

# 11 How does the Act affect research projects involving a person who lacks capacity?

It is important that research involving people who lack capacity can be carried out, and that is carried out properly. Without it, we would not improve our knowledge of what causes a person to lack or lose capacity, and the diagnosis, treatment, care and needs of people who lack capacity.

This chapter gives guidance on involving people who lack capacity to consent to take part in research. It sets out:

- what the Act means by 'research'
- the requirements that people must meet if their research project involves somebody who lacks capacity
- the specific responsibilities of researchers, and
- how the Act applies to research that started before the Act came into force.

This chapter only deals with research in relation to adults. Further guidance will be provided on how the Act applies in relation to research involving those under the age of 18.

In this chapter, as throughout the Code, a person's capacity (or lack of capacity) refers specifically to their capacity to make a particular decision at the time it needs to be made.

## Quick summary

The Act's rules for research that includes people who lack capacity to consent to their involvement cover:

- when research can be carried out
- the ethical approval process
- respecting the wishes and feelings of people who lack capacity
- other safeguards to protect people who lack capacity
- how to engage with a person who lacks capacity
- how to engage with carers and other relevant people.

This chapter also explains:

- the specific rules that apply to research involving human tissue and
- what to do if research projects have already been given the go-ahead.

The Act applies to all research that is intrusive. 'Intrusive' means research that would be unlawful if it involved a person who had capacity but had not consented to take part. The Act does not apply to research involving clinical trials (testing new drugs).

## Why does the Act cover research?

- 11.1 Because the Act is intended to assist and support people who may lack capacity, the Act protects people who take part in research projects but lack capacity to make decisions about their involvement. It makes sure that researchers respect their wishes and feelings. The Act does not apply to research that involves clinical trials of medicines – because these are covered by other rules.<sup>44</sup>

### How can research involving people who lack capacity help?

A high percentage of patients with Down's syndrome lack capacity to agree or refuse to take part in research. Research involving patients with Down's syndrome has shown that they are more likely than other people to get pre-senile dementia. Research has also shown that when this happens the pathological changes that occur in a person with Down's syndrome (changes affecting their body and brain) are similar to those that occur in someone with Alzheimer's disease. This means that we now know that treatment similar to that used for memory disorders in patients with Alzheimer's is appropriate to treat dementia in those with Down's syndrome.

## What is 'research'?

- 11.2 The Act does not have a specific definition for 'research'. The Department of Health and National Assembly for Wales publications *Research governance framework for health and social care* both state:

'research can be defined as the attempt to derive generalisable new knowledge by addressing clearly defined questions with systematic and rigorous methods.'<sup>45</sup>

Research may:

- provide information that can be applied generally to an illness, disorder or condition
- demonstrate how effective and safe a new treatment is
- add to evidence that one form of treatment works better than another
- add to evidence that one form of treatment is safer than another, or
- examine wider issues (for example, the factors that affect someone's capacity to make a decision).

- 11.3 Researchers must state clearly if an activity is part of someone's care and not part of the research. Sometimes experimental medicine or treatment may be performed for the person's benefit and be the best option for their care. But in

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<sup>44</sup> The Medicines for Human Use (Clinical Trials) Regulations 2004.

<sup>45</sup> [www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT\\_ID=4008777&chk=dMRd/5](http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4008777&chk=dMRd/5) and [www.word.wales.gov.uk/content/governance/governance-e.htm](http://www.word.wales.gov.uk/content/governance/governance-e.htm)

these cases, it may be difficult to decide whether treatment is research or care. Where there is doubt, the researcher should seek legal advice.

### **What assumptions can a researcher make about capacity?**

11.4 Researchers should assume that a person has capacity, unless there is proof that they lack capacity to make a specific decision (see chapter 3). The person must also receive support to try to help them make their own decision (see chapter 2). The person whose capacity is in question has the right to make decisions that others might not agree with, and they have the right not to take part in research.

### **What research does the Act cover?**

11.5 It is expected that most of the researchers who ask for their research to be approved under the Act will be medical or social care researchers. However, the Act can cover more than just medical and social care research. Intrusive research which does not meet the requirements of the Act cannot be carried out lawfully in relation to people who lack capacity.

11.6 The Act applies to research that:

- is 'intrusive' (if a person taking part had capacity, the researcher would need to get their consent to involve them)
- involves people who have an impairment of, or a disturbance in the functioning of, their mind or brain which makes them unable to decide whether or not to agree to take part in the research (i.e. they lack capacity to consent), and
- is not a clinical trial covered under the Medicines for Human Use (Clinical Trials) Regulations 2004.

11.7 There are circumstances where no consent is needed to lawfully involve a person in research. These apply to all persons, whether they have capacity or not:

- Sometimes research only involves data that has been anonymised (it cannot be traced back to individuals). Confidentiality and data protection laws do not apply in this case.
- Under the Human Tissue Act 2004, research that deals only with human tissue that has been anonymised does not require consent (see paragraphs 11.37–11.40). This applies to both those who have capacity and those who do not. But the research must have ethical approval, and the tissue must come from a living person.<sup>46</sup>
- If researchers collected human tissue samples before 31 August 2006, they do not need a person's consent to work on them. But they will normally have to get ethical approval.

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<sup>46</sup> Human Tissue Act 2004 section 1(9).

- Regulations<sup>47</sup> made under section 251 of the NHS Act 2006 (formerly known as section 60 of the Health and Social Care Act 2001<sup>48</sup>) allow people to use confidential patient information without breaking the law on confidentiality by applying to the Patient Information Advisory Group for approval on behalf of the Secretary of State.<sup>49</sup>

## **Who is responsible for making sure research meets the Act's requirements?**

11.8 Responsibility for meeting the Act's requirements lies with:

- the 'appropriate body', as defined in regulations made by the Secretary of State (for regulations applying in England) or the National Assembly for Wales (for regulations applying in Wales) (see paragraph 11.10), and
- the researchers carrying out the research (see paragraphs 11.20–11.40).

## **How can research get approval?**

11.9 Research covered by the Act cannot include people who lack capacity to consent to the research unless:

- it has the approval of 'the appropriate body', and
- it follows other requirements in the Act to:
  - consider the views of carers and other relevant people
  - treat the person's interests as more important than those of science and society, and
  - respect any objections a person who lacks capacity makes during research.

11.10 An 'appropriate body' is an organisation that can approve research projects. In England, the 'appropriate body' must be a research ethics committee recognised by the Secretary of State.<sup>50</sup> In Wales, the 'appropriate body' must be a research ethics committee recognised by the Welsh Assembly Government.

11.11 The appropriate body can only approve a research project if the research is linked to:

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<sup>47</sup> Health Service (Control of Patient Information) Regulations 2002 Section I. 2002/1438.

<sup>48</sup> Section 60 of the Health and Social Care Act 2001 was included in the NHS Act 2006 which consolidated all the previous health legislation still in force.

<sup>49</sup> The Patient Information Advisory Group considers applications on behalf of the Secretary of State to allow the common law duty of confidentiality to be aside. It was established under section 61 of the Health and Social Care Act 2006 (now known as section 252 of the NHS Act 2006). Further information can be found at [www.advisorybodies.doh.gov.uk/PIAG](http://www.advisorybodies.doh.gov.uk/PIAG).

<sup>50</sup> Mental Capacity Act 2005 (Appropriate Body) (England) Regulations 2006

- an impairing condition that affects the person who lacks capacity, or
- the treatment of that condition (see paragraph 11.17)

*and:*

- there are reasonable grounds for believing that the research would be less effective if only people with capacity are involved, and
- the research project has made arrangements to consult carers and to follow the other requirements of the Act.

11.12 Research must also meet one of two requirements:

1. The research must have some chance of benefiting the person who lacks capacity, as set out in paragraph 11.14 below. The benefit must be in proportion to any burden caused by taking part, or
2. The aim of the research must be to provide knowledge about the cause of, or treatment or care of people with, the same impairing condition – or a similar condition.

If researchers are relying on the second requirement, the Act sets out further requirements that must be met:

- the risk to the person who lacks capacity must be negligible
- there must be no significant interference with the freedom of action or privacy of the person who lacks capacity, and
- nothing must be done to or in relation to the person who lacks capacity which is unduly invasive or restrictive (see paragraphs 11.16–11.19 below).

11.13 An impairing condition:

- is caused by (or may be caused by) an impairment of, or disturbance in the functioning of, the person's mind or brain
- causes (or may cause) an impairment or disturbance of the mind or brain, or
- contributes to (or may contribute to) an impairment or disturbance of the mind or brain.

### **Balancing the benefit and burden of research**

11.14 Potential benefits of research for a person who lacks capacity could include:

- developing more effective ways of treating a person or managing their condition
- improving the quality of healthcare, social care or other services that they have access to
- discovering the cause of their condition, if they would benefit from that knowledge, or
- reducing the risk of the person being harmed, excluded or disadvantaged.

11.15 Benefits may be direct or indirect (for example, the person might benefit at a later date if policies or care packages affecting them are changed because of the research). It might be that participation in the research itself will be of benefit to the person in particular circumstances. For example, if the research involves interviews and the person has the opportunity to express their views, this could be considered of real benefit to a particular individual.

### **Providing knowledge about causes, treatment or care of people with the same impairing condition or a similar condition**

11.16 It is possible for research to be carried out which doesn't actually benefit the person taking part, as long as it aims to provide knowledge about the causes, treatment or care of people with the same impairing condition, or a similar condition. 'Care' and 'treatment' are not limited to medical care and treatment. For example, research could examine how day-to-day life in prison affects prisoners with mental health conditions.

11.17 It is the person's actual condition that must be the same or similar in research, not the underlying cause. A 'similar condition' may therefore have a different cause to that suffered by the participant. For example, research into ways of supporting people with learning disabilities to live more independently might involve a person with a learning disability caused by a head trauma. But its findings might help people with similar learning disabilities that have different causes.

### **Scenario: Research that helps find a cause or treatment**

Mr Neal has Down's syndrome. For many years he has lived in supported housing and worked in a local supermarket. But several months ago, he became aggressive, forgetful and he started to make mistakes at work. His consultant believes that this may indicate the start of Alzheimer's disease.

Mr Neal's condition is now so bad that he does not have capacity to consent to treatment or make other decisions about his care. A research team is researching the cause of dementia in people with Down's syndrome. They would like to involve Mr Neal. The research satisfies the Act's requirement that it is intended to provide knowledge of the causes or treatment of that condition, even though it may not directly benefit Mr Neal. So the approving body might give permission – if the research meets other requirements.

11.18 Any risk to people involved in this category of research must be 'negligible' (minimal). This means that a person should suffer no harm or distress by taking part. Researchers must consider risks to psychological wellbeing as well as physical wellbeing. This is particularly relevant for research related to observations or interviews.

11.19 Research in this category also must not affect a person's freedom of action or privacy in a significant way, and it should not be unduly invasive or restrictive. What will be considered as unduly invasive will be different for different people and different types of research. For example, in psychological research some people may think a specific question is intrusive, but others would not. Actions will not usually be classed as unduly invasive if they do not go beyond the experience of daily life, a routine medical examination or a psychological examination.

## **Scenario: Assessing the risk to research participants**

A research project is studying:

- how well people with a learning disability make financial decisions, and
- communication techniques that may improve their decision-making capacity.

Some of the participants lack capacity to agree to take part. The Research Ethics Committee is satisfied that some of these participants may benefit from the study because their capacity to make financial decisions may be improved. For those who will not gain any personal benefit, the Committee is satisfied that:

- the research meets the other conditions of the Act
- the research methods (psychological testing and different communication techniques) involve no risk to participants, and
- the research could not have been carried out as effectively with people who have capacity.

## **What responsibilities do researchers have?**

11.20 Before starting the research, the research team must make arrangements to:

- obtain approval for the research from the ‘appropriate body’
- get the views of any carers and other relevant people before involving a person who lacks capacity in research (see paragraphs 11.22–11.28).  
There is an exception to this consultation requirement in situations where urgent treatment needs to be given or is about to be given
- respect the objections, wishes and feelings of the person, and
- place more importance on the person’s interests than on those of science and society.

11.21 The research proposal must give enough information about what the team will do if a person who lacks capacity needs urgent treatment during research and it is not possible to speak to the person’s carer or someone else who acts or makes decisions on behalf of the person (see paragraphs 11.32–11.36).

## **Consulting carers**

11.22 Once it has been established that a person lacks capacity to agree to participate, then before they are included in research the researcher must consult with specified people in accordance with section 32 of the Act to determine whether the person should be included in the research.

## **Who can researchers consult?**

11.23 The researcher should as a matter of good practice take reasonable steps to identify someone to consult. That person (the consultee) must be involved in the person’s care, interested in their welfare and must be willing to help. They

must not be a professional or paid care worker. They will probably be a family member, but could be another person.

- 11.24 The researcher must take into account previous wishes and feelings that the person might have expressed about who they would, or would not, like involved in future decisions.
- 11.25 A person is not prevented from being consulted if they are an attorney authorised under a registered Lasting Power of Attorney or are a deputy appointed by the Court of Protection. But that person must not be acting in a professional or paid capacity (for example, person's solicitor).
- 11.26 Where there is no-one who meets the conditions mentioned at paragraphs 11.23 and 11.25, the researcher must nominate a person to be the consulted. In this situation, they must follow guidance from the Secretary of State for Health in England or the National Assembly for Wales (the guidance will be available from mid-2007). The person who is nominated must have no connection with the research project.
- 11.27 The researcher must provide the consultee with information about the research project and ask them:
- for advice about whether the person who lacks capacity should take part in the project, and
  - what they think the person's feelings and wishes would be, if they had capacity to decide whether to take part.
- 11.28 Sometimes the consultee will say that the person would probably not take part in the project or that they would ask to be withdrawn. In this situation, the researcher must not include the person in the project, or they should withdraw them from it. But if the project has started, and the person is getting treatment as part of the research, the researcher may decide that the person should not be withdrawn if the researcher reasonably believes that this would cause a significant risk to the person's health. The researcher may decide that the person should continue with the research while the risk exists. But they should stop any parts of the study that are not related to the risk to the person's health.

### **What other safeguards does the Act require?**

- 11.29 Even when a consultee agrees that a person can take part in research, the researcher must still consider the person's wishes and feelings.
- 11.30 Researchers must not do anything the person who lacks capacity objects to. They must not do anything to go against any advance decision to refuse treatment or other statement the person has previously made expressing preferences about their care or treatment. They must assume that the person's interests in this matter are more important than those of science and society.
- 11.31 A researcher must withdraw someone from a project if:

- they indicate in any way that they want to be withdrawn from the project (for example, if they become upset or distressed), or
- any of the Act's requirements are no longer met.

## **What happens if urgent decisions are required during the research project?**

11.32 Anyone responsible for caring for a person must give them urgent treatment if they need it. In some circumstances, it may not be possible to separate the research from the urgent treatment.

11.33 A research proposal should explain to the appropriate body how researchers will deal with urgent decisions which may occur during the project, when there may not be time to carry out the consultations required under the Act. For example, after a patient has arrived in intensive care, the doctor may want to chart the course of an injury by taking samples or measurements immediately and then taking further samples after some type of treatment to compare with the first set.

11.34 Special rules apply where a person who lacks capacity is getting, or about to get, urgent treatment and researchers want to include them in a research project. If in these circumstances a researcher thinks that it is necessary to take urgent action for the purposes of the research, and they think it is not practical to consult someone about it, the researcher can take that action if:

- they get agreement from a registered medical practitioner not involved with the research, or
- they follow a procedure that the appropriate body agreed to at approval stage.

11.35 The medical practitioner may have a connection to the person who lacks capacity (for example, they might be their doctor). But they must not be involved in the research project in any way. This is to avoid conflicts of interest.

11.36 This exception to the duty to consult only applies:

- for as long as the person needs urgent treatment, and
- when the researcher needs to take action urgently for research to be valid.

It is likely to be limited to research into procedures or treatments used in emergencies. It does not apply where the researcher simply wants to act quickly.

## **What happens for research involving human tissue?**

11.37 A person with capacity has to give their permission for someone to remove tissue from their body (for example, taking a biopsy (a sample) for diagnosis or removal of tissue in surgery). The Act allows the removal of tissue from the body of a person who lacks capacity, if it is in their best interests (see chapter 5).

11.38 People with capacity must also give permission for the storage or use of tissue for certain purposes, set out in the Human Tissue Act 2004, (for example, transplants and research). But there are situations in which permission is not required by law:

- research where the samples are anonymised and the research has ethical approval<sup>51</sup>
- clinical audit
- education or training relating to human health
- performance assessment
- public health monitoring, and
- quality assurance.

11.39 If an adult lacks capacity to consent, the Human Tissue Act 2004 says that tissue can be stored or used without seeking permission if the storage or use is:

- to get information relevant to the health of another individual (for example, before conducting a transplant), as long as the researcher or healthcare professional storing or using the human tissue believes they are doing it in the best interests of the person who lacks capacity to consent
- for a clinical trial approved and carried out under the Medicines for Human Use (Clinical Trials) Regulations 2004, or
- for intrusive research:
  - after the Mental Capacity Act comes into force
  - that meets the Act's requirements, and
  - that has ethical approval.

11.40 Tissue samples that were obtained before 31 August 2006 are existing holdings under the Human Tissue Act. Researchers can work with these tissues without seeking permission. But they will still need to get ethical approval. Guidance is available in the Human Tissue Authority Code of Practice on consent.<sup>52</sup>

## **What should happen to research that started before the Act came into force?**

### **What if a person has capacity when research starts but loses capacity?**

11.41 Some people with capacity will agree to take part in research but may then lose capacity before the end of the project. In this situation, researchers will be able to continue research as long as they comply with the conditions set out in

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<sup>51</sup> Section 1(9) of the Human Tissue Act 2004

<sup>52</sup> [www.hta.gov.uk](http://www.hta.gov.uk)

the Mental Capacity Act 2005 (Loss of Capacity During Research Project) (England) Regulations 2007 or equivalent Welsh regulations.

The regulations only apply to tissue and data collected before the loss of capacity from a person who gave consent before 31 March 2008 to join a project that starts before 1 October 2007.

11.42 The regulations do not cover research involving direct intervention (for example, taking of further blood pressure readings) or the taking of further tissue after loss of capacity. Such research must comply with sections 30 to 33 of the Act to be lawful.

11.43 Where the regulations do apply, research can only continue if the project already has procedures to deal with people who lose capacity during the project. An appropriate body must have approved the procedures. The researcher must follow the procedures that have been approved.

11.44 The researcher must also:

- seek out the views of someone involved in the person's care or interested in their welfare and if a carer can't be found they must nominate a consultee (see paragraphs 11.22–11.28)
- respect advance decisions and expressed preferences, wishes or objections that the person has made in the past, and
- treat the person's interests as more important than those of science and society.

The appropriate body must be satisfied that the research project has reasonable arrangements to meet these requirements.

11.45 If at any time the researcher believes that procedures are no longer in place or the appropriate body no longer approves the research, they must stop research on the person immediately.

11.46 Where regulations do apply, research does not have to:

- be linked to an impairing condition of the person
- have the potential to benefit that person, or
- aim to provide knowledge relevant to others with the same or a similar condition.

### **What happens to existing projects that a person never had capacity to agree to?**

11.47 There are no regulations for projects that:

- started before the Act comes into force, and
- a person never had the capacity to agree to.

Projects that already have ethical approval will need to obtain approval from an appropriate body under sections 30 and 31 of the Mental Capacity Act and to comply with the requirements of sections 32 and 33 of that Act by 1 October 2008. Research that does not have ethical approval must get approval from

an appropriate body by 1 October 2007 to continue lawfully. This is the case in England and it is expected that similar arrangements will apply in Wales.

## 12 How does the Act apply to children and young people?

This chapter looks at the few parts of the Act that may affect children under 16 years of age. It also explains the position of young people aged 16 and 17 years and the overlapping laws that affect them.

This chapter does not deal with research. Further guidance will be provided on how the Act applies in relation to research involving those under the age of 18.

Within this Code of Practice, 'children' refers to people aged below 16. 'Young people' refers to people aged 16–17. This differs from the Children Act 1989 and the law more generally, where the term 'child' is used to refer to people aged under 18.

In this chapter, as throughout the Code, a person's capacity (or lack of capacity) refers specifically to their capacity to make a particular decision at the time it needs to be made.

### Quick summary

#### *Children under 16*

- The Act does not generally apply to people under the age of 16.
- There are two exceptions:
  - The Court of Protection can make decisions about a child's property or finances (or appoint a deputy to make these decisions) if the child lacks capacity to make such decisions within section 2(1) of the Act and is likely to still lack capacity to make financial decisions when they reach the age of 18 (section 18(3)).
  - Offences of ill treatment or wilful neglect of a person who lacks capacity within section 2(1) can also apply to victims younger than 16 (section 44).

#### *Young people aged 16–17 years*

- Most of the Act applies to young people aged 16–17 years, who may lack capacity within section 2(1) to make specific decisions.
- There are three exceptions:
  - Only people aged 18 and over can make a Lasting Power of Attorney (LPA).
  - Only people aged 18 and over can make an advance decision to refuse medical treatment.
  - The Court of Protection may only make a statutory will for a person aged 18 and over.

#### *Care or treatment for young people aged 16–17*

- People carrying out acts in connection with the care or treatment of a young person aged 16–17 who lacks capacity to consent within section 2(1) will generally have protection from liability (section 5), as long as the person carrying out the act:
  - has taken reasonable steps to establish that the young person lacks capacity

- reasonably believes that the young person lacks capacity and that the act is in the young person’s best interests, and
  - follows the Act’s principles.
- When assessing the young person’s best interests (see chapter 5), the person providing care or treatment must consult those involved in the young person’s care and anyone interested in their welfare – if it is practical and appropriate to do so. This may include the young person’s parents. Care should be taken not to unlawfully breach the young person’s right to confidentiality (see chapter 16).
  - Nothing in section 5 excludes a person’s civil liability for loss or damage, or his criminal liability, resulting from his negligence in carrying out the act.

#### *Legal proceedings involving young people aged 16-17*

- Sometimes there will be disagreements about the care, treatment or welfare of a young person aged 16 or 17 who lacks capacity to make relevant decisions. Depending on the circumstances, the case may be heard in the family courts or the Court of Protection.
- The Court of Protection may transfer a case to the family courts, and vice versa.

### **Does the Act apply to children?**

- 12.1 Section 2(5) of the Act states that, with the exception of section 2(6), as explained below, no powers under the Act may be exercised in relation to a child under 16.
- 12.2 Care and treatment of children under the age of 16 is generally governed by common law principles. Further information is provide at [www.dh.gov.uk/consent](http://www.dh.gov.uk/consent).

### **Can the Act help with decisions about a child’s property or finances?**

- 12.3 Section 2(6) makes an exception for some decisions about a child’s property and financial affairs. The Court of Protection can make decisions about property and affairs of those under 16 in cases where the person is likely to still lack capacity to make financial decisions after reaching the age of 18. The court’s ruling will still apply when the person reaches the age of 18, which means there will not be a need for further court proceedings once the person reaches the age of 18.
- 12.4 The Court of Protection can:
- make an order (for example, concerning the investment of an award of compensation for the child), and/or
  - appoint a deputy to manage the child’s property and affairs and to make ongoing financial decisions on the child’s behalf.

In making a decision, the court must follow the Act’s principles and decide in the child’s best interests as set out in chapter 5 of the Code.

### **Scenario: Applying the Act to children**

Tom was nine when a drunk driver knocked him off his bicycle. He suffered severe head injuries and permanent brain damage. He received a large amount of money in compensation. He is unlikely to recover enough to be able to make financial decisions when he is 18. So the Court of Protection appoints Tom's father as deputy to manage his financial affairs in order to pay for the care Tom will need in the future.

### **What if somebody mistreats or neglects a child who lacks capacity?**

- 12.5 Section 44 covers the offences of ill treatment or wilful neglect of a person who lacks capacity to make relevant decisions (see chapter 14). This section also applies to children under 16 and young people aged 16 or 17. But it only applies if the child's lack of capacity to make a decision for themselves is caused by an impairment or disturbance that affects how their mind or brain works (see chapter 4). If the lack of capacity is solely the result of the child's youth or immaturity, then the ill treatment or wilful neglect would be dealt with under the separate offences of child cruelty or neglect.

### **Does the Act apply to young people aged 16–17?**

- 12.6 Most of the Act applies to people aged 16 years and over. There is an overlap with the Children Act 1989. For the Act to apply to a young person, they must lack capacity to make a particular decision (in line with the Act's definition of lack of capacity described in chapter 4). In such situations either this Act or the Children Act 1989 may apply, depending upon the particular circumstances.

However, there may also be situations where neither of these Acts provides an appropriate solution. In such cases, it may be necessary to look to the powers available under the Mental Health Act 1983 or the High Court's inherent powers to deal with cases involving young people.

- 12.7 There are currently no specific rules for deciding when to use either the Children Act 1989 or the Mental Capacity Act 2005 or when to apply to the High Court. But, the examples below show circumstances where this Act may be the most appropriate (see also paragraphs 12.21–12.23 below).
- In unusual circumstances it might be in a young person's best interests for the Court of Protection to make an order and/or appoint a property and affairs deputy. For example, this might occur when a young person receives financial compensation and the court appoints a parent or a solicitor as a property and affairs deputy.
  - It may be appropriate for the Court of Protection to make a welfare decision concerning a young person who lacks capacity to decide for themselves (for example, about where the young person should live) if the court decides that the parents are not acting in the young person's best interests.
  - It might be appropriate to refer a case to the Court of Protection where there is disagreement between a person interested in the care and welfare of a young person and the young person's medical team about the young person's best interests or capacity.

## **Do any parts of the Act not apply to young people aged 16 or 17?**

### **LPAs**

12.8 Only people aged 18 or over can make a Lasting Power of Attorney (LPA) (section 9(2)(c)).

### **Advance decisions to refuse treatment**

12.9 Information on decisions to refuse treatment made in advance by young people under the age of 18 will be available at [www.dh.gov.uk/consent](http://www.dh.gov.uk/consent).

### **Making a will**

12.10 The law generally does not allow anyone below the age of 18 to make a will. So section 18(2) confirms that the Court of Protection can only make a statutory will on behalf of those aged 18 and over.

## **What does the Act say about care or treatment of young people aged 16 or 17?**

### **Background information concerning competent young people**

12.11 The Family Law Reform Act 1969 presumes that young people have the legal capacity to agree to surgical, medical or dental treatment.<sup>53</sup> This also applies to any associated procedures (for example, investigations, anaesthesia or nursing care).

12.12 It does not apply to some rarer types of procedure (for example, organ donation or other procedures which are not therapeutic for the young person) or research. In those cases, anyone under 18 is presumed to lack legal capacity, subject to the test of 'Gillick competence' (testing whether they are mature and intelligent enough to understand a proposed treatment or procedure).<sup>54</sup>

12.13 Even where a young person is presumed to have legal capacity to consent to treatment, they may not necessarily be able to make the relevant decision. As with adults, decision-makers should assess the young person's capacity to consent to the proposed care or treatment (see chapter 4). If a young person lacks capacity to consent within section 2(1) of the Act because of an impairment of, or a disturbance in the functioning of, the mind or brain then the Mental Capacity Act will apply in the same way as it does to those who are 18 and over. If however they are unable to make the decision for some other reason, for example because they are overwhelmed by the implications of the

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<sup>53</sup> Family Law Reform Act 1969, section 8(1)

<sup>54</sup> 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 years of age will be competent to consent to medical treatment if they have sufficient intelligence and understanding to understand what is proposed. This test applies in relation to all people under 18 where there is no presumption of competence in relation to the procedure – for example where the procedure is not one referred to in section 8 of the Family Law Reform Act 1969, e.g. organ donation.

decision, the Act will not apply to them and the legality of any treatment should be assessed under common law principles.

- 12.14 If a young person has capacity to agree to treatment, their decision to consent must be respected. Difficult issues can arise if a young person has legal and mental capacity and refuses consent – especially if a person with parental responsibility wishes to give consent on the young person’s behalf. The Family Division of the High Court can hear cases where there is disagreement. The Court of Protection has no power to settle a dispute about a young person who is said to have the mental capacity to make the specific decision.
- 12.15 It may be unclear whether a young person lacks capacity within section 2(1) of the Act. In those circumstances, it would be prudent for the person providing care or treatment for the young person to seek a declaration from the court.

### **If the young person lacks capacity to make care or treatment decisions**

- 12.16 Under the common law, a person with parental responsibility for a young person is generally able to consent to the young person receiving care or medical treatment where they lack capacity under section 2(1) of the Act. They should act in the young person’s best interests.
- 12.17 However if a young person lacks the mental capacity to make a specific care or treatment decision within section 2(1) of the Act, healthcare staff providing treatment, or a person providing care to the young person, can carry out treatment or care with protection from liability (section 5) whether or not a person with parental responsibility consents.<sup>55</sup> They must follow the Act’s principles and make sure that the actions they carry out are in the young person’s best interests. They must make every effort to work out and consider the young person’s wishes, feelings, beliefs and values – both past and present – and consider all other factors in the best interests checklist (see chapter 5).
- 12.18 When assessing a young person’s best interests, healthcare staff must take into account the views of anyone involved in caring for the young person and anyone interested in their welfare, where it is practical and appropriate to do so. This may include the young person’s parents and others with parental responsibility for the young person. Care should be taken not to unlawfully breach the young person’s right to confidentiality (see chapter 16).
- 12.19 If a young person has said they do not want their parents to be consulted, it may not be appropriate to involve them (for example, where there have been allegations of abuse).
- 12.20 If there is a disagreement about whether the proposed care or treatment is in the best interests of a young person, or there is disagreement about whether the young person lacks capacity and there is no other way of resolving the matter, it would be prudent for those in disagreement to seek a declaration or other order from the appropriate court (see paragraphs 12.23–12.25 below).

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<sup>55</sup> Nothing in section 5 excludes a person’s civil liability for loss or damage, or his criminal liability, resulting from his negligence in doing the Act.

## **Scenario: Working out a young person's best interests**

Mary is 16 and has Down's syndrome. Her mother wants Mary to have dental treatment that will improve her appearance but is not otherwise necessary.

To be protected under section 5 of the Act, the dentist must consider whether Mary has capacity to agree to the treatment and what would be in her best interests. He decides that she is unable to understand what is involved or the possible consequences of the proposed treatment and so lacks capacity to make the decision.

But Mary seems to want the treatment, so he takes her views into account in deciding whether the treatment is in her best interests. He also consults with both her parents and with her teacher and GP to see if there are other relevant factors to take into account.

He decides that the treatment is likely to improve Mary's confidence and self-esteem and is in her best interests.

- 12.21 There may be particular difficulties where young people with mental health problems require in-patient psychiatric treatment, and are treated informally rather than detained under the Mental Health Act 1983. The Mental Capacity Act and its principles apply to decisions related to the care and treatment of young people who lack mental capacity to consent, including treatment for mental disorder. As with any other form of treatment, somebody assessing a young person's best interests should consult anyone involved in caring for the young person or anyone interested in their welfare, as far as is practical and appropriate. This may include the young person's parents or those with parental responsibility for the young person.

But the Act does not allow any actions that result in a young person being deprived of their liberty (see chapter 6). In such circumstances, detention under the Mental Health Act 1983 and the safeguards provided under that Act might be appropriate (see also chapter 13).

- 12.22 People may disagree about a young person's capacity to make the specific decision or about their best interests, or it may not be clear whether they lack capacity within section 2(1) or for some other reason. In this situation, legal proceedings may be necessary if there is no other way of settling the disagreement (see chapters 8 and 15). If those involved in caring for the young person or who are interested in the young person's welfare do not agree with the proposed treatment, it may be necessary for an interested party to make an application to the appropriate court.

## **What powers do the courts have in cases involving young people?**

- 12.23 A case involving a young person who lacks mental capacity to make a specific decision could be heard in the family courts (probably in the Family Division of the High Court) or in the Court of Protection.
- 12.24 If a case might require an ongoing order (because the young person is likely to still lack capacity when they are 18), it may be more appropriate for the Court of Protection to hear the case. For one-off cases not involving property or finances, the Family Division may be more appropriate.

12.25 So that the appropriate court hears a case, the Court of Protection can transfer cases to the family courts, and vice versa (section 21).

**Scenario: Hearing cases in the appropriate court**

Shola is 17. She has serious learning disabilities and lacks the capacity to decide where she should live. Her parents are involved in a bitter divorce. They cannot agree on several issues concerning Shola's care – including where she should live. Her mother wants to continue to look after Shola at home. But her father wants Shola to move into a care home.

In this case, it may be more appropriate for the Court of Protection to deal with the case. This is because an order made in the Court of Protection could continue into Shola's adulthood. However an order made by the family court under the Children Act 1989 would end on Shola's eighteenth birthday.

## 13 What is the relationship between the Mental Capacity Act and the Mental Health Act 1983?

This chapter explains the relationship between the Mental Capacity Act 2005 (MCA) and the Mental Health Act 1983 (MHA). It:

- sets out when it may be appropriate to detain someone under the MHA rather than to rely on the MCA
- describes how the MCA affects people lacking capacity who are also subject to the MHA
- explains when doctors cannot give certain treatments for a mental disorder (in particular, psychosurgery) to someone who lacks capacity to consent to it, and
- sets out changes that the Government is planning to make to both Acts.

It does not provide a full description of the MHA. The MHA has its own Memorandum to explain the Act and its own Code of Practice to guide people about how to use it.<sup>59</sup>

In this chapter, as throughout the Code, a person's capacity (or lack of capacity) refers specifically to their capacity to make a particular decision at the time it needs to be made.

### Quick summary

- Professionals may need to think about using the MHA to detain and treat somebody who lacks capacity to consent to treatment (rather than use the MCA), if:
  - it is not possible to give the person the care or treatment they need without doing something that might deprive them of their liberty
  - the person needs treatment that cannot be given under the MCA (for example, because the person has made a valid and applicable advance decision to refuse an essential part of treatment)
  - the person may need to be restrained in a way that is not allowed under the MCA
  - it is not possible to assess or treat the person safely or effectively without treatment being compulsory (perhaps because the person is expected to regain capacity to consent, but might then refuse to give consent)
  - the person lacks capacity to decide on some elements of the treatment but has capacity to refuse a vital part of it – and they have done so, or
  - there is some other reason why the person might not get treatment, and they or somebody else might suffer harm as a result.
- Before making an application under the MHA, decision-makers should consider whether they could achieve their aims safely and effectively by using the MCA instead.

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<sup>59</sup> Department of Health & Welsh Office, *Mental Health Act 1983 Code of Practice* (TSO, 1999), [www.dh.gov.uk/assetRoot/04/07/49/61/04074961.pdf](http://www.dh.gov.uk/assetRoot/04/07/49/61/04074961.pdf)

- Compulsory treatment under the MHA is not an option if:
  - the patient’s mental disorder does not justify detention in hospital, or
  - the patient needs treatment only for a physical illness or disability.
- The MCA applies to people subject to the MHA in the same way as it applies to anyone else, with four exceptions:
  - if someone is detained under the MHA, decision-makers cannot normally rely on the MCA to give treatment for mental disorder or make decisions about that treatment on that person’s behalf
  - if somebody can be treated for their mental disorder without their consent because they are detained under the MHA, healthcare staff can treat them even if it goes against an advance decision to refuse that treatment
  - if a person is subject to guardianship, the guardian has the exclusive right to take certain decisions, including where the person is to live, and
  - Independent Mental Capacity Advocates do not have to be involved in decisions about serious medical treatment or accommodation, if those decisions are made under the MHA.
- Healthcare staff cannot give psychosurgery (i.e. neurosurgery for mental disorder) to a person who lacks capacity to agree to it. This applies whether or not the person is otherwise subject to the MHA.

## **Who does the MHA apply to?**

- 13.1 The MHA provides ways of assessing, treating and caring for people who have a serious mental disorder that puts them or other people at risk. It sets out when:
- people with mental disorders can be detained in hospital for assessment or treatment
  - people who are detained can be given treatment for their mental disorder without their consent (it also sets out the safeguards people must get in this situation), and
  - people with mental disorders can be made subject to guardianship or after-care under supervision to protect them or other people.
- 13.2 Most of the MHA does not distinguish between people who have the capacity to make decisions and those who do not. Many people covered by the MHA have the capacity to make decisions for themselves. Most people who lack capacity to make decisions about their treatment will never be affected by the MHA, even if they need treatment for a mental disorder.
- 13.3 But there are cases where decision-makers will need to decide whether to use the MHA or MCA, or both, to meet the needs of people with mental health problems who lack capacity to make decisions about their own treatment.

## **What are the MCA’s limits?**

- 13.4 Section 5 of the MCA provides legal protection for people who care for or treat someone who lacks capacity (see chapter 6). But they must follow the Act’s principles and may only take action that is in a person’s best interests (see

chapter 5). This applies to care or treatment for physical and mental conditions. So it can apply to treatment for people with mental disorders, however serious those disorders are.

- 13.5 But section 5 does have its limits. For example, somebody using restraint only has protection if the restraint is:
- necessary to protect the person who lacks capacity from harm, and
  - in proportion to the likelihood and seriousness of that harm.
- 13.6 There is no protection under section 5 for actions that deprive a person of their liberty (see chapter 6 for guidance). Similarly, the MCA does not allow giving treatment that goes against a valid and applicable advance decision to refuse treatment (see chapter 9).
- 13.7 None of these restrictions apply to treatment for mental disorder given under the MHA – but other restrictions do.

### **When can a person be detained under the MHA?**

- 13.8 A person may be taken into hospital and detained for assessment under section 2 of the MHA for up to 28 days if:
- they have a mental disorder that is serious enough for them to be detained in a hospital for assessment (or for assessment followed by treatment) for at least a limited period, and
  - they need to be detained to protect their health or safety, or to protect others.
- 13.9 A patient may be admitted to hospital and detained for treatment under section 3 of the MHA if:
- they have a mental illness, severe mental impairment, psychopathic disorder or mental impairment (the MHA sets out definitions for these last three terms)
  - their mental disorder is serious enough to need treatment in hospital
  - treatment is needed for the person's health or safety, or for the protection of other people – and it cannot be provided without detention under this section, and
  - (if the person has a mental impairment or psychopathic disorder) treatment is likely to improve their condition or stop it getting worse.
- 13.10 Decision-makers should consider using the MHA if, in their professional judgment, they are not sure it will be possible, or sufficient, to rely on the MCA. They do not have to ask the Court of Protection to rule that the MCA does not apply before using the MHA.
- 13.11 If a clinician believes that they can safely assess or treat a person under the MCA, they do not need to consider using the MHA. In this situation, it would be difficult to meet the requirements of the MHA anyway.
- 13.12 It might be necessary to consider using the MHA rather than the MCA if:

- it is not possible to give the person the care or treatment they need without carrying out an action that might deprive them of their liberty
- the person needs treatment that cannot be given under the MCA (for example, because the person has made a valid and applicable advance decision to refuse all or part of that treatment)
- the person may need to be restrained in a way that is not allowed under the MCA
- it is not possible to assess or treat the person safely or effectively without treatment being compulsory (perhaps because the person is expected to regain capacity to consent, but might then refuse to give consent)
- the person lacks capacity to decide on some elements of the treatment but has capacity to refuse a vital part of it – and they have done so, or
- there is some other reason why the person might not get the treatment they need, and they or somebody else might suffer harm as a result.

13.13 But it is important to remember that a person cannot be treated under the MHA unless they meet the relevant criteria for being detained. Unless they are sent to hospital under Part 3 of the MHA in connection with a criminal offence, people can only be detained where:

- the conditions summarised in paragraph 13.8 or 13.9 are met
- the relevant people agree that an application is necessary (normally two doctors and an approved social worker), and
- (in the case of section 3) the patient's nearest relative has not objected to the application.

'Nearest relative' is defined in section 26 of the MHA. It is usually, but not always, a family member.

### **Scenario: Using the MHA**

Mr Oliver has a learning disability. For the last four years, he has had depression from time to time, and has twice had treatment for it at a psychiatric hospital. He is now seriously depressed and his care workers are worried about him.

Mr Oliver's consultant has given him medication and is considering electro-convulsive therapy. The consultant thinks this care plan will only work if Mr Oliver is detained in hospital. This will allow close observation and Mr Oliver will be stopped if he tries to leave. The consultant thinks an application should be made under section 3 of the MHA.

The consultant also speaks to Mr Oliver's nearest relative, his mother. She asks why Mr Oliver needs to be detained when he has not needed to be in the past. But after she hears the consultant's reasons, she does not object to the application. An approved social worker makes the application and obtains a second medical recommendation. Mr Oliver is then detained and taken to hospital for his treatment for depression to begin.

13.14 Compulsory treatment under the MHA is not an option if:

- the patient's mental disorder does not justify detention in hospital, or
  - the patient needs treatment only for a physical illness or disability.
- 13.15 There will be some cases where a person who lacks capacity cannot be treated either under the MHA or the MCA – even if the treatment is for mental disorder.

### **Scenario: Deciding whether to use the MHA or MCA**

Mrs Carter is in her 80s and has dementia. Somebody finds her wandering in the street, very confused and angry. A neighbour takes her home and calls her doctor. At home, it looks like she has been deliberately smashing things. There are cuts on her hands and arms, but she won't let the doctor touch them, and she hasn't been taking her medication.

Her doctor wants to admit her to hospital for assessment. Mrs Carter gets angry and says that they'll never keep her in hospital. So the doctor thinks that it might be necessary to use the MHA. He arranges for an approved social worker to visit. The social worker discovers that Mrs Carter was expecting her son this morning, but he has not turned up. They find out that he has been delayed, but could not call because Mrs Carter's telephone has become unplugged.

When she is told that her son is on his way, Mrs Carter brightens up. She lets the doctor treat her cuts – which the doctor thinks it is in her best interests to do as soon as possible. When Mrs Carter's son arrives, the social worker explains the doctor is very worried, especially that Mrs Carter is not taking her medication. The son explains that he will help his mother take it in future. It is agreed that the MCA will allow him to do that. The social worker arranges to return a week later and calls the doctor to say that she thinks Mrs Carter can get the care she needs without being detained under the MHA. The doctor agrees.

### **How does the MCA apply to a patient subject to guardianship under the MHA?**

- 13.16 Guardianship gives someone (usually a local authority social services department) the exclusive right to decide where a person should live – but in doing this they cannot deprive the person of their liberty. The guardian can also require the person to attend for treatment, work, training or education at specific times and places, and they can demand that a doctor, approved social worker or another relevant person have access to the person wherever they live. Guardianship can apply whether or not the person has the capacity to make decisions about care and treatment. It does not give anyone the right to treat the person without their permission or to consent to treatment on their behalf.
- 13.17 An application can be made for a person who has a mental disorder to be received into guardianship under section 7 of the MHA when:
- the situation meets the conditions summarised in paragraph 13.18
  - the relevant people agree an application for guardianship should be made (normally two doctors and an approved social worker), and

- the person's nearest relative does not object.

13.18 An application can be made in relation to any person who is 16 years or over if:

- they have a mental illness, severe mental impairment, psychopathic disorder or mental impairment that is serious enough to justify guardianship (see paragraph 13.20 below), and
- guardianship is necessary in the interests of the welfare of the patient or to protect other people.

13.19 Applicants (usually approved social workers) and doctors supporting the application will need to determine whether they could achieve their aims without guardianship. For patients who lack capacity, the obvious alternative will be action under the MCA.

13.20 But the fact that the person lacks capacity to make relevant decision is not the only factor that applicants need to consider. They need to consider all the circumstances of the case. They may conclude that guardianship is the best option for a person with a mental disorder who lacks capacity to make those decisions if, for example:

- they think it is important that one person or authority should be in charge of making decisions about where the person should live (for example, where there have been long-running or difficult disagreements about where the person should live)
- they think the person will probably respond well to the authority and attention of a guardian, and so be more prepared to accept treatment for the mental disorder (whether they are able to consent to it or it is being provided for them under the MCA), or
- they need authority to return the person to the place they are to live (for example, a care home) if they were to go absent.

Decision-makers must never consider guardianship as a way to avoid applying the MCA.

13.21 A guardian has the exclusive right to decide where a person lives, so nobody else can use the MCA to arrange for the person to live elsewhere. Somebody who knowingly helps a person leave the place a guardian requires them to stay may be committing a criminal offence under the MHA. A guardian also has the exclusive power to require the person to attend set times and places for treatment, occupation, education or training. This does not stop other people using the MCA to make similar arrangements or to treat the person in their best interests. But people cannot use the MCA in any way that conflicts with decisions which a guardian has a legal right to make under the MHA. See paragraph 13.16 above for general information about a guardian's powers.

## **How does the MCA apply to a patient subject to after-care under supervision under the MHA?**

13.22 When people are discharged from detention for medical treatment under the MHA, their responsible medical officer may decide to place them on after-care under supervision. The responsible medical officer is usually the person's consultant psychiatrist. Another doctor and an approved social worker must support their application.

13.23 After-care under supervision means:

- the person can be required to live at a specified place (where they can be taken to and returned, if necessary)
- the person can be required to attend for treatment, occupation, education or training at a specific time and place (where they can be taken, if necessary), and
- their supervisor, any doctor or approved social worker or any other relevant person must be given access to them wherever they live.

13.24 Responsible medical officers can apply for after-care under supervision under section 25A of the MHA if:

- the person is 16 or older and is liable to be detained in a hospital for treatment under section 3 (and certain other sections) of the MHA
- the person has a mental illness, severe mental impairment, psychopathic disorder or mental impairment
- without after-care under supervision the person's health or safety would be at risk of serious harm, they would be at risk of serious exploitation, or other people's safety would be at risk of serious harm, and
- after-care under supervision is likely to help make sure the person gets the after-care services they need.

'Liable to be detained' means that a hospital is allowed to detain them. Patients who are liable to be detained are not always actually in hospital, because they may have been given permission to leave hospital for a time.

13.25 After-care under supervision can be used whether or not the person lacks capacity to make relevant decisions. But if a person lacks capacity, decision-makers will need to decide whether action under the MCA could achieve their aims before making an application. The kinds of cases in which after-care under supervision might be considered for patients who lack capacity to take decisions about their own care and treatment are similar to those for guardianship.

## **How does the Mental Capacity Act affect people covered by the Mental Health Act?**

13.26 There is no reason to assume a person lacks capacity to make their own decisions just because they are subject (under the MHA) to:

- detention

- guardianship, or
- after-care under supervision.

13.27 People who lack capacity to make specific decisions are still protected by the MCA even if they are subject to the MHA (this includes people who are subject to the MHA as a result of court proceedings). But there are four important exceptions:

- if someone is liable to be detained under the MHA, decision-makers cannot normally rely on the MCA to give mental health treatment or make decisions about that treatment on someone's behalf
- if somebody can be given mental health treatment without their consent because they are liable to be detained under the MHA, they can also be given mental health treatment that goes against an advance decision to refuse treatment
- if a person is subject to guardianship, the guardian has the exclusive right to take certain decisions, including where the person is to live, and
- Independent Mental Capacity Advocates do not have to be involved in decisions about serious medical treatment or accommodation, if those decisions are made under the MHA.

### **What are the implications for people who need treatment for a mental disorder?**

13.28 Subject to certain conditions, Part 4 of the MHA allows doctors to give patients who are liable to be detained treatment for mental disorders without their consent – whether or not they have the capacity to give that consent. Paragraph 13.31 below lists a few important exceptions.

13.29 Where Part 4 of the MHA applies, the MCA cannot be used to give medical treatment for a mental disorder to patients who lack capacity to consent. Nor can anyone else, like an attorney or a deputy, use the MCA to give consent for that treatment. This is because Part 4 of the MHA already allows clinicians, if they comply with the relevant rules, to give patients medical treatment for mental disorder even though they lack the capacity to consent. In this context, medical treatment includes nursing and care, habilitation and rehabilitation under medical supervision.

13.30 But clinicians treating people for mental disorder under the MHA cannot simply ignore a person's capacity to consent to treatment. As a matter of good practice (and in some cases in order to comply with the MHA) they will always need to assess and record:

- whether patients have capacity to consent to treatment, and
- if so, whether they have consented to or refused that treatment.

For more information, see the MHA Code of Practice.

13.31 Part 4 of the MHA does not apply to patients:

- admitted in an emergency under section 4(4)(a) of the MHA, following a single medical recommendation and awaiting a second recommendation
- temporarily detained (held in hospital) under section 5 of the MHA while awaiting an application for detention under section 2 or section 3
- remanded by a court to hospital for a report on their medical condition under section 35 of the MHA
- detained under section 37(4), 135 or 136 of the MHA in a place of safety, or
- who have been conditionally discharged by the Mental Health Review Tribunal (and not recalled to hospital).

13.32 Since the MHA does not allow treatment for these patients without their consent, the MCA applies in the normal way, even if the treatment is for mental disorder.

13.33 Even when the MHA allows patients to be treated for mental disorders, the MCA applies in the normal way to treatment for physical disorders. But sometimes healthcare staff may decide to focus first on treating a detained patient's mental disorder in the hope that they will get back the capacity to make a decision about treatment for the physical disorder.

13.34 Where people are subject to guardianship or after-care under supervision under the MHA, the MCA applies as normal to all treatment. Guardianship and after-care under supervision do not give people the right to treat patients without consent.

### **Scenario: Using the MCA to treat a patient who is detained under the MHA**

Mr Peters is detained in hospital under section 3 of the MHA and is receiving treatment under Part 4 of the MHA. Mr Peters has paranoid schizophrenia, delusions, hallucinations and thought disorder. He refuses all medical treatment. Mr Peters has recently developed blood in his urine and staff persuaded him to have an ultrasound scan. The scan revealed suspected renal carcinoma.

His consultant believes that he needs a CT scan and treatment for the carcinoma. But Mr Peters refuses a general anaesthetic and other medical procedures. The consultant assesses Mr Peters as lacking capacity to consent to treatment under the MCA's test of capacity. The MHA is not relevant here, because the CT scan is not part of Mr Peters' treatment for mental disorder.

Under section 5 of the MCA, doctors can provide treatment without consent. But they must follow the principles of the Act and believe that treatment is in Mr Peters' best interests.

### **How does the Mental Health Act affect advance decisions to refuse treatment?**

13.35 The MHA does not affect a person's advance decision to refuse treatment, unless Part 4 of the MHA means the person can be treated for mental disorder without their consent. In this situation healthcare staff can treat patients for

their mental disorder, even if they have made an advance decision to refuse such treatment.

- 13.36 But even then healthcare staff must treat a valid and applicable advance decision as they would a decision made by a person with capacity at the time they are asked to consent to treatment. For example, they should consider whether they could use a different type of treatment which the patient has not refused in advance. If healthcare staff do not follow an advance decision, they should record in the patient's notes why they have chosen not to follow it.
- 13.37 Even if a patient is being treated without their consent under Part 4 of the MHA, an advance decision to refuse other forms of treatment is still valid. Being subject to guardianship or after-care under supervision does not affect an advance decision in any way. See chapter 9 for further guidance on advance decisions to refuse treatment.

### **Scenario: Deciding on whether to follow an advance decision to refuse treatment**

Miss Khan gets depression from time to time and has old physical injuries that cause her pain. She does not like the side effects of medication, and manages her health through diet and exercise. She knows that healthcare staff might doubt her decision-making capacity when she is depressed. So she makes an advance decision to refuse all medication for her physical pain and depression.

A year later, she gets major depression and is detained under the MHA. Her GP (family doctor) tells her responsible medical officer (RMO) at the hospital about her advance decision. But Miss Khan's condition gets so bad that she will not discuss treatment. So the RMO decides to prescribe medication for her depression, despite her advance decision. This is possible because Miss Khan is detained under the MHA.

The RMO also believes that Miss Khan now lacks capacity to consent to medication for her physical pain. He assesses the validity of the advance decision to refuse medication for the physical pain. Her GP says that Miss Khan seemed perfectly well when she made the decision and seemed to understand what it meant. In the GP's view, Miss Khan had the capacity to make the advance decision. The RMO decides that the advance decision is valid and applicable, and does not prescribe medication for Miss Khan's pain – even though he thinks it would be in her best interests. When Miss Khan's condition improves, the consultant will be able to discuss whether she would like to change her mind about treatment for her physical pain.

### **Does the MHA affect the duties of attorneys and deputies?**

- 13.38 In general, the MHA does not affect the powers of attorneys and deputies. But there are two exceptions:
- they will not be able to give consent on a patient's behalf for treatment under Part 4 of the MHA, where the patient is liable to be detained under the MHA (see 13.28–13.34 above), and
  - they will not be able to take decisions:

- about where a person subject to guardianship should live, or
  - that conflict with decisions that a guardian has a legal right to make.
- 13.39 Being subject to the MHA does not stop patients creating new Lasting Powers of Attorney (if they have the capacity to do so). Nor does it stop the Court of Protection from appointing a deputy for them.
- 13.40 In certain cases, people subject to the MHA may be required to meet specific conditions relating to:
- leave of absence from hospital
  - after-care under supervision, or
  - conditional discharge.
- Conditions vary from case to case, but could include a requirement to:
- live in a particular place
  - maintain contact with health services, or
  - avoid a particular area.
- 13.41 If an attorney or deputy takes a decision that goes against one of these conditions, the patient will be taken to have gone against the condition. The MHA 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.
- 13.42 Attorneys and deputies are able to exercise patients' rights under the MHA on their behalf, if they have the relevant authority. In particular, some personal welfare attorneys and deputies may be able to apply to the Mental Health Review Tribunal (MHRT) for the patient's discharge from detention, guardianship or after-care under supervision.
- 13.43 The MHA also gives various rights to a patient's nearest relative. These include the right to:
- insist that a local authority social services department instructs an approved social worker to consider whether the patient should be made subject to the MHA
  - apply for the patient to be admitted to hospital or guardianship
  - object to an application for admission for treatment
  - order the patient's discharge from hospital (subject to certain conditions) and
  - order the patient's discharge from guardianship.
- 13.44 Attorneys and deputies may not exercise these rights, unless they are themselves the nearest relative. If the nearest relative and an attorney or deputy disagree, it may be helpful for them to discuss the issue, perhaps with the assistance of the patient's clinicians or social worker. But ultimately they have different roles and both must act as they think best. An attorney or deputy must act in the patient's best interests.

13.45 It is good practice for clinicians and others involved in the assessment or treatment of patients under the MHA to try to find out if the person has an attorney or deputy. But this may not always be possible. So attorneys and deputies should contact either:

- the healthcare professional responsible for the patient's treatment (generally known as the patient's RMO)
- the managers of the hospital where the patient is detained
- the person's guardian (normally the local authority social services department), or
- the person's supervisor (if the patient is subject to after-care under supervision).

Hospitals that treat detained patients normally have a Mental Health Act Administrator's office, which may be a useful first point of contact.

### **Does the MHA affect when Independent Mental Capacity Advocates must be instructed?**

13.46 As explained in chapter 10, there is no duty to instruct an Independent Mental Capacity Advocate (IMCA) for decisions about serious medical treatment which is to be given under Part 4 of the MHA. Nor is there a duty to do so in respect of a move into accommodation, or a change of accommodation, if the person in question is to be required to live in it because of an obligation under the MHA. 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.

13.47 However, the rules for instructing an IMCA for patients subject to the MHA who might undergo serious medical treatment not related to their mental disorder are the same as for any other patient.

13.48 The duty to instruct an IMCA would also apply as normal if accommodation is being planned as part of the after-care under section 117 of the MHA following the person's discharge from detention (and the person is not going to be required to live in it as a condition of after-care under supervision). This is because the person does not have to accept that accommodation.

### **What is the effect of section 57 of the Mental Health Act on the MCA?**

13.49 Section 57 of the MHA states that psychosurgery (neurosurgery for mental disorder) requires:

- the consent of the patient, and
- the approval of an independent doctor and two other people appointed by the Mental Health Act Commission.

Psychosurgery is any surgical operation that destroys brain tissue or the function of brain tissue.

13.50 The same rules apply to other treatments specified in regulations under section 57. Currently, the only treatment included in regulations is the surgical implantation of hormones to reduce a man's sex drive.

13.51 The combined effect of section 57 of the MHA and section 28 of the MCA is, effectively, that a person who lacks the capacity to consent to one of these treatments for mental disorder may never be given it. Healthcare staff cannot use the MCA as an alternative way of giving these kinds of treatment. Nor can an attorney or deputy give permission for them on a person's behalf.

## **What changes does the Government plan to make to the MHA and the MCA?**

13.52 The Government has introduced a Mental Health Bill into Parliament in order to modernise the MHA. Among the changes it proposes to make are:

- some amendments to the criteria for detention, including a new requirement that appropriate medical treatment be available for patients before they can be detained for treatment
- the introduction of supervised treatment in the community for suitable patients following a period of detention and treatment in hospital. This will help make sure that patients get the treatment they need and help stop them relapsing and returning to hospital
- the replacement of the approved social worker with the approved mental health professional. This will open up the possibility of approved mental healthcare professionals being drawn from other disciplines as well as social work. Other changes will open up the possibility of clinicians who are not doctors being approved to take on the role of the responsible medical officer. This role will be renamed the responsible clinician.
- provisions to make it possible for patients to apply to the county court for an unsuitable nearest relative to be replaced, and
- the abolition of after-care under supervision.

13.53 The Bill will also amend the MCA to introduce new procedures and provisions to make relevant decisions but who need to be deprived of their liberty, in their best interests, otherwise than under the Mental Health Act 1983 (the so-called 'Bournewood provisions').<sup>60</sup>

13.54 This chapter, as well as chapter 6, will be fully revised in due course to reflect those changes. Information about the Government's current proposals in respect of the Bournewood safeguards is available on the Department of Health website. This information includes draft illustrative Code of Practice guidance about the proposed safeguards.<sup>61</sup>

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<sup>60</sup> This refers to the European Court of Human Rights judgement (5 October 2004) in the case of *HL v The United Kingdom* (Application no, 45508/99).

<sup>61</sup> See [www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationSPolicyAndGuidanceArticle/fs/en?CONTENT\\_ID=4141656&chk=jlw07L](http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationSPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4141656&chk=jlw07L)

13.55 In the meantime, people taking decisions under both the MCA and the MHA must base those decisions on the Acts as they stand now.

## 14 What means of protection exist for people who lack capacity to make decisions for themselves?

This chapter describes the different agencies that exist to help make sure that adults who lack capacity to make decisions for themselves are protected from abuse. It also explains the services those agencies provide and how they supervise people who provide care for or make decisions on behalf of people who lack capacity. Finally, it explains what somebody should do if they suspect that somebody is abusing a vulnerable adult who lacks capacity.

In this chapter, as throughout the Code, a person's capacity (or lack of capacity) refers specifically to their capacity to make a particular decision at the time it needs to be made.

### Quick summary

- Always report suspicions of abuse of a person who lacks capacity to the relevant agency.

#### *Concerns about an appointee*

- When someone is concerned about the collection or use of social security benefits by an appointee on behalf a person who lacks capacity, they should contact the local Jobcentre Plus. If the appointee is for someone who is over the age of 60, contact The Pension Service.

#### *Concerns about an attorney or deputy*

- If someone is concerned about the actions of an attorney or deputy, they should contact the Office of the Public Guardian.

#### *Concerns about a possible criminal offence*

- If there is a good reason to suspect that someone has committed a crime against a vulnerable person, such as theft or physical or sexual assault, contact the police.
- In addition, social services should also be contacted, so that they can support the vulnerable person during the investigation.

#### *Concerns about possible ill-treatment or wilful neglect*

- The Act introduces new criminal offences of ill treatment or wilful neglect of a person who lacks capacity to make relevant decisions (section 44).
- If someone is not being looked after properly, contact social services.
- In serious cases, contact the police.

#### *Concerns about care standards*

- In cases of concern about the standard of care in a care home or an adult placement scheme, or about the care provided by a home care worker, contact social services.

- It may also be appropriate to contact the Commission for Social Care Inspection (in England) or the Care and Social Services Inspectorate for Wales.

### *Concerns about healthcare or treatment*

- If someone is concerned about the care or treatment given to the person in any NHS setting (such as an NHS hospital or clinic) contact the managers of the service.
- It may also be appropriate to make a formal complaint through the NHS complaints procedure (see chapter 15).

## **What is abuse?**

14.1 The word 'abuse' covers a wide range of actions. In some cases, abuse is clearly deliberate and intentionally unkind. But sometimes abuse happens because somebody does not know how to act correctly – or they haven't got appropriate help and support. It is important to prevent abuse, wherever possible. If somebody is abused, it is important to investigate the abuse and take steps to stop it happening.

14.2 Abuse is anything that goes against a person's human and civil rights. This includes sexual, physical, verbal, financial and emotional abuse. Abuse can be:

- a single act
- a series of repeated acts
- a failure to provide necessary care, or
- neglect.

Abuse can take place anywhere (for example, in a person's own home, a care home or a hospital).

14.3 The main types of abuse are:

<b>Type of abuse</b>	<b>Example</b>
Financial	<ul style="list-style-type: none"> <li>• theft</li> <li>• fraud</li> <li>• undue pressure</li> <li>• misuse of property, possessions or benefits</li> <li>• dishonest gain of property, possessions or benefits.</li> </ul>
Physical	<ul style="list-style-type: none"> <li>• slapping, pushing, kicking or other forms of violence</li> <li>• misuse of medication (for example, increasing dosage to make someone drowsy)</li> <li>• inappropriate punishments (for example, not giving someone a meal)</li> </ul>

	because they have been 'bad').
Sexual	<ul style="list-style-type: none"> <li>• rape</li> <li>• sexual assault</li> <li>• sexual acts without consent (this includes if a person is not able to give consent or the abuser used pressure).</li> </ul>
Psychological	<ul style="list-style-type: none"> <li>• emotional abuse</li> <li>• threats of harm, restraint or abandonment</li> <li>• refusing contact with other people</li> <li>• intimidation</li> <li>• threats to restrict someone's liberty.</li> </ul>
Neglect and acts of omission	<ul style="list-style-type: none"> <li>• ignoring the person's medical or physical care needs</li> <li>• failing to get healthcare or social care</li> <li>• withholding medication, food or heating.</li> </ul>

14.4 The Department of Health and the National Assembly for Wales have produced separate guidance on protecting vulnerable adults from abuse. *No secrets*<sup>62</sup> (England) and *In safe hands*<sup>63</sup> (Wales) both define vulnerable adults as people aged 18 and over who:

- need community care services due to a mental disability, other disability, age or illness, and
- may be unable to take care of themselves or protect themselves against serious harm or exploitation.

This description applies to many people who lack capacity to make decisions for themselves.

14.5 Anyone who thinks that someone might be abusing a vulnerable adult who lacks capacity should:

- contact the local social services (see paragraphs 14.27–14.28 below)
- contact the Office of the Public Guardian (see paragraph 14.8 below), or
- seek advice from a relevant telephone helpline<sup>64</sup> or through the Community

<sup>62</sup> 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) [www.dh.gov.uk/assetRoot/04/07/45/40/04074540.pdf](http://www.dh.gov.uk/assetRoot/04/07/45/40/04074540.pdf)

<sup>63</sup> National Assembly for Wales, *In safe hands: Implementing adult protection procedures in Wales* (2000), [http://new.wales.gov.uk/about/departments/dhss/publications/social\\_services\\_publications/reports/insafehands?lang=en](http://new.wales.gov.uk/about/departments/dhss/publications/social_services_publications/reports/insafehands?lang=en)

<sup>64</sup> For example, the Action on Elder Abuse (0808 808 8141), Age Concern (0800 009966) or

Full contact details are provided in Annex A.

- 14.6 In most cases, local adult protection procedures will say who should take action (see paragraphs 14.28–14.29 below). But some abuse will be a criminal offence, such as physical assault, sexual assault or rape, theft, fraud and some other forms of financial exploitation. In these cases, the person who suspects abuse should contact the police urgently. The criminal investigation may take priority over all other forms of investigation. So all agencies will have to work together to plan the best way to investigate possible abuse.
- 14.7 The Fraud Act 2006 (due to come into force in 2007) creates a new offence of ‘fraud by abuse of position’. This new offence may apply to a range of people, including:
- attorneys under a Lasting Power of Attorney (LPA) or an Enduring Power of Attorney (EPA), or
  - deputies appointed by the Court of Protection to make financial decisions on behalf of a person who lacks capacity.

Attorneys and deputies may be guilty of fraud if they dishonestly abuse their position, intend to benefit themselves or others, and cause loss or expose a person to the risk of loss. People who suspect fraud should report the case to the police.

## **How does the Act protect people from abuse?**

### **The Office of the Public Guardian**

- 14.8 Section 57 of the Act creates a new Public Guardian, supported by staff of the Office of the Public Guardian (OPG). The Public Guardian helps protect people who lack capacity by:
- setting up and managing a register of LPAs
  - setting up and managing a register of EPAs
  - setting up and managing a register of court orders that appoint deputies
  - supervising deputies, working with other relevant organisations (for example, social services, if the person who lacks capacity is receiving social care)
  - sending Court of Protection Visitors to visit people who may lack capacity to make particular decisions and those who have formal powers to act on their behalf (see paragraphs 14.10–14.11 below)
  - receiving reports from attorneys acting under LPAs and from deputies
  - providing reports to the Court of Protection, as requested, and

- dealing with representations (including complaints) about the way in which attorneys or deputies carry out their duties.

14.9 Section 59 of the Act creates a Public Guardian Board to oversee and review how the Public Guardian carries out these duties.

### **Court of Protection Visitors**

14.10 The role of a Court of Protection Visitor is to provide independent advice to the court and the Public Guardian. They advise on how anyone given power under the Act should be, and is, carrying out their duties and responsibilities. There are two types of visitor: General Visitors and Special Visitors. Special visitors are registered medical practitioners with relevant expertise. The court or Public Guardian can send whichever type of visitor is most appropriate to visit and interview a person who may lack capacity. Visitors can also interview attorneys or deputies and inspect any relevant healthcare or social care records. Attorneys and deputies must co-operate with the visitors and provide them with all relevant information. If attorneys or deputies do not co-operate, the court can cancel their appointment, where it thinks that they have not acted in the person's best interests.

#### **Scenario: Using a General Visitor**

Mrs Quinn made an LPA appointing her nephew, Ian, as her financial attorney. She recently lost capacity to make her own financial decisions, and Ian has registered the LPA. He has taken control of Mrs Quinn's financial affairs.

But Mrs Quinn's niece suspects that Ian is using Mrs Quinn's money to pay off his own debts. She contacts the OPG, which sends a General Visitor to visit Mrs Quinn and Ian. The visitor's report will assess the facts. It might suggest the case go to court to consider whether Ian has behaved in a way which:

- goes against his authority under the LPA, or
- is not in Mrs Quinn's best interests.

The Public Guardian will decide whether the court should be involved in the matter. The court will then decide if it requires further evidence. If it thinks that Ian is abusing his position, the court may cancel the LPA.

14.11 Court of Protection Visitors have an important part to play in investigating possible abuse. But their role is much wider than this. They can also check on the general wellbeing of the person who lacks capacity, and they can give support to attorneys and deputies who need help to carry out their duties.

### **How does the Public Guardian oversee LPAs?**

14.12 An LPA is a private arrangement between the donor and the attorney (see chapter 7). Donors should only choose attorneys that they can trust. The OPG provides information to help potential donors understand:

- the impact of making an LPA
- what they can give an attorney authority to do

- what to consider when choosing an attorney.
- 14.13 The Public Guardian must make sure that an LPA meets the Act's requirements. Before registering an LPA, the OPG will check documentation. For property and affairs LPAs, it will check whether an attorney appointed under the LPA is bankrupt since this would revoke the authority.
- 14.14 The Public Guardian will not usually get involved once somebody has registered an LPA – unless someone is worried about how an attorney is carrying out their duties. If concerns are raised about an attorney, the OPG works closely with organisations such as local authorities and NHS Trusts to carry out investigations.

### **How does the Public Guardian supervise deputies?**

- 14.15 Individuals do not choose who will act as a deputy for them. The court will make the decision. There are measures to make sure that the court appoints an appropriate deputy. The OPG will then supervise deputies and support them in carrying out their duties, while also making sure they do not abuse their position.
- 14.16 When a case comes before the Court of Protection, the Act states that the court should make a decision to settle the matter rather than appoint a deputy, if possible. Deputies are most likely to be needed for financial matters where someone needs continued authority to make decisions about the person's money or other assets. It will be easier for the courts to make decisions in cases where a one-off decision is needed about a person's welfare, so there are likely to be fewer personal welfare deputies. But there will be occasions where ongoing decisions about a person's welfare will be required, and so the court will appoint a personal welfare deputy (see chapter 8).

#### **Scenario: Appointing deputies**

Peter was in a motorbike accident that left him permanently and seriously brain-damaged. He has minimal awareness of his surroundings and an assessment has shown that he lacks capacity to make most decisions for himself.

Somebody needs to make several decisions about what treatment Peter needs and where he should be treated. His parents feel that healthcare staff do not always consider their views in decisions about what treatment is in Peter's best interests. So they make an application to the court to be appointed as joint personal welfare deputies.

There will be many care or treatment decisions for Peter in the future. The court decides it would not be practical to make a separate decision on each of them. It also thinks Peter needs some continuity in decision-making. So it appoints Peter's parents as joint personal welfare deputies.

- 14.17 The OPG may run checks on potential deputies if requested to by the court. It will carry out a risk assessment to determine what kind of supervision a deputy will need once they are appointed.

14.18 Deputies are accountable to the court. The OPG supervises the deputy's actions on the court's behalf, and the court may want the deputy to provide financial accounts or other reports to the OPG. The Public Guardian deals with complaints about the way deputies carry out their duties. It works with other relevant agencies to investigate them. Chapter 8 gives detailed information about the responsibilities of deputies.

### **What happens if someone says they are worried about an attorney or deputy?**

14.19 Many people who lack capacity are likely to get care or support from a range of agencies. Even when an attorney or deputy is acting on behalf of a person who lacks capacity, the other carers still have a responsibility to the person to provide care and act in the person's best interests. Anybody who is caring for a person who lacks capacity, whether in a paid or unpaid role, who is worried about how attorneys or deputies carry out their duties should contact the Public Guardian.

14.20 The OPG will not always be the most appropriate organisation to investigate all complaints. It may investigate a case jointly with:

- healthcare or social care professionals
- social services
- NHS bodies
- the Commission for Social Care Inspection in England or the Care and Social Services Inspectorate for Wales (CSSIW)<sup>66</sup>
- the Healthcare Commission in England or the Healthcare Inspectorate for Wales, and
- in some cases, the police.

14.21 The OPG will usually refer concerns about personal welfare LPAs or personal welfare deputies to the relevant agency. In certain circumstances it will alert the police about a case. When it makes a referral, the OPG will make sure that the relevant agency keeps it informed of the action it takes. It will also make sure that the court has all the information it needs to take possible action against the attorney or deputy.

14.22 Examples of situations in which a referral might be necessary include where:

- someone has complained that a welfare attorney is physically abusing a donor – the OPG would refer this case to the relevant local authority adult protection procedures and possibly the police
- the OPG has found that a solicitor appointed as a financial deputy for an elderly woman has defrauded her estate – the OPG would refer this case to the police and the Law Society Consumer Complaints Service.

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<sup>66</sup> In April 2007, the Care Standards Inspectorate for Wales (CSIW) and the Social Services Inspectorate for Wales (SSIW) came together to form the Care and Social Services Inspectorate for Wales.

## How does the Act deal with ill treatment and wilful neglect?

14.23 The Act introduces two new criminal offences: ill treatment and wilful neglect of a person who lacks capacity to make relevant decisions (section 44). The offences may apply to:

- anyone caring for a person who lacks capacity – this includes family carers, healthcare and social care staff in hospital or care homes and those providing care in a person's home
- an attorney appointed under an LPA or an EPA, or
- a deputy appointed for the person by the court.

14.24 These people may be guilty of an offence if they ill-treat or wilfully neglect the person they care for or represent. Penalties will range from a fine to a sentence of imprisonment of up to five years – or both.

14.25 Ill treatment and neglect are separate offences.<sup>67</sup> For a person to be found guilty of ill treatment, they must either:

- have deliberately ill-treated the person, or
- be reckless in the way they were ill-treating the person or not.

It does not matter whether the behaviour was likely to cause, or actually caused, harm or damage to the victim's health.

14.26 The meaning of 'wilful neglect' varies depending on the circumstances. But it usually means that a person has deliberately failed to carry out an act they knew they had a duty to do.

### Scenario: Reporting abuse

Norma is 95 and has Alzheimer's disease. Her son, Brendan, is her personal welfare attorney under an LPA. A district nurse has noticed that Norma has bruises and other injuries. She suspects Brendan may be assaulting his mother when he is drunk. She alerts the police and the local Adult Protection Committee.

Following a criminal investigation, Brendan is charged with ill-treating his mother. The Public Guardian applies to the court to cancel the LPA. Social services start to make alternative arrangements for Norma's care.

## What other measures protect people from abuse?

14.27 Local agencies have procedures that allow them to work together (called multi-agency working) to protect vulnerable adults – in care settings and elsewhere. Most areas have Adult Protection Committees. These committees:

- create policy (including reporting procedures)
- oversee investigations and other activity between agencies

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<sup>67</sup> *R v Newington (1990) 91 Cr App R 247, CA*

- carry out joint training, and
- monitor and review progress.

Other local authorities have developed multi-agency Adult Protection Procedures, which are managed by a dedicated Adult Protection Co-ordinator.

14.28 Adult Protection Committees and Procedures (APCP) involve representatives from the NHS, social services, housing, the police and other relevant agencies. In England, they are essential points of contact for anyone who suspects abuse or ill treatment of a vulnerable adult. They can also give advice to the OPG if it is uncertain whether an intervention is necessary in a case of suspected abuse. In Wales, APCPs are not necessarily points of contact themselves, but they publish details of points of contact.

### **Who should check that staff are safe to work with vulnerable adults?**

14.29 Under the Safeguarding Vulnerable Groups Act 2006, criminal record checks are now compulsory for staff who:

- have contact with service users in registered care homes
- provide personal care services in someone's home, and
- are involved in providing adult placement schemes.

14.30 Potential employers must carry out a pre-employment criminal record check with the Criminal Records Bureau (CRB) for all potential new healthcare and social care staff. This includes nursing agency staff and home care agency staff.

See Annex A for sources of more detailed information.

14.31 The Protection of Vulnerable Adults (POVA) list has the names of people who have been barred from working with vulnerable adults (in England and Wales). Employers providing care in a residential setting or a person's own home must check whether potential employees are on the list.<sup>68</sup> If they are on the list, they must:

- refuse to employ them, or
- employ them in a position that does not give them regular contact with vulnerable adults.

It is an offence for anyone on the list to apply for a care position. In such cases, the employer should report the person making the application.

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## **Who is responsible for monitoring the standard of care providers?**

- 14.32 All care providers covered by the Care Standards Act 2000 must register with the Commission for Social Care Inspection in England (CSCI) or the Care and Social Services Inspectorate for Wales (CSSIW).<sup>69</sup> These agencies make sure that care providers meet certain standards. They require care providers to have procedures to protect people from harm or abuse. These agencies can take action if they discover dangerous or unsafe practices that could place people at risk.
- 14.33 Care providers must also have effective complaints procedures. If providers cannot settle complaints, CSCI or CSSIW can look into them.
- 14.34 CSCI or CSSIW assesses the effectiveness of local adult protection procedures. They will also monitor the arrangements local councils make in response to the Care Standards Act.

## **What is an appointee, and who monitors them?**

- 14.35 The Department for Work and Pensions (DWP) can appoint someone (an appointee) to claim and spend benefits on a person's behalf<sup>70</sup> if that person:
- gets social security benefits or pensions
  - lacks the capacity to act for themselves
  - has not made a property and affairs LPA or an EPA, and
  - the court has not appointed a property and affairs deputy.
- 14.36 The DWP checks that an appointee is trustworthy. It also investigates any allegations that an appointee is not acting appropriately or in the person's interests. It can remove an appointee who abuses their position. Concerns about appointees should be raised with the relevant DWP agency (the local Jobcentre Plus, or if the person is aged 60 or over, The Pension Service).

## **Are there any other means of protection that people should be aware of?**

- 14.37 There are a number of additional means that exist to protect people who lack capacity to make decisions for themselves. Healthcare and social care staff, attorneys and deputies should be aware of:
- National Minimum Standards (for example, for healthcare, care homes, and home care agencies) which apply to both England and Wales (see paragraph 14.38)
  - National Service Frameworks, which set out national standards for specific health and care services for particular groups (for example, for mental

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<sup>69</sup> See note 64 above regarding the merger of the Care Standards Inspectorate for Wales and the Social Services Inspectorate for Wales.

<sup>70</sup> [www.dwp.gov.uk/publications/dwp/2005/gl21\\_apr.pdf](http://www.dwp.gov.uk/publications/dwp/2005/gl21_apr.pdf)

health services<sup>71</sup> or services for older people<sup>72</sup>)

- complaints procedures for all NHS bodies and local councils (see chapter 15)
- Stop Now Orders (also known as Enforcement Orders) that allow consumer protection bodies to apply for court orders to stop poor trading practices (for example, unfair door-step selling or rogue traders).<sup>73</sup>
- The Public Interest Disclosure Act 1998, which encourages people to report malpractice in the workplace and protects people who report malpractice from being sacked or victimised.

14.38 Information about all national minimum standards are available on the CSCI<sup>74</sup> and Healthcare Commission websites<sup>75</sup> and the Welsh Assembly Government website. Chapter 15 gives guidance on complaints procedures. Individual local authorities will have their own complaints system in place.

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<sup>71</sup> [www.dh.gov.uk/assetRoot/04/07/72/09/04077209.pdf](http://www.dh.gov.uk/assetRoot/04/07/72/09/04077209.pdf) and [www.wales.nhs.uk/sites3/page.cfm?orgid=438&pid=11071](http://www.wales.nhs.uk/sites3/page.cfm?orgid=438&pid=11071)

<sup>72</sup> [www.dh.gov.uk/assetRoot/04/07/12/83/04071283.pdf](http://www.dh.gov.uk/assetRoot/04/07/12/83/04071283.pdf) and [www.wales.nhs.uk/sites3/home.cfm?orgid=439&redirect=yes&CFID=298511&CFTOKEN=6985382](http://www.wales.nhs.uk/sites3/home.cfm?orgid=439&redirect=yes&CFID=298511&CFTOKEN=6985382)

<sup>73</sup> [www.ofc.gov.uk/Business/Legal/Stop+Now+Regulations.htm](http://www.ofc.gov.uk/Business/Legal/Stop+Now+Regulations.htm)

<sup>74</sup> [www.csci.org.uk/information\\_for\\_service\\_providers/national\\_minimum\\_standards/default.htm](http://www.csci.org.uk/information_for_service_providers/national_minimum_standards/default.htm)

<sup>75</sup> [www.healthcarecommission.org.uk/\\_db/\\_documents/The\\_annual\\_health\\_check\\_in\\_2006\\_2007\\_assessing\\_and\\_rating\\_the\\_NHS\\_200609225143.pdf](http://www.healthcarecommission.org.uk/_db/_documents/The_annual_health_check_in_2006_2007_assessing_and_rating_the_NHS_200609225143.pdf)

# 15 What are the best ways to settle disagreements and disputes about issues covered in the Act?

Sometimes people will disagree about:

- a person's capacity to make a decision
- their best interests
- a decision someone is making on their behalf, or
- an action someone is taking on their behalf.

It is in everybody's interests to settle disagreements and disputes quickly and effectively, with minimal stress and cost. This chapter sets out the different options available for settling disagreements. It also suggests ways to avoid letting a disagreement become a serious dispute. Finally, it sets out when it might be necessary to apply to the Court of Protection and when somebody can get legal funding.

In this chapter, as throughout the Code, a person's capacity (or lack of capacity) refers specifically to their capacity to make a particular decision at the time it needs to be made.

## Quick summary

- When disagreements occur about issues that are covered in the Act, it is usually best to try and settle them before they become serious.
- Advocates can help someone who finds it difficult to communicate their point of view. (This may be someone who has been assessed as lacking capacity.)
- Some disagreements can be effectively resolved by mediation.
- Where there is a concern about healthcare or social care provided to a person who lacks capacity, there are formal and informal ways of complaining about the care or treatment.
- The Health Service Ombudsman or the Local Government Ombudsman (in England) or the Public Services Ombudsman (in Wales) can be asked to investigate some problems that have not been resolved through formal complaints procedures.
- Disputes about the finances of a person who lacks capacity should usually be referred to the Office of the Public Guardian (OPG).
- When other methods of resolving disagreements are not appropriate, the matter can be referred to the Court of Protection.
- There are some decisions that are so serious that the Court of Protection should always make them.

## What options are there for settling disagreements?

15.1 Disagreements about healthcare, social or other welfare services may be between:

- people who have assessed a person as lacking capacity to make a decision

and the person they have assessed (see chapter 4 for how to challenge an assessment of lack of capacity)

- family members or other people concerned with the care and welfare of a person who lacks capacity
- family members and healthcare or social care staff involved in providing care or treatment
- healthcare and social care staff who have different views about what is in the best interests of a person who lacks capacity.

15.2 In general, disagreements can be resolved by either formal or informal procedures, and there is more information on both in this chapter. However, there are some disagreements and some subjects that are so serious they can only be resolved by the Court of Protection.

15.3 It is usually best to try and settle disagreements before they become serious disputes. Many people settle them by communicating effectively and taking the time to listen and to address worries. Disagreements between family members are often best settled informally, or sometimes through mediation. When professionals are in disagreement with a person's family, it is a good idea to start by:

- setting out the different options in a way that is easy to understand
- inviting a colleague to talk to the family and offer a second opinion
- offering to get independent expert advice
- using an advocate to support and represent the person who lacks capacity
- arranging a case conference or meeting to discuss matters in detail
- listening to, acknowledging and addressing worries, and
- where the situation is not urgent, allowing the family time to think it over.

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'.<sup>76</sup>

## **When is an advocate useful?**

15.4 An advocate helps communicate the feelings and views of someone who has communication difficulties. The definition of advocacy set out in the Advocacy Charter adopted by most advocacy schemes is as follows: 'Advocacy is taking action to help people say what they want, secure their rights, represent their interests and obtain services they need. Advocates and advocacy schemes work in partnership with the people they support and take their side. Advocacy promotes social inclusion, equality and social justice.'<sup>77</sup>

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<sup>76</sup> CLS (Community Legal Services) Direct Information Leaflet Number 23, [www.clsdirect.org.uk/legalhelp/leaflet23.jsp?lang=en](http://www.clsdirect.org.uk/legalhelp/leaflet23.jsp?lang=en)

<sup>77</sup> Advocacy across London, *Advocacy Charter* (2002)

An advocate may be able to help settle a disagreement simply by presenting a person's feelings to their family, carers or professionals. Most advocacy services are provided by the voluntary sector and are arranged at a local level. They have no link to any agency involved with the person.

- 15.5 Using advocates can help people who find it difficult to communicate (including those who have been assessed as lacking capacity) to:
- say what they want
  - claim their rights
  - represent their interests, and
  - get the services they need.
- 15.6 Advocates may also be involved in supporting the person during mediation (see paragraphs 15.7–15.13 below) or helping with complaints procedures. Sometimes people who lack capacity or have been assessed as lacking capacity have a legal right to an advocate, for example:
- when making a formal complaint against the NHS (see paragraph 15.18), and
  - where the Act requires the involvement of an Independent Mental Capacity Advocate (IMCA) (see chapter 10).

## **When is mediation useful?**

- 15.7 A mediator helps people to come to an agreement that is acceptable to all parties. Mediation can help solve a problem at an early stage. It offers a wider range of solutions than the court can – and it may be less stressful for all parties, more cost-effective and quicker. People who come to an agreement through mediation are more likely to keep to it, because they have taken part in decision-making.
- 15.8 Mediators are independent. They have no personal interest in the outcome of a case. They do not make decisions or impose solutions. The mediator will decide whether the case is suitable for mediation. They will consider the likely chances of success and the need to protect the interests of the person who lacks capacity.
- 15.9 Any case that can be settled through negotiation is likely to benefit from mediation. It is most suitable when people are not communicating well or not understanding each other's point of view. It can improve relationships and stop future disputes, so it is a good option when it is in the person's interests for people to have a good relationship in the future.

### **Scenario: Using mediation**

Mrs Roberts has dementia and lacks capacity to decide where she should live. She currently lives with her son. But her daughter has found a care home where she thinks her mother will get better care. Her brother disagrees.

Mrs Roberts is upset by this family dispute, and so her son and daughter decide to try mediation. The mediator believes that Mrs Roberts is able to communicate her feelings and agrees to take on the case. During the

sessions, the mediator helps them to focus on their mother's best interests rather than imposing their own views. In the end, everybody agrees that Mrs Roberts should continue to live with her son. But they agree to review the situation again in six months to see if the care home might then be better for her.

- 15.10 In mediation, everybody needs to take part as equally as possible so that a mediator can help everyone involved to focus on the person's best interests. It might also be appropriate to involve an advocate to help communicate the wishes of the person who lacks capacity.
- 15.11 The National Mediation Helpline<sup>78</sup> helps callers to identify an effective means of resolving their difficulty without going to court. It will arrange an appointment with a trained and accredited mediator. The Family Mediation Helpline<sup>79</sup> can provide information on family mediation and referrals to local family mediation services. Family mediators are trained to deal with the emotional, practical and financial needs of those going through relationship breakdown.
- 15.12 Healthcare and social care staff may also take part in mediation processes. But it may be more appropriate to follow the relevant healthcare or social care complaints procedures (see paragraphs 15.14–15.32).
- 15.13 In certain situations (mainly family mediation), legal aid may be available to fund mediation for people who meet the qualifying criteria (see paragraphs 15.38–15.44).

## **How can someone complain about healthcare?**

- 15.14 There are formal and informal ways of complaining about a patient's healthcare or treatment. Healthcare staff and others need to know which methods are suitable in which situations.
- 15.15 In England, the Patient Advice and Liaison Service (PALS) provides an informal way of dealing with problems before they reach the complaints stage. PALS operate in every NHS and Primary Care Trust in England. They provide advice and information to patients (or their relatives or carers) to try to solve problems quickly. They can direct people to specialist support services (for example, advocates, mental health support teams, social services or interpreting services). PALS do not investigate complaints. Their role is to explain complaints procedures and direct people to the formal NHS complaints process, if necessary. NHS complaints procedures deal with complaints about something that happened in the past that requires an apology or explanation. A court cannot help in this situation, but court proceedings may be necessary in some clinical negligence cases (see paragraph 15.22).
- 15.16 In Wales, complaints advocates based at Community Health Councils provide advice and support to anyone with concerns about treatment they have had.

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<sup>78</sup> National Mediation Helpline, Tel: 0845 60 30 809, [www.nationalmediationhelpline.com](http://www.nationalmediationhelpline.com)

<sup>79</sup> Family Mediation Helpline, Tel: 0845 60 26 627, [www.familymediationhelpline.co.uk](http://www.familymediationhelpline.co.uk)

## **Disagreements about proposed treatments**

15.17 If a case is not urgent, the supportive atmosphere of the PALS may help settle it. In Wales, the local Community Health Council may be able to help. But urgent cases about proposed serious treatment may need to go to the Court of Protection (see paragraphs 15.35–15.36).

### **Scenario: Disagreeing about treatment or an assessment**

Mrs Thompson has Alzheimer's and 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, because he believes she has capacity to refuse treatment.

Mrs Thompson's daughter goes to PALS. A member of staff gives her information and advice about what is meant by capacity to consent to or refuse treatment, and tells her how to find out about the flu jab. The PALS staff speak to the doctor, and then they explain his clinical assessment to Mrs Thompson's daughter.

The daughter is still unhappy. PALS staff advise her that the Independent Complaints Advocacy Service can help if she wishes to make a formal complaint.

## **The formal NHS complaints procedure**

15.18 The formal NHS complaints procedure deals with complaints about NHS services provided by NHS organisations or primary care practitioners. As a first step, people should try to settle a disagreement through an informal discussion between:

- the healthcare staff involved
- the person who may lack capacity to make the decision in question (with support if necessary)
- their carers, and
- any appropriate relatives.

If the person who is complaining is not satisfied, the Independent Complaints Advocacy Service (ICAS) may help. In Wales, the complaints advocates based at Community Health Councils will support and advise anyone who wants to make a complaint.

15.19 In England, if the person is still unhappy after a local investigation, they can ask for an independent review by the Healthcare Commission. If the patient involved in the complaint was or is detained under the Mental Health Act 1983, the Mental Health Act Commission can be asked to look into the complaint. If people are still unhappy after this stage, they can go to the Health Service Ombudsman. More information on how to make a complaint in England is available from the Department of Health.

15.20 In Wales, if patients are still unhappy after a local investigation, they can ask for an independent review of their complaint by independent lay reviewers. After this, they can take their case to the Public Services Ombudsman for Wales. People can take their complaint direct to the Ombudsman if:

- the complaint is about care or treatment that took place after 1 April 2006, and
- they have tried to settle the problem locally first.

The Mental Health Act Commission may also investigate complaints about the care or treatment of detained patients in Wales, if attempts have been made to settle the complaint locally without success.

15.21 Regulations about first trying to settle complaints locally do not apply to NHS Foundation Trusts. But these Trusts are covered by the independent review stage operated by the Healthcare Commission and by the Health Service Ombudsman. People who have a complaint about an NHS Foundation Trust should contact the Trust for advice on how to make a complaint.

### **Cases of clinical negligence**

15.22 The NHS Litigation Authority oversees all clinical negligence cases brought against the NHS in England. It actively encourages people to try other forms of settling complaints before going to court. The National Assembly for Wales also encourages people to try other forms of settling complaints before going to court.

### **How can somebody complain about social care?**

15.23 The social services complaints procedure has been reformed. The reformed procedure came into effect on 1 September 2006 in England and on 1 April 2006 in Wales.

15.24 A service provider's own complaints procedure should deal with complaints about:

- the way in which care services are delivered
- the type of services provided, or
- a failure to provide services.

15.25 Care agencies contracted by local authorities or registered with the Commission for Social Care Inspection (CSCI) in England or Care and Social Services Inspectorate for Wales (CSSIW) are legally obliged to have their own written complaints procedures. This includes residential homes, agencies providing care in people's homes, nursing agencies and adult placement schemes. The procedures should set out how to make a complaint and what to do with a complaint that cannot be settled locally.

### **Local authority complaints procedures**

15.26 For services contracted by a local authority, it may be more appropriate to use the local authority's complaints procedure. A simple example would be a situation where a local authority places a person in a care home and the person's family are not happy with the placement. If their complaint is not about the services the home provides (for example, it might be about the local authority's assessment of the person's needs), it might be more appropriate to use the local authority's complaints procedure.

15.27 As a first step, people should try to settle a disagreement through an informal discussion, involving:

- the professionals involved
- the person who may lack capacity to make the decision in question (with support if necessary)
- their carers, and
- any appropriate relatives.

15.28 If the person making the complaint is not satisfied, the local authority will carry out a formal investigation using its complaints procedure. In England, after this stage, a social service Complaints Review Panel can hear the case. In Wales complaints can be referred to the National Assembly for Wales for hearing by an independent panel.

### **Other complaints about social care**

15.29 People can take their complaint to the CSCI in England or the CSSIW in Wales, if:

- the complaint is about regulations or national minimum standards not being met, and
- the complainants are not happy with the provider's own complaints procedure or the response to their complaint.

15.30 If a complaint is about a local authority's administration, it may be referred to the Commission for Local Administration in England (the Local Government Ombudsman) or the Public Services Ombudsman for Wales.

### **What if a complaint covers healthcare and social care?**

15.31 Taking a complaint through NHS or local authority complaints procedures can be a complicated process – especially if the complaint covers a number of service providers or both healthcare and social care. In such situations, local authorities and the NHS must work together and agree which organisation will lead in handling the complaint. If a person is not happy with the outcome, they can take their case to the Health Service Ombudsman or to the Local Government Ombudsman (in England). There is guidance which sets out how organisations should work together to handle complaints that cover healthcare and social care (in England *Learning from Complaints* and in Wales *Listening and learning*). The Public Services Ombudsman for Wales handles complaints that cover both healthcare and social care.

### **Who can handle complaints about other welfare issues?**

15.32 The Independent Housing Ombudsman deals with complaints about registered social landlords in England. This applies mostly to housing associations. But it also applies to 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. More information about complaints to an Ombudsman is available on the relevant websites (see Annex A).

## **What is the best way to handle disagreement about a person's finances?**

15.33 Some examples of disagreements about a person's finances are:

- disputes over the amount of money a person who lacks capacity should pay their carer
- disputes over whether a person who lacks capacity should sell their house
- somebody questioning the actions of a carer, who may be using the money of a person who lacks capacity inappropriately or without proper authority
- somebody questioning the actions of an attorney appointed under a Lasting Power of Attorney or an Enduring Power of Attorney or a deputy appointed by the court.

15.34 In all of the above circumstances, the most appropriate action would usually be to contact the Office of the Public Guardian (OPG) for guidance and advice. See chapter 14 for further details on the role of the OPG.

## **How can the Court of Protection help?**

15.35 The Court of Protection deals with all areas of decision-making for adults who lack capacity to make particular decisions for themselves (see chapter 8 for more information about its roles and responsibilities). But the court is not always the right place to settle problems involving people who lack capacity. Other forms of settling disagreements may be more appropriate and less distressing.

15.36 There are some decisions that are so serious that the court should always make them. There are also other types of cases that the court should deal with when another method would generally not be suitable. See chapter 8 for more information about both kinds of cases.

## **Right of Appeal**

15.37 Section 53 of the Act describes the rights of appeal against any decision taken by the Court of Protection. There are further details in the Court of Protection Rules. It may be advisable for anyone who wishes to appeal a decision made by the court to seek legal advice.

## **Will public legal funding be available?**

15.38 Depending on their financial situation, once the Act comes into force people may be entitled to:

- publicly funded legal advice from accredited solicitors or advice agencies
- legal representation before the new Court of Protection (in the most serious

cases).

Information about solicitors and organisations who give advice on different areas of law is available from Community Legal Services Direct (CLS Direct).<sup>80</sup> Further information about legal aid and public funding can be obtained from the Legal Services Commission.<sup>81</sup> See Annex A for full contact details.

15.39 People who lack capacity to instruct a solicitor or conduct their own case will need a litigation friend. This person could be a relative, friend, attorney or the Official Solicitor (when no-one else is available). The litigation friend is able to instruct the solicitor and conduct the case on behalf of a person who lacks capacity to give instructions. If the person qualifies for public legal funding, the litigation friend can claim funding on their behalf.

### **When can someone get legal help?**

15.40 Legal help is a type of legal aid (public funding) that pays for advice and assistance on legal issues, including those affecting a person who lacks capacity. But it does not provide representation for a full court hearing, although there is a related form of funding called 'help at court' under which a legal representative can speak in court on a client's behalf on an informal basis. To qualify for legal help, applicants must show that:

- they get specific social security benefits, or they earn less than a specific amount and do not have savings or other financial assets in excess of a specific amount
- they would benefit sufficiently from legal advice to justify the amount it costs, and
- they cannot get another form of funding.

15.41 Legal help can include:

- help from a solicitor or other representative in writing letters
- in exceptional circumstances, getting a barrister's opinion, and
- assistance in preparing for Court of Protection hearings.

15.42 People cannot get legal help for making a Lasting Power of Attorney or an advance decision to refuse treatment. But they can get general help and information from the OPG. The OPG cannot give legal or specialist advice. For example, they will not be able to advise someone on what powers they should delegate to their attorney under an LPA.

### **When can someone get legal representation?**

15.43 Public funding for legal representation in the Court of Protection will be available from solicitors with a relevant contract – but only for the most serious

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<sup>80</sup> CLS Direct, Tel: 0845 345 4 345, [www.clsdirect.org.uk](http://www.clsdirect.org.uk)

<sup>81</sup> [www.legalservices.gov.uk](http://www.legalservices.gov.uk)

cases. To qualify, applicants will normally face the same test as for legal help to qualify financially (paragraph 15.40). They will generally have to satisfy more detailed criteria than applicants for legal help, relating, for instance, to their prospects of being successful, to whether legal representation is necessary and to the cost benefit of being represented. They will also have to establish that the case could not be brought or funded in another way and that there are not alternatives to court proceedings that should be explored first.

- 15.44 Serious personal welfare cases that were previously heard by the High Court will continue to have public funding for legal representation when they are transferred to the Court of Protection. These cases will normally be related to personal liberty, serious welfare decisions or medical treatment for a person who lacks capacity. But legal representation may also be available in other types of cases, depending on the particular circumstances.

## 16 What rules govern access to information about a person who lacks capacity?

This chapter gives guidance on:

- what personal information about someone who lacks capacity people involved in their care have the right to see, and
- how they can get hold of that information.

This chapter is only a general guide. It does not give detailed information about the law. Nor does it replace professional guidance or the guidance of the Information Commissioner's Office on the Data Protection Act 1998 (this guidance is available on its website, see Annex A). Where necessary, people should take legal advice.

This chapter is mainly for people such as family carers and other carers, deputies and attorneys, who care for or represent someone who lacks capacity to make specific decisions and in particular, lacks capacity to allow information about them to be disclosed. Professionals have their own codes of conduct, and they may have the support of experts in their organisations.

In this chapter, as throughout the Code, a person's capacity (or lack of capacity) refers specifically to their capacity to make a particular decision at the time it needs to be made.

### Quick summary

*Questions to ask when requesting personal information about someone who may lack capacity*

- Am I acting under a Lasting Power of Attorney or as a deputy with specific authority?
- Does the person have capacity to agree that information can be disclosed? Have they previously agreed to disclose the information?
- What information do I need?
- Why do I need it?
- Who has the information?
- Can I show that:
  - I need the information to make a decision that is in the best interests of the person I am acting for, and
  - the person does not have the capacity to act for themselves?
- Do I need to share the information with anyone else to make a decision that is in the best interests of the person who lacks capacity?
- Should I keep a record of my decision or action?
- How long should I keep the information for?
- Do I have the right to request the information under section 7 of the Data Protection Act 1998?

### *Questions to ask when considering whether to disclose information*

- Is the request covered by section 7 of the Data Protection Act 1998? Is the request being made by a formally authorised representative?

If not:

- Is the disclosure legal?
- Is the disclosure justified, having balanced the person's best interests and the public interest against the person's right to privacy?

### *Questions to ask to decide whether the disclosure is legal or justified*

- Do I (or does my organisation) have the information?
- Am I satisfied that the person concerned lacks capacity to agree to disclosure?
- Does the person requesting the information have any formal authority to act on behalf of the person who lacks capacity?
- Am I satisfied that the person making the request:
  - is acting in the best interests of the person concerned?
  - needs the information to act properly?
  - will respect confidentiality?
  - will keep the information for no longer than necessary?
- Should I get written confirmation of these things?

## **What laws and regulations affect access to information?**

16.1 People caring for, or managing the finances of, someone who lacks capacity may need information to:

- assess the person's capacity to make a specific decision
- determine the person's best interests, and
- make appropriate decisions on the person's behalf.

16.2 The information they need varies depending on the circumstances. For example:

- a daughter providing full-time care for an elderly parent will make decisions based on her own experience and knowledge of her parent
- a deputy may need information from other people. For instance, if they were deciding whether a person needs to move into a care home or whether they should sell the person's home, they might need information from family members, the family doctor, the person's bank and their solicitor to make sure they are making the decision in the person's best interests.

- 16.3 Much of the information needed to make decisions under the Act is sensitive or confidential. It 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 (the right to respect for private and family life), which means that it is only lawful to reveal someone's personal information if:
    - there is a legitimate aim in doing so
    - a democratic society would think it necessary to do so, and
    - the kind and amount of information disclosed is in relation to the need.

### **What information do people generally have a right to see?**

- 16.4 Section 7 of the Data Protection Act 1998 gives everyone the right to see personal information that an organisation holds about them. They may also authorise someone else to access their information on their behalf. The person holding the information has a legal duty to release it. So, where possible, it is important to try to get a person's consent before requesting to see information about them.
- 16.5 A person may have the capacity to agree to someone seeing their personal information, even if they do not have the capacity to make other decisions. In some situations, a person may have previously given consent (while they still had capacity) for someone to see their personal information in the future.
- 16.6 Doctors and lawyers cannot share information about their clients, or that clients have given them, without the client's consent. Sometimes it is fair to assume that a doctor or lawyer already has someone's consent (for example, patients do not usually expect healthcare staff or legal professionals to get consent every time they share information with a colleague – but staff may choose to get clients' consent in writing when they begin treating or acting for that person). But in other circumstances, doctors and lawyers must get specific consent to 'disclose' information (share it with someone else).
- 16.7 If someone's capacity changes from time to time, the person needing the information may want to wait until that person can give their consent. Or they may decide that it is not necessary to get access to information at all, if the person will be able to make a decision on their own in the future.
- 16.8 If someone lacks the capacity to give consent, someone else might still be able to see their personal information. This will depend on:
- whether the person requesting the information is acting as an agent (a representative recognised by the law, such as a deputy or attorney) for the person who lacks capacity
  - whether disclosure is in the best interests of the person who lacks capacity, and
  - what type of information has been requested.

## **When can attorneys and deputies ask to see personal information?**

- 16.9 An attorney acting under a valid LPA or EPA (and sometimes a deputy) can ask to see information concerning the person they are representing, as long as the information applies to decisions the attorney has the legal right to make.
- 16.10 In practice, an attorney or deputy may only require limited information and may not need to make a formal request. In such circumstances, they can approach the information holder informally. Once satisfied that the request comes from an attorney or deputy (having seen appropriate authority), the person holding information should be able to release it. The attorney or deputy can still make a formal request for information in the future.
- 16.11 The attorney or deputy must treat the information confidentially. They should be extremely careful to protect it. If they fail to do so, the court can cancel the LPA or deputyship.
- 16.12 Before the Act came into effect, only a few receivers were appointed with the general authority to manage a person's property and affairs. So they needed specific authority from the Court of Protection to ask for access to the person's personal information. Similarly, a deputy who only has authority to act in specific areas only has the right to ask for information relating to decisions in those specific areas. For information relating to other areas, the deputy will need to apply to the Court of Protection.
- 16.13 Requests for personal information must be in writing, and there might be a fee. Information holders should release it promptly (always within 40 calendar days). Fees may be particularly high for getting copies of healthcare records – particularly where information may be in unusual formats (for example, x-rays). The maximum fee is currently £50. Complaints about a failure to comply with the Data Protection Act 1998 should be directed to the Information Commissioner's Office (see Annex A for contact details).

### **What limitations are there?**

- 16.14 Attorneys and deputies should only ask for information that will help them make a decision they need to make on behalf of the person who lacks capacity. For example, if the attorney needs to know when the person should take medication, they should not ask to see the entire healthcare record. The person who releases information must make sure that an attorney or deputy has official authority (they may ask for proof of identity and appointment). When asking to see personal information, attorneys and deputies should bear in mind that their decision must always be in the best interests of the person who lacks capacity to make that decision.
- 16.15 The attorney or deputy may not know the kind of information that someone holds about the person they are representing. So sometimes it might be difficult for them to make a specific request. They might even need to see all the information to make a decision. But again, the 'best interests' principle applies.

### **Scenario: Giving attorneys access to personal information**

Mr Yapp is in the later stages of Alzheimer's disease. His son is responsible for Mr Yapp's personal welfare under a Lasting Power of Attorney. Mr Yapp has been in residential care for a number of years. But his son does not think that the home is able to meet his father's current needs as his condition has recently deteriorated.

The son asks to see his father's records. He wants specific information about his father's care, so that he can make a decision about his father's best interests. But the manager of the care home refuses, saying that the Data Protection Act stops him releasing personal information.

Mr Yapp's son points out that he can see his father's records, because he is his personal welfare attorney and needs the information to make a decision. The Data Protection Act 1998 requires the care home manager to provide access to personal data held on Mr Yapp.

- 16.16 The deputy or attorney may find that some information is held back (for example, when this contains references to people other than the person who lacks capacity). This might be to protect another person's privacy, if that person is mentioned in the records. It is unlikely that information relating to another person would help an attorney make a decision on behalf of the person who lacks capacity. The information holder might also be obliged to keep information about the other person confidential. There might be another reason why the person does not want information about them to be released. Under these circumstances, the attorney does not have the right to see that information.
- 16.17 An information holder should not release information if doing so would cause serious physical or mental harm to anyone – including the person the information is about. This applies to information on health, social care and education records.
- 16.18 The Information Commissioner's Office can give further details on:
- how to request personal information
  - restrictions on accessing information, and
  - how to appeal against a decision not to release information.

## **When can someone see information about healthcare or social care?**

- 16.19 Healthcare and social care staff may disclose information about somebody who lacks capacity only when it is in the best interests of the person concerned to do so, or when there is some other, lawful reason for them to do so.
- 16.20 The Act's requirement to consult relevant people when working out the best interests of a person who lacks capacity will encourage people to share the information that makes a consultation meaningful. But people who release information should be sure that they are acting lawfully and that they can justify releasing the information. They need to balance the person's right to privacy with what is in their best interests or the wider public interest (see paragraphs 16.24–16.25 below).

- 16.21 Sometimes it will be fairly obvious that staff should disclose information. For example, a doctor would need to tell a new care worker about what drugs a person needs or what allergies the person has. This is clearly in the person's best interests.
- 16.22 Other information may need to be disclosed as part of the process of working out someone's best interests. A social worker might decide to reveal information about someone's past when discussing their best interests with a close family member. But staff should always bear in mind that the Act requires them to consider the wishes and feelings of the person who lacks capacity.
- 16.23 In both these cases, staff should only disclose as much information as is relevant to the decision to be made.

### **Scenario: Sharing appropriate information**

Mr Jeremy has learning disabilities. His care home is about to close down. His care team carries out a careful assessment of his needs. They involve him as much as possible, and use the support of an Independent Mental Capacity Advocate. Following the assessment, he is placed with carers under an adult placement scheme.

The carers ask to see Mr Jeremy's case file, so that they can provide him with appropriate care in his best interests. The care manager seeks Mr Jeremy's consent to disclosure of his notes, but believes that Mr Jeremy lacks capacity to make this decision. She recognises that it is appropriate to provide the carers with sufficient information to enable them to act in Mr Jeremy's best interests. But it is not appropriate for them to see all the information on the case file. Much of it is not relevant to his current care needs. The care manager therefore only passes on relevant information from the file.

- 16.24 Sometimes a person's right to confidentiality will conflict with broader public concerns. Information can be released if it is in the public interest, even if it is not in the best interests of the person who lacks capacity. It can be difficult to decide in these cases, and information holders should consider each case on its merits. The NHS Code on Confidentiality gives examples of when disclosure is in the public interest. These include situations where disclosing information could prevent, or aid investigation of, serious crimes, or 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.
- 16.25 For disclosure to be in the public interest, it must be proportionate and limited to the relevant details. Healthcare or social care staff faced with this decision should seek advice from their legal advisers. It is not just things for 'the public's benefit' that are in the public interest – disclosure for the benefit of the person who lacks capacity can also be in the public interest (for example, to stop a person who lacks capacity suffering physical or mental harm).

## **What financial information can carers ask to see?**

16.26 It is often more difficult to get financial information than it is to get information on a person's welfare. A bank manager, for example, is less likely to:

- know the individual concerned
- be able to make an assessment of the person's capacity to consent to disclosure, and
- be aware of the carer's relationship to the person.

So they are less likely than a doctor or social worker to be able to judge what is in a person's best interests and are bound by duties to keep clients' affairs confidential. It is likely that someone wanting financial information will need to apply to the Court of Protection for access to that information. This clearly does not apply to an attorney or a deputy appointed to manage the person's property and affairs, who will generally have the authority (because of their appointment) to obtain all relevant information about the person's property and affairs.

## **Is information still confidential after someone shares it?**

16.27 Whenever a carer gets information, they should treat the information in confidence, and they should not share it with anyone else (unless there is a lawful basis for doing so). In some circumstances, the information holder might ask the carer to give a formal confirmation that they will keep information confidential.

16.28 Where the information is in written form, carers should store it carefully and not keep it for longer than necessary. In many cases, the need to keep the information will be temporary. So the carer should be able to reassure the information holder that they will not keep a permanent record of the information.

## **What is the best way to settle a disagreement about personal information?**

16.29 A carer should always start by trying to get consent from the person whose information they are trying to access. If the person lacks capacity to consent, the carer should ask the information holder for the relevant information and explain why they need it. They may need to remind the information holder that they have to make a decision in the person's best interests and cannot do so without the relevant information.

16.30 This can be a sensitive area and disputes will inevitably arise. Healthcare and social care staff have a difficult judgement to make. They might feel strongly that disclosing the information would not be in the best interests of the person who lacks capacity and would amount to an invasion of their privacy. This may be upsetting for the carer who will probably have good motives for wanting the information. In all cases, an assessment of the interests and needs of the person who lacks capacity should determine whether staff should disclose information.

- 16.31 If a discussion fails to settle the matter, and the carer still is not happy, there are other ways to settle the disagreement (see chapter 15). The carer may need to use the appropriate complaints procedure. Since the complaint involves elements of data protection and confidentiality, as well as best interests, relevant experts should help deal with the complaint.
- 16.32 In cases where carers and staff cannot settle their disagreement, the carer can apply to the Court of Protection for the right to access to the specific information. The court would then need to decide if this was in the best interests of the person who lacks capacity to consent. In urgent cases, it might be necessary for the carer to apply directly to the court without going through the earlier stages.

## Key words and phrases used in the Code

The table below is not a full index or glossary. Instead, it is a list of key terms used in the Code or the Act, and the main references to them. References in bold indicate particularly valuable content for that term.

<b>Acts in connection with care or treatment</b>	Tasks carried out by carers, healthcare or social care staff which involve the personal care, healthcare or medical treatment of people who lack capacity to consent to them – referred to in the Act as ‘section 5 acts’.	<b>Chapter 6</b> 2.13–2.14, 4.39 Best interests and _ 5.10, 5.39 Deprivation of liberty and _ 6.39. 6.49–6.52
<b>Advance decision to refuse treatment</b>	A decision to refuse specified treatment made in advance by a person who has capacity to do so. This decision will then apply at a future time when that person lacks capacity to consent to, or refuse, the specified treatment. This is set out in Section 24(1) of the Act.  Specific rules apply to advance decisions to refuse life-sustaining treatment.	<b>Chapter 9 (all)</b> Best interests and _ 5.5, 5.35, 5.45 Protection from liability and _ 6.37–6.38 LPAs and _ 7.55 Deputies and _ 8.28 Research and _ 11.30 Young people and _ 12.9 Mental Health Act 13.35–13.37
<b>Adult protection procedures</b>	Procedures devised by local authorities, in conjunction with other relevant agencies, to investigate and deal with allegations of abuse or ill treatment of vulnerable adults, and to put in place safeguards to provide protection from abuse.	<b>Chapter 14</b> 14.6, 14.22, 14.27–28, 14.34 IMCAs and _ 10.66–10.67
<b>After-care under supervision</b>	Arrangements for supervision in the community following discharge from hospital of certain patients previously detained under the Mental Health Act 1983.	<b>Chapter 13</b> <b>13.22–13.25</b> , 13.34, 13.37, 13.40, 13.42, 13.45, 13.48, 13.52
<b>Agent</b>	A person authorised to act on behalf of another person under the law of agency. Attorneys appointed under an LPA or EPA are agents and court-appointed deputies are deemed to be agents and must undertake certain duties as agents.	LPAs and _ 7.58–7.68 Deputies and _ 8.55–8.68
<b>Appointee</b>	Someone appointed under Social Security Regulations to claim and collect social security benefits or pensions on behalf of a person who lacks capacity to manage their own benefits. An appointee is permitted to use the money claimed to meet the person’s needs.	Role of _ 6:65–6.66 Deputies and _ 8.56 Concerns about _ 14:35–14.36

<b>Appropriate body</b>	A committee which is established to advise on, or on matters which include, the ethics of intrusive research in relation to people who lack capacity to consent to it, and is recognised for those purposes by the Secretary of State (in England) or the National Assembly for Wales (in Wales).	<b>Chapter 11</b> 11.8–11.11, 11.20, 11.33–11.34, 11.43–11.47.
<b>Approved Social Worker (ASW)</b>	A specially trained social worker with responsibility for assessing a person's needs for care and treatment under the Mental Health Act 1983. In particular, an ASW assesses whether the person should be admitted to hospital for assessment and/or treatment.	<b>Chapter 13</b> 13.16, 13.22–13.23, 13.43, 13.52
<b>Artificial Nutrition and Hydration (ANH)</b>	Artificial nutrition and hydration (ANH) has been recognised as a form of medical treatment. ANH involves using tubes to provide nutrition and fluids to someone who cannot take them by mouth. It bypasses the natural mechanisms that control hunger and thirst and requires clinical monitoring.	<b>9.26</b> 5.34 6.18 8.18
<b>Attorney</b>	Someone appointed under either a Lasting Power of Attorney (LPA) or an Enduring Power of Attorney (EPA), who has the legal right to make decisions within the scope of their authority on behalf of the person (the donor) who made the Power of Attorney.	<b>Chapter 7</b> Best interests principle and _ 5.2, 5.13, 5.49, 5.55 Protection from liability as _ 6.54–6.55 Court of Protection and _ 8.30 Advance decisions and _ 9.33 Mental Health Act and _ 13.38–13.45 Public Guardian and _ 14.7–14.14 Legal help and _ 15.39–15.42 Accessing personal information as _ 16.9–16.16
<b>Best interests</b>	Any decisions made, or anything done for a person who lacks capacity to make specific decisions, must be in the person's best interests. There are standard minimum steps to follow when working out someone's best interests. These are set out in section 4 of the Act, and in the non-exhaustive checklist in 5.13.	<b>Chapter 2 (Principle 4)</b> <b>Chapter 5</b> Protection from liability and _ 6.4–6.18 Reasonable belief and _ 6.32–6.36 Deprivation of liberty and _ 6.51–6.53 Acting as an attorney and _ 7.19–7.20, 7.29, 7.53 Court of Protection

		and _ 8.14–8.26 Acting as a deputy and _ 8.50–8.52 Advance decisions and _ 9.4–9.5
<b>Bournewood provisions</b>	A name given to some proposed new procedures and safeguards for people who lack capacity to make relevant decisions but who need to be deprived of their liberty, in their best interests, otherwise than under the Mental Health Act 1983. The name refers to a case which was eventually decided by the European Court of Human Rights.	6.53–6.54 13.53–13.54
<b>Capacity</b>	The ability to make a decision about a particular matter at the time the decision needs to be made. The legal definition of a person who lacks capacity is set out in section 2 of the Act.	<b>Chapter 4</b>
<b>Carer</b>	Someone who provides <i>unpaid</i> care by looking after a friend or neighbour who needs support because of sickness, age or disability. In this document, the role of the carer is different from the role of a professional care worker.	<b>Acting as decision-maker 5.8–5.10</b> <b>Protection from liability 6.20–6.24</b> Assessing capacity as _ 4.44–4.45 Acting with reasonable belief 6.29–6.34 Paying for goods and services 6.56–6.66 Accessing information 16.26–16.32
<b>Care worker</b>	Someone employed to provide personal care for people who need help because of sickness, age or disability. They could be employed by the person themselves, by someone acting on the person's behalf or by a care agency.	Assessing capacity as _ 4.38, 4.44–4.45 Protection from liability 6.20 Paying for goods and services 6.56–6.66 Acting as an attorney 7.10 Acting as a deputy 8.41
<b>Children Act 1989</b>	A law relating to children and those with parental responsibility for children.	<b>Chapter 12</b>
<b>Complaints Review Panel</b>	A panel of people set up to review and reconsider complaints about health or social care services which have not been resolved under the first stage of the relevant complaints procedure.	15.28
<b>Consultee</b>	A person who is consulted, for example about the involvement in a research project of a person who	11.23, 11.28–29,

	lacks capacity to consent to their participation in the research.	11.44
<b>Court of Protection</b>	The specialist Court for all issues relating to people who lack capacity to make specific decisions. The Court of Protection is established under section 45 of the Act.	<b>Chapter 8</b> _ must always make decisions about these issues 6.18 Decisions about life-sustaining treatment 5.33–5.36 LPAs and _ 7.45–7.49 Advance decisions and _ 9.35, 9.54, 9.67–9.69 Decisions regarding children and young people 12.3–12.4, 12.7, 12.10, 12.23–12.25 Access to legal help 15.40–15.44
<b>Court of Protection Visitor</b>	Someone who is appointed to report to the Court of Protection on how attorneys or deputies are carrying out their duties. Court of Protection Visitors are established under section 61 of the Act. They can also be directed by the Public Guardian to visit donors, attorney and deputies under section 58 (1) (d).	<b>14.10–14.11</b> Attorneys and _ 7.71 Deputies and _ 8.71
<b>Criminal Records Bureau (CRB)</b>	An Executive Agency of the Home Office which provides access to criminal record information. Organisations in the public, private and voluntary sectors can ask for the CRB to check candidates for jobs to see if they have any criminal records which would make them unsuitable for certain work, especially that involves children or vulnerable adults.  For some jobs, a CRB check is mandatory.	Checking healthcare and social care staff 14.29–14.30 Checking IMCAs 10.18
<b>Data Protection Act 1998</b>	A law controlling the handling of, and access to, personal information, such as medical records, files held by public bodies and financial information held by credit reference agencies.	<b>Chapter 16</b>
<b>Decision-maker</b>	Under the Act, many different people may be required to make decisions or act on behalf of someone who lacks capacity to make decisions for themselves. The person making the decision is referred to throughout the Code, as the 'decision-maker', and it is the decision-maker's responsibility to work out what would be in the best interests of the person who lacks capacity.	<b>Chapter 5</b> Working with IMCAs 10.4, 10.21–10.29 Applying the MHA 13.3, 13.10, 13.27
<b>Declaration</b>	A kind of order made by the Court of Protection.	<b>8.13–8.19</b>

	For example, a declaration could say whether a person has or lacks capacity to make a particular decision, or declaring that a particular act would or would not be lawful. The Court's power to make declarations is set out in section 15 of the Act.	Advance decisions and _ 9.35
<b>Deprivation of liberty</b>	Deprivation of liberty is a term used in the European Convention on Human Rights about circumstances when a person's freedom is taken away. Its meaning in practice is being defined through case law.	<b>6.49–6.54</b> Protection from liability 6.13–6.14 Attorneys and _ 7.44 Mental Health Act and _ 13.12, 13.16
<b>Deputy</b>	Someone appointed by the Court of Protection with ongoing legal authority as prescribed by the Court to make decisions on behalf of a person who lacks capacity to make particular decisions as set out in Section 16(2) of the Act.	<b>Chapter 8</b> Best interests principle and _ 5.2, 5.13, 5.49, 5.55 Protection from liability as _ 6.54–6.55 Attorneys becoming _ 7.56 Advance decisions and _ 9.33 IMCAs and _ 10.70–72 Acting for children and young people 12.4, 12.7 Public Guardian and _ 14.15–14.18 Complaints about 14.19–14.25 Accessing personal information as _ 16.9–16.16
<b>Donor</b>	A person who makes a Lasting Power of Attorney or Enduring Power of Attorney.	<b>Chapter 7</b>
<b>Enduring Power of Attorney (EPA)</b>	A Power of Attorney created under the Enduring Powers of Attorney Act 1985 appointing an attorney to deal with the donor's property and financial affairs. Existing EPAs will continue to operate under Schedule 4 of the Act, which replaces the EPA Act 1985.	<b>Chapter 7</b> See also LPA
<b>Family carer</b>	A family member who looks after a relative who needs support because of sickness, age or disability. It does not mean a professional care-worker employed by a disabled person or a care assistant in a nursing home, for example.	See carer
<b>Family Division of the High</b>	The Division of the High Court that has the jurisdiction to deal with all matrimonial and civil partnership matters, family disputes, matters	12.14, 12.23

<b>Court</b>	relating to children and some disputes about medical treatment.	
<b>Fiduciary duty</b>	Anyone acting under the law of agency will have this duty. In essence, it means that any decision taken or act done as an agent (such as an attorney or deputy) must not benefit themselves, but must benefit the person for whom they are acting.	_ for attorneys 7.58 _ for deputies 8.58
<b>Guardianship</b>	Arrangements, made under the Mental Health Act 1983, for a guardian to be appointed for a person with mental disorder to help ensure that the person gets the care they need in the community.	<b>13.16–13.21</b> 13.1, 13.25–13.27, 13.54
<b>Health Service Ombudsman</b>	An independent person whose organisation investigates complaints about National Health Service (NHS) care or treatment in England which have not been resolved through the NHS complaints procedure.	15.19, 15.21, 15.31
<b>Human Rights Act 1998</b>	A law largely incorporating into UK law the substantive rights set out in the European Convention on Human Rights.	6.49 16.3
<b>Human Tissue Act 2004</b>	A law to regulate issues relating to whole body donation and the taking, storage and use of human organs and tissue.	11.7 11.38–11.39
<b>Ill treatment</b>	Section 44 of the Act introduces a new offence of ill treatment of a person who lacks capacity by someone who is caring for them, or acting as a deputy or attorney for them. That person can be guilty of ill treatment if they have deliberately ill-treated a person who lacks capacity, or been reckless as to whether they were ill-treating the person or not. It does not matter whether the behaviour was likely to cause, or actually caused, harm or damage to the victim's health.	14.23–14.26
<b>Independent Complaints Advocacy Service (ICAS)</b>	In England, a service to support patients and their carers who wish to pursue a complaint about their NHS treatment or care.	15.18
<b>Independent Mental Capacity Advocate (IMCA)</b>	Someone who provides support and representation for a person who lacks capacity to make specific decisions, where the person has no-one else to support them. The IMCA service is established under section 35 of the Act and the functions of IMCAs are set out in section 36. It is not the same as an ordinary advocacy service.	<b>Chapter 10</b> Consulting to work out best interests 5.51 Involvement in changes of residence 6.9 Involvement in serious medical decisions 6.16

		MHA and _ 13.46–13.48
<b>Information Commissioner's Office</b>	An independent authority set up to promote access to official information and to protect personal information. It has powers to ensure that the laws about information, such as the Data Protection Act 1998, are followed.	16.13 16.18
<b>Lasting Power of Attorney (LPA)</b>	A Power of Attorney created under the Act (see Section 9(1)) appointing an attorney (or attorneys) to make decisions about the donor's personal welfare (including healthcare) and/or deal with the donor's property and affairs.	<b>Chapter 7</b> Best interests principle and _ 5.2, 5.13, 5.49, 5.55 Protection from liability as _ 6.54–6.55 Court of Protection and _ 8.30 Advance decisions and _ 9.33 Mental Health Act and _ 13.38–13.45 Public Guardian and _ 14.7–14.14 Legal help and _ 15.39–15.42 Accessing personal information as _ 16.9–16.16
<b>Life-sustaining treatment</b>	Treatment that, in the view of the person providing healthcare, is necessary to keep a person alive See Section 4(10) of the Act.	<b>Providing or stopping _ in best interests 5.29–5.36</b> <b>Advance decisions to refuse _ 9.10–9.11, 9.19–9.20, 9.24–9.28</b> Protection from liability when providing _ 6.16, 6.55 Attorneys and _ 7.22, 7.27, 7.29–7.30 Deputies and _ 8.17, 8.46 Conscientious objection to stopping _ 9.61–9.63 IMCAs and _ 10.44
<b>Litigation friend</b>	A person appointed by the court to conduct legal proceedings on behalf of, and in the name of, someone who lacks capacity to conduct the litigation or to instruct a lawyer themselves.	4.54 10.38 15.39

<b>Local Government Ombudsman</b>	In England, an independent organisation that investigates complaints about councils and local authorities on most council matters including housing, planning, education and social services.	15.30–15.32
<b>Makaton</b>	A language programme using signs and symbols, for the teaching of communication, language and literacy skills for people with communication and learning difficulties.	3.11
<b>Mediation</b>	A process for resolving disagreements in which an impartial third party (the mediator) helps people in dispute to find a mutually acceptable resolution.	15.7–15.13
<b>Mental capacity</b>	See capacity	
<b>Mental Health Act 1983</b>	A law mainly about the compulsory care and treatment of patients with mental health problems. In particular, it covers detention in hospital for mental health treatment.	<b>Chapter 13</b> Deprivation of liberty other than in line with _ 6.50–6.53, 7.44 Attorneys and _ 7.27 Advance decisions and _ 9.37 IMCAs and 10.44, 10.51, 10.56–10.58 Children and young people and _ 12.6, 12.21 Complaints regarding _ 15.19
<b>Mental Health Review Tribunal</b>	An independent judicial body with powers to direct the discharge of patients who are detained under the Mental Health Act 1983.	13.31 13.42
<b>NHS Litigation Authority</b>	A Special Health Authority (part of the NHS), responsible for handling negligence claims made against NHS bodies in England.	15.22
<b>Office of the Public Guardian (OPG)</b>	The Public Guardian is an officer established under Section 57 of the Act. The Public Guardian will be supported by the Office of the Public Guardian, which will supervise deputies, keep a register of deputies, Lasting Powers of Attorney and Enduring Powers of Attorney, check on what attorneys are doing, and investigate any complaints about attorneys or deputies. The OPG replaces the Public Guardianship Office (PGO) that has been in existence for many years.	<b>14.8–14.22</b> Registering LPAs with _ 7.14–7.17 Supervision of attorneys by _ 7.69–7.74 Registering EPAs with _ 7.78 Guidance for EPAs _ 7.79 Guidance for receivers_ 8.5 Panel of deputies of _ 8.35

		Supervision of deputies by _ 8.69–8.77
<b>Official Solicitor</b>	Provides legal services for vulnerable persons, or in the interests of achieving justice. The Official Solicitor represents adults who lack capacity to conduct litigation in county court or High Court proceedings in England and Wales, and in the Court of Protection.	Helping with formal assessment of capacity 4.54 Acting in applications to the Court of Protection 8.10 Acting as litigation friend 10.38, 15.39
<b>Patient Advice and Liaison Service (PALS)</b>	In England, a service providing information, advice and support to help NHS patients, their families and carers. PALS act on behalf of service users when handling patient and family concerns and can liaise with staff, managers and, where appropriate, other relevant organisations, to find solutions.	15.15–15.17
<b>Permanent vegetative state (PVS)</b>	A condition caused by catastrophic brain damage whereby patients in PVS have a permanent and irreversible lack of awareness of their surroundings and no ability to interact at any level with those around them.	6.18 8.18
<b>Personal welfare</b>	Personal welfare decisions are any decisions about person's healthcare, where they live, what clothes they wear, what they eat and anything needed for their general care and well-being. Attorneys and deputies can be appointed to make decisions about personal welfare on behalf of a person who lacks capacity. Many acts of care are to do with personal welfare.	_ <b>LPAs 7.21–7.31</b> _ <b>deputies 8.38–8.39</b> Advance decisions about _ 9.4, 9.35 Role of High Court in decisions about _ 15.44
<b>Property and affairs</b>	Any possessions owned by a person (such as a house or flat, jewellery or other possessions), the money they have in income, savings or investments and any expenditure. Attorneys and deputies can be appointed to make decisions about property and affairs on behalf of a person who lacks capacity.	_ <b>LPAs 7.32–7.42</b> _ <b>deputies 8.34–8.37</b> Restrictions on _ LPA 7.56 Duties of _ attorney 7.58, 7.67–7.68 _ EPAs 7.76–7.77 OPG panel of _ deputies 8.35 Duties of _ deputy 8.56, 8.67–8.68 _ of children and young people 12.3–12.4, 12.7
<b>Protection from liability</b>	Legal protection, granted to anyone who has acted or made decisions in line with the Act's principles.	<b>Chapter 6</b>

<b>Protection of Vulnerable Adults (POVA) list</b>	A register of individuals who have abused, neglected or otherwise harmed vulnerable adults in their care or placed vulnerable adults at risk of harm. Providers of care must not offer such individuals employment in care positions.	14.31
<b>Public Services Ombudsman for Wales</b>	An independent body that investigates complaints about local government and NHS organisations in Wales, and the National Assembly for Wales, concerning matters such as housing, planning, education, social services and health services.	15.20 15.30–15.32
<b>Receiver</b>	Someone appointed by the former Court of Protection to manage the property and affairs of a person lacking capacity to manage their own affairs. Existing receivers continue as deputies with legal authority to deal with the person's property and affairs.	8.5 8.35
<b>Restraint</b>	See Section 6(4) of the Act. The use or threat of force to help do an act which the person resists, or the restriction of the person's liberty of movement, whether or not they resist. Restraint may only be used where it is necessary to protect the person from harm and is proportionate to the risk of harm.	<b>6.39–6.44, 6.47–53</b> Use of _ in moves between accommodation 6.11 Use of _ in healthcare and treatment decisions 6.15 Attorneys and _ 7.43-7.44 Deputies and _ 8.46 MHA and _ 13.5
<b>Statutory principles</b>	The five key principles are set out in Section 1 of the Act. They are designed to emphasise the fundamental concepts and core values of the Act and to provide a benchmark to guide decision-makers, professionals and carers acting under the Act's provisions. The principles generally apply to all actions and decisions taken under the Act.	<b>Chapter 2</b>
<b>Two-stage test of capacity</b>	Using sections 2 and 3 of the Act to assess whether or not a person has capacity to make a decision for themselves at that time.	<b>4.10–4.13</b> Protection from liability 6.27 Applying _ to advance decisions 9.39
<b>Wilful neglect</b>	An intentional or deliberate omission or failure to carry out an act of care by someone who has care of a person who lacks (or whom the person reasonably believes lacks) capacity to care for themselves. Section 44 introduces a new offence of wilful neglect of a person who lacks capacity.	14.23–14.26
<b>Written statements of</b>	Written statements the person might have made before losing capacity about their wishes and	5.34 5.37

<b>wishes and feelings</b>	feelings regarding issues such as the type of medical treatment they would want in the case of future illness, where they would prefer to live, or how they wish to be cared for. They should be used to help find out what someone's wishes and feelings might be, as part of working out their best interests. They are not the same as advance decisions to refuse treatment and are not binding.	5.42–5.44
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## Annex A

The following list provides contact details for some organisations that provide information, guidance or materials related to the Code of Practice and the Mental Capacity Act. The list is not exhaustive: many other organisations may also produce their own materials.

### **British Banking Association**

Provides guidance for bank staff on '*Banking for mentally incapacitated and learning disabled customers*'.

Available from [www.bba.org.uk/bba/jsp/polopoly.jsp?d=146&a=5757](http://www.bba.org.uk/bba/jsp/polopoly.jsp?d=146&a=5757), price £10 (members) /£12 (non-members). Not inclusive of VAT.

**web:** [www.bba.org.uk](http://www.bba.org.uk)

**telephone:** 020 7216 8800

### **British Medical Association**

Co-authors (with the Law Society) of *Assessment of Mental Capacity: Guidance for Doctors and Lawyers* (Second edition) (London: BMJ Books, 2004).

[www.bma.org.uk/ap.nsf/Content/Assessmentmental?OpenDocument&Highlight=2,mental, capacity](http://www.bma.org.uk/ap.nsf/Content/Assessmentmental?OpenDocument&Highlight=2,mental, capacity)

Available from BMJ Books ([www.bmjbookshop.com](http://www.bmjbookshop.com)), price £20.99

**web:** [www.bma.org.uk](http://www.bma.org.uk)

**telephone:** 020 7387 4499

### **British Psychological Society**

Publishers of *Guidelines on assessing capacity* – professional guidance available online to members.

**web:** [www.bps.org.uk](http://www.bps.org.uk)

**telephone:** (0)116 254 9568

### **Commission for Social Care Inspection**

The Commission for Social Care Inspection (CSCI) registers, inspects and reports on social care services in England.

**web:** [www.csci.org.uk](http://www.csci.org.uk)

**telephone:** 0845 015 0120 / 0191 233 3323

**textphone:** 0845 015 2255 / 0191 233 3588

### **Community Legal Services Direct**

Provides free legal information to people living in England and Wales to help them deal with legal problems.

**web:** [www.clsdirect.org.uk](http://www.clsdirect.org.uk)  
**telephone (helpline):** 0845 345 4 345

### **Criminal Records Bureau (CRB)**

The CRB runs criminal records checks on people who apply for jobs working with children and vulnerable adults.

**web:** [www.crb.org.uk](http://www.crb.org.uk)  
**telephone:** 0870 90 90 811

### **Department for Constitutional Affairs**

The government department with responsibility for the Mental Capacity Act and the Code of Practice. Also publishes guidance for specific audiences  
[www.dca.gov.uk/legal-policy/mental-capacity/guidance.htm](http://www.dca.gov.uk/legal-policy/mental-capacity/guidance.htm)

### **Department of Health**

Publishes guidance for healthcare and social care staff in England. Key publications referenced in the Code include:

- on using restraint with people with learning disabilities and autistic spectrum disorder, see *Guidance for restrictive physical interventions*  
[www.dh.gov.uk/assetRoot/04/06/84/61/04068461.pdf](http://www.dh.gov.uk/assetRoot/04/06/84/61/04068461.pdf)
- on adult protection procedures, see *No secrets: Guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse*  
[www.dh.gov.uk/assetRoot/04/07/45/44/04074544.pdf](http://www.dh.gov.uk/assetRoot/04/07/45/44/04074544.pdf)
- on consent to examination and treatment, including advance decisions to refuse treatment [www.dh.gov.uk/consent](http://www.dh.gov.uk/consent)
- on the proposed Bournemouth safeguards, a draft illustrative Code of Practice  
[www.dh.gov.uk/assetRoot/04/14/17/64/04141764.pdf](http://www.dh.gov.uk/assetRoot/04/14/17/64/04141764.pdf)
- on IMCAs and the IMCA pilots [www.dh.gov.uk/imca](http://www.dh.gov.uk/imca)

DH also is responsible for the *Mental Health Act 1983 Code of Practice* (TSO 1999)  
[www.dh.gov.uk/assetRoot/04/07/49/61/04074961.pdf](http://www.dh.gov.uk/assetRoot/04/07/49/61/04074961.pdf)

### **Family Mediation Helpline**

Provides general information on family mediation and contact details for mediation services in your local area.

**web:** [www.familymediationhelpline.co.uk](http://www.familymediationhelpline.co.uk)  
**telephone:** 0845 60 26 627

### **Healthcare Commission**

The health watchdog in England, undertaking reviews and investigations into the provision of NHS and private healthcare services.

**web:** [www.healthcarecommission.org.uk](http://www.healthcarecommission.org.uk)  
**telephone helpline:** 0845 601 3012  
**switchboard:** 020 7448 9200

### **Healthcare Inspectorate for Wales**

Undertakes reviews and investigations into the provision of NHS funded care, either by or for Welsh NHS organisations.

**web:** [www.hiw.org.uk](http://www.hiw.org.uk)  
**email:** [hiw@wales.gsi.gov.uk](mailto:hiw@wales.gsi.gov.uk)  
**telephone:** 029 2092 8850

### **Housing Ombudsman Service**

The Housing Ombudsman Service considers complaints against member organisations, and deals with other housing disputes.

**web:** [www.ihos.org.uk](http://www.ihos.org.uk)  
**email:** [info@housing-ombudsman.org.uk](mailto:info@housing-ombudsman.org.uk)  
**telephone:** 020 7421 3800

### **Information Commissioner's Office**

The Information Commissioner's Office is the UK's independent authority set up to promote access to official information and to protect personal information.

**web:** [www.ico.gov.uk](http://www.ico.gov.uk)  
**telephone helpline:** 08456 30 60 60

### **Legal Services Commission**

Looks after legal aid in England and Wales, and provides information, advice and legal representation.

**web:** [www.legalservices.gov.uk](http://www.legalservices.gov.uk)  
See also Community Legal Services Direct.

### **Local Government Ombudsman**

The Local Government Ombudsmen investigate complaints about councils and certain other bodies.

**web:** [www.lgo.org.uk](http://www.lgo.org.uk)  
**telephone:** 0845 602 1983

### **National Mediation Helpline**

Provides access to a simple, low cost method of resolving a wide range of disputes. The National Mediation Helpline is operated on behalf of the Department for Constitutional Affairs (DCA) in conjunction with the Civil Mediation Council (CMC).

**web:** [www.nationalmediationhelpline.com](http://www.nationalmediationhelpline.com)

**telephone:** 0845 60 30 809

### **Office of the Public Guardian**

The new Public Guardian is established under the Act and will be supported by the Office of the Public Guardian, which will replace the current Public Guardianship Office (PGO). The OPG will be an executive agency of the Department for Constitutional Affairs. Amongst its other roles, it provides forms for LPAs and EPAs.

**web:**

From October 2007, a new website will be created at [www.publicguardian.gov.uk](http://www.publicguardian.gov.uk)

### **Official Solicitor**

Provides legal services for vulnerable people and is able to represent people who lack capacity and act as a litigation friend.

**web:** [www.officialsolicitor.gov.uk](http://www.officialsolicitor.gov.uk)

**telephone:** 020 7911 7127

### **Patient Advice and Liaison Service (PALS)**

Provides information about the NHS and help resolve concerns or problems with the NHS, including support when making complaints.

**web:** [www.pals.nhs.uk](http://www.pals.nhs.uk)

The site includes contact details for local PALS offices around the country.

### **Patient Information Advisory Group**

Considers applications on behalf of the Secretary of State to allow the common law duty of confidentiality to be aside.

**web:** [www.advisorybodies.doh.gov.uk/PIAG](http://www.advisorybodies.doh.gov.uk/PIAG)

### **Public Service Ombudsman for Wales**

Investigates complaints about local authorities and NHS organisations in Wales, and about the National Assembly Government for Wales.

**web:** [www.ombudsman-wales.org.uk](http://www.ombudsman-wales.org.uk)

**telephone:** 01656 641 150

## **Welsh Assembly Government**

Produces key pieces of guidance for healthcare and social care staff, including:

- *In safe hands – Implementing Adult Protection Procedures in Wales* (July 2000)  
[http://new.wales.gov.uk/about/departments/dhss/publications/social\\_services\\_publications/reports/insafehands?lang=en](http://new.wales.gov.uk/about/departments/dhss/publications/social_services_publications/reports/insafehands?lang=en)
- *Framework for restrictive physical intervention policy and practice* (available at [www.childrenfirst.wales.gov.uk/content/framework/phys-int-e.pdf](http://www.childrenfirst.wales.gov.uk/content/framework/phys-int-e.pdf))

Copies of this publication can be downloaded from [www.guardianship.gov.uk](http://www.guardianship.gov.uk)

Hard copies of this publication are available from TSO

For more information on the Mental Capacity Act contact the  
Public Guardianship Office:

9am - 5pm, Mon - Fri

Telephone: 0845 330 2900 (local call rate)

or +44 207 664 7000 (for callers outside UK)

Text Phone: 020 7664 7755

Fax: 0870 739 5780 (UK callers)

Email: [custserv@guardianship.gsi.gov.uk](mailto:custserv@guardianship.gsi.gov.uk)

Website: [www.guardianship.gov.uk](http://www.guardianship.gov.uk)

Post: Public Guardianship Office  
Archway Tower  
2 Junction Road  
London N19 5SZ