authorise their attorneys to act in relation to all matters concerning their personal welfare or they can list specific matters for which they wish the attorney(s) to have power to act. However, a personal welfare LPA can only be used at a time when the donor lacks capacity to make the particular welfare decision in question.

6.13 The types of decisions that welfare attorneys could be authorised to take, and the powers an LPA would confer on them, might include any or all of the following:

- Decisions about where the donor should live;
- Decisions about the donor's day-to-day care;
- Giving or refusing consent to medical examination and/or treatment;
- Arranging for the donor to be provided with medical, dental or optical treatment;
- Arranging for the donor to be assessed for and provided with community care services.

6.14 The list above gives examples of the types of powers that might be included in a personal welfare LPA and is not intended to be exhaustive. A general LPA in respect of personal welfare will authorise the attorney to make all of the decisions set out above. In any particular case, specific powers may need to be included. The donor may wish to specify the types of powers s/he wishes the attorney to have, or to exclude particular types of decisions.

Mrs H has recently been diagnosed as being in the very early stages of Alzheimer's disease. She is anxious to get all her affairs in order while she is still able to do so. She decides to make a personal welfare LPA, appointing her daughter as attorney so that when she lacks capacity, her daughter can

make decisions on her behalf concerning the care she receives, including deciding if residential or nursing home care is necessary (in other words, where Mrs H will live). However, Mrs H has always believed quite strongly that doctors should be the ones who should decide whether a person receives particular medical treatments if that person lacks capacity to make those decisions themselves. She does not think it is right for her daughter to be able to make such decisions on her behalf and so she states in the LPA that her daughter's authority as her personal welfare attorney does not extend to making decisions on her behalf relating to medical treatment.

6.15 Before using any power under a personal welfare LPA, the attorney must be sure that:

- The LPA has been registered with the Public Guardian;
- The donor lacks the capacity to make the decision in question, or the attorney reasonably believes that the donor lacks capacity (having taken account of the principles in section 1); and
- The decision being made is in the donor's best interests.

LPAs authorising healthcare decisions

6.16 As indicated above, an LPA which authorises the attorney to make personal welfare decisions generally also includes the authority to give or refuse consent to medical treatment or make other healthcare decisions (section 11(7)(c)) unless such decisions are specifically excluded by the donor when creating the power. This means that when creating or updating a care plan for a donor who has appointed an attorney to make healthcare decisions, or in deciding what particular treatment would be in the donor's best interests, healthcare professionals must consult the attorney and seek his/her consent in the same way as they would with a patient who had the capacity to consent.

6.17 However, an LPA relating to personal welfare will not authorise an attorney to give or refuse consent to treatment in the following circumstances:

- An attorney has no power to consent to or refuse treatment at any time when the donor has the capacity to make his/her own treatment decisions (section 11(7)(a));
- An attorney has no power to consent to treatment specified by the donor in an advance decision refusing treatment which is valid and applicable in the particular circumstances (section 11(7)(b) - see also chapter 8);
  However, if after making the advance decision, the donor created an LPA conferring authority on the attorney to give or refuse consent to the treatment specified in the advance decision, this has the effect of making the advance decision invalid and the attorney's decision would then take precedence.
- An attorney has no power to consent to or refuse life-sustaining treatment, unless the LPA document expressly authorises this (section 11(8)).
  If the donor wishes to authorise his/her chosen attorney to make decisions about the carrying out or continuation of life-sustaining treatment in circumstances where the donor lacks capacity to make

such decisions, then the donor must include a clear statement to this effect in the LPA instrument.

6.18 When attorneys are involved in giving or refusing consent to medical treatment on behalf of the donor, they must always act in accordance with the Act's principles and any decisions they make must be in the donor's best interests. If a doctor disagrees with the attorney's assessment of best interests, the doctor should discuss the case with other medical experts and others and/or formally get a second opinion and discuss the matter further with the attorney. If the matter cannot be resolved in any other way and the case needs to go to court (see chapter 7), the doctor can provide life-sustaining treatment or treatment to prevent a serious deterioration in the person's condition whilst clarification is sought from the court.

6.19 It is also important to remember that, in the same way that a person with capacity cannot demand a particular treatment, LPAs cannot give attorneys the power to demand specific forms of medical treatments that doctors or other health professionals do not believe are clinically necessary or appropriate for the donor's care or treatment.

Mrs J has never trusted doctors and prefers to rely on alternative therapies and remedies. Having seen her father suffer for many years after invasive treatment for cancer, she is clear that she would wish to refuse such treatment for herself, even with the knowledge that she may die without it. When she is diagnosed with bowel cancer, Mrs J again discusses this issue with her husband. Mrs J trusts her husband more than anyone else and knows he will respect her wishes about the forms of treatment she would or would not accept. She therefore asks him to act as her attorney to make welfare and healthcare decisions on her behalf, should she lack the capacity to make her own decision at any time in the future. Mrs J makes a general personal welfare LPA appointing her husband to make all her welfare decisions, and includes a specific statement authorising him to refuse life-sustaining treatment on her behalf. He will then be able to make decisions about treatment in her best interests, taking into account what he knows about his wife's feelings as part of making the best interests determination.

(2) Property and affairs LPAs

6.20 An LPA for property and affairs enables an adult aged 18 or over, with capacity, to make an LPA appointing one or more attorneys to make decisions relating to the management of the donor's property and financial affairs on his/her behalf. The LPA may be used in respect of property and affairs decisions that the donor has the capacity to make personally if s/he so wishes, and will continue to have effect when the donor no longer has capacity to make some types of decisions. Alternatively, the donor can specify that the LPA can only be used after s/he lacks capacity. In either case, the LPA must be registered with the Public Guardian before it can be used.

6.21 If a donor states that the LPA can only be used when s/he lacks capacity, it will be the donor's responsibility to decide how this lack of capacity is to be verified. The donor may trust the attorney to make an assessment of the donor's capacity to make a particular decision if any doubt arises. Alternatively, the donor might say on the LPA that it can only be used when

his/her G.P. has confirmed, in writing, that the donor lacks capacity to manage certain aspects of his/her property and financial affairs.

6.22 The fact that someone has made a property and affairs LPA does not mean that they cannot continue to carry out financial transactions for themselves. The donor may have full capacity, but perhaps anticipates that s/he may lack capacity at some future time. Or s/he may have fluctuating or partial capacity and therefore be able to make some decisions (or at some times), but need an attorney to make others (or at other times). The attorney should allow and encourage the donor do as much as possible and only act when the donor needs or requests it. In cases where the donor has placed restrictions on what the attorney can do, banks may seek an indemnity from attorneys (i.e. a declaration signed by the attorney when an account is opened that indemnifies the bank against the attorney's misuse of the account).[30]

Mr Q has bipolar disorder. He has appointed his brother as financial attorney under an LPA to act for him when he lacks capacity, but he continues to act for himself when he has capacity to do so. He is unable to deal with more complex financial decisions such as investments but still wishes to retain control over day-to-day finance matters. Staff at Mr Q's bank can therefore deal with both with Mr Q and his brother in relation to Mr Q's finances.

6.23 As a particular safeguard, donors may also wish to nominate someone, (perhaps a family member or a professional) periodically to go through the accounts of their financial affairs with the attorney. This might help to reassure donors that a regular check will be kept on their financial affairs when they lack capacity to check for themselves. It may also be helpful for attorneys to have a regular check that everything is being done properly. Any such requirement must be included in the LPA instrument, which will be signed by both the donor and the attorney indicating agreement for this to take place.

6.24 Donors can authorise their attorney(s) to act in relation to all matters concerning their property and financial affairs or they can list specific matters where they wish the attorney(s) to have power to act. The types of decisions or actions financial attorneys could be authorised to take, and the powers an LPA would confer on them, might include any or all of the following:

- Buying or selling property (land, buildings or other assets);
- Opening, closing or operating any bank, building society or other account containing the donor's funds;
- Giving access to financial information to others concerning the donor;
- Claiming, receiving and using on the donor's behalf all benefits, pensions, allowances, rebates etc to which the donor may be entitled (unless someone else had already been appointed by the Department for Work and Pensions (DWP) to do this and everyone wanted that arrangement to continue);
- Receiving any income, inheritance or other entitlement on behalf of the donor;
- Dealing with the donor's tax affairs;
- Paying the donor's mortgage, rent and/or household expenses;

[30] See British Banking Association's guidance for bank staff on *'Banking for mentally incapacitated and learning disabled customers'*

- Making appropriate arrangements to insure, maintain and repair the donor's property;
- Investing the donor's savings in interest bearing accounts, bonds, stocks and shares or any other form of investment;
- Making gifts on the donor's behalf (but see paragraphs 6.26-6.28 below);
- Paying for private medical care and/or residential care or nursing home fees;
- Using the donor's income or capital to purchase a vehicle or any aids, adaptations or equipment required by the donor where these are not provided free of charge;
- Borrowing money on behalf of the donor and repaying interest and capital on any loan taken out by the donor or attorney on his/her behalf.

6.25 The above list gives examples of the types of powers that might be included in a property and affairs LPA and again, is not intended to be exhaustive. A general LPA in respect of property and financial affairs will authorise the attorney to undertake any or all of the acts set out above. The donor may wish to specify the types of powers s/he wishes the attorney to have, or to exclude particular types of decisions. In using any power under an LPA, an attorney must first be satisfied that the decision being made or the action taken will be in the donor's best interests.

Scope of financial LPAs: gifts

6.26 Section 12 of the Act imposes limitations on an attorney's power to make gifts from the property and estate of the donor. An attorney is only permitted to make gifts to people who are related to or connected with the donor (including the attorney him/herself) on "customary occasions" (section 12(2)(a)). These are defined as being the occasion or anniversary of a birth, marriage, civil partnership or any other occasion when presents are usually given among families, friends or associates (section 12(3)(b)), which might include for example gifts for Christmas, Diwali or other religious festivals that the person lacking capacity would be likely to celebrate, or the giving of house-warming presents.

6.27 If the donor had previously made regular or periodic donations to any charity, the attorney would also be permitted to continue to make such donations from the donor's funds (section 12(2)(b)). Moreover, the attorney may make donations if the donor could have been expected to make regular or periodic payments. However, the value of any gift or charitable donation must be reasonable in the particular circumstances and taking account of the size of the donor's estate. For example, it may not be reasonable to buy distant relations expensive gifts at Christmas if the donor was living on modest means and had to do without essential items in order to pay for them.

6.28 In addition to the above limitations, the donor may impose any other conditions or restrictions on the attorney's powers to make gifts, which must be specified in the LPA document at the time the LPA is created. The attorney should consider the donor's wishes and feelings and the factors that s/he would have taken into account, when deciding what would be appropriate gifts. If the attorney wishes to make other gifts that have not been provided for

either by the LPA instrument or provisions of the Act, s/he can apply to the court for authorisation.

Other restrictions on Lasting Powers of Attorney

6.29 Section 11 of the Act imposes certain restrictions on the powers of attorneys acting under either a personal welfare LPA or a property and affairs LPA. Particular restrictions apply to the use of restraint, similar to those that apply to anyone carrying out acts under section 5 in connection with the care or treatment of a person lacking capacity to consent. Attorneys should therefore also take account of the guidance on the use of restraint set out in chapter 5.

6.30 Section 11(1) provides that an LPA does not authorise the attorney to do anything that is intended to restrain the donor (i.e. to use, or threaten to use force in order to do something which the donor resists or to restrict the donor's liberty of movement, whether or not the donor resists) unless three conditions are satisfied. These are:

- That the attorney reasonably believes that the donor lacks capacity;
- The attorney reasonably believes that it is necessary to do the act in order to prevent harm to the donor; and
- That the act is a proportionate response to the likelihood and the seriousness of that harm.

6.31 Section 11(6) expressly confirms that an attorney will do more than "merely restrain" a person lacking capacity if s/he deprives that person of liberty within the meaning of Article 5(1) of the European Convention on Human Rights. Actions amounting to a deprivation of liberty will only be lawful if accompanied by further safeguards, such as those surrounding detention under the Mental Health Act 1983 (see chapter 12) or a court ruling. Further guidance on the distinction between restriction and deprivation of liberty is given in chapter 5.

Registering an LPA before use

6.32 An LPA must be registered with the Office of the Public Guardian before it can be used. An LPA instrument that has not been registered will not create a valid LPA and consequently will not give any powers to the attorney once the donor lacks capacity (sections 9(2)-(3)). If the LPA has not already been registered, for example on the application of the donor, the prospective attorney must ensure the proper procedures are followed to register it before attempting to exercise any powers under the LPA. If the LPA has been registered but not used for some time, the attorney is advised to inform the OPG when s/he begins to act under the LPA.

6.33 In addition there is an expectation that the attorney will inform the OPG of any permanent changes of address for himself and the donor as well as any change in circumstances. Examples include, the bankruptcy of an attorney of a financial LPA, or the dissolution or annulment of a marriage or civil partnership between the donor and the attorney. This will help to ensure that the details that the Public Guardian holds in the register of LPAs remain up-to-date.

Who can be an attorney?

6.34 Section 10 clarifies that attorneys of an LPA can be individuals who are at least 18 years of age. For property and affairs LPAs, the attorney could be either an individual (so long as s/he is not bankrupt at the time of appointment or at any time in the future), or a trust corporation (often parts of banks or other financial institutions). The bankruptcy of an individual, while preventing him/her acting as a property and affairs attorney, would not prevent him/her acting as attorney in relation to the donor's personal welfare.

6.35 The donor must appoint named individuals as attorneys rather than an office holder (such as the 'Director of Social Services' or the 'bank manager' of a certain branch of bank). While a person holding these offices can be appointed if that is the donor's choice, the office holder's name must be specified in the LPA instrument (see also paragraphs 6.48-6.49 concerning the limits on delegation by attorneys**).** A paid carer (such as a care home manager) should not usually agree to act as an attorney other than in exceptional circumstances (for example, if the carer is also the only close relative of the donor).

6.36 Section 10(4) also makes provision for two or more attorneys to be appointed and for the donor to specify whether they should act 'jointly' or 'jointly and severally'.

- Joint attorneys must always act together and the agreement of all attorneys must be obtained before a decision can be made or an act carried out;
- Joint and several attorneys can act together but may also act independently if they wish, so that any action taken by any attorney alone would be as valid as if s/he were the sole attorney.

6.37 The donor may want to appoint attorneys to act jointly in respect of some specified matters but jointly and severally in others. For example, a donor could choose to appoint two or more financial attorneys jointly and severally but specify that in respect of any sale of the donor's house, the attorneys would be required to act jointly. The donor may appoint welfare attorneys to act jointly and severally but specify that they must act jointly in relation to giving consent to surgery. If the donor does not specify whether the attorneys are to act jointly or jointly and severally, it will be assumed that they must always act jointly (section 10(5)).

6.38 In making an LPA, the donor may choose to name one or more persons to be appointed as replacement attorneys in certain circumstances, for example if an attorney is no longer willing or able to act or in the event of the attorney's death (section 10(8)). It is not possible for the donor to authorise the attorney(s) to appoint a substitute or successor.

Part 2: Duties and responsibilities of attorneys

6.39 When a donor chooses a particular person to appoint as attorney in a Lasting Power of Attorney, s/he does not have the right to insist that the attorney accepts the appointment. Once an attorney accepts the appointment and starts to act under an LPA, s/he will assume a number of duties and responsibilities and will be required to act in accordance with certain

standards. Failure to comply with the duties set out below could result in an application being made to the Court of Protection for the attorney to be removed, and in some circumstances the attorney could be personally liable to criminal charges of fraud or negligence.

Duties imposed by the Act

6.40 Some specific duties are imposed by the Act itself. Attorneys acting under an LPA have a duty:

- To act in accordance with the Act's principles;
- To act or make decisions in the donor's best interests;
- To have regard to the guidance in the Code of Practice;
- To act within the scope of their authority as attorney.

Principles and best interests

6.41 Section 9(4)(a) stipulates that the authority conferred by an LPA is subject to the provisions of the Act, and in particular, requires attorneys to act in accordance with the principles set out in section 1, and always to act in the best interests of the donor, as determined under section 4. These duties are discussed in paragraphs 6.10-6.11 above and further details are provided in other chapters of the Code of Practice (see below). In particular, it will be important to consider whether the donor has capacity, or will have capacity at some point in the future to make the decision in question and if so, whether the decision can be delayed until that time.

The Code of Practice

6.42 Section 42(4)(a) requires attorneys acting under an LPA to have regard to any relevant Code of Practice. Attorneys should have particular regard to the guidance in chapter 2 setting out how the principles should be applied, chapter 3 on the definition and assessment of capacity and chapter 4 on determining the donor's best interests in relation to any particular decision taken under the LPA. In addition, chapter 5 explains the circumstances in which attorneys who have caring responsibilities may have protection from liability for carrying out necessary acts in connection with the care or treatment of the donor, if those acts are not covered by the scope of the LPA. Chapter 5 also provides guidance on the limited circumstances when the use of restraint may be permitted for acts in connection with care and treatment.

Duty to act within the scope of the LPA

6.43 An attorney has a duty to act only within the scope of their authority as set out in the LPA. Thus a welfare attorney has no authority to act in relation to the donor's property and affairs, or vice versa (although the same person could be appointed in separate LPAs to carry out both these roles). The scope of the attorney's powers will be quite broad where the LPA is expressed in general terms, but where a donor has specified any conditions or restrictions in the LPA, the attorney may act only within the authority conferred by the LPA (section 9(4)(b)). If the attorney considers that additional powers are needed and the donor no longer has capacity to amend the LPA, an application may be made to the Court of Protection which could result in a single order or the appointment of a deputy (see chapter 7).

6.44 Although an attorney can only act within the scope of the LPA, the Act requires that anyone appointed as a person's attorney, (whenever appropriate and practicable to do so), to be consulted whenever a determination is being made about that person's best interests, whether or not the decision or act in question comes within the scope of the LPA. This is because an attorney is likely to have known the donor for sometime and may have important information about the donor's wishes and feelings etc. Attorneys may also be consulted when researchers are seeking views on the donor's participation in research (see chapter 10).

Duties of an attorney

6.45 An attorney of an LPA is acting as the chosen agent of the donor and therefore, under the law of agency, the attorney has certain obligations and duties towards the donor. The attorney owes a duty of care to the donor and to respect the degree of trust the donor has placed in the attorney.

6.46 When agreeing to act as attorney under a Lasting Power of Attorney, whether in relation to personal welfare or property and affairs, the attorney is taking on a role which carries a great deal of power which s/he must use carefully and responsibly. The standard of conduct expected of attorneys involves compliance with the following duties. Attorneys have a duty:

- Of care;
- To carry out instructions;
- Not to delegate unless authorised to do so;
- Not to benefit themselves but to benefit the donor;
- Of good faith;
- Of confidentiality;
- To comply with the directions of the Court of Protection;
- Not to disclaim without complying with the relevant Regulations.

And specifically in relation to property and affairs LPAs:

- To keep the donor's money and property separate from their own

These duties are described in more detail below.

Duty of care

6.47 An attorney owes a duty of care to the donor in carrying out his/her functions under the LPA. This means meeting a certain standard of due care and skill depending on whether the attorney is being paid for his/her services or holds relevant professional qualifications:

- Attorneys who are not being paid must act with due care, skill and diligence, as they would do in making their own decisions and conducting their own affairs. An attorney who claims to have particular skills or qualifications must show greater skill in those particular areas than someone who does not make such claims.
- If attorneys are being paid for their services, this is taken into account in determining the degree of care or skill expected for the proper

performance of their duties and will mean that a higher degree of care and skill is expected from them.

- Attorneys who undertake their duties in the course of their professional work (such as solicitors or accountants) must display professional competence and abide by their own profession's rules and standards.

Duty not to delegate

6.48 It is a basic principle of the law of agency that an agent cannot delegate his/her authority. Since an attorney is the chosen agent of the donor, s/he must carry out the functions under the LPA personally and cannot, as a general rule, delegate those functions to anyone else. The attorney may seek professional or expert advice (such as investment advice from a financial adviser, or advice on medical treatment from a doctor), but cannot transfer decision-making responsibility to someone else (for example, by appointing a discretionary investment manager to make investment decisions or delegating treatment decisions to healthcare professionals).

6.49 In certain circumstances, the law of agency allows attorneys limited implied powers to delegate, for example through necessity or unforeseen circumstances or for specific tasks, which the donor would not have expected the attorney to attend to personally. (For example, where a personal welfare attorney arranges for a paid carer to undertake administrative tasks such as the making of doctor's appointments). However as a general rule, an attorney cannot delegate any powers, which involve the exercise of discretion.

Duty not to benefit themselves but to benefit the donor

6.50 An attorney has a duty not to take advantage of his/her position. They have a fiduciary duty not to benefit themselves but to benefit the donor. Attorneys must try to avoid conflicts of interest between their responsibilities towards the donor and their own personal interests, and in particular must not profit or acquire any personal benefit from their position, whether or not at the donor's expense. They must constantly follow the principles of the Act, notably the requirement to act in the donor's best interests.

Duty of good faith

6.51 Attorneys must act in good faith when exercising their authority under an LPA. Acting in good faith means acting with honesty, integrity and due diligence. For example, an attorney must try to ensure his/her actions do not negate previous decisions made by the donor while still competent (unless it would be in the donor's best interests to do so).

Duty of confidentiality

6.52 Attorneys have a duty to keep the donor's affairs confidential, unless the donor has consented to disclosure of personal or financial information, or unless there is some other good reason to release it, such the donor's best interests or in cases where the public interest may override the duty of confidentiality. The considerations raised by this duty are discussed in more detail in chapter 15.

Duty to comply with the directions of the Court of Protection

6.53 Under sections 22 and 23 of the Act, the Court of Protection has wide powers to determine any question as to the meaning or effect of an LPA. The court may also give specific directions to extend the powers available to attorneys under an LPA, or to require attorneys to keep records (such as financial accounts) or provide specific information or documentation to the court. Attorneys have a duty to comply with any direction given by the court.

Duty not to disclaim without notifying the donor and the court

6.54 While there is no duty on attorneys to accept the appointment, once they have started to exercise their functions as attorneys under an LPA, they cannot give up that role without first notifying the donor and the Office of the Public Guardian. If an attorney wishes to disclaim his/her appointment, the disclaimer must be in accordance with certain requirements prescribed in Regulations.[31]

Duty to keep the donor's money and property separate

6.55 Property and affairs attorneys should, in general, keep the donor's money and property separate from their own or anyone else's. There may be occasions, for example where a husband is acting as his wife's attorney or vice versa, where a prior arrangement was made to keep their money in a joint bank account and it may be appropriate for this to continue under the LPA. But in most circumstances, attorneys must keep finances separate to avoid any possibility of mistakes or confusion in handling the donor's affairs.

Information on keeping accounts

6.56 If the Court of Protection requires it, an attorney appointed under a property and affairs LPA is expected to keep, and be constantly ready to produce, correct accounts of all his/her dealings and transactions on the donor's behalf. Where a lay person, such as a family member, is acting as attorney, and the donor's affairs are relatively straightforward, all that may be required is a record of the donor's income, any major or regular expenditure and details of the donor's bank accounts. The more complicated the donor's affairs, the more detailed the accounts may need to be. As indicated above, the Court of Protection can give directions requiring the submitting of accounts and the production of records kept by the attorney.

6.57 When making an LPA, donors may decide to nominate someone (perhaps a family member or a professional), periodically to go through the accounts with the attorney (see paragraph 6.23 above). This may be a sensible safeguard against possible abuse (see below). Any such requirement must be included in the LPA document, which will be signed by both the donor and the attorney indicating agreement for this to take place.

[31] A reference to these Regulations will be included once known

Protection against abuse

6.58 Because attorneys are in a position of trust there is always the potential for abuse to take place. The main protection from abuse is for the donor to choose carefully in selecting a suitable attorney. But others have a role to play in looking out for possible signs of abuse or exploitation and reporting any concerns to the Office of the Public Guardian, who will then follow this up in co-operation with relevant agencies.

6.59 There are some signs that are sufficient to raise concerns that an attorney may be exploiting the donor or failing to act in the donor's best interests, for example:

- The denial of relatives or friends of access to the donor – either active denial by the attorney or where the donor suddenly refuses visits or telephone calls from family members or longstanding friends for no apparent reason;
- Sudden unexplained changes in living arrangements, such as where someone moves in to care for the donor with whom they have had little previous contact;
- The denial of access to a medical practitioner or care worker to see the donor;
- Unpaid bills, such as arrears of residential care or nursing home fees;
- The opening of credit card accounts for the donor by the attorney;
- Expenditure that is not obviously related to the donor's needs;
- Unusual or extravagant expenditure by the attorney;
- The transfer of assets to another country.

6.60 Any concerns or suspicions of abuse should be raised immediately with the OPG, which has specific responsibilities in respect of attorneys of LPAs (section 58). The OPG may direct a Court of Protection Visitor to visit an attorney to investigate any matter of concern. The OPG will be able to investigate any concerns or complaints against attorneys but in cases where physical abuse, theft or serious fraud is suspected, the matter should also be referred directly to the police.

6.61 In serious cases, the OPG will refer the matter for consideration by the Court of Protection. The court may revoke an LPA (or direct the Public Guardian that an instrument purporting to be an LPA not be registered), if as a result of proceedings before it, the court decides:

- That a requirement for creating the LPA was not met;
- That the LPA has been revoked or otherwise come to an end;
- That the LPA was created as a result of fraud or undue pressure;
- That the attorney has behaved, is behaving or proposes to behave, in a way that contravenes his/her authority or is not in the donor's best interests.

The court might then to consider whether the authority previously given to an attorney can be managed by making a single order or by appointing a deputy.

6.62 The protection of vulnerable people from the risk of abuse, ill treatment or neglect and the duties and responsibilities of the various agencies involved,

including the OPG and local authorities, are discussed in more detail in chapter 13. In particular under the Act, it is a criminal offence for an attorney (amongst others) to wilfully neglect or ill-treat a person who lacks capacity. Anyone found guilty of the offence is liable on summary conviction to a maximum prison sentence of 5 years or a fine or both.

Part 3: Arrangements for existing Enduring Powers of Attorney

6.63 The scheme for LPAs described in this chapter is designed to replace Enduring Powers of Attorney (EPAs) since the Act repeals the Enduring Powers of Attorney Act 1985. It will no longer be possible to execute an EPA once the Act is in force. However, many EPAs will have been created before the Act came into force, with the expectation that attorneys appointed by them will have authority to manage the donor's property and financial affairs when the donor lacks capacity.

6.64 Many donors of EPAs who still have capacity when the Act comes into effect may prefer to destroy the EPA and make an LPA under the new statutory provisions, as described above. Some donors will lack capacity to make an LPA and others will omit, or choose not, to do so. The Act therefore makes transitional provisions for existing EPAs, whether registered or not, to continue to be valid so that the donors' expectations in making them can continue to be met.

Enduring Powers of Attorney

6.65 Schedule 4 reproduces the Enduring Powers of Attorney Act 1985 in its entirety with some minor amendments to take account of changes to the Court of Protection and the new role of the Public Guardian. The provisions are not described in detail here, since they are covered in guidance on EPAs issued by the OPG (see Annex for details of publications and contact information). However, an attorney under an EPA can also be found liable under Section 44, which sets out a new criminal offence of ill treatment and neglect.

Chapter 7 - The Court of Protection and deputies

Introduction

7.1 This chapter gives guidance to professionals about the role of the court, with particular detail about deputies appointed by the court. Official guidance and information for deputies will be issued by the Public Guardian and provided in Regulations made by the Lord Chancellor, as well as Rules of Court and Practice Notes given by the court.

7.2 **Part 1** explains the powers of the court and describes the circumstances where it may be necessary to apply to the court, as well as broadly outlining how to make an application. **Part 2** looks in more detail at the appointment of deputies to act and make decisions on behalf of people lacking capacity. **Part 3** sets out the duties and responsibilities for deputies and describes the standards of conduct expected together with the actions that can be taken against a deputy who fails to meet appropriate standards.

Part 1: The Court of Protection

7.3 Section 45 of the Act establishes a specialist court, known as the Court of Protection, with a new jurisdiction to deal with decision-making for adults who lack capacity. The new court takes over the role and functions of the former Court of Protection in relation to the management of property and financial affairs of people lacking capacity. It also deals with serious decisions affecting healthcare and personal welfare matters that were previously dealt with by the High Court under its inherent jurisdiction.

7.4 The new Court of Protection is a superior court of record able to establish precedent and build up a body of case law and expertise in all matters affecting people who lack capacity. It has the same powers, rights, privileges and authority as the High Court. The Public Guardian supports the court in its role. When reaching any decision the court must apply all the principles set out in section 1 of the Act and in particular must decide the matter before it in the best interests of the person lacking capacity. Applications to the court will be subject to a fee, although the amount has yet to be determined.

7.5 It is expected that, in the vast majority of cases, the structures for decision-making or acting in connection with the care or treatment of a person lacking capacity, as set out in Part 1 of the Act, will enable appropriate decisions to be made or any concerns or disputes to be resolved. The Court of Protection provides a judicial forum to deal with particularly complex decisions or difficult disputes (see chapter 14).

When should an application be made to the Court of Protection?

7.6 The Court of Protection will have comprehensive jurisdiction in relation to welfare (including healthcare) and financial matters. It is anticipated that it will be specified in which circumstances cases should be referred to the court, the types of cases which are likely to require a hearing and those which may be resolved without recourse to the court.

16 and 17 year olds and courts dealing with Family Proceedings

7.7 A case relating to a 16 or 17 year old who lacks capacity could be heard either in a court dealing with family proceedings or in the Court of Protection. Under section 21, the new Court of Protection will have power in certain circumstances to transfer cases concerning children to a court that has jurisdiction under the Children Act 1989. Moreover, a case started in a court having jurisdiction under the Children Act 1989, in which the main relief claims relates to a time after adulthood, can be transferred to the Court of Protection. Further details of such cases are provided in chapter 11. The intention behind this is to ensure that cases involving vulnerable 16 and 17 year olds are approached in the most appropriate way possible.

Who should make the application?

The following information will be subject to the provisions of the Court of Protection Rules to be consulted upon separately. The outcome of the consultation will be used to update the information accordingly.

7.8 The Act makes flexible provision as to who can make an application to the court, since this will depend on the type and circumstances of the case under consideration. For example, in relation to disputes between family members, it will be a decision for the aggrieved family member as to whether court action is warranted, bearing in mind the need in most cases to obtain permission beforehand (see below).

7.9 Where the dispute relates to the provision of medical treatment, and where local complaints procedures, dispute resolution or mediation systems have been unable to find a solution, the NHS Trust or other body responsible for the patient's care will in most cases make the application to the court. A local authority wishing to intervene in decisions affecting the personal welfare of a person lacking capacity should make the application. Regardless of who makes the application, the person lacking capacity in relation to the matter in question should in most cases be a party to the proceedings, unless the court decides that this is either unnecessary or inappropriate. The court may appoint the Official Solicitor to act for the person lacking capacity.

Permission to apply to the Court of Protection

The following information will be subject to the provisions of the Court of Protection Rules to be consulted upon separately. The outcome of the consultation will be used to update the information accordingly.

7.10 Section 50 of the Act sets out specific requirements relating to applications to the Court of Protection. As a general rule, the court's permission must first be sought before an application can be made. Some categories of people can apply as of right without the need to obtain permission from the court. These include:

- A person who lacks, or who is alleged to lack, capacity (or anyone with parental responsibility if the person is under 18 years);
- The donor of, or attorney appointed under, a Lasting Power of Attorney to which the application relates;
- A court-appointed deputy acting for the person concerned;

- A person named in an existing court order to which the application relates.

7.11 In all other cases, (subject to the finalisation of the Court of Protection Rules and paragraph 20(2) of Schedule 3 (declarations relating to private international law)), permission will be required before an application can be made to the court. In deciding whether to grant permission, the court must take account of a number of factors designed to ensure that any application will promote the interests of the person lacking capacity (or alleged to lack capacity) who is the subject of the proceedings (section 50(3)). In particular, the court must consider:

- The applicant's connection with the person lacking capacity to whom the application relates;
- The reasons for the application;
- The benefit to the person lacking capacity to whom the application relates of any proposed order or direction of the court; and
- Whether that benefit can be achieved in any other way.

A charity providing outdoor adventure holidays for adults with learning disabilities wishes to take a young man on a mountaineering holiday but his mother objects, as she thinks it would be too dangerous. Local authority care workers wish to support this opportunity for the young man's personal development and consider seeking permission to apply to the Court of Protection on his behalf. However, after discussing the situation with the young man's parents, the local authority care workers decide that a resolution can instead be reached via negotiation, which would benefit all parties.

Powers of the Court of Protection

7.12 The Court of Protection has wide ranging powers to make declarations, decisions and orders affecting people who lack, or are alleged to lack, capacity. It may also appoint deputies to act and make decisions on behalf of people lacking capacity, and has the power to remove deputies or attorneys acting under a Lasting Power of Attorney (LPA) who act improperly. The various powers are briefly described in the following paragraphs, covering:

- Power to make declarations (section 15);
- Power to make decisions and appoint deputies (section 16);
- Powers in relation to Lasting Powers of Attorney (sections 22-23).

Power to make declarations

7.13 In some cases, it may be helpful to ask the court to make a ruling on whether or not a person has capacity to make a particular decision or in relation to the particular matter under consideration. In order to make such a ruling, the court will require specific evidence of capacity, or lack of capacity over the matter in question. Where the court decides that the person has capacity to make the relevant decision(s), the court has no further role in the matter since the person has the right to decide for him/herself.

7.14 There will be relatively few circumstances where there will be a need to apply to the court asking for a declaration as to capacity. Often these questions can

be resolved informally (see chapters 3 and 14). However, recourse to the court may be appropriate in the following circumstances:

- Where there is a dispute between professionals over a person's capacity to make a particular (invariably serious) decision. For example, where professionals disagree as to whether a person with learning disabilities has the capacity to refuse consent to major heart surgery;
- Where there is a more wide-ranging dispute; for example, between family members over whether an elderly member of the family has the capacity to make an LPA.

7.15 In addition to establishing whether or not someone has capacity, the court may also make declarations as to:

- Whether an act done, in relation to a person lacking capacity was lawful, (for example by a carer acting without formal powers), or whether a proposed act would be lawful.

7.16 This ability to make declarations as to the lawfulness of an act particularly concerns major medical treatment cases, where there is doubt or disagreement. The Act provides for life-sustaining treatment or other actions to be taken to prevent the serious deterioration of a person's condition pending a court decision.

Serious healthcare and treatment decisions

7.17 Before the Act came into force, the courts decided that some decisions relating to the provision of medical treatment were so serious that in each case, an application should be made to the court for a declaration that the proposed action was lawful before that action was taken. It is anticipated that the following cases should continue to be brought before a court namely:

- The proposed withholding or withdrawal of artificial nutrition and hydration (ANH) from patients in a permanent vegetative state (PVS);
- Cases involving organ or bone marrow donation by a person lacking capacity to consent;
- The proposed non-therapeutic sterilisation of a person lacking capacity to consent to this (e.g. for contraceptive purposes);
- Some termination of pregnancy cases; and
- Other cases where there is a doubt or dispute about whether a particular treatment will be in a person's best interests.

7.18 The case law requirement to seek a declaration in cases involving the withholding or withdrawing of artificial nutrition and hydration to people in a permanent vegetative state (PVS) is unaffected by the Act[32] and as a matter of practice cases should be put to the Court of Protection for approval.

7.19 Other cases that should be referred to the court involve organ or bone marrow donation by a person lacking capacity to consent. Such cases

[32] *Airedale NHS Trust v Bland* [1993] AC 789

involve medical procedures being performed on a person lacking capacity which would benefit a third party but would not necessarily be in the medical best interests of the person lacking capacity. However, sometimes such procedures will be in the person's overall best interests (see chapter 4). In such situations the person might receive emotional, social and psychological benefits as a result of the benefit provided to the third party but would not necessarily receive physical benefits (and in some cases the person may experience only minimal physical detriment).

7.20 A prime example of this is the case of *Re Y*[33] where it was found to be in Y's best interests for her to donate bone marrow to her sister. The court decided that it was in Y's best interests to continue to receive strong emotional support from her mother, which might be diminished if her sister's health were to deteriorate further, or she were to die. Further details on this area are available in Department of Health guidance[34].

7.21 Non-therapeutic sterilisation is the sterilisation for contraceptive purposes of a person who cannot consent. Such cases will require a careful assessment of whether such sterilisation would be in the best interests of the person who lacks capacity and such cases should also continue to be referred to the court[35]. Moreover the court has given guidelines on when certain termination of pregnancy cases should be brought before the court. [36]

7.22 Other cases likely to be referred to the court include those involving ethical dilemmas in untested areas, or where there are otherwise irresolvable conflicts between professionals, or between professionals and family members.

7.23 There are also a few types of cases that should generally be dealt with by the court, (see chapter 14). For example, where it is unclear whether proposed serious and/or invasive medical treatment is likely to be in the best interests of the person lacking capacity to consent.

Powers to make decisions and appoint deputies

7.24 In cases of serious dispute, where there is no other way of finding a solution or when the authority of the court is needed in order to make a particular decision or take a particular action, it may be appropriate to ask the court to make a decision on the matter in question, using its powers under section 16. The court has the power to make a single order to settle the matter. However, if there is a need for on-going decision-making powers and the person lacking capacity has not previously made an LPA authorising an attorney to make such decisions, the court may appoint a deputy to make those decisions on the person's behalf. The court's powers concerning the appointment and role of deputies are described in Part 3 of this chapter.

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33 *Re Y (Mental incapacity: Bone marrow transplant)* [1996] 2 FLR 787

34 Reference Guide to Consent for Examination or Treatment, Department of Health, March 2001 http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4006757&chk=snmdw8

35 See e.g. *Re A (medical treatment: male sterilisation)* (1999) 53 BMLR 66 where a mother applied for a declaration that a vasectomy was in the best interests of A, her son, (who had Down's syndrome and was borderline between significant and severe impairment of intelligence), in the absence of his consent. After balancing the burdens and benefits of the proposed vasectomy to A, the Court of Appeal held that the vasectomy would not be in A's best interests.

36 *D v An NHS Trust (Medical Treatment: Consent: Termination)* [2004] 1 FLR 1110

7.25 In deciding what type of order to make, the court must apply the Act's principles and the best interests checklist. In addition, section 16(4) requires the court to have regard to two further principles intended to make any intervention as limited as possible:

- First, where possible a single court order should be made in preference to the appointment of a deputy (see below);
- Secondly, if a deputy needs to be appointed, his/her appointment should be as limited in scope and duration as possible.

Single orders of the court

7.26 There are a few types of cases where the court must deal with the application, as authority to act cannot be given via another route. These include:

- Where formal authority is needed to deal with one-off significant financial decisions for a person lacking capacity to manage financial affairs, (such as paying a costly bill for house repairs or selling a valuable item of property), but where there is no need for on-going financial powers, the court could be asked to make an order providing the necessary authority;
- Where it is necessary to make a will, or amend an existing will, on behalf of a person lacking testamentary capacity.

7.27 Examples of other types of cases where the court may decide that a single order of declaration would be appropriate are as follows:

- When there is genuine doubt or disagreement about the existence, validity or applicability of an advance decision to refuse treatment (see chapter 8);
- Where there is a major dispute regarding a serious decision for example, about where a person lacking capacity should live;
- Where it is suspected that a person lacking capacity is at risk of harm or abuse from a named individual, the court could be asked to make an order prohibiting that individual from having contact with the person who lacks capacity;
-

The son and daughter of a woman with Alzheimer's disease, who live some distance apart, argue over which care home their mother should move to. Although she lacks the capacity to make this decision herself, she has enough money to pay the fees of a care home. Her solicitor acts as attorney in relation to her financial affairs under a registered Enduring Power of Attorney, but has no power, and is unwilling, to get involved in this family dispute, which is becoming increasingly bitter. The Court of Protection makes a single order in the mother's best interests, having taken account of her relationship with her children and decides which care home can best meet her needs. Once this matter is resolved, there is no need to appoint a deputy.

Powers in relation to Lasting Powers of Attorney

7.28 As described in chapter 6, the Court of Protection has a range of powers to determine the validity of an LPA and to give directions as to how the LPA should be operated (if, for example, the attorney was not acting in the best interests of the person who lacks capacity). In particular, where the donor no longer has capacity, the court has power to revoke an LPA with the effect of terminating the attorney's appointment if for example, the attorney was not carrying out his/her duties in the best interests of the donor.

7.29 For example, where there are concerns about the validity of the LPA, the court may be asked to:

- Decide whether the requirements for making an LPA have been met;
- Decide whether the LPA has been revoked or otherwise come to an end.

7.30 The court also has power to direct that an LPA should not be registered, or if it has already been registered, that an LPA should be revoked in circumstances where:

- The LPA was made as a result of undue pressure or fraud;
- The attorney has behaved, is behaving or proposes to behave, in a way that contravenes his/her authority or is not in the donor's best interests.

7.31 If someone feels that the drafting of an LPA is not entirely clear, the court can be asked to clarify the meaning or effect of the LPA. It may give specific directions to attorneys as to how an LPA should be operated. If an attorney considers that the powers available under the LPA are insufficient, s/he may apply to the court for an extension of powers where the donor no longer has capacity to grant authority for such an extension. In particular, the court may authorise the making of gifts of the donor's property which attorneys are not otherwise permitted to make under section 12(2) (see chapter 6).

7.32 All attorneys should keep records of their dealings with the donor's affairs. The court has the power to require attorneys to produce records (such as financial accounts) and to provide specific reports, information or documentation as directed by the court. If concerns are raised about any remuneration or expenses claimed by attorneys in carrying out their duties, the court could give directions to resolve the matter.

Part 2: Deputies appointed by the Court of Protection

7.33 Where the court believes that there is a need for on-going decision-making powers for a person lacking capacity, it may under section 16(2) appoint a deputy to act for and make such decisions on behalf of the person. Section 16(4)(b) also requires the court to have regard to the principle that the powers conferred on a deputy should be as limited in scope and duration as is reasonably practicable in the circumstances (see below).

Appointment of deputies

7.34 It is for the court to decide who to appoint as a deputy. The court will consider whether the proposed deputy is reliable and trustworthy and has an appropriate level of skill and competence to carry out the necessary tasks. Different skills may be required according to whether the deputy is appointed to make welfare (including healthcare) decisions or financial decisions or both.

When might a deputy need to be appointed?

7.35 When deciding what order is in the best interests of the person lacking capacity, the court must first consider the principle that a single decision on the matter in question is to be preferred to the appointment of a deputy (see paragraph 7.26 above). The need for a deputy to be appointed will vary according to the individual circumstances of the person lacking capacity, whether future or on-going decisions are likely to be necessary and whether the appointment relates to property and affairs or personal welfare matters.

Property and affairs

7.36 The appointment of a deputy to manage the person's property and financial affairs is likely to be needed in similar circumstances to those that previously governed the appointment of a receiver under Part VII of the Mental Health Act 1983 (which this Act repeals). There may be a need to apply to the court for an order making arrangements to deal with the person's property and affairs when:

- More than a specified amount of cash assets remain to be dealt with after any debts have been paid; or
- There is property to be sold; or
- The person has a level of income or capital that the court considers requires to be managed by a deputy.

7.37 A deputy may be appointed in a situation where there is already a benefits appointee in existence (i.e. an individual who has been appointed under social security legislation to receive and deal with benefits on behalf of a person who lacks capacity to do this himself or herself). The deputy may be the same person as the benefits appointee or someone else. Although the appointeeship scheme remains completely outside the legal framework created by the Act, the deputy would be expected to act in close conjunction with the appointee regarding actions taken on behalf of the person lacking capacity.

7.38 When making an application to the court, the proposed deputy will need to sign a declaration giving details of his/her own personal circumstances and ability to manage financial affairs. The declaration will include details of the tasks and duties the deputy will be required to carry out, and the deputy is required to give a personal undertaking that s/he has the skills, knowledge and time to perform and complete each task and to carry out his/her duties as deputy.

Personal welfare (including healthcare)

7.39 It is expected that the appointment of a deputy to make personal welfare or healthcare decisions is likely to be needed only in the most difficult cases, when necessary action cannot be taken without formal powers and/or there is no other way of making a decision that is in the best interests of the person lacking capacity. As noted above, where possible, the court will seek to make a single order. Examples of circumstances which may require the appointment of a personal welfare deputy for a person lacking capacity are as follows:

- Where there is a history of acrimonious and serious family disputes which could have a detrimental effect on decisions about the person's future care;
- Where the person's best interests are best met by a deputy consulting with everyone concerned and having the final authority to make the necessary decisions;
- In exceptional cases where the person is felt to be at risk of serious harm if left in the care of family members, a local authority officer or other independent person could be appointed as deputy to make personal care decisions – this could, for example, be combined with a court order prohibiting those family members from having contact with the person;
- When a series of linked welfare decisions need to be made over time, for which single orders of the court are not appropriate - in such circumstances, it may be appropriate for a person (such as a family carer) who is close to someone with, for example, profound and multiple learning disabilities to apply for an order with a view to being appointed as a deputy with powers to make the required decisions which the individual concerned lacks the capacity to make.

Having spent most of her childhood in care, a young woman with learning disabilities, lacks the capacity to decide where she should live and goes to live with her father when she becomes 18. Staff at the day centre she attends notice that she is becoming increasingly disturbed and often has bruises on her arms and legs. They arrange for her to be seen by a doctor who finds signs of physical and sexual abuse. The father denies this and criminal proceedings against him fail for lack of evidence. The local authority social services try to persuade him that a move to independent supported housing would be in his daughter's best interests, but he objects. The authority therefore applies to the court for a deputy to be appointed to make decisions about the woman's future care and welfare. The court is likely to make a range of orders including declarations that it is lawful for the local authority to remove and house the young woman in supported accommodation, together with an order regulating contact with the father.

Who can be a deputy?

7.40 Section 19(1) clarifies that deputies appointed by the court must be individuals who are at least 18 years of age. Where appointed to make decisions in relation to property and affairs, the deputy can be either an individual or a trust corporation (often parts of banks or other financial institutions). No one can be appointed as a deputy without his/her consent.

7.41 Paid carers should not usually be appointed as deputies because of the possible conflict of interest. However, it is possible for the court to appoint as deputy someone who holds a specified office or position, such as a Director of Social Services.

7.42 Section 19(4) also makes provision for two or more deputies to be appointed and for the court to specify whether they should act 'jointly' or 'jointly and severally'.

- Joint deputies must always act together and the agreement (and in some circumstances, the signature) of all deputies must be obtained before a decision can be made or an act carried out;
- Joint and several deputies can act together but may also act independently if they wish, so that any action taken by any deputy alone would be as valid as if s/he were the sole deputy.

7.43 Deputies may be appointed jointly in respect of some matters and jointly and severally for others. For example, two deputies could be appointed jointly and severally but the order appointing them could specify that in respect of any sale of the house of the person lacking capacity, the deputies would be required to act jointly.

A young woman receives a significant award of damages following an accident at work, which resulted in serious brain damage and other disabilities. Her parents have recently divorced and are arguing about how the money should be used and where their daughter should live. She has always been close to her sister, who is keen to be involved but is anxious about dealing with such a large amount of money. The court decides to appoint the sister and a solicitor as joint and several deputies to decide where the young woman will live and how to manage her property and affairs.

Successor deputies

7.44 When appointing a deputy or deputies, the court will also have the power to appoint a successor or successors to the original deputy(s). The court will specify the circumstances under which this could occur and in some cases, the period, when the substitute deputy may be appointed to act. This arrangement may be particularly helpful when the best candidate for appointment is already elderly and wishes to be sure that someone else can take over their role as deputy in the future.

A man with Down's syndrome inherits a substantial amount of money and property from his grandfather. His parents were already retired when they were appointed as deputies to manage his property and affairs. They have always been worried about what will happen to their son when they are no longer able to cope with their responsibilities as deputies. The court agrees that other specified relatives should be appointed to act as successors to the deputyship and take over following the parents' death or when they are no longer able to carry out their responsibilities as deputies.

Powers of court-appointed deputies

7.45 The court will decide the extent of powers it wishes to confer on a deputy and the order of appointment will specify the particular decisions or actions the deputy is authorised to take, the powers available to him/her as deputy and the duration of the appointment.

Restrictions on deputies

7.46 Section 20 sets out some specific restrictions and limitations on deputies' powers. In particular, a deputy has no authority to make decisions in the following circumstances:

- Where the deputy does an act that is intended to restrain the person concerned except if certain conditions are satisfied - the restrictions on the use of restraint are similar to those in section 6 in relation to acts in connection with care or treatment, (further guidance is given in chapter 5):

- If the deputy knows or has reason to believe that the person concerned has capacity to make the decision(s) or do the act in question;
- Where the deputy's decisions are inconsistent with a decision made by the attorney acting under a Lasting Power of Attorney granted by the person before s/he lost capacity;
- A deputy cannot refuse consent to the carrying out or continuation of life-sustaining treatment for a person lacking capacity.

In relation to the first bullet point in the list above, the word "or" in section 20(11)(a) is a drafting error. It should have been "and" in order to be consistent with sections 6(3)(a) and 11(4)(a). The government will make the necessary amendment to correct this error at the earliest available legislative opportunity.

7.47 If a deputy considers that the powers conferred on him/her are insufficient for carrying out necessary duties towards the person lacking capacity, the deputy must apply to the court either to make the decision in question or for a variation of powers in his/her order of appointment.

Requirement to give security

7.48 Under section 19(9)(a), the court may require a deputy to give to the Public Guardian whatever type of security the court considers appropriate. For example, deputies appointed to deal with property and affairs may be required to purchase insurance such as a guarantee bond, to cover any loss to the person lacking capacity as a result of the deputy's misbehaviour in his/her role. Under section 19(9)(b) the court may also require a deputy to submit to the Public Guardian reports and accounts as it sees fit.

Part 3: Duties and responsibilities of deputies

7.49 Once the deputy's powers have been set out by a court order, the deputy will assume a number of duties and responsibilities and will be required to act in accordance with certain standards. Failure to comply with the duties set out below could result in the Court of Protection revoking the order appointing the deputy and, in some circumstances, the deputy could be personally liable to claims for negligence or criminal charges of fraud.

7.50 In order to make their position clear at the outset, deputies should always notify any third party with whom they are dealing that they have been appointed by the Court of Protection to act as deputy on behalf of the person lacking capacity.

Duty to act

7.51 An order appointing a deputy imposes on the deputy a duty to act where necessary, and to take decisions on behalf of the person lacking capacity, as required under the order. A deputy who fails to act at all when a decision is called for which falls within the scope of his/her authority, could be in breach of duty.

Duty to apply the Act's principles

7.52 Deputies must apply the Act's principles set out in section 1 in making a decision on behalf of the donor, and in particular must act in the best interests of the donor. This requirement applies equally to court-appointed deputies as to any other decision-maker under the Act.

Duty to have regard to the Code of Practice

7.53 Section 42(4)(b) requires deputies to have regard to any relevant Code of Practice. Deputies must therefore in particular take into account the guidance in chapter 2 of the Code setting out how the principles should be applied, chapter 3 on the definition and assessment of capacity and chapter 4 on determining the person's best interests in relation to any particular decision. In addition, chapter 5 explains the circumstances in which deputies who have caring responsibilities may have protection from liability for carrying out necessary acts in connection with the care or treatment of a person lacking capacity, if those acts are not covered by the scope of their appointment. Chapter 5 also provides guidance on the limited circumstances when the use of restraint may be permitted.

Duties as an agent and statutory requirements

7.54 Section 19(6) clarifies that a deputy is to be treated as the agent of the person lacking capacity in relation to anything done or decided by him/her within the scope of his/her appointment. Under the law of agency, the deputy has

certain obligations and a range of duties to his/her principal (the person lacking capacity).

7.55 When agreeing to act as deputy whether in relation to welfare or financial affairs, the deputy is taking on a role which carries power that s/he must use carefully and responsibly. The standard of conduct expected of deputies involves compliance with the following duties as an agent and statutory requirements:

- Duty to act within the scope of his/her authority;
- Duty to act with due care and skill;
- Duty to carry out his/her instructions;
- Duty to discharge a fiduciary duty;
- Duty to indemnify the principal (i.e. the person lacking capacity) against liability to third parties by reason of the agent's (i.e. the deputy's) negligence;
- Duty not to delegate unless authorised to do so;
- Duty of good faith;
- Duty of confidentiality;
- Duty to comply with the directions of the Court of Protection.

And specifically in relation to property and affairs:

- Duty to keep accounts;
- Duty to keep the person's money and property separate from own finances.

These duties are described in more detail in the following paragraphs.

Duty to act within the scope of the authority granted by the court

7.56 A deputy has a duty to act only within the scope of the actual powers conferred by the court and set out in the order of appointment. The terms of appointment may impose duties upon deputies such as requiring them to keep accounts. If the deputy considers that additional powers are needed, an application must be made to the Court of Protection for the scope of the order to be varied.

Duty to act with due care and skill

7.57 A deputy owes a duty to act with due care and skill to the person lacking capacity in carrying out his/her functions as deputy. However, deputies may have different obligations depending on whether they are undertaking the role in a paid capacity or as a professional.

- Deputies who are not holding themselves out as being skilled and are not being paid must act with due care, skill and diligence, as they would do in making their own decisions and conducting their own affairs. However it should be noted that even a deputy who is not being paid may be liable in tort for acting negligently. A deputy who holds him/herself out as having particular skills must show they have greater skills than a person who does not;
- If deputies are being paid for their services, this is taken into account in determining the degree of care or skill expected for the proper performance of their duties;

- Deputies who undertake their duties in the course of their professional work (such as solicitors or accountants) must display normal professional competence and abide by their own professional rules and standards.

Duty to discharge a fiduciary duty

7.58 In discharging a fiduciary duty to the person who lacks capacity, the deputy should ensure that they do not put themselves in a position where their personal interests and duty as an agent conflict. For example, deputies should not buy property for themselves that they are employed to sell for a person who lacks capacity. They should also not accept a third party commission in any transactions.

7.59 Moreover, a deputy has a duty not to take advantage of his/her position. Deputies must avoid any conflicts of interest between their responsibilities towards the person lacking capacity and their own personal interests. They must not allow any other influences to affect the way in which they exercise the powers conferred by the court. In particular, deputies cannot use their position to acquire any personal benefit, whether or not at the person's expense.

7.60 In many cases it will be family members who are the most appropriate people to act as deputies, but this may lead to potential conflicts of interests e.g. where the deputy is also a beneficiary of the will. In reaching any decision, all deputies should follow the principles of the Act and the best interests checklist. In this way they will ensure that the decisions they reach are in the best interests of the person who lacks capacity.

7.61 If the court decides to appoint the Director of Social Services as a deputy, arrangements must be put in place to avoid possible conflicts of interest, for example where the person lacking capacity receives community care services from the local authority and decisions about the person's finances or welfare may have implications for the services provided.

Duty not to delegate

7.62 It is a basic principle of the law of agency that in general an agent cannot delegate his/her authority unless the delegation is permitted by the express authority of the principal or statutory authority. Since a deputy is the agent appointed by the court to undertake specific functions on behalf of the person lacking capacity, s/he must generally carry out those functions personally and cannot, as a general rule, delegate those functions to anyone else. In certain circumstances, the court will authorise the delegation of specific matters, for example where professional assistance is needed for conduct of investment business. However, deputies cannot transfer all decision-making responsibilities to someone else (for example, a welfare deputy appointed to make healthcare decisions including giving consent to treatment cannot routinely delegate all treatment decisions to healthcare professionals).

7.63 In certain circumstances, the law of agency allows deputies limited implied powers to delegate, for example through necessity or unforeseen circumstances, or for specific tasks which the court would not have expected the deputy to attend to personally. For example, where a personal welfare

deputy arranges for a paid carer to provide home-care services for the person lacking capacity. However as a general rule, a deputy cannot delegate any powers which involve the exercise of discretion.

Duty of good faith

7.64 In exercising his/her authority, a deputy must look after the interests of the person who lacks capacity, and act dutifully and in good faith. Acting in good faith means acting with honesty, integrity and due diligence. For example, a deputy must try to ensure his/her actions do not negate previous decisions made by the person while still competent.

Duty of confidentiality

7.65 Deputies have a duty to keep the person's affairs confidential, unless the person, before losing capacity, consented to the disclosure of personal or financial information, or unless there is some other good reason to release it, such as the public interest or the best interests of the person lacking capacity, that overrides the duty of confidentiality. Disclosure of personal information is considered in more detail in chapter 15.

Duty to comply with the directions of the Court of Protection

7.66 The Court of Protection may give specific directions to deputies as to how they should exercise their powers. The court may also require deputies to submit to the Public Guardian specific reports (such as financial accounts or reports on the welfare of the person lacking capacity), at any time or at such intervals as the court directs. Deputies have a duty to comply with any direction given by the court and the Public Guardian.

Duty to keep accounts

7.67 A deputy appointed to manage property and affairs is expected to keep, and periodically submit to the Public Guardian, correct accounts of all his/her dealings and transactions on the person's behalf.

Duty to keep the person's money and property separate from their own

7.68 Deputies should, in general, keep the person's money and property separate from their own or anyone else's except where there is good reason not to do so, for example where a husband is acting as his wife's deputy and they have, for many years, had a shared bank account in both their names. But in most circumstances, deputies must keep everything separate to avoid any possibility of mistakes or confusion in handling the person's affairs.

Changes of contact details

7.69 In addition there is an expectation that a deputy will inform the Public Guardian of any changes of contact details for him/herself and the person for whom s/he acts, as well as any change in circumstances. This will help to ensure that the details that the Public Guardian holds remain up-to-date.

Supervision of deputies

7.70 Since the Court of Protection appoints deputies, they remain accountable to the court for their actions in carrying out their duties during the duration of their appointment. The court has power to discharge the order appointing a deputy at any time if it decides the appointment is no longer in the best interests of the person lacking capacity.

7.71 The Public Guardian is responsible for the supervision of deputies appointed by the court and for supporting deputies in their role. However, the Public Guardian also has a role in protecting people subject to the court's powers from possible abuse or exploitation. Any concerns or suspicions of abuse by deputies should be raised immediately with the Public Guardian. The Public Guardian may also direct a Court of Protection Visitor to visit a deputy to investigate any matter of concern. The supervisory duties of the Public Guardian are described in more detail in chapter 13. The Public Guardian will consider carefully any concerns or complaints against deputies. However, in serious cases, where physical abuse or serious fraud is suspected, the matter should be referred directly to the police and/or social services, and the Public Guardian informed. The protection of vulnerable people from the risk of abuse, ill treatment or neglect and the duties and responsibilities of the various agencies involved is discussed in detail in chapter 13.

Chapter 8 - Advance Decisions to Refuse Treatment

Introduction

8.1 This chapter describes the provisions in the Act relating to advance decisions to refuse medical treatment and provides basic guidance on their practical implications. **Part 1** explains the Act's definition of an advance decision to refuse treatment. It sets out guidance on making, updating and withdrawing advance decisions, and in particular, the formalities required for advance decisions concerning life-sustaining treatment. It also looks at the relationship of advance decisions with other decision-making mechanisms. **Part 2** sets out the safeguards in the Act aimed at ensuring that an advance decision exists and is both valid and applicable. **Part 3** looks at the effect of advance decisions and implications for the duties and responsibilities of healthcare professionals. **Part 4** describes the actions that can be taken in the event of a dispute or disagreement about an advance decision.

Part 1: What is an advance decision to refuse treatment?

8.2 It is a general principle of law and medical practice that people have a right to consent to or refuse treatment. Valid consent must be obtained before giving medical treatment, carrying out physical investigations or providing personal care. This principle reflects the right of competent patients to determine what happens to their own bodies by making their own treatment decisions.[37] Patients who lack capacity to consent may be treated without consent only if it is in their best interests (see chapter 5).

8.3 The courts have decided that competent and informed adults who are capable of understanding the implications of their decisions have an established legal right to refuse specified medical procedures or treatment in advance, intending that refusal to take effect when they no longer have the capacity to refuse procedures or treatment. An advance refusal of treatment is as valid as a contemporaneous decision if an advance decision exists and is valid and applicable in the particular circumstances. The Act makes statutory provision for this right.

8.4 Sections 24 – 26 of the Act set out the provisions, which enable those adults, aged 18 or over, who have the capacity to do so, to make an advance decision to refuse medical treatment. The Act also prescribes important safeguards and procedures in relation to advance decisions to protect the rights and interests of people lacking capacity, while enabling any qualifying advance decisions they have made to refuse medical treatment to be respected. Not respecting a valid and applicable advance decision may expose a health professional to civil liability (for example, the person refusing the treatment might claim damages for a tort such as battery) or criminal prosecution (for example for the battery of the person refusing treatment or a more serious offence under the Offences Against the Person Act 1861).

[37] Department of Health, *Reference Guide to Consent for Examination or Treatment,* (2001). For Wales see Welsh Health Circular WHC (2002)42 dated April 2002 contained enclosures *Reference guide for consent to examination and treatment* and *Good practice in consent implementation guide: consent to examination or treatment.* However, treatment without consent may be given for mental disorder under the provisions of the Mental Health Act (see chapter 12)

Individual choice

8.5 It is entirely a matter for individual choice as to whether or not a person wishes to make an advance decision to refuse treatment. There is no obligation on anyone to make an advance decision, but they are entirely free to do so. Some people choose to make advance decisions while they are still healthy with no prospect of illness, because they wish to retain some control and influence over what may happen to them in the future. Others may think of an advance decision as part of their preparations for growing older, similar to making a will. However, many people prefer to leave healthcare decisions to their doctors to decide what is appropriate at the time any treatment might need to be considered. Others may prefer to make a Lasting Power of Attorney appointing a trusted family member to make healthcare decisions on their behalf (see paragraphs 8.29-8.30 below and chapter 6).

8.6 These provisions apply only to advance decisions to **refuse** treatment. No patient, whether or not s/he has capacity, has the right, in law, to demand specific forms of medical treatment and therefore no-one can insist, either at the time or in advance, on being given treatments that doctors consider to be clinically unnecessary, futile or inappropriate However, requests for specific forms of treatment or expressions of wishes or preferences made in advance by a person who subsequently lacks capacity to consent to treatment should be taken into account (in particular those that are expressed in a relevant written statement) in deciding what treatment would be in that person's best interests (see chapter 4).

8.7 It must also be stressed that no one can ask for and be given unlawful procedures, such as assistance in committing suicide. As section 62 sets out, the law relating to murder, manslaughter or assisting suicide is unchanged by any provision in the Act.

Definition of an advance decision to refuse treatment

8.8 Section 24(1) of the Act defines an advance decision to refuse treatment. An *advance decision* for the purposes of the Act is a decision to refuse future medical treatment which is made by a person after s/he has reached the age of 18 at a time when s/he has capacity to make such a decision (see paragraphs 8.14-8.15 and chapter 3). The effect of an advance decision will be to enable that person to refuse specified medical treatment at a point in the future when s/he lacks the capacity to consent to that treatment.

8.9 An advance decision to refuse treatment:

- Must specify the treatment that is to be refused - this can be expressed either in medical language or lay terms, as long as it is clear what is meant. A statement or note, which merely indicates a general desire not to be treated, would not constitute an advance decision.
- May set out the circumstances in which the refusal will apply - it is helpful to include as much detail as possible on the circumstances in which the refusal will apply. Again lay terms can be used.
- An advance decision will only apply at a time when the person lacks capacity to consent to the specified treatment.

8.10 There are additional requirements and specific safeguards for advance decisions to refuse life-sustaining treatment. These are set out in paragraphs 8.20-8.24 below.

Making an advance decision to refuse treatment

8.11 Valid and applicable advance decisions (as defined in the Act) have the same legal status as contemporaneous decisions to refuse treatment. The Act does not impose any particular formalities concerning the format of advance decisions to refuse treatment or the procedures involved in making an advance decision, except for decisions relating to life-sustaining treatment (see paragraph 8.20 below) Advance decisions concerning the refusal of other types of treatment may be written or oral.

8.12 It is recommended that anyone wishing to make an advance decision should discuss it fully with healthcare professionals, in particular the person's GP or the doctor most closely involved with the person's current healthcare or treatment. Or they may want to seek advice from a patient support group or other organisation that can provide information based on experience of specific conditions or situations. But this is entirely voluntary. Such discussions will help to ensure that the person making the advance decision can take relevant information about treatment options into account. Details of the decision can be recorded in the person's medical records, to be activated at a later time when the person lacks capacity.

8.13 Some people may also wish to seek legal advice to ensure the decision is accurately expressed and set out clearly and unambiguously in any written document. In any event, it is a good idea to ensure that possible future circumstances are anticipated, for example, if relevant the advance decision should state whether it should continue to apply if the person later became pregnant. If the advance decision relates to life-sustaining treatment, the strict formalities must be complied with (see paragraph 8.20 below).

Capacity to make an advance decision

8.14 Only people aged 18 and over, who have the capacity to do so, can make an advance decision. Capacity to make a decision and how capacity is assessed are discussed in chapter 3. For most people planning in advance for possible future lack of capacity, their capacity to make an advance decision will not be in question. But in some cases it may be helpful to obtain evidence to confirm the person's capacity to make the advance decision, for example if there is a possibility that the advance decision may be challenged in the future.

> Mrs L, a 38-year-old woman, has been suffering from serious lower abdominal pain. During discussions her doctor informs her that it is possible that there may be a problem with her ovaries and that he wants her to undergo an exploratory operation. His advice is that if her ovaries have a non-cancerous cyst it may be necessary to remove it and this may lead to the removal of one or more ovaries. Mrs L is concerned that this may affect her fertility and therefore draws up an advance decision stating that under no circumstances should the ovaries be removed. She asks her doctor to witness the advance decision. If during the exploratory operation the doctor found a non-cancerous cyst the doctor would not be able to remove Mrs L's

ovaries because of the advance decision. He would need to discuss the matter with Mrs L once she had regained consciousness and capacity to make the relevant decision after the exploratory operation.

8.15 Particular concerns about capacity may arise in relation to advance decisions made by people who have suicidal tendencies. A doctor faced with an advance decision made by someone who was clearly suicidal may raise questions as to whether the person had capacity to make the advance decision. If the doctor is not satisfied that an advance decision was made with capacity, or if there are doubts about its existence, validity or applicability (see Part 2 below), treatment may be given without fear of liability (see Part 3 below). Although the Act does not require a record of an assessment of capacity, it would be good practice to do so.

Format of written advance decisions

8.16 A written document may provide proof that an advance decision to refuse treatment actually exists, so long as it can be authenticated as having been made by the person concerned (who was over 18 years of age at the time and had capacity). If the advance decision is written, it is helpful to notify others of its existence and where it can be located. There is no prescribed statutory form on which a written advance decision must be made, since the contents of advance decisions will vary considerably according to the wishes and circumstances of individual makers. However, it would be helpful for the following information to be included:

- Full details of maker, including date of birth, home address, and any distinguishing features (so that an unconscious person, for example, might be identified);
- Name and address of General Practitioner and whether they have a copy.
- A statement that the decision is intended to have effect if the maker lacks capacity to make treatment decisions;
- A clear statement of the decision, specifying the treatment to be refused and the circumstances in which the decision will apply or which will trigger a particular course of action;
- Date the document was written (or reviewed) and, if appropriate, the time interval between creation and review;
- The maker's signature (or if the maker is unable to write or otherwise sign the document, the signature of another person who has been directed by the maker to sign on his/her behalf and in his/her presence);
- The signature of the witness who witnessed the maker's signature (or the maker's direction that it be signed on his/her behalf). It maybe helpful to include the nature of the relationship between the witness and the maker of the advance decision.

Please refer to paragraphs 8.20 onwards for issues where life-sustaining treatment is being refused

8.17 Apart from advance decisions refusing life-sustaining treatment (see paragraphs 8.20-8.24 below), for which certain formalities must be complied with, witnessing the maker's signature to an advance decision is not essential. The witness should only witness the maker's signature and attest that it appears that the maker intends the signature to give effect to the advance decision. The role of the witness does not involve certifying the

capacity of the person making the advance decision. In some situations, a professional such as a doctor may be asked to act as witness.

Oral advance decisions

8.18 There is also no prescribed statutory style for how oral advance decisions to refuse treatment should be made. Again this is because the contents of the advance decision will vary considerably according to the situations of the individual makers. For example, a person may be known to have refused consent in advance to a particular form of treatment (such as being given an organ donated by someone who has died) but this refusal may not have been formally recorded. If the refusal was made at a time when the person had capacity, it may constitute an oral advance decision to be respected if at the time the treatment (e.g. organ donation) was proposed, the person lacked capacity to consent. A person receiving on-going medical treatment may express views to healthcare professionals that s/he would not be willing to consent to some types of treatment. For example, someone may consent to surgery for diagnostic purposes, but refuse consent in advance for removal of an organ, even if the surgeon considered it should be done immediately.

8.19 Health professionals will need to consider whether an oral advance decision exists and meets the Act's requirements of validity and applicability (see Part 2 below). Wherever possible, an oral advance decision to refuse treatment should be documented in the patient's healthcare record, which will then form a written record of the advance decision. The following information should be included in such a written record:

- A note that the decision is intended to have effect if the maker lacks capacity to make treatment decisions in the future;
- A clear note of the decision, specifying the treatment to be refused and the circumstances in which the decision will apply;
- Details of someone who was present when the oral advance decision was made.

Advance decisions to refuse life-sustaining treatment

8.20 The Act imposes strict formalities and safeguards on the making of advance decisions refusing life-sustaining treatment. An advance decision refusing life-sustaining treatment **must** fulfil the following requirements in order to be applicable:

- The advance decision must be in writing;
- The written document must be signed by the maker. Where the maker is unable to sign, (for example because of physical disability), arrangements may be made for the advance decision to be signed by someone else at the maker's direction and in his/her presence;
- The maker must sign the advance decision in the presence of a witness to the signature, who must also sign the document in the maker's presence. If the maker is unable to sign the advance decision may be signed by someone else at the maker's direction, also in the presence of a witness;
- The written document must be verified by a specific statement made by the maker, either included in the document or a separate

statement, expressly and explicitly stating that the advance decision is to apply to the specified treatment "even if life is at risk";

- This statement must also be signed by the maker (or by someone else at his/her direction), in the presence of a witness, who must also sign the statement. This is in addition to the need to sign and witness the advance decision itself.

What is life-sustaining treatment?

8.21 Life-sustaining treatment is defined (in section 4(10)) as treatment which a person providing health care regards as necessary to sustain life. Whether a treatment is 'life sustaining' depends not only on the type of treatment, but also on the particular circumstances in which it may be prescribed. For example, in some situations giving antibiotics may be life sustaining, whereas in other circumstances antibiotics are used to treat non-life-threatening conditions. The important factor here is that the treatment is necessary to sustain life at that time. It is for the doctor to assess whether a treatment is life-sustaining in each particular situation.

8.22 Artificial nutrition and hydration (ANH) has been recognised as a form of medical treatment. ANH requires clinical intervention to bypass the natural mechanisms that control hunger and thirst and has a number of consequences that require careful ongoing clinical monitoring. Refusing ANH in an advance decision is likely to result in the person's death, if the advance decision is followed.

8.23 It is therefore particularly important, but not compulsory, for anyone who is considering making an advance decision refusing life-sustaining treatment to discuss it fully with a healthcare professional, both to clarify what treatment is considered to be life sustaining in which circumstances and to be fully informed of the implications of refusing such treatment and what may happen as a result, (see also paragraphs 8.12-8.13).

8.24 There are some measures that are necessary to keep a patient comfortable, sometimes called basic or essential care. An advance decision may not refuse for example, warmth, shelter, and hygiene measures to maintain body cleanliness. This also includes the offer of oral food and water but not artificial nutrition and hydration. Health professionals may provide such care, in the best interests of a person lacking capacity to consent to it, under the provisions of section 5 (see chapter 5).

Reviewing and updating advance decisions

8.25 It is important that any advance decision to refuse treatment is kept under review and regularly updated, as necessary. Decisions made a long time in advance are not automatically invalid or inapplicable, but there may be doubts over the validity and applicability of such advance decisions. For example, questions may be raised by doctors or concerned family members about an advance decision refusing life-sustaining treatment made at a different time of the maker's life. A regularly reviewed written advance decision is more likely to be both valid and applicable as it will have been possible to reflect circumstances that may have changed since it was first made.

8.26 Views and circumstances may change over time. In particular, a new stage in a patient's illness, the development of new treatments or a major change in personal circumstances may be appropriate times to review and update an advance decision to refuse treatment. An advance decision that relates to treatment for a progressive condition is more likely to be both valid and applicable if it is shown that the maker has clearly taken account of circumstances that have changed since it was first made.

Withdrawing or amending an advance decision

8.27 Section 24(3) confirms that an advance decision to refuse treatment may be withdrawn or altered at any time while the maker still has the capacity to do so. No formal procedures are required to withdraw an advance decision and this can be done either orally or in writing. Where possible, the maker should inform anyone who knows about the advance decision that it has been withdrawn. Any written document can simply be destroyed and/or the person can inform relatives and/or healthcare staff verbally at any time that the advance decision has been withdrawn (or partially withdrawn). This could be, for example, while the person is being taken to the operating theatre or immediately before an anaesthetic is administered. Where a withdrawal is made orally to healthcare staff, this should be documented in the patient's healthcare record, which will then form a record of the withdrawal of the advance decision.

8.28 Similarly, whether or not advance decisions are set out in writing, they can be altered either orally or in writing, as the person's particular situation requires. However, if the maker wants to amend an existing advance decision to include the refusal of life-sustaining treatment, the particular requirements and formalities for making a written, signed and witnessed document and written, signed and witnessed accompanying statement must be complied with (see paragraphs 8.20-8.24 above).

Relationship of Advance Decisions to other Decision-Making Mechanisms

8.29 A valid and applicable advance decision to refuse treatment will be as effective as a contemporaneous refusal of consent and will therefore take precedence over:

- Any attempt to give consent by an attorney acting under a welfare Lasting Power of Attorney (LPA) made before the advance decision was made;
- Any attempt to give consent by a court-appointed deputy;
- The provisions of section 5, as far as they would otherwise allow a doctor to provide treatment which is considered to be in the patient's best interests.

8.30 However, if after making the advance decision, the person has created an LPA conferring authority on the attorney to give or refuse consent to the treatment specified in the advance decision, this has the effect of making the advance decision invalid (see paragraph 8.38 below) and the attorney's decision would then take precedence.

8.31 The Court of Protection may make declarations as to the existence, validity and applicability of an advance decision (see Part 4 below), but it has no power to override an effective advance decision to refuse treatment.

8.32 The best interests principle (section 1(5)) does not apply where an advance decision to refuse treatment is put into effect. This is because advance decisions reflect the instructions of competent adults, who when making an advance decision, have decided for themselves what will be in their best interests in the future. Therefore a valid and applicable advance decision must be complied with, even if it conflicts with an objective evaluation of the person's best interests at the time.

Advance decisions regarding treatment for mental disorder

8.33 For people who are being treated on a voluntary basis for a mental disorder, an advance decision refusing specific types of treatment for that disorder should be respected in the same way as any other advance decision, so long as it is valid and applicable to the treatment in question. However, where a patient is liable to be detained under the Mental Health Act 1983, the contents of any advance decision refusing treatment for mental disorder may be overridden by the compulsory treatment provisions of Part 4 of that Act. Where treatment for mental disorder may be given under the 1983 Act without the patient's consent, it may therefore also be given even though the patient has made an advance decision to refuse that treatment.

8.34 It is important to remember that only treatment for mental disorder is regulated by the Mental Health Act 1983. Where a detained patient is also having treatment for physical disorder, an advance decision to refuse treatment could still be valid and effective, regardless of the fact that s/he was also being treated for mental disorder under the 1983 Act. For example, an advance decision to refuse treatment (e.g. blood transfusions) for conditions unconnected with a patient's mental disorder would remain relevant even where the patient was also being treated compulsorily for schizophrenia under the 1983 Act.

Part 2: Existence, validity and applicability of advance decisions to refuse treatment – including decisions to refuse life sustaining treatment

8.35 An advance decision to refuse treatment is an important decision and could have serious and significant consequences for the maker. It could also have a significant impact on the person's family and friends and for professionals involved in his/her care or treatment. To meet the statutory requirements set out in the Act, it must first be shown that an advance decision to refuse treatment ***exists***. In addition, section 25 makes provision for two important safeguards. In order for the refusal to be legally effective at the time when it is proposed to carry out or continue treatment, an advance decision to refuse it must be both ***valid*** and ***applicable*** to the proposed treatment. These tests are crucial.

Existence

8.36 One practical matter to be considered when making an advance decision to refuse treatment is making sure that it will be drawn to the attention of a doctor or other healthcare professional when it may be needed. Storage of an advance decision and notification of its existence are primarily the responsibility of the maker. Some people may wish to carry a card, bracelet or other means indicating the existence of an advance decision to refuse treatment and where any written document is kept. Whilst there is no obligation to do so, the maker should think about informing close relatives and friends of the existence of the advance decision, where the original document is kept and any evidence to support its validity. It would be helpful for a copy of any written document to be given to the maker's General Practitioner, or for the existence of an advance decision to be recorded in the person's healthcare record.

8.37 An important factor in deciding whether an advance decision exists is to establish that it is in fact an advance decision to refuse treatment as defined in section 24. This includes establishing whether the person concerned was aged 18 years of age or older and had capacity to make the decision at the time it was made (see paragraphs 8.14-8.15 above).

Validity

8.38 An existing advance decision must still be valid at the time it needs to be put into effect. Events that would make an advance decision invalid are defined in section 25(2). These are:

- That the person has withdrawn the decision while s/he still had capacity to do so;
- That after making the advance decision, the person has created a Lasting Power of Attorney (LPA) conferring authority on the attorney to give or refuse consent to the treatment specified in the advance decision (an LPA conferring different powers or made before the advance decision would not affect the advance decision – see paragraph 8.29 above);
- That the person has done something which is clearly inconsistent with the advance decision which implies that s/he has had a change of mind.

A young man, whose friend died after prolonged hospital treatment, made a signed and witnessed advance decision and statement refusing any treatment to keep him alive by artificial means. A few years later, he is seriously injured in a road traffic accident and is paralysed from the neck down and is only able to breathe with artificial ventilation. Initially he remains conscious and is able to consent to treatment on being taken to hospital. He participates actively in a rehabilitation programme. Some months later he loses consciousness. It is at this point that his written advance decision is located, though he has not mentioned it during his treatment. His previous consent to treatment and involvement in rehabilitation place considerable doubt on the validity of the advance decision because it is clearly inconsistent with his actions prior to his lack of capacity.

Applicability

8.39 The next consideration, once the advance decision is established as valid, is whether it is applicable to the situation in question. It must first be determined whether or not the person still has capacity to give or refuse consent to the treatment in question at the time the treatment is proposed (section 25(3)). If the person has capacity, s/he can refuse the treatment there and then – or s/he can change the decision and consent to the treatment if s/he so wishes. The advance decision is not relevant and not applicable in those circumstances.

8.40 The advance decision must also be applicable to the treatment now proposed to be given to the person. Under section 25(4), an advance decision is not applicable to the treatment in question if:

- The proposed treatment is not the treatment specified in the advance decision;
- The circumstances are different from any set out in the advance decision; or
- There are reasonable grounds for believing that circumstances have now arisen which were not anticipated by the person when making the advance decision and which would have affected the advance decision had s/he anticipated them at the time.

8.41 In deciding whether an advance decision is applicable to the treatment in question, it will be important to consider how long ago the advance decision was made and whether, for instance, there have been changes in the patient's personal life or developments in medical treatment.

8.42 This will cover advances in medical science and the development of new medications or other forms of treatment or therapies not available at the time when the advance decision was made. Such developments might extend the treatment options available and could have affected the person's decision to refuse treatment. But it may also include changes in personal circumstances, which might affect the person's decision. For example, if the patient is now pregnant, and this had not been anticipated at the time the person made the advance decision, the decision might not be applicable in the present circumstances. For an advance decision to apply to life-sustaining treatment additional formalities must be complied with (see paragraphs 8.20 onwards).

Mr M is HIV positive and some years ago began to experience AIDS-related symptoms. Though willing to consent to standard treatment, for instance during a bout of pneumonia, he was initially unwilling to try the new retro-viral treatments, saying he didn't want to be a guinea pig for the medical profession. He made an advance decision refusing specific retro-virals if he lacks capacity to give or refuse consent in the future. Five years later he was suddenly admitted to hospital seriously ill and was drifting in and out of consciousness. Doctors examining his advance decision considered that the advances in knowledge surrounding the retro-viral options had been significant since Mr A made his advance decision. They talked to his partner about the advance decision. Both parties agreed that Mr M was not fully up-to-date on the research in this area and there were reasonable grounds for believing that, were he aware of the developments in this field, this would have affected his decision to refuse retro-virals. They decided the advance

decision to refuse was therefore not applicable to the retro-virals and gave him retro-virals as part of his treatment. If Mr M should regain capacity he will have the option of changing his previous advance decision and will be able to consent to or refuse the treatment recommended at that time.

Invalid or inapplicable advance decisions

8.43 Where an individual has made an advance decision to refuse treatment but that advance decision is not valid and/or applicable, but there are reasonable grounds for believing that it is a legitimate expression of the person's wishes, it must then be taken into account as part of any best interests determination (see chapter 4). The absence of a valid and applicable advance decision to refuse treatment should not automatically lead to the presumption that treatment (including life-sustaining treatment) must always be provided. Any such decision must be based upon an overall assessment of the patient's best interests.

Part 3: Effect of advance decisions and implications for healthcare professionals

8.44 This section summarises the effect of advance decisions to refuse treatment and their implications for the duties and responsibilities of healthcare professionals.

Responsibilities of health care professionals

8.45 Healthcare professionals should be aware of the possibility that a patient may have made an advance decision to refuse treatment. When discussing treatment options with people when they have capacity, healthcare professional should discuss, if appropriate, any treatments their patients may not wish to receive in the event that they lack capacity to refuse consent to treatment in the future. If, during the course of diagnosing or treating a patient who now lacks capacity to consent, healthcare professionals are alerted to the existence of a relevant written or oral advance decision, or have reasonable grounds to believe that one exists, they should, if time permits, make reasonable efforts to find out what that decision was. Reasonable efforts might include having discussions with relatives of the patient, looking in the patient's clinical notes held in the hospital or contacting the patient's GP.

8.46 Once healthcare professionals who are considering treatment have been informed of the existence of an oral advance decision or presented with a written advance decision, they need to consider:

- Whether it is an advance decision within the meaning of the Act;
- Whether it is valid; and
- Whether it is applicable to the treatment.

Guidance on these matters is set out in Part 2 above.

8.47 If the advance decision exists, is valid and applicable then healthcare professionals must act in accordance with the person's decision.

8.48 In particular, healthcare professionals must consider whether the advance decision is applicable in the circumstances, which have now arisen (see paragraph 8.39-8.42 above). Particular care will need to be taken for advance decisions that do not appear to have been reviewed or updated, for instance, in the light of changes in personal circumstances or developments in medical treatment. If the circumstances specified in the advance decision do not appear to correspond to the current situation, the decision may not be applicable. If any individuals have been named in the advance decision as people to contact or be consulted, they may be able to clarify the maker's wishes.

8.49 If there is any doubt whatsoever about the existence, validity or applicability of an advance decision to refuse treatment and healthcare professionals are not satisfied a valid and applicable advance decision exists, healthcare professionals may provide or continue any necessary treatment without fear or liability so long as that treatment is in the person's best interests (see chapter 4). In some cases providing treatment will be a potentially short term measure whilst doubts are resolved. This may be solved without the need for court intervention and could involve getting in touch with someone who can provide information about the person's capacity when the advance decision was made. An application may be made to the Court of Protection to determine any dispute about the existence, validity or applicability of an advance decision within the meaning of the Act (see Part 4 below). Section 26 provides that a doctor may provide necessary treatment to prevent serious deterioration in the person's condition or life-sustaining treatment while a decision is being sought from the court.

Emergency situations

8.50 A doctor may safely provide treatment which is considered to be in the patient's best interests unless satisfied that there is (1) a qualifying advance decision that is (2) valid and (3) applicable in the circumstances. Emergency treatment should not be delayed in order to look for an advance decision to refuse treatment if there is no clear indication that one exists.

Liability of healthcare professionals

8.51 Where a healthcare professional is satisfied that an advance decision to refuse treatment exists, and is both valid and applicable in the circumstances which have arisen (see Part 2 above), anyone who provides treatment contrary to the advance decision may be liable to a claim for damages for battery or possibly face criminal liability for assault. However, treatment providers would be protected from such liability if they were unaware of an advance decision or were not "satisfied" that an advance decision existed which was both valid and applicable to the particular treatment (section 26(2)). If health professionals have genuine doubts, and are therefore not "satisfied", about the existence, validity or applicability of the advance decision, treatment can be provided without incurring liability.

8.52 Health professionals who follow what they reasonably believe to be a valid and applicable advance decision to refuse treatment would not be liable for the consequences of withholding or withdrawing treatment specified in the advance decision, so long as they can demonstrate that their belief was reasonable (section 26(3)).

8.53 Having a 'reasonable belief' means that health care professionals must be able to point to reasonable grounds as to why they believe that a valid and applicable advance decision exists. Clearly, doctors and health professionals can only exercise their professional judgement based on the evidence available to them at the time, in determining whether they consider an advance decision exists, is valid and applicable.

8.54 There are some situations that may be sufficient to raise concerns about the existence, validity or applicability of an advance decision to refuse treatment, which might alert health professionals to the need to make more careful enquiries. In cases where serious doubt remains and cannot be resolved in any other way, it will be possible to seek a declaration from the court. Grounds for concern might include:

- A disagreement between relatives and health professionals about whether the person's oral comments really amounted to an advance decision;
- Evidence about the person's state of mind at the time of making the advance decision that raises questions about his/her capacity to have made the advance decision;
- Evidence of significant changes in the person's behaviour prior to lacking capacity that might indicate a change of mind since the advance decision was made.

Conscientious objection

8.55 Some health professionals may disagree in principle with patients' rights to refuse life-sustaining treatment or may have moral objections to withdrawing or withholding life-prolonging treatment in some circumstances. The current position on issues of conscience remains unchanged under the Act.

8.56 Wherever possible, doctors or health care professionals with a conscientious objection to limiting treatment in line with their patients' advance decision should make their views clear when the matter is initially raised. Patients should then be given the option of their care and treatment being transferred to another doctor or health professional, where this is feasible without jeopardising the patient's care. Doctors are entitled to have their personal beliefs respected and will not be pressurised to act contrary to those beliefs. However, doctors must not simply abandon patients or otherwise cause their care to suffer.

8.57 In cases where the patient lacks capacity but has made a valid and applicable advance decision to refuse treatment which a doctor or health professional cannot, for reasons of conscience, accede to, arrangements should be made for the management of the patient's care to be transferred to another health professional.[38] If for any reason such a transfer cannot be agreed, the Court of Protection has the power (under section 17(1)(e)) to give a direction that a different doctor or healthcare professional take over responsibility for the person's healthcare.

[38] *Re B (Adult: Refusal of Medical Treatment)* [2002] 2 All ER 449 at paragraph 100 –

Part 4: Disputes and disagreements about advance decisions

8.58 It is ultimately the responsibility of the relevant health care professional who is in charge of the person's care when the treatment is required, to decide whether there is a qualifying advance decision which is valid and applicable in the circumstances. In the event of disagreement between health professionals, or between health professionals and family members or others close to the person about an advance decision, the senior clinician must consider all the available evidence. This is likely to be a hospital consultant or the GP where the person is being treated in the community.

8.59 The senior clinician may need to consult with relevant colleagues and others who are close to or familiar with the patient. All staff involved in the person's care should be given the opportunity to express their views. If the person is in hospital, his/her GP may also have relevant information.

8.60 The point of such discussions should not be to try to overrule the person's advance decision but rather to seek evidence concerning its validity and to confirm its scope and its applicability to the current circumstances. Details of these discussions should be recorded in the person's healthcare records. Where the senior clinician has a reasonable belief that a qualifying advance decision to refuse medical treatment is both valid and applicable, the person's advance decision should be complied with.

Applications to the Court of Protection

8.61 Where there continues to be genuine doubt or disagreement about the existence, validity or applicability of an advance decision to refuse treatment a declaration can be sought from the Court of Protection. However, the court does not have the power to overturn a valid and applicable advance decision.

8.62 The court has a range of powers (under sections 16 -17) to resolve disputes concerning the personal care and medical treatment of a person lacking capacity (see chapter 7). In particular, in relation to advance decisions to refuse treatment, the court has the power to make declarations as to:

- Whether a person has or lacks capacity to consent to or refuse; treatment at the time the treatment is proposed;
- Whether an advance decision to refuse treatment is valid;
- Whether an advance decision is applicable to the proposed treatment in the circumstances which have now arisen.

8.63 While a decision is sought from the court life-sustaining treatment can be provided and action may be taken to prevent a serious deterioration in the condition of the person. The court has emergency procedures, which operate 24 hours a day, to ensure that urgent cases can be dealt with promptly and speedily. Guidance on applications to the court is given in chapter 7.

Chapter 9 - The Independent Mental Capacity Advocate service

This chapter deals with the provisions in the Mental Capacity Act that establishes the Independent Mental Capacity Advocate (IMCA) service. Much of the detail as to how the IMCA service will operate is not contained in the Act itself but will instead be contained in Regulations made under the Act. During the Parliamentary passage of the Act, the Government committed to consulting with interested parties about how these powers should be used in relation to the appointment of IMCAs, their functions, the definition of serious medical treatment and how the IMCA service might be extended to other groups and situations.

The Department of Health conducted a formal consultation in England in 2005, with the National Assembly of Wales carrying out a consultation in Wales. The responses to the consultations are still being considered, and the policy underpinning the Regulations that will set out how the IMCA service will operate will be developed taking into account the consultation comments.

The Regulations and other guidance will cover many aspects of the service including:

- *Standards, monitoring, accountability and training of IMCA's;*
- *Procedures for resolving disagreements;*
- *The types of treatment that may be considered 'serious medical treatment';*
- *How the IMCA service will be commissioned.*

Therefore this chapter will be subject to further development as more work is done on the IMCA service. In particular, it will need to reflect any differences between the Regulations made in England and Wales.

Introduction

9.1 This chapter describes the new service provided under the Act, the Independent Mental Capacity Advocate (IMCA) service. Its purpose is to provide representation and support for particularly vulnerable people who lack capacity who are facing important decisions about certain serious, potentially life-changing situations. **Part 1** sets out how the service will be set up. **Part 2** sets out the detailed role and functions of an IMCA. **Part 3** explains the particular situations which will require the appointment of an IMCA and the categories of vulnerable people to whom the safeguard will apply. **Part 4** describes the obligations placed on public authorities (relevant NHS bodies or local authorities) relating to the requirement to consult with IMCAs and take account of their advice.

Background

9.2 Sections 35-41 of the Act establish a new statutory scheme, known as the "Independent Mental Capacity Advocate Service". The aim of the service is to provide additional safeguards for people who lack capacity to take decisions in certain specific, important situations and who are particularly vulnerable because they have no close relatives, friends or any other person to help protect their interests.

The need for additional safeguards

9.3 In the vast majority of cases, individuals with capacity problems will have a network of support, whether from family members or friends who take an interest in their welfare, from an attorney appointed under a Lasting Power of Attorney (see chapter 6) or from a deputy appointed by the Court of Protection (see chapter 7). When determining what would be in the best interests of a person lacking capacity in relation to a particular decision or course of action, all those people in the person's network of support must be consulted where it is appropriate or practicable to do so (see chapter 4).

9.4 The role of the IMCA will be to support and represent people who lack capacity who have no-one else to support them when major, potentially life-changing decisions are being contemplated. The NHS body or local authority involved in the decision must take into account any information given or submissions made by the IMCA when determining what decision is in the best interests of the person lacking capacity. Further details of the IMCA's role are set out in part 2.

Part 1: Setting up the IMCA service

Appointment of IMCAs

9.5 Section 35 of the Act places an obligation on the "appropriate authority" (in England, the Secretary of State for Health; in Wales, the National Assembly for Wales) to make appropriate arrangements to ensure that IMCAs are available in particular circumstances to protect the interests of vulnerable people who qualify for the service. Separate guidance will be available setting out how the IMCA service should be commissioned. [39]

Who can be an IMCA?

9.6 Section 35(2) allows the appropriate authority to make Regulations as to the appointment of IMCAs. The intention is for the Regulations to provide that individual IMCAs must meet common standards and receive appropriate training, to ensure consistency across the country.

9.7 The particular qualifications, experience or training requirements necessary for approval of IMCAs will be set out in Regulations made under the Act, supplemented by guidance to be issued by the Department of Health and the National Assembly for Wales, depending on the outcome of the consultations.

[39] References to this guidance and to Regulations and other guidance relating to the IMCA service will be added once known

Independence

9.8 In order to ensure their independence, it is envisaged that individuals will not be able to act as an IMCA if:

- They have any professional or paid involvement with the provision of care or treatment for any vulnerable person for whom they may be appointed to act; and
- They are not completely independent of the person responsible for making the decision or doing the act in question.

Part 2: The role and functions of the IMCA

9.9 Under section 42(4)(d) of the Act, IMCAs are required to have regard to any relevant guidance in the Code of Practice when carrying out their functions. Some of the possible functions of the IMCA are set out in the Act in section 36(2), although the actual functions of the IMCA will be set out in Regulations in England and Wales. The functions listed in the Act include:

- Representing and supporting the person who lacks capacity, so that the person may participate as far as possible in any relevant decision;
- Obtaining and evaluating information;
- As far as possible, ascertaining the person's wishes and feelings, beliefs and values, or what these would be likely to be;
- Ascertaining alternative courses of action – for example, looking at different care arrangements or residential homes; and
- Obtaining a further medical opinion, if necessary.

9.10 In order to carry out these functions, the IMCA will need to:

- Investigate the particular circumstances of the vulnerable person;
- Consider whether the principles set out in section 1 of the Act have been complied with (see chapter 2);
- Consider the factors set out in best interests check list (see below); and
- Take account of any relevant guidance in the Code of Practice.

Representing and supporting the person who lacks capacity

9.11 In making appropriate representations to the decision maker, the IMCA should take account of the guidance given in chapter 4 when considering in particular:

- Whether the person is likely to regain capacity in relation to the matter in question, and if so, when that is likely to be – for example, the IMCA may wish to make representations that the decision in question is delayed if the IMCA considers that the person may regain capacity in the foreseeable future;
- The need to permit and encourage the person to participate, or to improve his/her ability to participate, as fully as possible in any act done for and any decision affecting him/her. The IMCA should

consider whether the person has been given adequate support to try to make his/her own decision. Where the vulnerable person has communication difficulties, the IMCA may consider seeking specialist help, for example from a speech therapist or translator (see chapter 3);

- Where the decision relates to life-sustaining treatment, the need to ensure that the decision-maker is not motivated by a desire to bring about the person's death;
- The past and present wishes and feelings, beliefs and values of the person lacking capacity, so far as these can be ascertained (see paragraphs 9.16-9.17 below);
- The need to consider the views of anyone engaged in caring for the person or interested in his/her welfare; and
- Any other relevant factors including, for example, cultural factors.

9.12 In some situations, particularly where the matter is urgent, it may not be possible or practicable for the IMCA to carry out extensive investigations. The IMCA will therefore need to make a judgement about what investigations are necessary and appropriate in the particular circumstances in order to support and represent the person. There may be occasions when, despite their best efforts, IMCAs are unable to form an opinion about what the person concerned might have wanted. Nevertheless, they will usually be able to raise relevant issues and questions, and provide additional information to ensure that all relevant factors are taken into account in determining whether the decision is in the person's best interests.

Obtaining and evaluating information

9.13 Section 35(6) provides IMCAs with certain powers to enable them to carry out their functions under the Act. These include:

- The right to visit and have a private discussion with the person concerned;
- The right to examine, and take copies of, any records (such as clinical records, care plans or social care assessment documents) which the person holding the record considers are relevant to the IMCA's investigation.

9.14 The IMCA may also need to hold discussions with professionals or paid carers involved in providing care or treatment for the person lacking capacity, in order to evaluate the information obtained from case records or other sources, or to discuss possible alternative courses of action (see paragraphs 9.18-9.19 below.

9.15 The IMCA is not the decision-maker. It is ultimately the responsibility of the person proposing an action or decision to decide what is in the best interests of the person lacking capacity to make the decision or to act, but the decision-maker has a duty to take account of the information given by the IMCA. In most cases, a decision will be achieved through discussion and reaching a consensus with all those involved, including, so far as possible, the person lacking capacity.

Ascertaining the person's wishes and feelings, beliefs and values

9.16 The IMCA should ascertain, as far as possible, the past and present wishes and feelings of the person concerned, any beliefs and values that may have influenced the decision in question, and the factors which the person would consider if able to do so. This is likely to involve observation and communication with the person themselves, although there may be cases where the person is unable to communicate at all e.g. where they are unconscious. It may also include talking to other professionals or paid carers directly involved in providing care or treatment for the vulnerable person; examining health and social care records and any written statements of preferences. Detailed guidance on ways of ascertaining the past and present views of people lacking capacity is given in chapter 4.

9.17 Further guidance on helping someone to make his/her own decisions, communication techniques and choosing the best time and location is given in chapter 3.

Ascertaining alternative courses of action

9.18 Where there is more than one course of action or a range of decisions that might be made, the IMCA will need to check whether all possible options or alternatives have been explored. They will need to consider whether the proposed option would be least restrictive of the person's future choices or would allow him/her the most freedom, in line with the principles in section 1 of the Act.

9.19 The IMCA may wish to discuss possible options with other professionals or paid carers directly involved in providing care or treatment for the vulnerable person, bearing in mind the duty of confidentiality towards the person concerned.

> A young man with severe learning disabilities was admitted to hospital for voluntary treatment for his mental disorder when the care home in which he lived could no longer cope with his challenging behaviour. It is now proposed to discharge him into a specialist care home where there are more appropriate facilities to meet his needs. Despite various efforts to explain the situation to him, the young man is assessed as now lacking the capacity to agree to the move. As he has no outside contacts other than his professional carers, an IMCA is appointed to support and represent him. The IMCA will wish to visit the young man, try to ascertain his wishes and feelings about the move, look at his clinical records and care plans and discuss the proposals for his future care with a multi-disciplinary team, with his past carers and with staff at the new care home, or arrange for the young man to be taken on a visit to observe his reaction. The IMCA may also wish to investigate possible alternative placements and obtain specialist advice about the young man's needs.

Obtaining a second medical opinion

9.20 Where the decision or action concerns medical treatment, the IMCA may consider seeking a second opinion from a doctor with an appropriate specialty as to whether the proposed treatment is necessary and in the person's best interests.

Resolving disagreements

9.21 Having asked questions, raised issues and offered information about the vulnerable person lacking capacity in relation to a specific matter, there may be occasions when the IMCA feels that insufficient regard has been given to that advice and information. When the IMCA is sufficiently concerned about a decision that has been made whether because of the process followed or the outcome reached, the IMCA may need to take steps to challenge it.

9.22 Section 36(3) of the Act provides that Regulations made in England and Wales may make provision for the circumstances in which the IMCA can challenge, or assist in challenging, the decision-maker.

9.23 Different methods of resolving disagreements are set out in chapter 14, which will vary depending on the type and urgency of the particular dispute. It is envisaged that the IMCA, as with a family member or carer, should have access to informal methods for resolving disputes at the earliest possible stage. Possibilities include:

- In relation to disagreements about health care or treatment:
  - Involving the Patient Advice and Liaison Service (PALS) (in England) or the Community Health Council (in Wales);
  - Using the NHS Complaints Procedure;
  - Referring the matter to the local continuing care review panel.

- In relation to disagreements about social care:
  - If the person is in a care home, using the care home's own complaints procedure;
  - Using the local authority complaints procedure.

- In particularly serious cases where there is no other way of resolving the matter an IMCA may seek permission to refer the matter to the Court of Protection (see chapter 7).

Additional functions of IMCAs

9.24 In order to ensure sufficient flexibility to meet any additional needs for safeguards which may be identified in future, the Act allows for additional functions to be ascribed to IMCAs (over and above those already set out in the Act), or to extend the IMCA scheme. Additional Regulations would have to be made in England and/or Wales under section 41 of the Act to expand the role of the IMCA service in this way.

Part 3: Situations requiring an IMCA

9.25 The IMCA will provide safeguards for people who have nobody to speak for them when important decisions need to be made. The following paragraphs provide further details of:

- The specific situations in which an IMCA will be required; and
- The categories of people who qualify for the additional safeguards provided by the IMCA service.

What acts or decisions require the appointment of an IMCA?

9.26 The need for additional safeguards for particularly vulnerable people (i.e. people who lack capacity who have no-one else to support them), has been identified in the following situations:

- Decisions relating to providing, withholding or withdrawing serious medical treatment;
- Where it is proposed to move a person into long-term care in a hospital or care home; or
- Where a long-term move to a different hospital or care home is proposed.

Serious medical treatment decisions

9.27 Where a serious medical treatment decision is contemplated for a person lacking capacity to consent, who qualifies for additional safeguards, section 37 imposes a duty on the NHS body responsible for the patient's treatment to make sure that advice is sought from an IMCA (Part 4 below explains which NHS body may be responsible).

9.28 Regulations in England and Wales will set out the types of serious medical treatment decisions which will require an IMCA and/or the characteristics of the decision, depending on the outcome of the consultation processes. It is likely that the Regulations will cover treatments for both mental and physical conditions, and they are likely to include treatments with serious or irreversible consequences where:

- The balance of the expected benefit for the patient against the level of risk and invasiveness of the treatment is unclear; or
- There is a fine balance between the choice of treatments available e.g. chemotherapy and surgery for certain types of cancer.

> A man with Down's syndrome has been in care for most of his life and has lost touch with his family. He now has a serious heart condition requiring open-heart surgery, which also involves considerable risks. He lacks capacity to consent to the treatment in question. An IMCA is appointed to support him and represent his interests when clinicians and other staff are making their decision as to his best interests. The IMCA may wish to seek a second opinion from a clinician specialising in heart surgery of this type.

9.29 The only situation in which the duty to seek advice from an IMCA could be dispensed with is where the proposed treatment needs to be provided as a

matter of urgency, for example to save the person's life or prevent a serious deterioration in his/her condition (section 37(4) of the Act).

Treatment for mental disorder

9.30 Treatment which is regulated by Part IV of the Mental Health Act 1983 cannot be included in the definition of "serious medical treatment" once the Act is in force (because the 1983 Act provides its own safeguards – see chapter 12). For the most part this means treatment (of all types) for mental disorder given to patients who have been detained under the Mental Health Act 1983. But it also includes treatments for mental disorder to which special safeguards apply under section 57 of the 1983 Act, whether or not the patient concerned is detained under the Act. At present, those treatments are surgical operations for destroying brain tissue or for destroying the functioning of brain tissue ("psychosurgery") and the surgical implantation of hormones for the purpose of reducing male sex drive. In neither case can the treatment be given without the patient's consent, even if the patient lacks capacity. Therefore, it would not be necessary to include these treatments in any list of "serious medical treatments".

Decisions about accommodation or changes of residence

9.31 Sections 38-39 impose similar duties on NHS bodies or local authorities which are responsible for the placement in accommodation of a person lacking capacity to agree to the placement, and who also qualifies for the additional safeguards of an IMCA. It applies to long-stay accommodation in a hospital or care home, or a move between such accommodation where that accommodation is provided or arranged by the NHS. It also applies to residential accommodation provided in accordance with section 21 or 29 of the National Assistance Act 1948. This may be accommodation in a care home, nursing home, ordinary and sheltered housing, housing association or other registered social housing, or in private sector housing provided by a local authority or in hostel accommodation.

9.32 These duties will be triggered where:

- An NHS body proposes to place a person, who lacks the capacity to agree, in a hospital for a period likely to exceed 28 days or care home for a period likely to exceed 8 weeks;
- An NHS body proposes to move the person to another hospital for a period likely to exceed 28 days or another care home for a period likely to exceed 8 weeks;
- During an assessment under the NHS and Community Care Act 1990 of a person who lacks the capacity to agree to accommodation arrangements, a local authority proposes to provide community care services in the form of residential accommodation and to place the person in accommodation for a period likely to exceed 8 weeks or where a local authority proposes to move the person to another care home for a period likely to exceed 8 weeks.

9.33 If, in any of the cases above, the placement is expected to be for less than 28 days / 8 weeks, but it is then extended, an IMCA should be involved as soon as it is realised that the stay will outlast the 28 day / 8 week period.

An NHS Trust has a long stay ward which houses older people with mental health problems in less than adequate accommodation. Plans have been made to close the ward and make new placements for the residents. One of the residents has been on this same ward for the last ten years and no longer has any contact with the outside world. She now lacks capacity to consent to the move or to make decisions about her future care. An IMCA is appointed to support and represent her

9.34 The only situation in which the duty to instruct an IMCA to support and represent the person can be dispensed with is where the proposed placement or move needs to be made as a matter of urgency, for example an emergency admission to hospital, or where the person lacking capacity would be made homeless unless admitted immediately to a care home.

9.35 Where the person concerned is to be detained in hospital or otherwise required to live in the accommodation in question under the Mental Health Act 1983, the IMCA does not need to be consulted, since the 1983 Act provides its own safeguards and rights of appeal (see chapter 12).

Additional situations

9.36 In addition to these particular situations set out in the Act which relate to placements in hospital or care homes, the Act allows for Regulations in England and Wales to provide for the extension of the IMCA scheme to other types of situations, should a need be identified in the future.

Care reviews

In both England and Wales, the consultations asked whether IMCAs should be given an additional role under statutory guidance issued to local authorities[40] and directions issued to NHS bodies.[41] The following section may be included in the final version of the Code , depending on the outcome of the consultations.

9.37 Statutory guidance and directions may require the relevant local authority or NHS body to involve an IMCA in the annual reviews of people in long-term care (whether in hospital or care home where the accommodation is provided by an NHS body, or any residential accommodation provided by a local authority, irrespective of whether it is owned independently or not). This might apply where the person concerned lacks capacity to participate in the review and has no relative, friend or other person to take an interest in his/her welfare. This would apply only where an IMCA was involved in the original decision about the person's long-term care.

Who qualifies for an IMCA?

9.38 The additional safeguards of an IMCA are intended to apply to people who have no network of support and no-one close to them who takes an interest in their welfare. This lack of support means that there is no-one to help the person who lacks capacity in communicating his/her own wishes and feelings or participating so far as possible in the decision in question. It also makes the determination of best interests particularly difficult since there is no-one

[40] Section 7, Local Authority Social Services Act 1970

[41] Section 17, National Health Service Act 1977

who can be consulted, other than people who provide care or treatment in a professional capacity or for remuneration, who have a different role to play in deciding the best interests of a person lacking capacity.

9.39 Therefore, the people who qualify for the additional safeguards provided by an IMCA are those who:

- Lack capacity in relation to one of the decisions or acts described in paragraphs 9:26 to 9:36 above; and
- Have no-one close to them who *"it would be appropriate to consult"*, other than people engaged in their care or treatment in a professional or paid capacity (see paragraphs 9.42-9.47 below).

Therefore, in cases where it would be appropriate to consult family members or close friends who are involved with a person lacking capacity and who are able to support and speak up for that person, the services of an IMCA will not be available.

9.40 Section 40 clarifies the particular categories of people who will not require the services of an IMCA - these are people where there is someone else who can be consulted about the person's best interests and support that person. The categories are as follows:

- Where a person who now lacks capacity in relation to a particular matter has previously expressed a wish that a named person should be consulted in matters affecting his/her interests, and that person is available and willing to be consulted;
- Where there is an attorney appointed under a Lasting Power of Attorney;
- Where there is an attorney appointed under an Enduring Power of Attorney, and the attorney continues to manage the person's affairs;
- Where a deputy has been appointed by the Court of Protection

9.41 Even if the attorney or deputy has been appointed to manage the person's financial affairs, they are likely to have some knowledge about the person's wishes and feelings and about the particular circumstances, which are relevant to his/her best interests.

Who is appropriate to consult?

9.42 The Act does not define "who it would be appropriate to consult" when determining the best interests of a person lacking capacity. The final decision will rest with the decision maker. Section 4(7) lists the people whose views should be taken into account by the decision maker. This includes anyone named by the person, or engaged in caring for him/her or interested in his/her welfare (see chapter 4).

9.43 The responsible body should therefore consider whether there is anyone, other than the people listed at paragraph 9.40, engaged in caring for the person or interested in his/her welfare, (apart from paid or professional carers), and if so, whether it is practicable and appropriate to consult them. Where there are family members or close friends who are appropriate and available to be consulted, an IMCA will not be required. If they are satisfied that there is no such person, then the duty to instruct an IMCA is triggered.

9.44 There may be situations where a person who lacks capacity has family or friends, but it is not practicable or appropriate to consult them. For example, an elderly person with dementia may have an adult child who now lives in Australia, making it impracticable for that person to be able to help and support their elderly relative in relation to an important decision. Alternatively, there may be relatives of the person lacking capacity who live in the UK but have little personal knowledge of the person and only a limited interest in the person's care and welfare, and it would not be appropriate to consult them. In such circumstances, an IMCA should be appointed.

9.45 Similarly, the person who lacks capacity may have friends or neighbours who may know about their wishes and feelings but not be willing or able to be consulted about the particular decision. In this situation, the NHS body or local authority should involve an IMCA.

> A woman with severe learning disabilities has lived in a care home for most of her life. Although her parents used to visit her, her father died several years ago and her mother now has a serious heart condition and is also crippled with arthritis. Her mother also has problems with her short-term memory and feels she would not be able to help and support her daughter when a change of accommodation is proposed. As the daughter lacks capacity to make the decision herself, and no-one else takes an interest in her welfare, an IMCA is appointed to support and represent her.

9.46 Where the person who lacks capacity already has an independent advocate they may still be entitled to an IMCA, depending on the situation:

- Where the person who lacks capacity has an independent advocate acting under restrictions on the areas where s/he is to be involved and the person is now unable to give instructions as to whether the independent advocate should be consulted about a serious medical treatment or long-term care decision. An IMCA should be appointed, and the IMCA should consult and work with the independent advocate in supporting the person and particularly in ascertaining the person's wishes and feelings;
- Where the independent advocate meets the appointment criteria for the IMCA service, s/he may be appointed to fulfil the IMCA functions in addition to their other duties.

9.47 Where the person has previously appointed an independent advocate him/herself, and has indicated that s/he wishes the independent advocate to be consulted on all affairs and decisions, which the person concerned lacks capacity to make, section 40(a) applies. The person lacking capacity would not therefore be entitled to an IMCA.

Extending the service to other groups of people

9.48 The Act provides for extension of the categories of people who qualify for these additional safeguards provided by the IMCA service through Regulations in England and Wales, should further needs be identified in the future.

Part 4: Duties of public authorities

9.49 The duty to make sure that arrangements for the IMCA service are put in place lies with the "appropriate authority", namely the Secretary of State for Health in England, and in Wales, the National Assembly for Wales. The appointment of IMCAs and management of the service must be carried out in accordance with the Regulations made in each country.

9.50 The duty to instruct an IMCA to represent the person and the duty to consult an IMCA in the situations described in Part 3 above lies with the relevant public authority, the "responsible body" which is responsible for the proposed decision or course of action.

Which is the 'responsible body'?

9.51 This will depend on the type of decision or proposed course of action.

- In relation to serious medical treatment decisions, the responsible body that will have a duty to instruct and consult with an IMCA will normally be the NHS body involved in providing healthcare or treatment for the person concerned. The "NHS body" will be defined in Regulations in England and Wales[42]. The intention is that in most cases, this will be the relevant local NHS Trust or Foundation Trust but could also be a Primary Care Trust (PCT) (for example where the PCT runs a small community hospital), or in Wales, a Local Health Board;
- However, where the serious medical treatment is being carried out in an independent (private) hospital, the responsible authority in those cases will be the NHS body which agreed to fund the person's care in that hospital. The "NHS body" will be defined in Regulations in England and Wales. This could be either an NHS Trust or Foundation Trust, a PCT, or in Wales, a Local Health Board;
- In relation to decisions about admission to a hospital or care home, the responsible body with the duty to instruct and consult an IMCA, will be the NHS body (to be defined in Regulations) which either manages the hospital or care home to which it is proposed to admit the person or agrees to fund the person's care in an independent hospital;
- In relation to decisions about moves into long-term care, the responsible body under a duty to instruct and consult an IMCA will be the local authority, which carried out the assessment of the person under the NHS and Community Care Act 1990 and has decided to provide community care services in the form of residential accommodation.

Duties of the responsible body

9.52 The responsible body is under a statutory duty to instruct an IMCA to support and represent the person concerned in the situations set out in Part 3.

9.53 The responsible body is also under a statutory duty to consult the IMCA and make sure that the particular decision-maker or person proposing to take the

[42] A reference to these Regulations will be added once known

action in question takes account of the information provided and submissions made by the IMCA in determining the best interests of the person concerned.

9.54 In order to comply with these duties, the responsible body must have in place procedures to ensure that:

- All relevant staff are aware of the particular situations requiring an IMCA (see Part 2 above);
- All relevant staff are aware of how to access the IMCA service;
- All reasonable requests for information or access to records made by IMCAs in carrying out their functions under the Act are complied with;
- Proper records are made of the involvement of an IMCA and of the advice and representations made by the IMCA;
- Proper records are made by the person proposing the decision or action as to how the IMCA's advice has been taken into account and, where relevant, his/her reasons for disagreeing with or ignoring that advice.

9.55 Where a disagreement arises between the IMCA and anyone employed by or acting on behalf of the responsible body, every effort must be made to resolve the disagreement at the earliest possible stage, where necessary using the authority's dispute resolution or complaints procedures (see paragraphs 9.21– 9.23 above).

CHAPTER 10 - Research

Introduction

10.1 **Part 1** of this chapter describes what is meant by research and summarises the provisions made in the Act to ensure that any research involving people who lack capacity to consent to their participation is appropriate and subject to stringent safeguards. **Part 2** describes when the Act applies and outlines the responsibilities of the different parties that must be involved before a person lacking capacity can be involved in research. It also sets out the requirements for approval of a research proposal. **Part 3** sets out the specific responsibilities of researchers and describes the additional safeguards imposed by this Act and the Human Tissue Act 2004. **Part 4** deals with transitional arrangements for research already in progress when the Act comes into force.

Part 1: Research involving people lacking capacity to consent

10.2 The Mental Capacity Act ("the Act") contains provisions for the authorisation and regulation of research (including medical research) involving people who lack capacity to consent to their participation. These provisions reflect the importance of properly conducted research to gain knowledge of the causes, diagnosis, treatment and/ or care of people who lack capacity, as well as the need to protect their interests and safety, and to respect their current and previously expressed wishes and feelings. Anyone carrying out research to which the Act applies has a duty to act in accordance with the principles and provisions of the Act and to have regard to the guidance given in the Code of Practice.

10.3 Without research involving those who lack capacity, the development of proven treatments and / or improvements in services for people with conditions affecting their decision-making capacity may not be possible. The provisions of the Act therefore aim to strike a balance between protecting and respecting the interests, wishes and feelings of those who lack capacity with the need for appropriate research, regulated by strict requirements and safeguards. As a general rule, people who lack capacity to consent for themselves should only be involved in research projects likely to benefit them directly, or to benefit people affected by similar conditions, where that research cannot be undertaken on people who have capacity to consent.

10.4 One of the main issues for research in this area is around the potential benefit to the individual involved in a research study or to others with a similar condition. Potential benefits may include:

- Developing new and more effective ways of treating a condition;
- Improving the quality of health and social care services;
- Discovering the cause of a debilitating illness or learning disability;
- Preventing harm, exclusion or disadvantage on the part of people who lack capacity;
- Checking to see what type of intervention works best in any particular situation.

10.5 It is not always possible to be certain that any one individual will benefit directly from a research project. But there might be a range of possible indirect benefits; for example, it might benefit that person at a later stage if policies or care pathways are changed, or new forms of therapy are introduced, as a result of the research evidence. The Act seeks to ensure that any additional risk of the research, over and above the risks associated with the condition or treatment itself, is kept to an absolute minimum and is either proportionate to the potential benefit to the person lacking capacity, or in the case of research to provide knowledge, the risk is negligible.

10.6 Researchers also need to understand the relationship between common law consent and the Act's provisions, particularly in deciding whether the research could in fact be carried out as effectively on those with capacity to consent, without the need to involve people who lack capacity. Where people lacking capacity are involved, researchers must comply with the requirements of sections 30–33 in order to be afforded protection from liability.

Definition and examples of research covered by the Act

10.7 Sections 30-34 of the Act apply to "intrusive research". This is defined as research that can normally only lawfully take place if the participant concerned, having the capacity to consent, has consented to his/her participation in that research (section 30(2)). However, research that involves the clinical trials of medicines is excluded from the provisions of sections 30-34 because this type of research is the subject of separate regulation[43].

10.8 Research itself is not defined in the Act, but is generally defined as being either descriptive, evaluative or explanatory. The Department of Health publication "Research Governance Framework for Health and Social Care" states "research can be defined as the attempt to derive generalisable new knowledge by addressing clearly defined questions with systematic and rigorous methods."[44] This definition includes studies that aim to generate hypotheses as well as studies that aim to test them. The knowledge gained may provide information that can be generalised to the particular illness, disorder, or circumstances under investigation. Studies may demonstrate the relative safety and efficacy of a new medical treatment or other intervention (e.g. surgical procedure, psychological treatment); they may add to the evidence showing whether one treatment or intervention works better or is safer than another; or they may have wider implications, such as informing the development of policy and / or practice in a range of agencies (e.g. investigating factors that influence or maximise the potential decision-making capacity of someone with impaired capacity). This evidence is usually cumulative, so the knowledge from a particular study may also inform further research.

10.9 The definition of intrusive research in the Act is deliberately wider than health or medical research. It applies to a wide range of both natural and social scientific research, including:

[43] Currently the Medicines for Human Use (Clinical Trials) Regulations 2004 (S.I. 2004/1031), which implements a European Directive 2001/20/EC - Schedule 1 to the Regulations provides protection for people who lack capacity similar to that provided under the Act for other types of intrusive research.

[44] http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4008777&chk=dMRd/5

- Clinical research into new types of treatments (except clinical trials of medicines that are covered by separate Regulations – see paragraph 10.7 above);
- Health or social care services research to evaluate the effectiveness of a policy or service innovation;
- Research in other fields, (e.g. criminal justice, psychological studies, lifestyle or socio-economic surveys);
- Research on tissue samples (i.e. blood or spare tissue removed during surgical or diagnostic procedures) - this is also covered by the Human Tissue Act (see paragraphs 10.37-10.40 below);
- Research on health and other personal data collected from records; and
- Observations, photography or videoing of people who lack capacity (some of which may be done covertly so as not to distract the person).

Part 2: Duties and responsibilities imposed by the Act

When does the Act apply to research?

10.10 In the context of research, the following factors determine whether the provisions of the Act apply:

- The proposed research is defined as 'intrusive' i.e. it is of a kind that would otherwise require the consent of the potential participant in order to be lawful;
- The research includes participants who have an impairment of, or disturbance in, the functioning of the mind or brain that results in a lack of capacity to consent to participating in the research; and
- The research proposed is not a clinical trial covered under the Medicines for Human Use (Clinical Trials) Regulations 2004.

Who do these provisions apply to?

10.11 Where these circumstances apply, the Act confers specific functions and responsibilities on the following persons or bodies:-

- The 'appropriate body' as designated in Regulations[45] made by the appropriate authority (see paragraph 10.15 below);
- A person (referred to as a 'consultee') who knows the potential participant and who must be consulted about whether it is appropriate to involve the person lacking capacity in the research (see paragraphs 10.23-10.28 below); and
- The researchers directly undertaking the research (see Part 3 below).

Requirements for approval of a research project

10.12 If the Act applies to the research (see paragraph 10.10 above), research cannot take place on or in relation to a person lacking capacity unless:

- The approval of "the appropriate body" has been obtained; and

[45] The content of these Regulations will form the basis of a separate consultation in due course and this aspect of the Code may therefore need to be revised or added to once that consultation is complete and the Regulations have been finalised.

- The research is carried out in accordance with other conditions specified in the Act, which relate to the consultation of the carer of a person lacking capacity (or other consultee) and respecting the objections of a person lacking capacity during the course of the research.

10.13 The Secretary of State for Health (in respect of England) and the National Assembly for Wales (in respect of Wales) are required to set out in Regulations[46] who is the "appropriate body" to give approval in relation to particular types of research project. It is currently envisaged that "the appropriate body" is likely to be an independent Research Ethics Committee.

10.14 The Report of the "Ad Hoc Advisory Group on the Operation of NHS Research Ethics Committees" was published in June 2005. Changes to the NHS research ethics committee system will be phased in from spring 2006.

10.15 The appropriate body can only approve a research project if the following requirements are met:

- The research is connected with an impairing condition affecting the person lacking capacity or the treatment of that condition (see paragraphs 10.16-10.17 below);
- There are reasonable grounds for believing that research of comparable effectiveness cannot be carried out if the project is confined to those who have capacity to consent to it;
- The research has a potential benefit to the person lacking capacity that is not disproportionate to the burden imposed on him/her by participating in the research; or
- The research is intended to provide knowledge of the cause or treatment of, or the care of persons with, the same or similar condition as the person lacking capacity - if research falls into this category only, the risk to the person lacking capacity of taking part in the research must be negligible and anything done to or in relation to him/her must not interfere with his/her freedom of action or privacy in a significant way, or be unduly invasive or restrictive (see paragraphs 10.18-10.19 below); and
- Reasonable arrangements are in place to ensure that the necessary consultation with carers (or other consultee) will take place and other safeguards implemented (see paragraphs 10.20-10.21 and Part 3 below).

What is an "impairing condition"?

10.16 The Act allows research that is connected to an impairing condition or its treatment (treatment includes a diagnostic or other procedure). An "impairing condition" is defined in section 31(3) as a condition which is (or may be) attributable to, or which causes or contributes to (or may cause or contribute to), the impairment of, or disturbance in the functioning of, the person's mind or brain. This definition recognises that the link between a person's condition and any impairment of, or disturbance in the person's mind or brain may be

[46] The content of these Regulations will form the basis of a separate consultation in due course and this aspect of the Code may therefore need to be revised or added to once that consultation is complete and the Regulations have been finalised.

unclear or only hypothesised and it may be valid to conduct research to see whether the condition and the particular impairment or disturbance are linked.

> Mr N has Down's syndrome and is now in his early 40s. He has lived for many years in supported housing and worked in a local supermarket. Several months ago he became very bad tempered and aggressive whereas he had previously been very easy-going. While previously his work had always been of a reliably good standard, he started to make mistakes and became confused and forgetful. His consultant believes that these are indications of the onset of Alzheimer's Disease. Mr N's condition has continued to deteriorate, to the extent that he no longer has capacity to consent to the treatment he is given or to make other decisions relating to his care. His consultant is seeking approval to involve Mr N in a research project to investigate the detection and cause of dementia in people with Down's syndrome.

10.17 The definition also recognises the need for research into matters that are not directly connected to the main cause of the lack of capacity - for example, research into a possible side-effect of drug treatment for schizophrenia. Another example might be research into the failure of bodily systems that might accompany a heart attack, or to prevent kidney failure in a person in a coma following a car accident or heart attack. The impairing condition would be the trauma or shock following the sudden crash or heart attack. The appropriate body would have to be satisfied that there was a good case for believing that the research into kidney failure was connected to the impairing condition, or its treatment, before it could approve such research. The definition also covers research that focuses on the lack of capacity in itself, and the life experiences that the person has as a result of losing decision-making capacity. This might include, for example, research on the role of health facilitators for people with learning disabilities; or research that explores the consequences of a lack of capacity on the wider health or well-being of the individual.

What is "negligible risk"?

10.18 Research projects vary considerably in the invasiveness or discomfort of the procedures involved. For example, research may involve no more than observation of people lacking capacity or asking questions of carers or other informants. Or it may include direct physical or psychological assessment of people lacking capacity to consent. It can also involve specific investigations, such as blood tests or brain scans. Such research interventions involve different levels of potential inconvenience or discomfort. Where research is intended to provide knowledge, rather than direct benefit to the person lacking capacity, the approving body will need to be satisfied that the person will suffer no harm or distress and only minimum inconvenience or discomfort, in order to conclude that the risk in taking part in the research is negligible.

> A research project is devised to study the abilities of people with a 'mental disability' (such as a learning disability, dementia or severe mental illness) to make particular financial decisions and to investigate specific communication techniques which may enhance their decision-making capacity. Some of the potential participants lack capacity to consent to their participation in the research. The Research Ethics Committee is satisfied that some participants may benefit from the study, in that their capacity to make financial decisions

may be improved. For those who will not gain any direct benefit, the Committee is satisfied that the research methods to be used (psychological testing and different communication techniques) will involve no risk to participants nor any significant inconvenience to participants and that the research could not have been undertaken as effectively on those without capacity.

What is "unduly invasive or restrictive"?

10.19 Similarly, research intended to provide knowledge rather than direct benefit to the participant must also not interfere with the person's freedom of action or privacy, or be "unduly invasive or restrictive". For example, taking a single blood sample for research into the genetic causes of a learning disability could be deemed to be not unduly invasive. But the taking of repeated blood samples – perhaps hourly or daily solely for the purposes of research, to follow the course of a disease - could be said to be unduly invasive.

Consultation requirements and other safeguards

10.20 The appropriate body must also be satisfied that there are reasonable arrangements in place for ensuring that the requirements set out in sections 32 and 33 of the Act are met. These requirements (described in more detail in Part 3 of this chapter) relate to:

- Consultation with carers of the person lacking capacity whom it is proposed to involve in the research (see paragraphs 10.23-10.28 below); and
- The need to respect the objections, wishes and feelings of the person participating in the research during the research project.

10.21 In addition, under the requirements of section 32, the appropriate body will need to consider whether the research proposal provides sufficient information about the procedure that will apply where, as part of the research project, treatment might need to be provided to a person lacking capacity as a matter of urgency where it is not possible to consult that person's carer in accordance with section 32 (see paragraphs 10.29-10.31 below).

Part 3: Responsibilities of researchers and additional safeguards

The research proposal

10.22 Prior to seeking approval for any particular research project, researchers must ensure that the research proposal meets the requirements for approval as set out in section 31 (see paragraph 10.15 above) and that the arrangements and procedures for meeting all these requirements are fully documented in the proposal. The appropriate body, as set out above, may only approve the research project if the requirements are met.

Consulting carers

10.23 Once the research project is approved, section 32 imposes important requirements on the researcher conducting the research whenever, as part of that project, s/he wishes to carry out research on, or in relation to, a person

who lacks capacity to consent to taking part in the project. The requirements relate to consulting a carer of the person lacking capacity or someone who is interested in the person's welfare.

Who can be a consultee?

10.24 The researcher must take reasonable steps to identify someone who is engaged in caring for the person lacking capacity (but not in a professional capacity or for remuneration) or who takes an interest in the person's welfare and who is willing to be the consultee. The consultee is most likely to be a family carer, but could be an attorney acting under a Lasting Power of Attorney, or a court appointed deputy. However, a court-appointed deputy who had no relationship with, or personal knowledge of, the person lacking capacity before his/her appointment as deputy (such as a solicitor appointed as a financial deputy) should not act as the consultee if s/he had not been engaged in caring for the person who lacks capacity.

10.25 If the researcher is unable to identify a carer who is not acting in a professional capacity or for remuneration, or no such person who is willing to be a consultee, the researcher is required to nominate a person to be the consultee. That nomination is to be undertaken in accordance with guidance issued by either the Secretary of State for Health (in England) or the National Assembly for Wales (in Wales).[47] The person who is nominated must have no connection with the particular research project.

10.26 In deciding whether someone is 'connected with the project' researchers should use a wide interpretation. The term is intended to capture a range of possible connections with the particular study – it would include someone who is involved or has a connection with either the research itself or a member of the research team, and also wider connections such as direct links to sources of funding for the study or with the appropriate body which approved the project. However, some connections will be irrelevant – for example, a person who had worked with the researcher in a previous research project but who has no connection with the current project would not be excluded. It is also not intended to exclude people whose only connection is working in the same hospital as the researcher, or living in the same street, for example.

Consultation issues

10.27 Once a consultee has been identified, the researcher must then provide the consultee with information about the research project and ask him/her:

- For advice about whether the person lacking capacity should take part in the project; and
- What, in the consultee's opinion, would be the wishes and feelings of the person lacking capacity about taking part in the project, if the person had capacity to express a view.

10.28 If at any time, the consultee advises the researcher that in his/her opinion, the wishes and feelings of the person lacking capacity would be likely to lead him/her to:

[47] This section of the Code may be expanded once that guidance has been finalised.

- Decline to take part in the project; or
- Wish to withdraw from it, …

…then the researcher must ensure that the person lacking capacity is not enrolled in the project or is withdrawn from it (as appropriate). However, if the person lacking capacity is already taking part in the research project and has been receiving treatment as part of that project, the researcher may decide that the treatment should continue if there are reasonable grounds for believing that to withdraw it would cause a significant risk to the person's health. The person may therefore not be withdrawn from the research project for as long as that risk exists.

When consultation may not be practicable

10.29 Section 32(8)-(9) sets out limited circumstances in which the researcher may not be required to seek the advice of the consultee. These circumstances apply where, as a matter of urgency, treatment is being, or is about to be, provided for a person lacking capacity. If the researcher considers that, having regard to the nature of the research and the particular circumstances of the case, it is also necessary to take urgent action for the purposes of the research, but it is not reasonably practicable to seek the consultee's advice, treatment may nevertheless be provided if:

- The researcher has the agreement of a registered medical practitioner who is not involved or connected to the research project; or
- If obtaining that agreement is not practicable, s/he acts in accordance with a procedure approved by the appropriate body at the time when the research project was approved.

10.30 The medical practitioner may have a connection to the person lacking capacity (for example being his/her GP) but must not be involved in the organisation or conduct of the research project. The intention here is to avoid potential conflicts of interest where there may be seen to be an incentive or other motive to enrol the person in the project or continue the research.

10.31 This exception to the requirement to consult only applies for as long as the researcher has reasonable grounds for believing that taking the action concerned is urgent. In this context, urgency means those situations where immediate treatment is essential, for example in trauma care or if the person suffers a heart attack or stroke at home or in a primary care setting. It does not apply where the researcher simply wants to act quickly.

Additional safeguards

10.32 Where a person lacking capacity is taking part in a research project that has been approved by the appropriate body, section 33 imposes some further requirements that are intended to act as additional safeguards to protect the person lacking capacity.

10.33 In the course of the research, the researcher may not do anything to, or in relation to, the person lacking capacity:

- To which the person appears to object (whether by showing signs of resistance or otherwise) except where what is being done is intended to protect him/her from harm or reduce or prevent pain or discomfort (for example steadying a person's arm in case s/he flinches when a blood sample is taken); or
- Which would be contrary to an advance decision to refuse treatment (see chapter 8) or any other form of statement made by the person and not subsequently withdrawn, of which the researcher is aware.

10.34 Section 33 also makes clear the general principle that the interests of the person lacking capacity must always be assumed to outweigh those of science and society.

10.35 As a further safeguard, section 33(4)-(5) require that the person lacking capacity be withdrawn from a research project without delay:

- If the person indicates in any way that s/he wishes to be withdrawn from the project; or
- If anyone conducting the research has reasonable grounds for believing that the requirements upon which the approval of the appropriate body were given (see paragraph 10.15 above) are no longer met.

10.36 However, the person lacking capacity need not be withdrawn where s/he has been receiving treatment as part of the research project and the researcher has reasonable grounds for believing that there would be a significant risk to that person's health if that treatment were to be withdrawn (see paragraph 10.28 above).

The Human Tissue Act 2004

10.37 The Human Tissue Act 2004 is concerned with the storage and use for 'scheduled purposes' of tissue removed from living persons, and with the removal, storage and use for scheduled purposes of tissue from deceased persons. The removal of tissue from a living person (e.g. taking a sample for diagnosis or removal of tissue in surgery) may only be done with the person's consent, or, in the case of people lacking capacity to consent, under the provisions of this Act (see chapter 5). The storage and use of tissue after a person's death, albeit removed whilst they were alive, is still treated as tissue from a living person.

10.38 'Scheduled purposes' include transplantation, research, and the obtaining of medical or scientific information that may be of use to another person. Storage and use of tissue for these purposes requires the consent of the individual from whom they came, if they have capacity to give such consent.

10.39 The storage or use of tissue from living persons for certain other purposes does not require consent, whether the tissue has been taken from people who have capacity or who lack capacity to consent. The Act does not therefore apply where the tissue is used for the following purposes:

- Clinical audit;
- Education or training relating to human health;
- Performance assessment;

- Public health monitoring;
- Quality assurance;
- Research where the samples are anonymised and the research has ethical approval.

10.40 Where consent is required for the storage and use of tissue (such as for transplantation, research or obtaining scientific or medical information), the Human Tissue Act provides for Regulations[48] to specify the circumstances in which consent from a person lacking capacity may be deemed to be in place. The Regulations provide for such tissue to be stored or used lawfully for a scheduled purpose in the following circumstances:

- Where it is in the best interests of the individual concerned;
- Where it is in the context of research that is authorised under the Medicines for Human Use (Clinical Trials) Regulations 2004; or
- Where it is in the context of research that is permitted under sections 30-34 of the Mental Capacity Act 2005.

Further guidance on the storage and use of tissue taken from people lacking capacity to consent is given in the Human Tissue Authority's Codes of Practice.[49]

Part 4: Transitional arrangements

10.41 Section 34 sets out the arrangements required by the Secretary of State for Health (in England) and the National Assembly for Wales (in Wales) to govern research started before section 30 of the Act comes into force. Such research involves people who had capacity to consent to participation when first enrolled in the project, but who later lose the capacity to consent to continue to be involved before the end of the research. These arrangements are intended to smooth the transition for researchers from the common law position to the statutory safeguards set out in the Act and to avoid the need to stop ongoing and essential research.

10.42 Section 34 provides for Regulations[50] to provide flexibility in the interpretation of the safeguards that may be applicable to protect people lacking capacity in specific circumstances. Only specific types of research will fall under these Regulations – that is research:

- That started before Section 30 came into force;
- That enrolled people who had capacity and then went on to lose it; and
- Which involves material and data collected before the onset of the lack of capacity.

It is envisaged that the protections that will apply in such cases will be similar to those in sections 31-33 of the Act, as described in Part 3 above.

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48 The Human Tissue Act 2004 (Persons who Lacking Capacity to Consent) Regulations 2005 have been consulted on in draft. It is proposed that provisions referring to sections 30 to 34 of the Mental Capacity Act will be consulted on and put before Parliament to come into force at the same time as those sections

49 A reference to the Codes will be included once known

50 The content of these Regulations will form the basis of a separate consultation in due course and this aspect of the Code may therefore need to be revised once that consultation is complete and the Regulations have been finalised.

Chapter 11 - Children and young persons

Introduction

11.1 The Mental Capacity Act applies primarily to adults who lack capacity, leaving matters concerned with the care and welfare of children and young persons to be resolved under the Children Act 1989, or the inherent jurisdiction of the High Court. However, some overlap is unavoidable, as explained in this chapter. **Part 1** looks at the Act's provisions in relation to children under 16 years. **Part 2** explains the position of young persons aged 16 and 17 years and the overlapping jurisdictions that may affect them.

11.2 Within the Code, those under 16 are referred to as 'children', whilst those aged 16-17 are referred to as 'young persons'. All references to 'the Act' mean the Mental Capacity Act 2005, whereas other legislation such as the Children Act 1989, are referred to in full.

11.3 This chapter highlights the overlap between the various provisions relating to children and young persons who lack capacity. It focuses on the powers contained within the Act and should not be taken as a definitive guide to the powers contained within other legislation, such as the Children Act 1989.

Part 1: Children under 16 years

11.4 Section 2(5) of the Act makes it clear that powers under the Act generally only arise where the person lacking capacity is aged 16 or over. Any decisions that need to be made on behalf of children who lack capacity to make them, and any acts in connection with their care or treatment, can be carried out by or with the consent of those who have parental responsibility. Any disputes arising on these matters are resolved under the Children Act 1989 or the inherent jurisdiction of the High Court, or where the child is subject to detention in hospital for treatment for mental disorder, by the Mental Health Act 1983.[51]

Property and Affairs

11.5 The only power provided by the Act for children under 16 is provided under Section 18(3). This extends the powers of the Court of Protection to make decisions relating to the property and affairs of a person under 16, in circumstances where the court considers it is likely that the person will still lack capacity to make decisions in respect of the matters in question, after reaching the age of 18. This prevents the need for new proceedings to be commenced once the child reaches adulthood, and continues the jurisdiction of the previous Court of Protection in relation to children under 16.

11.6 The Court of Protection can use any of the powers available under section 16 to make arrangements for the management of the child's property and affairs, with the exception of making a will on the child's behalf (section 18(2)). The powers available include:

[51] Guidance on the position of children and young people under the age of 18 in relation to the Mental Health Act was issued by the Department of Health & Welsh Office, *Mental Health Act 1983 Code of Practice* (TSO, 1999), chapter 31,http://www.dh.gov.uk/assetRoot/04/07/49/61/04074961.pdf

- Making a single order (for example, concerning the investment of an award of compensation for the child); and/or
- Appointing a deputy with authority to manage the child's property and affairs and to make on-going financial decisions on the child's behalf.

11.7 As with any other case, the court must make the decision it considers to be in the child's best interests, having had regard to the Act's principles.

> Tom was 9 years old when a drunk driver knocked him off his bicycle. He suffered severe head injuries causing permanent brain damage and was awarded a significant amount of damages in the personal injury claim taken by his parents on his behalf. Tom is unlikely to recover sufficiently to have the capacity to be able to make financial decisions for himself when he reaches 18. The Court of Protection makes an order appointing Tom's father as deputy to manage his financial affairs, and pay for the care Tom will need in the future

Ill Treatment and Neglect

11.8 Section 44, concerning the offence of ill treatment or wilful neglect of a person lacking capacity, also applies to children under 16 as no lower age limit is specified for the victim of such an offence. However, the lack of capacity of a child victim at the time of the offence must be caused by an impairment of, or disturbance in the functioning of, the child's mind or brain (see chapter 3) and not solely as a result of the child's youth or immaturity.

Part 2: Young Persons aged 16 or 17 years

11.9 Most of the Act's provisions apply to young persons aged 16 years and over. In respect of young persons the provisions made under the Children Act 1989 are not displaced by the Act, but an overlap exists between the provisions. In order for the decision-making arrangements set out in the Mental Capacity Act to apply to young persons, they must lack capacity within the meaning of the Act. In such situations the provisions of the Act or the Children Act 1989 may apply, depending upon the particular circumstances. Similarly, the Act does not replace the Wardship jurisdiction of the High Court.

11.10 There are no criteria for deciding when to use either Act, or to commence proceedings under the inherent jurisdiction of the High Court. The facts and outcomes required will be individual to each case and will need to be considered. However, the following highlight some issues for consideration (see also paragraphs 11.20-11.22 below).

11.11 For example, there may be circumstances where it is in the young person's best interests for a parent or, in some cases, someone independent of the family, to be appointed as deputy to make financial or personal welfare decisions. One example may be where a young person is awarded a significant amount of compensation in a personal injury case, and a solicitor is appointed as a financial deputy, working with a case manager to ensure that the money is suitably invested to provide for the young person's needs throughout his/her lifetime. Or it may be appropriate for the Court of Protection to make welfare decisions, for example where the young person should live, or decisions concerning medical treatment for a young person

lacking capacity to consent, where it is considered that those with parental responsibility are not acting in the young person's best interests.

Provisions of the Act not available to 16 or 17 year olds

(i) Lasting Powers of Attorney

11.12 Section 9(2)(c) confirms that a Lasting Power of Attorney (LPA) may only be made by a person who has reached the age of 18.

(ii) Advance decisions to refuse treatment

11.13 Similarly, section 24(1) confirms that advance decisions to refuse treatment can only be made by a person who has reached the age of 18. While 16 and 17 years olds who have capacity may give, and sometimes refuse, consent to medical treatment at the time it is offered (see paragraph 11.15 below), they have no power to make an advance decision under the terms of the Act. However, their wishes surrounding the refusal of particular forms of treatment should be taken into account as part of a best interests assessment if they no longer have capacity to give or refuse consent in the future. Any views they have previously expressed, either orally or in writing, about treatment preferences or dislikes should be fully taken into account in deciding what may be in their best interests at a time when they may lack capacity to express those views.

(iii) Making a will

11.14 The law generally does not permit anyone below the age of 18 years to make a will. Therefore, section 18(2) confirms that the Court of Protection has no power to make a statutory will on behalf of young people aged less than 18.

Acts in connection with care or treatment

11.15 A young person is presumed in law to be competent to give consent for themselves for their own surgical, medical or dental treatment, and any associated procedures, such as investigations, anaesthesia or nursing care.[52] In relation to decisions about other types of care and treatment, which are not covered by the Family Law Reform Act 1969, the test laid down in the case of Gillick v West Norfolk and Wisbech Area Health Authority[53] will apply. A person with parental responsibility for a young person also retains the concurrent right to give consent in such situations. So long as the young person is considered to have the mental capacity to consent to his/her own treatment decisions, his/her views must be respected.[54] However, if a young person of 16 or 17 who has capacity refuses treatment, a person with parental responsibility may overrule the refusal to give consent. A court may also overrule the young person's refusal or, where necessary, the person with parental responsibility's refusal. Any dispute about the care or treatment to be provided to a young person with capacity to decide for him/herself, cannot

[52] Family Law Reform Act 1969, section 8(1)

[53] In the case of *Gillick v West Norfolk and Wisbech Area Health Authority,* [1986] 1 AC 112 the court found that a child below 16 who has sufficient intelligence and understanding to understand what is proposed will be competent to consent to medical treatment.

[54] *Re W (A minor) (Medical treatment: Court's jurisdiction)* [1993] Fam 64, [1992] 4 All E R 627, CA

be decided by the Court of Protection and can only be decided in legal proceedings in the Family Division of the High Court.

11.16 Where 16 or 17 year olds lack capacity to consent to an act in connection with their care or treatment, then the act can be performed either with the consent of a person with parental responsibility acting in the young person's best interests, or under the protection of section 5 of the Act (see chapter 5) or, in disputed cases, by the court. The court has identified some procedures that should not be performed where one person with parental responsibility refuses to consent.[55] In any case, every effort should be made to ascertain the young person's wishes and feelings, both past and present, as well as his/her other beliefs, values and other factors so far as this is possible, as these will be relevant in deciding what is in the young person's best interests under section 4 of the Act.

11.17 The Act does not require that parental consent be sought in all situations for 16 and 17 year olds who lack capacity and in the absence of such consent, professionals providing necessary care or treatment in the young person's best interests would attract protection from liability under section 5 of the Act. However, anyone involved in caring for the young person or interested in his/her welfare, in particular those with parental responsibility, must be consulted as part of the assessment of the young person's best interests (section 4(7)) where it would be practicable and appropriate to do so (see chapter 4).

11.18 Particular difficulties may arise in relation to young people with mental health problems who require in-patient psychiatric treatment, and who are treated informally rather than detained under the Mental Health Act 1983. If they are over 16 and lack capacity, decision-making for these young people, and in particular, acts in connection with their care or treatment, can be regulated by the Act's provisions, and in accordance with the principles set out in section 1. In such cases, anyone with parental responsibility and other relevant people involved in the care or interested in the welfare of the young person should be consulted in determining the young person's best interests (see chapter 4). However, the Act does not permit any actions that amount to a deprivation of a young person's liberty (see chapter 5). In such circumstances, additional safeguards are required, either through detention under the Mental Health Act 1983 (see also chapter 12) or authorisation by a court, for example via section 25 Children Act 1989 or through legal proceedings in the Family Division of the High Court or the Court of Protection (see paragraphs 11.20-11.22 below).

11.19 If there is a disagreement about the young person's capacity, or about whether a particular act is in his/her best interests, legal proceedings may be necessary to resolve the dispute, if it cannot be resolved in any other way (see chapter 14).

Legal proceedings in relation to young people who lack capacity

11.20 In some cases, legal proceedings may be required to resolve disputes concerning the care, treatment or welfare of young persons aged 16 or 17 who lack capacity to make such decisions, or to make legally effective arrangements for their care. A case relating to a 16 or 17 year old who lacks

[55] See *Re B (a child)(immunisation)* [2003] EWCA Civ 1148

capacity could, potentially, be heard either in the Family Division of the High Court or in the Court of Protection.

11.21 However, it would not make sense to require two sets of legal proceedings to be conducted within a short period of time where the problems arising from the young person's lack of capacity are likely to continue after aged 18. It may be more appropriate for the Court of Protection to hear those cases, while one-off cases, such as those relating to urgent medical treatment for a 16 or 17 year old lacking capacity to consent, may be referred to the Family Division of the High Court.

11.22 The Act, therefore, allows the Lord Chancellor to make an order allowing for transfer of proceedings from the Court of Protection to the family courts, and vice versa (section 21).[56] The choice of court will depend on what is appropriate in the particular circumstances of the case. Practice Directions are likely to be issued in due course giving guidance on the types of cases appropriate to each jurisdiction.[57]

Sheila is 17 and has profound learning disabilities, and lacks the capacity to decide where she should live. Her parents are involved in a bitter divorce and cannot agree on a number of decisions about Sheila's care including where she should live. Her mother wants to continue to look after Sheila at home, but her father wants Sheila to move into a care home. In this case, it may be more appropriate for the Court of Protection to deal with the disputed issues. This is because an order made in the Court of Protection will continue into Sheila's adulthood, whereas any orders made by the family court under the Children Act 1989 will expire on Sheila's 18th birthday.

[56] A reference will be included once known

[57] A reference will be included once known

Chapter 12 - Relationship between the Mental Capacity Act and the Mental Health Act 1983

The Government intends that the Mental Health Act 1983 will be replaced by a new Mental Health Bill, which is due to be introduced in Parliament during 2006. This chapter will be revised to take account of the new mental health legislation when appropriate.

Introduction

12.1 This chapter gives guidance on the interface and overlap between the Mental Capacity Act 2005 (the Act) and the Mental Health Act 1983 in relation to the provision of treatment for mental disorder of adults who lack capacity to make decisions relating to the proposed treatment. **Part 1** summarises the main provisions relating to treatment for mental disorder in both the Mental Health Act 1983 and the Act and describes when the powers of detention and treatment under the Mental Health Act 1983 should be used rather than the care and treatment provisions in the Act. **Part 2** describes the implications of the Act for people lacking capacity who are subject to the provisions of the Mental Health Act 1983.

Part 1: The Mental Health Act and people who lack capacity

Mental Health Act 1983

12.2 The Mental Health Act 1983 exists primarily to provide a framework in which care and treatment can be given without consent to people who suffer from a serious mental disorder, which puts them, or other people at risk. In particular:

- It defines the circumstances in which mentally disordered people can be detained in hospital for assessment or treatment;
- It allows people detained in hospital to be treated for their mental disorder without their consent, subject to various safeguards;
- It defines the circumstances in which mentally disordered people can be made subject to guardianship or after-care under supervision, and sets out the powers of guardians and supervisors (respectively).

12.3 It is assumed that health and social care professionals working with people who may be affected by the Mental Health Act 1983 will be familiar with its provisions and with the guidance on the application and operation of the Act given in the Mental Health Act Code of Practice[58].

12.4 People who are subject to the Mental Health Act 1983 do not necessarily lack capacity, and most people who lack capacity will never be affected by the provisions of the Mental Health Act 1983. However, there will be some people who are subject to the Mental Health Act 1983 and who also lack capacity in relation to some decisions, and who will therefore inevitably be affected both by the Mental Health Act 1983 and the Act.

[58] Department of Health and Welsh Office, *Mental Health Act 1983 Code of Practice* (TSO, 1999), available on http://www.dh.gov.uk/assetRoot/04/07/49/61/04074961.pdf

Treatment for mental disorder and the Mental Capacity Act

12.5 As described in chapter 5 above, acts in connection with the care or treatment of people lacking capacity to consent may be carried out under the protection from liability provided by section 5 of the Act, so long as the Act's principles have been applied and the actions taken are in the best interests of the person lacking capacity. Section 5 applies to care or treatment for both physical and mental conditions. It can therefore provide a legal basis for the treatment of people with serious mental disorders, whether or not they could instead be treated under the Mental Health Act 1983. The question may arise, therefore, as to which legal framework should be used to provide care or treatment for mental disorder for people who lack capacity to consent to that care or treatment.

Which legal framework should be used?

12.6 It is important to remember the scope of both pieces of legislation, which can be summarised as follows:

- The Act is only relevant in relation to persons aged 16 years or over who lack capacity to consent at the time a decision needs to be made or action needs to be taken in connection with the person's care or treatment;
- If treatment is required for a physical condition, the Mental Health Act 1983 is irrelevant and the Act must be used;
- If treatment is required for a mental disorder and the patient retains capacity, the Act is irrelevant. If detention is deemed necessary, the Mental Health Act 1983 must be used;
- The Mental Health Act 1983 can only be used where the relevant grounds for admission to hospital for assessment or treatment are met.

12.7 In situations where potentially either legal framework may apply, the relevance and appropriate use of either Act is a matter for professional judgement, taking account of the specific legal requirements and the individual needs and circumstances of patients who lack capacity. The following paragraphs give some pointers to assist professionals decide which legal framework is the most appropriate.

Detention under the Mental Health Act 1983

12.8 Section 6 of the Act sets out conditions which must be satisfied for an act of restraint to attract protection from liability under section 5 (and similar restrictions apply to decisions taken by attorneys and deputies). Restraint is defined as the use, or threatened use, of force, and any restriction on the person's liberty of movement. Broadly speaking, an act of restraint will only attract protection from liability under section 5 where it is necessary to protect the person lacking capacity from harm, and the restraint is proportionate to the likelihood and seriousness of that harm.

12.9 However, protection from liability under section 5 will not extend to actions which go so far as to *deprive a person of his/her liberty* (further guidance on the distinction between 'restriction' and 'deprivation' of liberty is given in chapter 5 and by the Department of Health and National Assembly for

Wales[59]). Actions amounting to a deprivation of liberty will only be lawful if they have some other legal basis and are accompanied by further safeguards, such as those surrounding detention under the Mental Health Act 1983. Therefore, if a person needs to be detained because of their mental disorder, consideration should be given to using the Mental Health Act 1983.

12.10 Possible circumstances which might indicate the need for assessment for admission to hospital under the Mental Health Act 1983 include:

- The person needs treatment which cannot lawfully be provided under the Act - for example because the person has made a valid and applicable advance decision to refuse a necessary element of the treatment (see paragraph 12.23 below and chapter 8);
- It is not possible to provide appropriate care or treatment in a way which does not amount to deprivation of the person's liberty;
- The person is resisting treatment and restraint is required regularly or frequently, or for a prolonged period, in order to ensure that s/he receives treatment;
- There is a risk that the person might otherwise not receive the necessary treatment and either the person him/herself or others might potentially suffer harm as a result.

Mr O is a 54 year old single man with learning difficulties. He lives in a group home. For the last four years, he has periodically suffered from depression, which has necessitated him being treated as an informal in-patient in a psychiatric hospital on two separate occasions. He is currently an informal patient on an open ward in a local psychiatric hospital. He is severely depressed and is on 24 hour close observation. He is described in the healthcare records as not resisting treatment. He is now declining to eat. Mr O's consultant has formulated a treatment plan, which includes a course of medication, ECT and feeding by naso-gastric tube if he continues to refuse to eat. Mr O's relatives are unsure that such intrusive measures are needed. The consultant considers that Mr O is not capable of consenting to treatment and now thinks that detention under the Mental Health Act 1983 may be appropriate, given the serious ongoing nature of Mr O's condition.

Guardianship and after-care under supervision

12.11 When deciding whether to make (or support) an application for a person to be made subject to guardianship under the Mental Health Act 1983, applicants (normally approved social workers) and doctors giving supporting medical recommendations are required to consider whether guardianship is necessary in the interests of the welfare of the person concerned or for the protection of other persons. In relation to people who lack capacity to make decisions concerning their own welfare, the Act (section 5) offers protection from liability for actions taken in connection with the care or treatment. While this is a factor to be taken into account, it will not by itself determine whether guardianship is necessary or unnecessary. Applicants need to consider all the circumstances of the particular case. The same approach applies to

[59] Department of Health, *Advice on the decision of the European Court of Human Rights in the case of HL v UK (the "Bournewood" case)* Gateway Ref 4269, (10 December 2004), available at http://www.dh.gov.uk/assetRoot/04/09/79/92/04097992.pdf; National Assembly for Wales, Welsh Health circular WHC (2005) 005

applications for after-care under supervision. (See also paragraph 12.28 on the effect of guardianship on the powers of attorneys and deputies.)

12.12 For a person subject to guardianship under section 7 of the Mental Health Act 1983, the guardian can require the person:

- To reside at a specific place (but does not have power to detain the person there);
- To attend for medical treatment, occupation, education or training (but not to consent to treatment on the person's behalf);
- To be seen by specified professionals such as doctors.

12.13 If the person lacking capacity meets the criteria for guardianship, and where any issues of concern lie within the guardian's powers listed above, an application for guardianship may be helpful both in clarifying the guardian's role and in making available to the person lacking capacity additional safeguards under the Mental Health Act 1983.

12.14 A particular example of when guardianship might be considered is where a person lacking capacity resides in a care home in conditions which severely restrict his/her freedom of movement. Although guardianship under the Mental Health Act 1983 does not provide authority for depriving the person of his/her liberty, an application for guardianship may:

- Provide a degree of protection and additional safeguards for the person through the formal requirements for review under the Mental Health Act 1983;
- Provide explicit authority for the person to be returned to the care home if s/he went absent, without the leave of the guardian, from the place where s/he is required to reside.

Part 2: Implications of the Mental Capacity Act on patients subject to the Mental Health Act

12.15 The Mental Health Act 1983 is concerned only with the provision of treatment for mental disorder. People who lack capacity who are also subject to the provisions of the Mental Health Act 1983 will still be protected by the Act in relation to other types of decisions or actions affecting them. Therefore, where a decision unrelated to treatment for mental disorder needs to be made (including decisions about physical healthcare, welfare or financial matters), an assessment must be made of the individual's capacity to make that particular decision at the time it needs to be made (see chapter 3). Following a finding of lack of capacity, the principles and provisions of the Act would apply to all such decisions or actions, regardless of whether the person was subject to the provisions of the Mental Health Act 1983.

12.16 The following paragraphs consider the impact of the Act on specific areas of decision-making affecting patients lacking capacity who are also subject to provisions of the Mental Health Act 1983.

Treatment for mental disorder

12.17 Section 28 of the Act ensures that the provisions of this Act do not apply to any treatment that is given to a patient provided under the authority of Part IV

of the Mental Health Act 1983. This means that the Act does not provide a defence for treatment given to a person lacking capacity who is detained under the provisions of the Mental Health Act 1983. It also means that attorneys and deputies cannot consent to, or refuse such treatment on patients' behalf. In other words, the consent to treatment provisions and safeguards in Part IV of the Mental Health Act 1983 will 'trump' the Act's provisions in relation to treatment for mental disorder of patients liable to be detained under the Mental Health Act 1983.

12.18 That is because Part IV of the Mental Health Act 1983 itself provides the authority to treat patients liable to be detained under the Mental Health Act 1983 for their mental disorder without their consent, subject to various safeguards. Mental disorder for these purposes is defined in section 1 of the Mental Health Act.

12.19 However, the provisions of the Act (section 5) will be relevant to treatment for mental disorder of:

- Patients who have been admitted to hospital in an emergency under section 4(4)(a) of the Mental Health Act 1983 on the basis of a single medical recommendation, where the second recommendation has yet to be received;
- Hospital patients temporarily detained under section 5 of the Mental Health Act 1983 pending a decision on whether to make an application for their substantive detention;
- Patients remanded by a court to hospital for a report on their medical condition under section 35 of the Mental Health Act 1983;
- Patients detained under section 37(4), 135 or 136 of the Mental Health Act 1983 in a place of safety;
- Patients subject to guardianship or supervised after-care, or who have been conditionally discharged (and not recalled to hospital).

12.20 Part IV of the Mental Health Act 1983 does not apply to such patients[60]. Therefore where such patients lack capacity to consent, treatment provided may attract protection from liability offered by section 5, so long as the Act's principles have been complied with and the treatment is in the patient's best interests.

Psychosurgery and other treatments subject to special safeguards under section 57 of the Mental Health Act

12.21 Section 57 of the Mental Health Act 1983 prevents psychosurgery being carried out as a treatment for mental disorder without the consent of the patient concerned and the approval of an independent doctor and two other people appointed by the Mental Health Act Commission. The same rules apply to other treatments specified in Regulations under section 57. At the time of writing, the only treatment included in Regulations is the surgical implantation of hormones for the purpose of reducing the male sex drive[61].

12.22 Section 57 is within Part IV of the Mental Health Act 1983. There is, therefore, no defence in the Act to giving such treatments to a person lacking

[60] Mental Health Act 1983 section 56
[61] Mental Health (Hospital, Guardianship and Consent to Treatment) Regulations 1983 (SI 1983/893), regulation 16

capacity to consent to them, nor can an attorney or deputy consent to such treatments on a patient's behalf. Unlike the rest of Part IV, this applies to all patients, not just those detained under the Mental Health Act 1983. The effect is that these treatments should never be given to a patient who lacks the capacity to consent to them.

Advance decisions and treatment under the Mental Health Act

12.23 A valid and applicable advance decision to refuse treatment is not affected by the fact that a patient is subject to the Mental Health Act 1983. However, because the Mental Health Act 1983 provides the authority to treat patients for their mental disorder without their consent, subject to various safeguards, it also provides the authority to treat them for mental disorder despite their advance refusal of the treatment. An advance decision to refuse treatment should be taken into account by the clinicians concerned when deciding whether it is appropriate to provide the treatment for mental disorder, as if it were a contemporaneous refusal of consent by a patient.

12.24 For advance decisions to refuse treatment for mental disorder provided under the Act, (rather than the Mental Health Act 1983), please refer to chapter 8.

Treatment for other purposes

12.25 The Act will also be relevant to the care and treatment of detained patients, which is not for their mental disorder. Therefore, for example, a patient detained under the Mental Health Act 1983 for treatment for schizophrenia may also need treatment for diabetes. Similarly, a patient detained for treatment for personality disorder who lacks capacity may need dental treatment.

12.26 In all these cases, if patients lack capacity to consent to treatment, and there is no attorney or deputy with authority to consent on their behalf, then clinicians will need to provide care and treatment in their best interests, as they would for any other patient who lacks capacity (see Chapter 5).

> An elderly patient Mr P is currently in hospital receiving treatment under section 3 of the Mental Health Act 1983. Mr P suffers from paranoid schizophrenia, delusions, hallucinations and thought disorder. He has a history of mental illness but refuses all medical treatment, regarding it as unnecessary and part of a plot against him. Mr P has recently developed blood in his urine and was persuaded by staff to cooperate with an ultrasound scan, which revealed suspected renal carcinoma. The consultant believes that a CT scan is essential for the proper investigation and treatment of the carcinoma but Mr P refuses to consent to a general anaesthetic or any further medical procedures. Mr P is assessed as lacking capacity to consent or refuse treatment under the Act's test of capacity, on the basis that his mental illness causes an inability to understand the information regarding the need for treatment or to use or weigh that information in order to reach a decision. The Mental Health Act 1983 is irrelevant here, but under section 5 of the Act, doctors have protection to provide treatment in the absence of consent, so long as the principles of the Act have been complied with and the treatment is in Mr P's best interests.

The role and powers of attorneys and deputies

12.27 The fact that a person is subject to the Mental Health Act 1983 does not affect the validity of any Lasting Power of Attorney (LPA) or the authority of a deputy appointed by the Court of Protection to make decisions on behalf of a person lacking capacity. Similarly, it does not prevent such a person creating a new LPA, so long as s/he has the capacity to do so, nor does it prevent the court from appointing a deputy if such a person lacks capacity.

12.28 Attorneys acting under an LPA and court-appointed deputies will therefore be able to take any decisions in relation to the welfare, property or affairs of a person lacking capacity that they are authorised to take, but with two exceptions:

- They will not be able to consent on the patient's behalf to treatment which is regulated by Part IV of the Mental Health Act 1983 (see paragraphs 12.17-12.18 above);
- Provisions of the Mental Health Act 1983 confer on a guardian or supervisor the power to make certain decisions, including deciding where the person concerned is to reside. Those powers are conferred to the exclusion of anyone else[62], including the person themselves, and therefore the attorney or deputy.

12.29 In certain cases, conditions may be imposed on patients subject to the Mental Health Act 1983 in relation to leave of absence from hospital[63], after-care under supervision[64] and conditional discharge of restricted patients[65]. Conditions vary from case to case, but could include a requirement to live in a particular place, maintain contact with health services, or to avoid a particular area. If an attorney or deputy were to take a decision on the patient's behalf, which went against one of these conditions, the patient would be taken to have breached the condition. The Mental Health Act 1983 sets out the actions that could be taken in such circumstances. In the case of leave of absence or conditional discharge, this might involve the patient being recalled to hospital.

Patients' rights under the Mental Health Act 1983

12.30 Deputies or attorneys with relevant authority will also be able to exercise patients' rights under the Mental Health Act 1983 on their behalf. In particular, they will be able to exercise the patient's various rights to apply to the Mental Health Review Tribunal for discharge from detention, guardianship or after-care under supervision. This will be in addition to any rights that the patient's nearest relative is given by the Mental Health Act 1983.

12.31 To ensure that they are informed, and where relevant consulted, about the patient's care, attorneys and deputies are advised to make themselves known either to the clinician responsible for the patient's care (normally known as the Responsible Medical Officer), or to the managers of the hospital at which the patient is detained, or to the patient's guardian (normally the local social services authority) or supervisor (if the patient is subject to after-care under

[62] Mental Health Act 1983, section 8(1)
[63] Ibid, section 17
[64] Ibid, section 25D
[65] Ibid, section 73

supervision.) Hospitals which treat detained patients normally have a Mental Health Act Administrator's office, which may be a useful first point of contact.

IMCA advocates

12.32 As explained in chapter 9, the duty to consult an Independent Mental Capacity Advocate (IMCA) in relation to serious medical treatment or accommodation does not arise if the treatment is to be provided under the Mental Health Act 1983, or if the patient is to be required to live in the accommodation as a result of an obligation under the Mental Health Act 1983. That obligation might be a condition of leave of absence or conditional discharge from hospital or a requirement imposed by a guardian or a supervisor.

12.33 However, a duty to consult an IMCA may arise in connection with accommodation being planned for when a person detained under the Mental Health Act 1983 is discharged from hospital and is therefore subject to the requirements for after-care set out in the Mental Health Act 1983[66]. The duty arises if the person has no close relatives, friends or any other person to protect their interests. (See chapter 9).

[66] Mental Health Act 1983, section 117

Chapter 13 - Protection and Supervision

Introduction

13.1 This chapter explains how professionals and people acting with formal powers under the Act (i.e. attorneys and deputies) are expected to interact with the relevant agencies responsible for the protection of adults lacking capacity. This information will also be useful to everyone who cares for people who lack capacity, both family carers and other carers, paid and unpaid. The chapter therefore explains the relevant services that those organisations provide in relation to protecting adults who lack capacity and those who care for them.

13.2 The Act provides for the supervision, via the Office of the Public Guardian (OPG), of court-appointed deputies in co-operation with other relevant bodies. The OPG also has the function of dealing with concerns about the way in which deputies or attorneys are carrying out their duties and responsibilities. The Act complements current initiatives put in place by the Department of Health and the National Assembly for Wales to protect vulnerable adults.

13.3 This chapter provides general information on the protection of adults. **Part 1** provides a brief explanation of what is meant by abuse. **Part 2** gives an overview of the supervisory functions of the OPG and an explanation of how we expect those acting under the legislation to interact with the OPG. **Part 3** sets out a brief overview of the criminal offence of ill treatment or wilful neglect and **Part 4** provides a brief summary of other measures put in place to protect adults lacking capacity.

Part 1: What do we mean by abuse?

13.4 Abuse can cover a wide spectrum of actions. In some cases, abuse is clearly a deliberate act or omission, done with a malicious intent. But, sometimes, abuse is not intentional and may occur because the carer or decision-maker does not know how to act correctly or has not accessed appropriate help and support. In all cases, it is important that abuse is prevented if at all possible, and where it does occur, that it is investigated and dealt with effectively.

13.5 Guidance on protecting vulnerable people from abuse has been issued by the Department of Health for England namely 'No Secrets' [67] and by the National Assembly for Wales namely 'In Safe Hands'[68]. Both documents define abuse as any violation of an individual's human and civil rights by any other person or persons. Both documents describe a variety of forms of abuse, such as sexual, physical, verbal, financial or emotional abuse. It can be a single act, a series of repeated acts or failure to act, or neglect. Abuse can take place in any setting, for example in a person's own home, a care home or a hospital. "No Secrets" and "In Safe Hands" set out multi-agency procedures that must be followed when allegations of abuse are made or suspected (see paragraphs 13.23-13.24 below).

[67] Department of Health and Home Office, *No secrets: Guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse,* (2000) http://www.dh.gov.uk/assetRoot/04/07/45/40/04074540.pdf

[68] National Assembly for Wales, *In safe hands: Implementing adult protection procedures in Wales* (2000), http://www.wales.gov.uk/subisocialpolicy/content/pdf/safehands_e.pdf

Examples of abuse

13.6 There are many types of abuse and the main forms are as follows:

- **Financial abuse:** such as theft, fraud, undue pressure or the misuse or misappropriation of property, possessions or benefits;
- **Physical abuse:** such as slapping, pushing and kicking. It also includes the misuse of medication (for example, giving someone a high dose of medication in order to make them drowsy and 'less difficult') and placing inappropriate sanctions on an individual, for example refusing to give food at meal times because the person being cared for has been 'bad';
- **Sexual abuse:** such as rape and sexual assault. It also includes sexual acts to which the person has not consented, or could not consent or was pressurised into consenting;
- **Psychological abuse:** such as emotional abuse, threats of harm, restraint or abandonment, deprivation of contact and intimidation. This type of abuse can also include verbal threats and intimidation and will include threats to restrain someone's liberty;
- **Neglect and acts of omission:** such as ignoring the person's medical or physical care needs, failure to provide access to appropriate health or social care and the withholding of medication, adequate nutrition and heating;
- **Discriminatory abuse:** such as racist or sexist abuse or abuse that is based on a person's disability, and other forms of harassment, slurs or similar treatment. This will include making decisions based upon an unfavourable view of a person's sex, age, race, or religion. This type of abuse may arise as an aspect across all the forms mentioned above.

13.7 Some instances of abuse will amount to a criminal offence, for example, physical assault, sexual assault and rape, theft, fraud and some other forms of financial exploitation. An adult protection strategy discussion (see paragraph 13.23) should decide who will initiate action, although in criminal cases the police will be responsible for initiating action. It is therefore essential that complaints about alleged abuse suggesting that a criminal offence may have been committed, should be referred to the police as a matter of urgency. The criminal investigation undertaken by the police may take priority over all other lines of inquiry and it will be necessary for all agencies to work closely together to plan the necessary lines of investigation.

Part 2: Mental Capacity Act - provisions for supervision

The Role and Functions of the Public Guardian

13.8 The Act creates a new public office – the Public Guardian. The Public Guardian has a range of functions that contribute to the protection of people who lack capacity including:

- Establishing and maintaining a register of Lasting Powers of Attorney (LPAs);
- Establishing and maintaining a register of orders appointing deputies;
- Supervising deputies appointed by the court, in co-operation with other relevant authorities (such as social services if the person who lacks capacity is receiving social care);

- Directing Court of Protection Visitors to visit people lacking capacity and those who have formal powers to act on their behalf (see paragraphs 13.10-13.11 below);
- Receiving reports from attorneys acting under LPAs and from deputies;
- Providing reports to the court as requested; and
- Dealing with representations (including complaints) about the way in which attorneys or deputies exercise their powers.

13.9 The way in which the Public Guardian carries out these functions is overseen and reviewed by the Public Guardian Board. The Board may make recommendations to the Lord Chancellor suggesting ways in which the work of the Office of the Public Guardian can be improved.

Court of Protection Visitors

13.10 The Court of Protection Visitors are individuals who have been appointed by the Lord Chancellor to a panel either of Special Visitors (approved healthcare practitioners with relevant expertise) or General Visitors. Their role is to provide independent advice to the court and the Public Guardian on matters relating to the exercise of powers under the Act.

Mrs Q made an LPA some time ago, appointing her nephew, Ian, as her attorney with a general power to make personal welfare and financial decisions on her behalf. The power has now been registered on the basis that Mrs Q no longer has the capacity to make many of these decisions herself. However, Mrs G's niece is concerned that Ian is not acting in Mrs Q's best interests. In particular, she suspects that Ian is using much of Mrs Q's income to pay off debts that he has incurred. She addresses these concerns to the Public Guardian, which then directs a General Visitor to visit Mrs Q and Ian. The Visitor report will provide an assessment of the facts and, should the circumstances suggest it, the report could recommend that the matter be referred to the court to consider the continuation of the attorneyship. On receipt of the report, the court may consider making an order revoking the LPA.

13.11 The Court of Protection Visitors will have an important part to play in investigating possible abuse. However, their role is much wider than this and their visits will also enable them, for example, to check on the general well-being of the person lacking capacity, and to give help and support to attorneys and deputies.

Functions in respect of Lasting Powers of Attorneys (LPAs)

13.12 An LPA is a private arrangement between the person who makes the LPA ('the donor') and the person who is appointed to act on behalf of the donor under this arrangement ('the donee' but more generally known as 'the attorney'). It will be important for individuals to choose someone in whom they have trust and confidence. The Public Guardian will provide information that will help potential donors understand the impact of making an LPA, what powers they could consider granting and what to consider when choosing who may act as an attorney.

13.13 The Act seeks to protect potential donors from abuse by requiring the Public Guardian to ensure that the appointment of the LPA complies with the statutory requirements. Before registering an LPA that covers finance and property, the Public Guardian will conduct a check on the bankruptcy register to ensure that someone attempting to register an LPA is not declared bankrupt.

13.14 The Public Guardian will not generally be involved once the LPA has been registered unless concerns are raised about the way in which the attorney or attorneys are exercising their powers under the LPA. Chapter 6 gives detailed information about the duties and responsibilities of attorneys.

Functions in respect of court-appointed Deputies

13.15 Whereas the execution of an LPA involves appointing an attorney of the person's choice, individuals are not able to choose the deputy appointed to make financial and/or welfare decisions on their behalf, as the appointment is made by the court at a time when they do not have capacity. Whilst this does not necessarily raise an additional risk, safeguards are in place to protect individuals who lack capacity.

13.16 As explained in chapter 7, deputies will most frequently be appointed for financial matters where there is likely to be a need for ongoing significant decisions. There are likely to be far fewer appointments to make health and/or welfare decisions as in these cases, the court is more likely to be able to make a single order where there is difficulty over a significant decision.

> Peter aged 18, sustained serious head injuries in a motorbike accident which has left him permanently and severely brain-damaged. His condition has been stabilised but he has minimal awareness of his surroundings and has been assessed as lacking capacity to make any decisions for himself. A number of important decisions need to be made about where Peter is treated and what sort of treatment he receives. Peter's parents are concerned that their views are not always fully taken into account when discussing what treatment is in Peter's best interests with his healthcare team. They therefore make an application to the court to be appointed as joint-personal welfare deputies. The court considers that as there are likely to be many healthcare decisions that need to be made for Peter over a number of years, it would be impracticable to make a single order in each case. Also, as the members of the healthcare team may change, it would also be advantageous to retain some continuity in decision-making and lastly, an appointment would ensure that Peter's parents will act jointly as personal welfare deputies for their son. The court therefore grants the application and appoints Peter's parents as joint welfare deputies.

13.17 Where the appointment of a deputy is suggested, a major focus of supervision will be at the application stage. In particular, the OPG will carry out a risk assessment of the case to ensure that the level of future supervision of the deputy and the amount and type of checks on the deputy are proportionate to the level of risk involved. Chapter 7 gives detailed information about the duties and responsibilities of deputies.

Where concerns are raised

13.18 Many people who lack capacity are likely to receive some care or support from a range of agencies. These agencies and their staff retain those responsibilities on the registration of a LPA or the appointment of a deputy. Thus, although concerns about the way in which LPAs or deputies exercise their powers may be directed to the Public Guardian, the Public Guardian will not always be the most appropriate body to investigate all of them. The Act states that the Public Guardian may co-operate with relevant agencies to ensure that concerns and complaints are referred to the right agency. In practice, this will most commonly include social services, NHS bodies, the Commission for Social Care Inspection in England or the Care Standards Inspectorate in Wales, the Healthcare Commission in England or the Healthcare Inspectorate in Wales, and the police.

13.19 The OPG may itself investigate cases where there are allegations of financial abuse on the part of the attorney or the deputy. Where the concerns relate to personal welfare LPAs or personal welfare deputies, the Public Guardian will refer them to the relevant health or social care agency, and in certain circumstances the police will be alerted. Where such a referral is made, the OPG will ensure that it is kept informed of the action taken by the relevant agency as well as ensuring that the court has all the information it needs in order to take possible action against the attorney or deputy. For example, the court might discharge a deputy or revoke an LPA. It should also be remembered that other agencies may also need to be involved, for example the relevant social services department, in situations where alternative care arrangements may need to be made for the person lacking capacity.

13.20 Referrals may take place in a wide range of situations. Some possible examples are:

- Where a complaint has been raised that a welfare attorney is physically abusing a donor. This would be referred to the relevant local authority adult protection committee and/or the police;
- Where a solicitor appointed as a financial deputy for an older person with dementia has been found to be defrauding that person's estate resulting in the loss of several thousand pounds. This would be referred to the police.

In both examples, the OPG would also need to be aware of the case and to ensure that a full report was made to the court.

Part 3: Criminal Offence: Ill-treatment or neglect

13.21 The Act introduces a new criminal offence of ill treatment or wilful neglect which applies to the following individuals:

- A person who has the care of a person who lacks capacity or is reasonably believed to lack capacity; or
- A person who is the attorney appointed under a LPA or Enduring Power of Attorney (EPA); or
- A person who is a deputy appointed for the person by the court.

13.22 Such individuals will be guilty of an offence if they ill-treat or wilfully neglect the person they have care of, or to whom the LPA, EPA or deputy appointment relates. The penalty for such an offence is a fine and/or a sentence of imprisonment of up to 5 years.

> Norma is 95 and suffering from Alzheimer's disease. She lives with her son, Brendan, who is her principal carer and who has also been appointed as her welfare attorney under an LPA. A district nurse regularly visits Norma at home to give her medication for arthritis. She is concerned that recently, Norma is displaying bruises and other injuries. She also suspects that Brendan may be assaulting his mother when drunk. She alerts the police and the local Adult Protection Committee. Following this, a number of things happen: following a criminal investigation, Brendan is charged with the ill treatment of his mother. In addition, the court, in conjunction with the Public Guardian, also takes steps to revoke the LPA. Lastly, local Social Services are alerted and procedures are set in motion to put in place alternative care arrangements for Norma.

Part 4: Other Protective Measures

13.23 The provisions of the Act are intended to complement and enhance existing measures to protect vulnerable adults. Vulnerable adults are defined in "No Secrets" and "In Safe Hands" as people who are or may be in need of community care services due to having some form of mental or other disability, age or illness and who may be unable to take care of themselves or protect themselves against significant harm or exploitation. This group obviously encompasses many people who lack capacity who have people acting for them under the terms of the Act.

Multi-agency policies and procedures

13.24 Following the publication of "No Secrets" in England and "In Safe Hands" in Wales, local agencies, under the leadership of local councils have developed and implemented multi-agency policies and procedures to protect vulnerable adults from abuse, both in care settings and elsewhere. The vast majority of localities have established Adult Protection Committees. These are cross-agency management committees that determine policy, co-ordinate investigations and other activity between agencies, facilitate joint training and monitor and review progress.

13.25 This multi-agency approach will aid the Public Guardian in providing a route for the referral of allegations of abuse and ill treatment. It will also aid those acting under the provisions of the legislation in crystallising the various procedures and bodies which they will be expected to be aware of. Adult Protection Committees draw members from the NHS, social services, housing, the police and others. They provide a good source of advice for the Public Guardian where any abuse is suspected and if there is uncertainty about whether or not an intervention is necessary.

Employment checks for care staff

13.26 Criminal record checks must now be made on staff working in registered care homes that have contact with service users. Potential employers must conduct a pre-employment criminal record check with the Criminal Records

Bureau (CRB) for all potential new health and social care staff, including nurses agency staff and domiciliary care agency staff (who provide personal care). More detailed information can be found in the Care Homes Regulations 2001, the Nurses Agencies or the Domiciliary Care Agencies Regulations[69].

Following the Bichard Inquiry, changes to current Regulations are anticipated to allow the Public Guardian to conduct criminal record checks when investigating potential deputies. The Code will be updated if these changes are introduced before publication.

13.27 The Protection of Vulnerable Adults (POVA) list contains details of those individuals who have been judged unsuitable to work with vulnerable adults. Employers in care homes (and domiciliary care agencies) are required to check whether potential employees are listed, to refuse employment to anyone whose name is on the list or take steps to employ them in a position which does not involve them in regular contact with vulnerable adults. There is a duty to refer people in the circumstances defined in the guidance[70]. The POVA list applies in both England and Wales.

Commission for Social Care Inspection, the Care Standards Inspectorate for Wales and the Social Services Inspectorate for Wales

13.28 All care providers that fall within the remit of the Care Standards Act 2000 are required to register with the Commission for Social Care Inspection in England (CSCI) or the Care Standards Inspectorate and Social Services Inspectorate for Wales. They work with care providers to ensure that the standards are met. Regulations require procedures to protect service users from harm or abuse to be put in place. In particular, their task is to take swift action if they identify any dangerous or unsafe practices that could place service users and residents at risk. The standards also guarantee that service users have access to effective complaints procedures and, if complaints cannot be resolved locally, they can be referred to CSCI or to the relevant inspectorate in Wales.

Social security benefits – appointees

13.29 For people who receive social security benefits or pensions, who are considered to lack the capacity to act for themselves and have not made an LPA, the Department for Work and Pensions (DWP) can appoint someone (an appointee) to claim and receive benefits and spend the money on the person's behalf[71]. The DWP carry out checks to ensure the appointee is trustworthy and also investigate any allegations that an appointee is not acting appropriately or in the person's interests. They may take steps to remove an appointee who is abusing his/her position.

[69] http://www.dh.gov.uk/PolicyAndGuidance/HealthAndSocialCareTopics/SocialCare/CSCIProject/

[70] http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4085855&chk=p0kQeS

[71] http://www.dwp.gov.uk/publications/dwp/2005/gl21_apr.pdf

Other Initiatives

13.30 There are a number of additional initiatives and requirements which people acting under the legislation will need to be aware of (although many will already be aware). These include:

- National Minimum Standards (for care homes, domiciliary care agencies etc) which apply to both England and Wales;
- National Service Frameworks (NSFs) which set out national standards for specific health and care services or for particular groups (for example for mental health services[72] or services for older people[73]);
- Complaints mechanisms relating to all NHS bodies and local councils (see chapter 14);
- 'Stop Now Orders' (also known as Enforcement Orders) enabling consumer protection bodies (such as local Trading Standards Offices) to apply for court orders preventing poor trading practices, including unfair door-step selling or banning rogue traders;[74]
- The Public Interest Disclosure Act 1998 encourages people to raise concerns about malpractice in the workplace and protects 'whistleblowers' from dismissal and victimisation.

13.31 All national minimum standards, national service frameworks and information in respect of NHS complaints are available on the CSCI[75] web-site, and in Wales on the Welsh Assembly Government web-site, and further details of complaints procedures are outlined in chapter 14. In addition, individual local authorities will have their own complaints system in place.

[72] http://www.dh.gov.uk/assetRoot/04/07/72/09/04077209.pdf
[73] http://www.dh.gov.uk/assetRoot/04/07/12/83/04071283.pdf
[74] http://www.oft.gov.uk/Business/Legal/Stop+Now+Regulations.htm
[75] http://www.csci.org.uk/information_for_service_providers/national_minimum_standards/default.htm

Chapter 14 - Resolving Disagreements

Introduction

14.1 Despite efforts to determine what a person who lacks capacity would want in relation to a particular decision and what would be in their best interests, sometimes disagreements may arise in the course of taking a decision for or acting for a person lacking capacity. It is generally in the interests of all involved to resolve the problem in a way that is quick, effective, involves minimal stress and is cost effective.

14.2 While the Act establishes a new, dedicated Court of Protection to settle serious and complex disputes, it may often be more appropriate to explore alternative solutions to solving problems. Moreover, in some cases it would be inappropriate to take the matter to court, as there are more appropriate mechanisms specifically available for the type of situation.

14.3 This chapter provides information about the various avenues available to resolve disagreements, including complaints procedures and alternatives to court proceedings and suggests what might be the appropriate or most desirable route to take. **Part 1** provides suggestions on how to try to avoid escalation of issues as well as outlining the existing complaint and dispute resolution mechanisms. **Part 2** describes when it may be necessary to consider applying to the Court of Protection. Accessing legal funding is considered in **Part 3**. Diagrams giving an overview of the dispute resolution options discussed in this chapter are set out (as examples only) in **Part 4.**

Part 1: Methods of resolving disagreements

14.4 The best way of resolving a disagreement or concern will depend on the people involved, the type of disagreement, its severity and the urgency. Disagreements may be:

- Between family members or other individuals – these can often be dealt with via informal routes or through mediation;
- About health, social or other welfare services – these can usually be dealt with through informal or formal complaints processes;
- About serious issues requiring resolution by the Court of Protection.

14.5 Moreover, it is in everyone's interests that any concerns are addressed before the matter escalates into a more serious dispute or complaint. In respect of disputes arising between family carers or other carers and expert advisers, many disputes may be avoided through effective communication of the issues and taking the time to listen and address concerns and issues. Some initial steps that might therefore be taken are:

- Outline the options fully in terms that are easy to understand;
- Invite a colleague to talk to the family;
- Offer recourse to independent expert advice;
- Listen to, acknowledge and address the concerns raised;
- Where the situation is not urgent allow time for reflection.

14.6 The following mechanisms can assist not only when disputes arise but also to aid the exchange and understanding of the views of both parties. Further guidance on how to deal with problems without going to court may also be found in the Community Legal Services Information Leaflet 'Alternatives to Court'[76].

Independent advocacy

14.7 Family members, friends, care managers, social workers, health care professionals and others may support and speak for a person, but where there are differences of opinion, or conflicting interests, that person might benefit from independent advocacy.

14.8 An independent advocate acts on behalf of and in the interests of a person who has difficulty speaking up for him/herself and is independent of any statutory agency or other party involved with the person. Most independent advocacy services are provided by the voluntary sector and are arranged at a local level. Most receive some statutory (local and/or health authority) and voluntary (charitable trust or national lottery grants) funding.

14.9 When disagreements arise, an independent advocate may be able to help resolve the dispute without the use of a mediator or complaints process, simply by presenting the person's feelings to his/her family, carers or professionals. Independent advocates may also be involved during mediation or in assisting with complaints procedures. In certain specific, defined circumstances, people who lack capacity have a statutory right to advocacy, for example, to support a person in making a formal complaint against the NHS (see paragraph 14.23 below) or where the Act requires the involvement of an Independent Mental Capacity Advocate (IMCA) (see chapter 9). Information about independent advocacy services can be obtained from advice agencies or from the local IMCA service.

Mediation

14.10 Mediation is a well established process for resolving disagreements where people in dispute are assisted by a mediator to come to a mutually acceptable outcome. It is a flexible process that is usually more cost effective, quicker and less stressful than going to court. Mediation can help to prevent problems becoming worse through early settlement and offers a wider range of outcomes than the court can provide. While there is no guarantee that the parties will be able to reach an agreement via mediation, if they can do so, they are more likely to keep to it since they have agreed something rather than having it imposed on them.

14.11 The mediator is a third party, who has no stake in the outcome of the process, does not make decisions or impose a solution. The parties control both the decision to settle as well as the terms of the settlement. The mediator should be able to decide whether the case is suitable for mediation, taking account of the likely chances of success and the need to safeguard the person lacking capacity.

14.12 Potentially, any case that is capable of settlement through negotiation may be suitable for mediation. Mediation will be most suitable when the dispute is

[76] CLS (Community Legal Services) Direct Information Leaflet Number 23

between individuals who are failing to communicate with each other or to understand each other's point of view. It can help to forge better relationships between the parties and avoid future disputes so it is a good option when it is in the person's interests for those involved to maintain a relationship in the future.

> Mrs R has dementia and lacks capacity to decide where she resides. She currently lives with her son and daughter-in-law, and spends a holiday with her daughter who lives 200 miles away. After the holiday her daughter refuses to bring her mother back, having found a care home nearby where she thinks her mother will be better looked after. Her brother disagrees that this is the right course of action. Mrs R is upset by this family dispute, and so her son and daughter decide to try mediation. The mediator believes that Mrs R is able to make her wishes known and agrees to take on the case. A decision is reached for Mrs R to continue to live with her son but to review the situation again in six months to see if her needs might be better met elsewhere.

14.13 The mediation process requires all parties to take part as equally as possible so that a mediator is able to ascertain the person's best interests. It might also be appropriate to involve an independent advocate to try to ascertain their wishes (see above).

> Mr S has learning disabilities. His parents are divorced and he lives in a care home although this is soon to close. Mr S does not have capacity to decide where he would like to live and his parents cannot agree as to where he should move. Mr S's social worker resolves the dispute by arranging counselling, advice and mediation and a consensus decision is reached: namely, that Mr S will move into supported housing.

14.14 In some cases mediation may be funded through public legal funding, for example for family mediation or where mediation may prevent the need for court proceedings. Anyone can apply for legal funding, but certain conditions will need to be satisfied in order for an application to be successful (see Part 3 below).

14.15 Health and social services might also be included in mediation processes. However, where they are a party to the dispute, it may be more appropriate to pursue the route of health and social care complaints procedures (see below).

14.16 The National Mediation Helpline, provides a single telephone point of contact for anyone who wishes to arrange a civil mediation appointment. The Helpline helps callers to identify an effective means of resolving their difficulty without going to court and will arrange an appointment with a trained and accredited independent mediator.

14.17 Some disputes arising under the Act arise between family members, for example disagreements about what is in the best interests of the person who lacks capacity. Family mediators are trained to deal with the emotional, practical and financial needs of those going through relationship breakdown. The Family Mediation Helpline can provide information on family mediation and referrals to local family mediation services. Contact details of both services can be found in Annex A.

Complaints about health care

14.18 Formal and informal mechanisms exist to resolve complaints about the health care received by patients, including those who lack capacity. Health care professionals and others need to be aware of these methods and in which situations their use is appropriate. In England, the Patient Advice and Liaison Service (PALS) provides an informal way of dealing with problems before they reach the complaints stage.

14.19 PALS operate in each NHS and Primary Care Trust in England and provide advice and information to patients or their relatives/carers in order to try to resolve problems quickly. Where appropriate, they are able to sign-post people to local specialist support services, for example, independent advocates, mental health support teams, social services and interpreting services. PALS do not investigate complaints and their role is to provide explanations of complaints procedures and, if appropriate, can direct patients, their relatives or carers to the formal NHS complaints process (see below).

14.20 A complaint about something that happened in the past, requiring for example, an apology or explanation, should be dealt with by NHS complaints procedures since a court cannot provide these solutions (see below).

14.21 In Wales, complaints advocates based at Community Health Councils provide advice and support to anyone with concerns about the treatment they have received.

Disagreements about proposed treatments

14.22 If a case is not urgent, it may be possible for it to be dealt within the supportive atmosphere that the Patient Advice and Liaison Service can provide. In Wales, the local Community Health Council may be able to help in finding a solution. However, urgent cases about serious proposed treatment may need to go directly to the Court of Protection (see Part 2).

> Mrs T, who has Alzheimer's, does not want a flu jab. Her daughter thinks she should have the injection. The doctor does not want to go against the wishes of his patient, as he believes she has capacity to give an informed refusal of treatment. Mrs T's daughter goes to the Patient Advice and Liaison Service (PALS) since she does not agree with the doctor's assessment of her mother's capacity. PALS provide information and advice about consent, and how to find more information about the flu jab. PALS speak to the doctor, and explain his clinical assessment to the family. The daughter remains unhappy. PALS advises her that the Independent Complaints Advocacy Service (see below) can help if she wishes to make a formal complaint.

NHS complaints procedure

14.23 The NHS has a formal procedure for resolving complaints about care and services. The procedure covers complaints made by an individual about any matter connected with the provision of NHS services by NHS organisations or primary care practitioners. The Independent Complaints Advocacy Service (ICAS) provides advice and support to patients and their carers who want to take forward formal NHS complaints, making the system more accessible to

those who lack mental capacity. Complaints are first investigated and responded to at a local level. In Wales, the complaints advocates based at Community Health Councils will support and advise anyone who wishes to make a complaint.

14.24 In England the complainant can also request an independent review by the Commission for Healthcare Audit and Inspection (also known as the Healthcare Commission) if s/he remains unhappy after attempts at local resolution. If complainants remain unhappy after the NHS complaints procedure has been exhausted, they (or the person acting on their behalf) can take the case to the Health Service Ombudsman. Information on how to make a complaint in England is available from the Department of Health.

14.25 In Wales, complaints advocates based at Community Health Councils provide advice and support to people wanting to complain about the NHS, and independent review is undertaken by lay reviewers appointed by the Welsh Assembly Government. The Public Services Ombudsman for Wales undertakes reviews of cases where the complainant remains unhappy

14.26 NHS Foundation Trusts are not covered by the regulations setting out the framework for the local resolution stage of the NHS complaints procedure. However, they are covered by the independent review stage operated by the Healthcare Commission and by the Health Service Ombudsman. Where someone has a complaint about an NHS Foundation Trust they should contact the Trust for advice on how to make a complaint.

14.27 The NHS Litigation Authority has an overview of all clinical negligence cases brought against the NHS in England and actively encourages the use of alternative dispute resolution (such as mediation) by both the NHS and complainants to enable cases to be settled effectively and without the need for resort to the courts. Similarly the National Assembly for Wales encourages alternative dispute resolution for cases in Wales.

Complaints about social care

The social care complaints procedures are currently subject to reform. The following information is based upon the current understanding but may be subject to review before the final Code is published.

14.28 A complaint about the way in which care services are delivered, the type of services provided, or failure to provide services, should be dealt with through the local authority's procedures for handling concerns and complaints.

14.29 An attempt should initially be made to resolve a complaint through an informal discussion between professionals, the person who lacks capacity (with support if necessary) and his/her carers and/or relatives. If the complainant is not satisfied, the local authority will conduct a formal investigation according to its complaints procedures. If the complaint is still not resolved, it can be referred, in England, to an independently chaired social service Complaints Review Panel administered by the local authority. In Wales complaints can be referred to the National Assembly for Wales for hearing by an independent panel established by the Assembly.

14.30 In cases of maladministration, complaints about local authorities may be referred to the Local Government Ombudsman for England or the Public Services Ombudsman for Wales where appropriate.

14.31 If someone is unhappy with care provided by a private or local authority care home, they should first use the care home's own complaints procedure (required under the Care Homes Regulations 2001). If they are dissatisfied with either the complaints procedure, or the response to their complaint, they may approach the Commission for Social Care Inspection (CSCI) in England, or the Care Standards Inspectorate for Wales – depending on where it is - as regulator of the home. If the person was placed in the home by the local authority, it might be more appropriate to use the social services complaints procedure if the concern is with that placement and the authority's assessment of the person's needs, rather than the services provided by the home.

> Following a social services assessment Mr V was placed in a care home. However, Mr V's family believe that the standard of care provided by the home is insufficient to meet his assessed needs. The family file a formal complaint with the care home and, following investigation by the home manager, additional support for Mr V is offered.

Other welfare issues

14.32 The Independent Housing Ombudsman deals with complaints about registered social landlords in England. This applies mostly to housing associations, but also many landlords who manage homes that were formerly run by local authorities and some private landlords. In Wales the Public Services Ombudsman for Wales deals with complaints about registered social landlords. Complaints about local authorities may be referred to the Local Government Ombudsman in England or the Public Services Ombudsman for Wales. They look at complaints about decisions on council housing, social services, Housing Benefit and planning applications. Further information about complaints to both Ombudsman services is available on their respective web-sites (see Annex A).

Disagreements regarding financial matters

14.33 Disagreements about the financial affairs of a person who lacks capacity in relation to those affairs might include the following:

- Disputes between family members or other individuals, for example over the size of an allowance to be paid by the person lacking capacity to a family member who acts as carer;
- Disputes over whether a house should be sold;
- Disputes involving a third party questioning the actions of an attorney appointed under a Lasting Power of Attorney or a deputy appointed by the court.

14.34 In all of the above circumstances, the most appropriate action would be to contact the Office of the Public Guardian (OPG) for guidance and advice. Staff at the OPG will be able to provide advice and guidance on the appropriate steps to take, according to the circumstances of each case (see chapter 13 for further details on the role of the OPG).

Part 2: Access to the Court of Protection

14.35 The new Court of Protection has powers to make decisions in relation to all areas of decision-making for adults who lack capacity. Chapter 7 of the Code describes the role, functions, operation and powers of the court, and sets out the duties and responsibilities of deputies appointed by the court to make decisions on behalf of a person lacking capacity.

14.36 The creation of a new Court of Protection, however, does not imply that all problems involving people who lack capacity will or should be determined by the court. Although the court will be relatively accessible and informal, the alternative methods of solving problems outlined above will generally be more appropriate, simpler, faster, cheaper and less distressing for all parties.

14.37 However, before the Act came into force, the courts decided that some decisions relating to the provision of medical treatment were so serious that in each case, an application should be made for a court declaration that the proposed action was lawful before that action was taken. There are also a few types of cases the court should deal with when another form of dispute resolution would generally not be suitable. Details of such cases are provided in chapter 7, along with details of when permission to apply must first be obtained.

> Ms W is a young woman who has been diagnosed as suffering from variant CJD. Her prognosis is poor but healthcare professionals and family members have become aware of a new treatment for her condition that is relatively untested but has been reported to produce improvements in some patients. However, there are side effects related to the treatment and both her healthcare team and members of her family are divided as to whether it would be in her best interests to receive the treatment. (Ms W herself lacks the capacity to consent to treatment.) Given the division of opinion, an application is made to the Court of Protection for a declaration that it would be lawful, and in Ms W's best interests, to receive the treatment. The court, after considering evidence from all relevant parties, makes such a declaration and the treatment is given to Ms W

Right of Appeal

14.38 Section 53 of the Act describes the rights of appeal from any decision taken by the Court of Protection. The right of appeal lies to a higher judge within the Court of Protection or to the Court of Appeal.

Part 3: Public Legal Funding

Legal Aid is currently the subject of a fundamental review. The following information is based upon the current understanding.

14.39 Every effort should be made to resolve disputes at an early stage through taking advice (including advice on complaint and dispute resolution mechanisms from the Office of the Public Guardian), discussion and agreement if possible (including mediation and PALS – see part 1 above). Public Funding for legal advice may be available through the Legal Services Commission (LSC) via, for example, solicitors or advice agencies with a

community legal service Quality Mark, to ensure that people who lack capacity are able to get Legal Help and where necessary Legal Representation at the Court of Protection. Further information about legal aid and public funding can be obtained from the Legal Services Commission.

14.40 Those who lack capacity to instruct a solicitor or conduct their own case will need a litigation friend, who could be a relative, friend, attorney or when there is no-one else appropriate, the Official Solicitor. The litigation friend is able to conduct a case on behalf of a person lacking capacity and funding will then be paid to the litigation friend, rather than direct to the applicant.

The means and merits tests

14.41 Applicants for Legal Help will need to satisfy the standard 'means test', (confirming receipt of specified benefits or income and capital below a specified amount), and 'merits test' (confirming that there is sufficient benefit to the applicant to justify providing the advice and that no other source of funding is available). People in receipt of 'passported' benefits (including income support) automatically qualify financially for legal aid.

Legal Help

14.42 Legal Help can cover advice and assistance on matters affecting a person lacking mental capacity including preparation work for court hearings. It will generally be available if an applicant satisfies the means and merit tests. Under the Legal Help scheme, applicants can receive up to £500 for initial assistance, to cover help from a solicitor in writing letters, getting a barrister's opinion, help with mediation and preparation for Court of Protection hearings. If necessary, additional funding can be applied for. Legal Help is not available to make a Lasting Power of Attorney or an advance decision to refuse treatment. Staff at the Office of the Public Guardian will be able to give general and procedural assistance on these matters, if required, but they will not be able to give legal or other specialised advice. For example, they will not be able to advise someone on what powers they should delegate to the person they want to appoint as their LPA.

Legal Representation

14.43 Legal Representation will only be available for representation at Court of Protection hearings for the most serious cases. Cases that were previously heard by the High Court would continue to attract Legal Representation when such cases are transferred to the Court of Protection. Primarily, these proceedings relate to the personal liberty, welfare or medical treatment of a person who lacks capacity.

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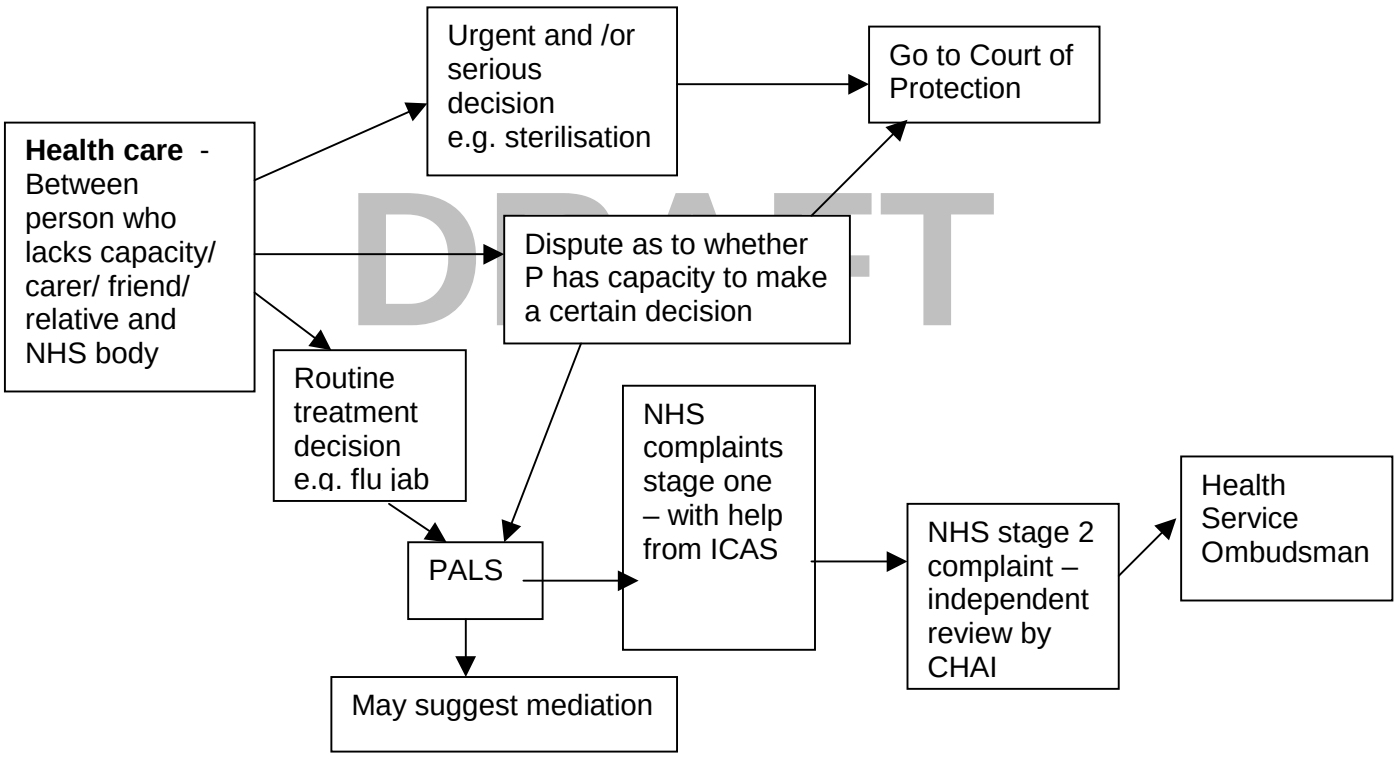
14.45 A Direction may be issued to the Legal Services Commission to ensure that Legal Representation is available for serious cases that meet the specified

criteria. In light of this, the information contained within the Code will be updated accordingly.

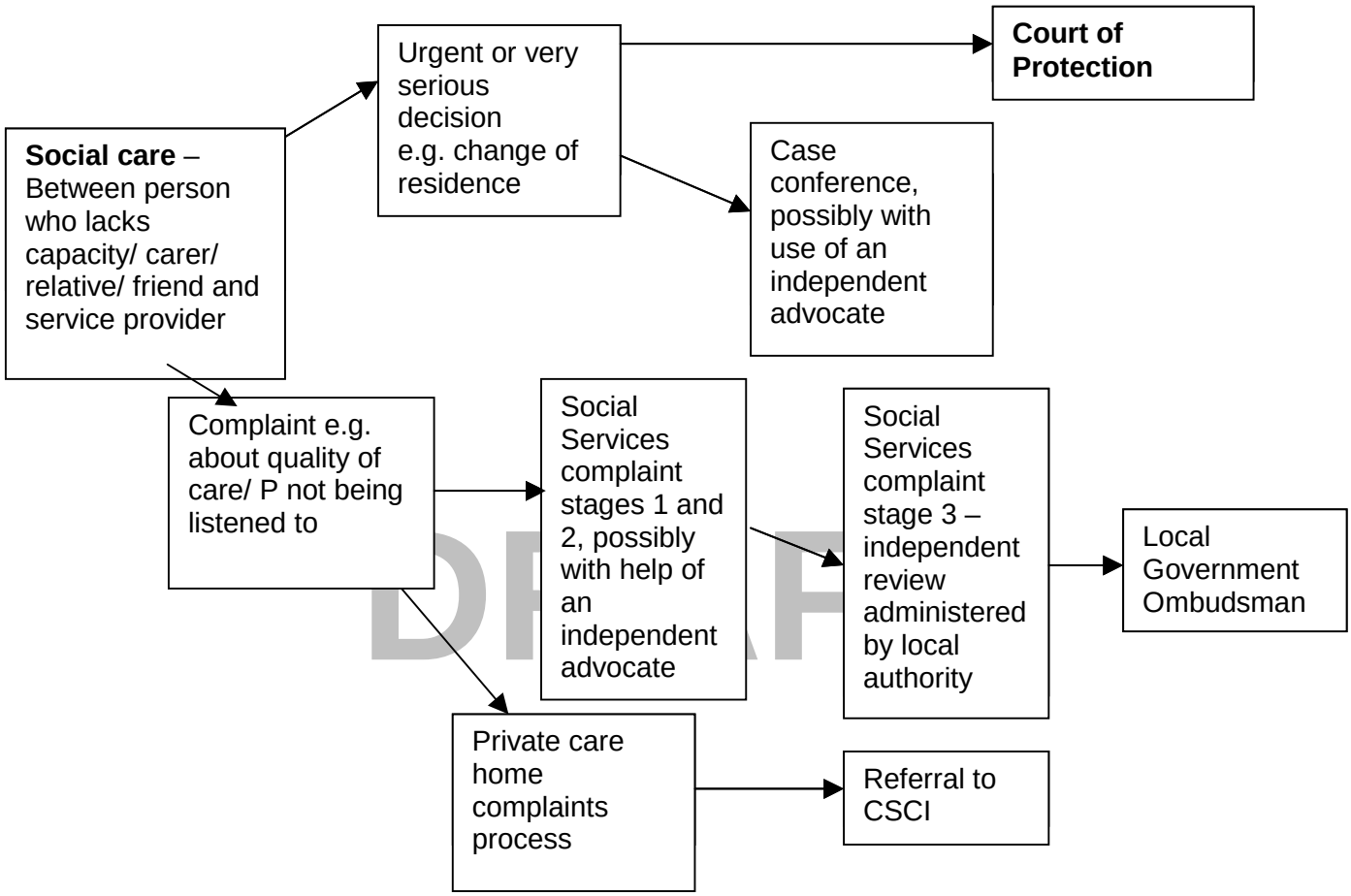
Part 4: Overview of Dispute Resolution Options

14.46 The following diagrams provide an overview of the possible processes that may be followed in order to resolve a dispute, based upon the type of disagreement. They are for quick reference only, may not indicate all possible options and should not be read in isolation to the above information.

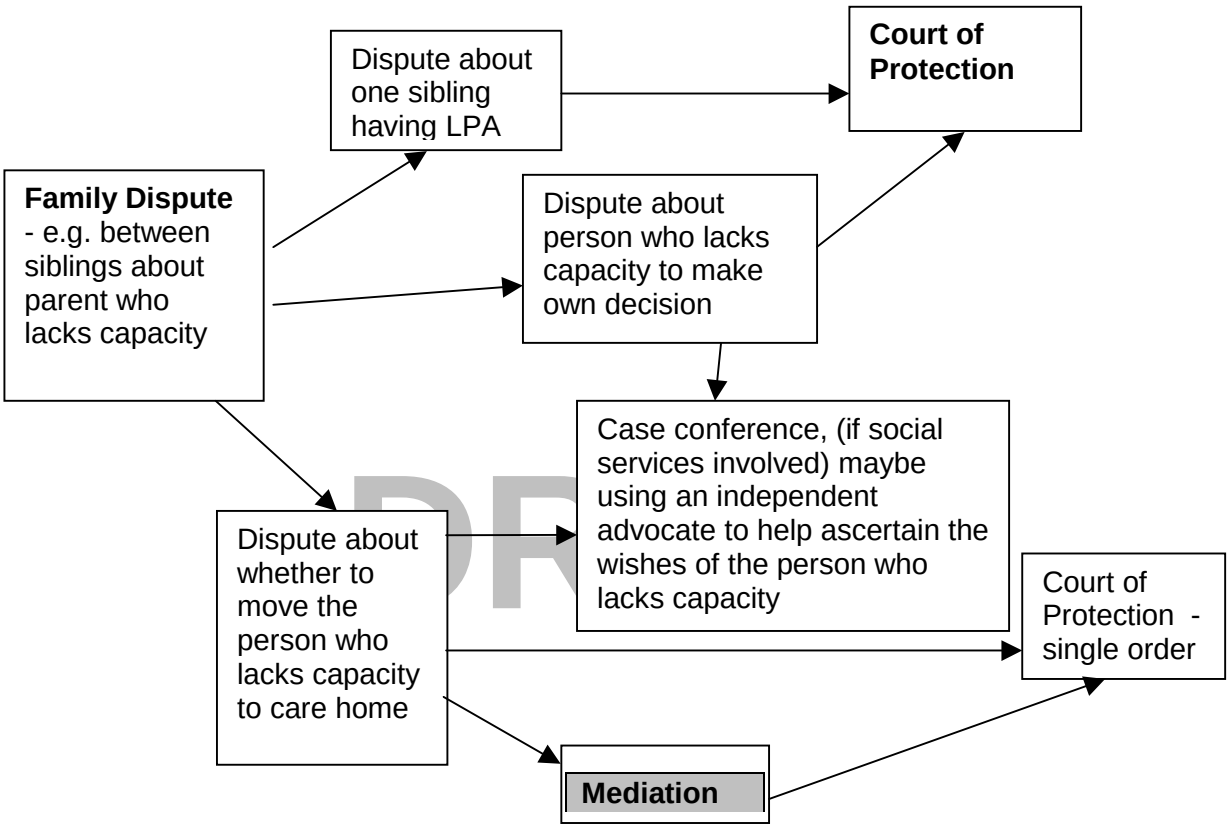
Overview of healthcare resolution process (example only)



Overview of social care resolution process (example only)



Overview of family dispute resolution process (example only)



Chapter 15 - Access to Personal Information

Introduction

15.1 People making decisions on behalf of those who lack capacity will often need to share personal information relating to the person lacking capacity, so that they can determine, and act in, that person's best interests. This chapter gives guidance as to what information people caring for persons lacking capacity can expect to have disclosed to them, and what they can do if they think they need access to information.

15.2 **Part 1** describes the general considerations that apply in respect of accessing and using information. **Part 2** deals with the ways in which attorneys under a Lasting Power of Attorney and deputies may access information together with limitations on disclosure. **Part 3** sets out how those who care for someone lacking capacity (but have not been appointed as an attorney or deputy), may access information and what to do when a dispute arises. **Part 4** provides a checklist of the most important considerations when information is requested or disclosed.

15.3 This guidance is aimed primarily at those who care for someone who lacks capacity. Professionals have their own professional codes of conduct (for example, the NHS Code of Practice on Confidentiality). They are also supported by experts within their organisations, such as Information/Data Protection Officers and Caldicott Guardians (in Social Services and NHS).

15.4 Disclosure of, and access to, information can be complex. The following is intended to provide only a general guide and should not be treated as a definitive statement of the law, nor as a substitute for consulting any code issued by the relevant professional body and, where necessary, taking legal advice. The Information Commissioner's Office has issued guidance and advice on the Data Protection Act 1998, which can be found on their web-site.[77] The information contained within this Code does not change or substitute the guidance from the Information Commissioner.

Part 1: General considerations regarding accessing and using information

15.5 People caring for someone who lacks capacity – whether paid or unpaid - or managing their affairs, need information in order to be able to assess capacity, determine best interests and make decisions. The information required will vary widely according to the circumstances. At one extreme, the daughter providing full-time care for an elderly parent will make day-to-day decisions using the information which she has acquired through years of experience, and which she carries in her head.

15.6 At the other extreme, a deputy may face making decisions about whether someone needs to move into residential care, or whether to sell the family home and invest the proceeds of the sale. In this case there may be a need for information from family members, the family doctor, the person's bank, solicitor, etc to enable him/her to make a decision that is in the best interests of the person lacking capacity.

[77]. The Information Commissioner's web-site is at www.informationcomissioner.gov.uk

15.7 Most of the information needed for the purposes of the Act will be personal information relating to the individual who lacks capacity, and much of it will be sensitive and/or confidential. Access to personal information must only be provided in accordance with the law. Disclosure of, and access to, such information is regulated by:

- The Data Protection Act 1998;
- The common law duty of confidentiality;
- Professional codes of conduct on confidentiality; and
- The Human Rights Act 1998 and European Convention on Human Rights, in particular Article 8.

15.8 As a general rule, and subject to a number of exceptions, everyone has a right of access to information held about them or may authorise another to access their information on their behalf. Doctors and lawyers are bound by a professional duty of confidentiality and may generally not reveal information communicated to them by patients or clients in the absence of the patient's or client's consent. There are very few exceptions to this rule. Therefore, when someone lacks the capacity to give consent to disclosure, and has not made provision for someone else to access information on their behalf, there are only a limited number of ways in which information can lawfully be disclosed, depending upon:

- Whether the person requesting the information is acting as an agent;
- Whether disclosure is in the best interests of the person who lacks capacity;
- The type of information requested.

The exceptions to the general rule that information cannot be disclosed in the absence of consent are further considered below.

Part 2: Requests for information by attorneys, deputies and receivers

15.9 Under section 7 of the Data Protection Act 1998, every individual has the right of access to personal data about him/herself, subject to certain exemptions particularly in respect of health, social work and education records. This is known as the "subject access" right. The individual exercising this right is known as the "data subject". The right can be exercised by an agent on behalf of an individual, which means that someone acting under an Lasting Power of Attorney can make a subject access request for relevant information and will be treated as if they were the person lacking capacity. A subject access request places a legal duty on the person holding the information (the data controller) to release it, rather than relying on his/her discretion to do so.

Attorneys acting under a Lasting Power of Attorney

15.10 The Act extends the areas in which donors under a Lasting Power of Attorney can authorise others to make decisions on their behalf. In addition to property and financial affairs, donors can now choose to delegate decisions affecting personal welfare, including healthcare and consent to medical treatment. As long as the attorneys are acting within the scope of their authority, they are

entitled to ask for the information as if "stepping into the shoes" of the person who lacks capacity, subject to the limitations mentioned below.

15.11 Subject access requests must be made in writing and a fee may be payable. Information should be supplied promptly and in any event within 40 calendar days. Fees may be particularly high for getting copies of medical records particularly where information may be in unusual formats – e.g. x-rays, although this is subject to a maximum of £50[78]. Complaints about a failure to comply with the Data Protection Act 1998 should be directed to the Information Commissioner's Office.

15.12 In practice, an attorney or deputy may only require limited information and may not need to make a full subject access request. In such circumstances, an informal approach to the person holding or controlling the data can be made. Once satisfied that the request comes from an attorney or deputy (having seen appropriate authority), the person holding the data should be able to provide the information requested. This informal approach does not prevent a subsequent formal subject access request being made.

15.13 The deputy or attorney is, of course, placed under a duty of confidentiality as regards the information released to him/her and should be extremely careful to protect it. Any failure to do so may result in the LPA or deputyship being revoked.

Requests for information by receivers and deputies

15.14 Before the Act came into force, receivers appointed by the previous Court of Protection were not permitted to make a subject access request without specific authority. The Data Protection Act 1998 Legal Guidance issued by the Information Commissioner[79] says that an attorney acting under an Enduring Power of Attorney or a receiver "who has general authority to manage property and affairs" may make a subject access request. Therefore a deputy who has been granted authority to act only in relation to specific matters (rather than a general power), may make a subject access request on behalf of the person who lacks capacity for such information as relates to the matter within his/her limited authority, without applying to the court.

15.15 Few receivers were given a general authority and those continuing to act for a person lacking capacity would need specific authority from the Court of Protection to make a full subject access request. It is anticipated that the situation will be the same under the Act. In addition, a deputy is even less likely than a receiver to be given a general authority over the affairs of the person who lacks capacity. Therefore, a deputy will only be able to make a subject access request if the terms of his/her appointment cover this – otherwise they will need a further order from the court.

Limitations on disclosure of information

15.16 When exercising subject access rights on behalf of another as attorney or court-appointed deputy, the person exercising those rights should, where possible, aim to secure the disclosure only of that personal data which will assist them in the decision(s) they need to make on behalf of that person. The

[78] Data Protection (Subject Access) (Fees and Miscellaneous Provisions) Regulations 2000 (S.I. 2000/191)

[79] The Information Commissioner's web-site at www.informationcomissioner.gov.uk at paragraph 4.1.7

data controller, on receipt of such a request, should satisfy him/herself of the attorney or deputy's authority to act (and may ask for proof of identity and appointment in order to do so). When making a request for personal data relating to the person who lacks capacity, the attorney or deputy should always bear in mind the requirements of s.1(5) of the Act, namely that any act or decision made under the Act must be in the best interests of the person who lacks capacity. The attorney or deputy may not know the kind of data that is held, in which case it may be difficult for them to particularise their request; and they may in fact require the full range of personal data in order to make an informed decision. Consideration of the "best interests" principle, and the decision that the attorney or deputy needs to make, should inform the scope of the attorney's or deputy's request. For example, if the attorney needs only to know the times at which the person who lacks capacity requires medication, s/he does not need to ask for details of their entire healthcare record.

Mr Y is an elderly man in the later stages of Alzheimer's. Mr Y's son is responsible for his care and welfare under a Lasting Power of Attorney. Mr Y has been in residential care for a number of years, but his son has become concerned about the ability of the current home to meets his needs, given an apparent recent deterioration of his condition. He asks for specific information from his father's file in respect of the care provided so that he may make an informed decision in the best interests of his father. But the manager of the care home refuses, saying that he is prevented from disclosing personal information in respect of his father because of the Data Protection Act. Mr Y's son points out that as a welfare attorney under the LPA he is, legally, his father's agent and that the LPA gives him authority to look after his father's welfare. He needs to access specific personal data in order to ensure proper care is provided to Mr Y. With the power under the LPA, the Data Protection Act 1998 requires the care home manager to provide access to personal data held on Mr Y in this respect.

15.17 The deputy or attorney may also find that some information is kept back. Information that relates to a third party, (i.e. someone other than the person who lacks capacity), might be withheld to protect that person's privacy. The entitlement under the Data Protection Act 1998 is to information "relating to" the person who lacks capacity (i.e. the data subject), and the information sought may relate to both that person and a third party. It is unlikely that information relating to a third party would be of assistance in determining the most appropriate course of action to take in relation to the person who lacks capacity. There may also be obligations of confidence owed to the third party, or other reasons that would make them reluctant for their personal information to be disclosed to the data subject or his/her carer.

15.18 Information which comprises data relating to the physical or mental health or condition of the data subject, or constitutes an educational record or relates to social work should not be disclosed if access to it would cause serious harm to the mental or physical health or condition of either the person who is the subject of the information or to anyone else. In addition, health and social work information will not be disclosed to someone acting as a deputy or attorney if the person lacking capacity previously asked for it not to be disclosed, or had an expectation that it would not be disclosed. This exemption applies where the data subject lacks the capacity to manage his/her own affairs and the person making the request has been appointed by a court to manage his/her affairs.

15.19 Further details on making a subject access request, possible restrictions to the information that can be disclosed and appeal mechanisms are available via the Information Commissioner's Office.

Part 3: Access for family carers or other carers[80]

Disclosure by health and social care professionals

15.20 Health and social care professionals have always disclosed information about people who lack capacity to, for example, family carers and other relatives, when it is clearly in the interests of the person lacking capacity do so. Professional codes make it clear that disclosure may be justified when it is in the best interests of the person who lacks capacity. The NHS Code on Confidentiality[81] says: "Where the patient is incapacitated and unable to consent, information should only be disclosed in the patient's best interests, and then only as much information as is needed to support their care."

15.21 Under the Act, the need for professionals to consult people who know the person who lacks capacity when determining best interests, will further encourage them to share information to make the consultation meaningful. However, at the same time, a person disclosing information concerning a person lacking capacity must be assured that they are acting lawfully and that the disclosure is justified. They need to balance the right to privacy of the person who lacks capacity against what is in his/her best interests and/or the public interest.

15.22 Sometimes it will be fairly obvious that information needs to be disclosed. For example, a doctor would need to tell a new paid carer what drugs need to be administered to someone lacking capacity and about any allergies the person has. That is clearly in the person's best interests. Other information may also need to be disclosed to determine what would be in the best interests of the person lacking capacity. A social worker might decide to reveal information about someone's past when discussing with a close family member what would be best for his/her future, always bearing in mind section 4 of the Act relating to the wishes, feelings etc of the person who lacks capacity. In both these cases, the social worker and doctor would only disclose as much information as was relevant to the act to be carried out or the question to be decided.

15.23 Information may also be disclosed where there is an overriding public interest. It can be difficult to judge when it is in the public interest to disclose information and each case must be considered on its merits. The NHS Code on Confidentiality gives examples of when disclosure is in the public interest. These include to prevent or aid investigation of serious crimes; and to prevent serious harm, such as spread of an infectious disease. It is then necessary to judge whether the public good that would be achieved by the disclosure outweighs both the obligation of confidentiality to the individual concerned and the broader public interest in the provision of a confidential service. Where disclosure is considered to be in the public interest, it must be proportionate and limited to the relevant details. Professionals faced with

[80] i.e. For the purposes of this section defined as persons who have not been appointed either under a Lasting Power of Attorney or with power to request information as a deputy

[81] Confidentiality HNS Code of Practice November 2003 available on the Department of Health web-site

weighing competing public interests would be advised to seek advice from their legal advisers.

15.24 It should also be noted that the public interest may require disclosure where this is needed to enable action to be taken, e.g. to prevent a person lacking capacity suffering physical or mental harm. It is not just things for "the public's" benefit that are in the public interest – disclosure for the benefit of the person lacking capacity can also be in the "public interest" in this broader sense. Under the Data Protection Act 1998, information about someone's health is subject to more stringent processing conditions than information about, for example, someone's property and affairs, since information about a person's mental or physical health or condition is classified as 'sensitive personal data', while financial information is not. However, in practice, it is often more difficult to obtain financial information. A doctor or social worker will often know both the carer and the person lacking capacity well and it will be much more obvious that the carer needs certain information.

15.25 A bank manager, on the other hand, is less likely to know the person lacking capacity, less able to make an assessment of capacity and less likely to be aware of the carer's relationship to the person lacking capacity. This means that s/he is less likely to be able to judge that it would be in the person's best interests to release the information than say a doctor or social worker. It is likely that someone seeking information on the finances of someone lacking capacity will need to apply to the Court of Protection for a single order or a financial deputyship authorising access to that information.

Disclosure and subsequent confidentiality

15.26 Whenever information is disclosed, the carer may be asked to give an undertaking that the information will be treated in confidence, it will not be disclosed to anyone else (unless there is a lawful basis for doing so) and that will not be kept for longer than necessary. In many cases, the need to keep the information will be transient, and in those cases, the carer should be able to reassure the information holder that s/he will not keep a permanent record of the information. If the carer does intend to keep a permanent record of a decision, s/he should make it clear for how long s/he needs to keep the information on which s/he has based the decision.

Consent

15.27 In some cases, where the person lacking capacity has retained some decision-making capabilities, the professional will be able to seek his/her consent to information being disclosed. In line with the general principles of the Act, a person may have the capacity to give consent to the release of personal information, even though they may not have the capacity to make more complex decisions. Alternatively, even though the person lacking consent may not have retained any decision-making capability, they may have previously indicated consent to disclosure of information while s/he was still able to do so, intending this consent to apply at a time when s/he no longer has capacity.

15.28 If someone has fluctuating capacity, the professional may want to wait until a time when s/he has capacity to consent to the information being shared.

Alternatively, it may be unnecessary to disclose information to others at all, if the person is likely to regain the capacity to make his/her own decisions.

Resolving disagreements over requests for information by family carers or other carers

15.29 If a professional does not offer information, a carer may sometimes need to be pro-active in seeking information because s/he believes it would help him/her to make a decision about the person lacking capacity. S/he should then ask the health or social care professional for information, explaining why s/he needs it. If the information is not forthcoming, s/he may need to remind the professional that, as a carer, s/he has a duty to act only in the best interests of the person lacking capacity and explain that s/he needs to have the information in order to be able to do so.

15.30 This can be a sensitive area and disputes will inevitably arise. The professional has a difficult judgement to make. S/he might feel strongly that to disclose the information the carer is seeking would not be in the best interests of the person lacking capacity and would amount to an unnecessary invasion of their privacy. This may be upsetting for the carer who might only want the information for the best of motives. In all cases, an assessment of the interests and needs of the person lacking capacity should determine whether or not, and to whom, any particular information is disclosed.

15.31 If a discussion fails to resolve the matter, and the carer is not satisfied with the professional's reason for withholding information, or no reason is given, the carer can use the appropriate complaints procedure, (see chapter 14). Since the complaint involves elements of data protection and confidentiality, as well as best interests, relevant experts in those fields will be involved in dealing with the complaint.

15.32 If the complaint is not upheld the only recourse would be to apply to the Court of Protection for a single order, or possibly a deputyship (see chapter 7) giving right of access to the specific information. The court would then need to decide if this was in the best interests of the person lacking capacity. In urgent cases, it might be necessary for the carer to apply directly to the court without going through the intermediary stages.

Part 4: Checklists

15.33 The following simple checklists set out some of the most important considerations when information is to be requested or disclosed.

15.34 The person requesting information should ask:

- Am I acting under a Lasting Power of Attorney or as a deputy with specific authority?
- What information do I need?
- Why do I need it?
- Who has the information?
- Can I show that I need the information for me to make a decision that is in the best interests of the person on whose behalf I am acting and that that person lacks the capacity to act for him/herself?

- Does the person concerned have capacity to consent to disclosure of the information, or has s/he previously given consent?
- Do I need to share the information with anyone else to make a decision that is in the best interests of the person lacking capacity?
- Should I keep a record of my decision or action?
- How long should I keep the information for?
- If so, should I request the information under the formal subject access provisions of section 7 of the Data Protection Act 1998?

15.35 The person who is asked or intends to disclose information should ask:

- Is the request for information a subject access request under section 7 Data Protection Act 1998 made by a formally authorised representative? If no, then consider;
- Is the disclosure lawful?
- Is the disclosure justified having balanced the best interests of the person lacking capacity and/or the public interest against the rights to privacy of the person lacking capacity?

15.36 The following subsidiary questions should help to answer these two latter key points:

- Do I (or does my organisation) have the information requested?
- Am I satisfied that the person concerned lacks capacity to consent to the information being disclosed?
- Does the person requesting the information have any formal authority to act on behalf of the person lacking capacity?
- Am I satisfied that the person making the request is acting in the best interests of the person who lacks the capacity?
- Am I satisfied that s/he needs the information in order to act properly?
- Am I satisfied that s/he will respect any confidentiality?
- Am I satisfied that s/he will keep the information for no longer than necessary?
- Should I seek a formal undertaking as to these matters?

Annex A – Contact addresses

Organisation	Website	Contact Details
Care Standards Inspectorate for Wales	www.csiw.wales.gov.uk	See web-site for local contacts
Commission for Social Care Inspection	www.csci.org.uk	Email enquiries@csci.gsi.gov.uk Customer services helpline ☎0845 015 0120
Community Legal Services	www.clsdirect.org.uk	☎0845 345 4 345
Department for Constitutional Affairs	www.dca.gov.uk	Department for Constructional Affairs Selborne House, 54 Victoria Street, London SW1E 6QW ☎020 7210 8614
Department for Health	www.dh.gov.uk	The Department of Health Richmond House 79 Whitehall London SW1A 2NS ☎020 7210 4850
Department for Work and Pensions	www.dwp.gov.uk	Department for Work and Pensions Public Enquiry OfficeRoom 112 The Adelphi 1-11 John Adam Street London WC2N 6HT ☎020 7712 2171
Family Mediation Helpline	www.familymediationhelpline.co.uk	☎0845 60 26 627
Healthcare Commission (England)	www.healthcarecommission.org.uk	See web-site for details
Healthcare Inspectorate Wales	www.hiw.wales.gov.uk	Healthcare Inspectorate Wales Unit 3C Caerphilly Business Park Van Road Caerphilly CF83 3ED ☎029 2092 8850

Health Service Ombudsman	www.ombudsman.org.uk	E-mail: phso.enquiries@ombudsman.org.uk ☎0845 015 4033
Independent Complaints Advocacy Service	http://www.cppih.org	See web-site for details General Enquiries The Commission for Patient and Public Involvement in Health The Help Desk 7th Floor, 120 Edmund Street Birmingham B3 2ES E-mail enquiries@cppih.org ☎0845 120 7111
Independent Housing Ombudsman (Housing Ombudsman Service)	http://www.ihos.org.uk/	Housing Ombudsman Service Norman House 105-109 Strand London WC2R 0AA Email ombudsman@ihos.org.uk ☎020 7836 3630
Information Commissioner	www.informationcommissioner.gov.uk	Information Commissioner Wycliffe House Water Lane Wilmslow Cheshire SK9 5AF ☎01625 524510
Local Government Ombudsman	www.lgo.org.uk	See web-site for details
National Assembly for Wales	www.wales.gov.uk	National Assembly for Wales Cardiff Bay Cardiff CF99 1NA ☎029 20 825111
National Health Service Litigation Authority	http://www.nhsla.com	E-mail GeneralEnquiries@nhsla.com See web-site for further contact details
National Mediation Helpline	www.nationalmediationhelpline.com	☎0845 60 30 809

Office of the Official Solicitor	http://www.offsol.demon.co.uk/	Official Solicitor and Public Trustee 81 Chancery Lane London WC2A 1DD ☎020 7911 7127
Office of the Public Guardian	www.guardianship.gov.uk	Office of the Public Guardian Archway Tower 2 Junction Road London N19 5SZ ☎0845 330 2900
Public Services Ombudsman for Wales	www.ombudsman-wales.org	Public Services Ombudsman For Wales, 1 Ffordd yr Hen Gae, Pencoed, CF35 5LJ Email ask@ombudsman-wales.org.uk ☎ 01656 641 150
Social Services Inspectorate Wales (All Wales Unit)	www.allwalesunit.gov.uk	All Wales Unit The Beeches 116 Eaton Crescent Uplands SWANSEA SA1 4QR Email: info@allwalesunit.gov.uk ☎01792 470616