



# A CARERS' GUIDE TO THE MENTAL CAPACITY ACT 2005

## What is the Mental Capacity Act?

On April 1<sup>st</sup> 2007 the Mental Capacity Act will come into force, and it will for the first time provide a statutory framework for assessing whether a person has capacity to make decisions for themselves, and it also sets out how others may make decisions on behalf of those people who do not have the capacity to make their own decisions.

The Act will apply to everyone who in the course of caring for someone might have to make a decision for someone who lacks capacity to make that decision for themselves. This includes informal carers such as family members.

The Act covers a wide range of decisions made, or actions taken, on behalf of people lacking capacity, whether they relate to day-to-day matters or represent major life-changing events. These include matters in connection with the personal welfare of people lacking capacity, their health care and medical treatment, and the management of their property and financial affairs.

When any decisions are made for a person who lacks capacity then the 'decision maker' will have to have regard for the Act, and will have to be able to demonstrate that they acted accordingly.

So they must abide by the Statutory Principles, which are:

- The presumption of capacity – every adult (the Act generally applies to people who are 16 years of age or older) has the right to make his/her own decisions and must be assumed to have the capacity to do so unless it is proved otherwise;
- The right for individuals to be supported to make their own decisions - people must be given all appropriate help before anyone concludes that they cannot make their own decisions;
- Individuals must retain the right to make what might be seen as eccentric or unwise decisions- so just because a person makes a decision that others may think is unwise this does not in itself show that the person lacks capacity;
- Anything done for, or on behalf of, people without capacity must be in their best interest;
- Anything done for, or on behalf of, people without capacity must be the least restrictive of their basic rights and freedoms.

Mrs A has been diagnosed as being in the early stages of dementia and her son is worried that she is becoming confused about money. She knows her pension is paid into the bank each month but cannot always remember which bills she has to pay or how to pay them. Her son must first assume she has capacity to manage her affairs and look at each financial decision as it has to

be made, giving his mother the help and support she may need to make these decisions for herself. As a start, he offers to help make arrangements to pay the bills by direct debit and explains to her what this means. Mrs A agrees this would be helpful and signs the relevant forms because she is able to understand what she is doing. He goes shopping with her and sees she is quite capable of finding the goods she needs and making sure she gets the right change when paying for them. But when it comes to deciding how to get the best returns from her investments Mrs A gets confused about the different options, no matter how they are explained to her, even though she has been able to make these decisions in the past. Her son concludes that at this time she has capacity to deal with everyday matters but not more complex affairs. He suggests that she should make an appointment to see her solicitor to discuss the possibility of making a Lasting Power of Attorney (more on this later) while she still has capacity to do so.

### **How do you assess if someone lacks capacity?**

Carers are not expected to be experts in assessing capacity and it is therefore sufficient for them to hold a 'reasonable belief' that the person they are caring for lacks capacity to make a particular decision in order to receive statutory protection from liability.

However any of the following factors might indicate the need for professional involvement:

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

There is a two stage test for capacity;

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

The first part of the test would need to be carried out by a clinician, possibly the person's GP.

If this first part of the process is met, it is then necessary to show that the impairment or disturbance causes the person to be unable to make the decision in question. It has to be borne in mind that this part of the test applies to each decision. So the person would be assumed to be incapable of making the decision if he/she were unable to:

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

Every effort should be made to provide the information and to explain it in a way that is appropriate to the individual. The information should include the likely consequences of deciding one way or another or of making no decision at all.

The information needs to be retained for long enough to use it in order to make a choice. So the ability to retain information for a short period only should not automatically disqualify the person from making the decision.

It is possible that a person could understand the information, but due to the effects of mental impairment or disturbance prevent him/her using the information or take it into account when making a decision. So this should be taken into account when making this part of the test.

Strenuous efforts should be made to assist and facilitate communication before concluding that the person is totally unable to communicate.

The Code of Practice, which will accompany the Act, sets out a number of ways that someone can help an individual to make his/her own decisions.

### **What does it mean when it says decisions must be in the ‘best interests’ of the individual?**

The Act does not define best interest but sets out steps that must be taken to determine what might be in the best interests of the person who lacks capacity. The focus must always be on what the person who lacks capacity might have wanted, and not on the wishes or views of the person making the decision.

To make a best interests decision the person making the decision must:

- take in to consideration all relevant circumstances, and
- decide whether the decision could be delayed until the person regains the capacity to make the decision, if this is a possibility, and
- make sure that every effort is made to engage the person in the decision making process, and

- not be motivated by a desire to bring about the person's death when the decision relates to life sustaining treatment, and
- take into account the person's beliefs and values, which would include religious, cultural and lifestyle choices, and
- take into account the person's past and present wishes, and
- take into account any written statements the person made when he/she had capacity, and
- consider other factors which might have influenced the person's decision, such as altruistic motives, consideration for others and duties and obligations towards dependants or future beneficiaries, and
- consult with others, such as family members, partners, carers and other relevant people, when it is practicable and practicable.

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

Carers, like others, can only be expected to have reasonable grounds for believing that what they are doing or deciding is in the best interests of the person concerned. However, this does not mean that decision makers can just impose their own views. Rather, they must be able to point to objective reasons to demonstrate why they believe they are acting in the person's best interests. They must consider all relevant circumstances and apply all elements of the checklist.

**Is there any protection from liability for carers who make best interests decisions?**

The Act recognises that everyday millions of acts are done to and for people who lack capacity either to care for themselves or to consent to someone else caring for them. This might include actions such as helping an individual to wash, dress, eat or attend to their personal hygiene, taking them to see the doctor or dentist, or helping them buy food or have gas and electricity supplied to their home.

However, according to basic legal principles, many of these actions, particularly those which involve touching a person or interfering with their property, could be unlawful. So for example if a person lacks the necessary capacity to dress him/herself and a carer dresses the person, the carer is potentially committing trespass to that person in touching him/her without consent (even if the action did not involve any violence or harm the person in any way). Or if a neighbour enters the house of a person lacking capacity in

order to do housework etc, they could be trespassing on the person's property.

The Act provides carers, and others, protection from any liability for their actions, as long as they can show that what they did was in the best interests of the person lacking capacity and carried out in accordance with the Act's principles (these were set out in the first section of this guide).

A woman with a severe learning disability who lives at home may have help with dressing by a family member, may be helped to eat her meals by a paid carer and taken to the park by a friend. Each of these individuals, provided they have taken reasonable steps to see if the person lacks capacity to consent to the actions they propose to take, and they are acting in the person's best interests, would be protected from any liability in any of the acts performed.

However, no protection is offered to people who restrain a person lacking capacity in order to carry out any act in connection with the care or treatment or to force that person to comply with the act, unless certain conditions are met.

### **What conditions need to be met before a person can be restrained?**

According to the Act someone is said to restrain a person lacking capacity if s/he:

- uses, or threatens to use, force to do an act which the person resists, or
- restricts the liberty of movement of someone who lacks capacity, whether or not the person resists.

Therefore any threat of force or use of actual force or violence will not attract protection from liability unless

- the person taking the actions reasonable believes that it is necessary to do an act which involves restraint in order to prevent harm to the person lacking capacity, and
- that the act is a proportionate response (in terms of both the degree and the duration of the restraint) to the likelihood of the person suffering harm and the seriousness of that harm.

The responsibility is on the person carrying out the restraint to identify objective reasons which justify his/her belief that restraint is necessary. The restraint must be to avert harm not simply to enable the carer or professional to do something more quickly or easily. Only the minimum force or other types of restraint may be used and for the shortest time possible.

An elderly man with dementia has been prescribed medication for a heart condition, which requires his blood pressure to be monitored regularly, and

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

### **Can Carers use the money of a person who lacks capacity to pay for goods and services?**

Carers of people who lack capacity often have to spend money on their behalf in order to provide care. The Act sets out the legal obligations for payment and the circumstances in which any expenditure incurred by carers in making necessary arrangements can be reclaimed from the person lacking capacity.

A person who lacks capacity who agrees to pay for necessary goods is legally obliged to pay a reasonable price for them. What is 'necessary' in this context means what is suitable to the person's condition in life and his/her actual requirements at the time when the goods are supplied or the services provided. So, while food, drink and clothing are necessary for everyone, the actual requirement for the type of food or the style or amount of clothing will vary according to the person's individual circumstances or 'condition in life'. The intention is to ensure that people can enjoy a similar standard of living and way of life as they experienced before losing capacity. Additionally goods will not be necessary if the person's supply is sufficient. So, for example, one or two pairs of shoes bought for a person lacking capacity to buy them for him/herself would be considered necessary, but a dozen pairs would probably not be.

Whilst the legal responsibility for paying for necessary goods and services lies with the person for whom they are supplied, even though that person lacks capacity to contract for them, the Act allows a carer to arrange for goods and services and to arrange settlement of the bill.

Naturally steps should have been taken to ascertain the person's capacity, and if s/he lacks capacity to decide what goods and services would be in the person's best interest.

The Act makes a distinction between the use of available cash already in the possession of the person lacking capacity, and access to that person's bank account or selling items of property. If the person has cash in his/her

possession then the carer may use that money to pay for goods and services. Or the carer may pay for the goods and services with their own money and be reimbursed from the money of the person lacking capacity.

However, the Act does not give any authority to a carer to gain access to income or assets, or to sell property belonging to the person who lacks capacity, unless there is formal authorisation. This formal authorisation may be through a Lasting Power of Attorney, a deputyship or a single order of the Court of Protection (more of these later). Additionally it is possible that someone, usually a carer, may have been appointed under Social Security Regulations to act as 'appointee' to claim benefit for a person lacking capacity and to use that money on the person's behalf.

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

### **What are Lasting Powers of Attorney?**

A power of attorney is a legal document by which one person gives another person, or persons, the authority to act on his/her behalf with regard to issues identified within the document. The person giving the authority is called the donor and the person or persons who will act for the donor are called the attorney(s) or donee(s). Therefore any decision made by an attorney acting within the scope of his/her authority under a power of attorney can be treated as if made by the donor him/herself.

It is quite likely that in many cases the person's carer or family members will be the person's chosen attorney.

The Enduring Power of Attorney Act in 1985 introduced the Enduring Power of Attorney (EPA), which gave attorney(s) the power to act for a person who lacked capacity, but only in relation to property and financial affairs.

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



LPAs and property and affairs LPAs. Different attorneys may be appointed to take different types of decisions.

As under EPAs, powers to make decisions about property and financial affairs under a LPA can be used before and after the donor loses capacity. So for example, if someone was going to be out of the country and not easily reached for a long period of time they could give someone the power of attorney to deal with their financial affairs until they returned. However, the power of attorney to make decisions about personal welfare issues under a LPA will only be valid when the donor loses the capacity to make these types of decisions.

Existing Enduring Power of Attorneys which are in place when the Act comes into force will have the same legal powers as they did before. However, donors, who have capacity, may prefer to destroy their EPAs and make an LPA under the new statutory provisions.

### **How do you make a Lasting Power of Attorney?**

A Lasting Power of Attorney is a legal document, authorising the attorney to make important decisions on behalf of the donor, so careful thought needs to be given when making a LPA, both in choosing the right person as attorney and in following the correct procedures to ensure the LPA is valid.

Only adults aged 18 or over who have the capacity to do so may make an LPA. The LPA instrument must include a certificate, completed by an independent third party, confirming that in the opinion of the third party the donor understands the purpose of the LPA and that neither fraud nor undue pressure was used to persuade the donor to make the LPA.

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

The scope of what decisions may be made by the attorney needs to be set out clearly within the LPA, as the attorney may only act within the authority conferred by the LPA. The scope of the attorney's powers made be quite broad where the LPA is expressed in general terms, but where a donor has specified conditions or restrictions in the LPA, the attorney must abide by them.

The attorney has specific duties and responsibilities, and these include:

- a duty to act in accordance with the principles of the Act
- a duty to act in the donor's best interest
- a duty to only act within the scope of the LPA
- a duty of care
- a duty not to delegate authority
- a duty not to benefit themselves

- a duty to act with honesty, integrity and due diligence
- a duty of confidentiality
- a duty to comply with the directions of the Court of Protection
- a duty to continue with their role once they have started unless certain requirements are met
- a duty to keep the donor's money and property separate from their own
- a duty to produce correct accounts if they have responsibilities under a financial and affairs LPA

For fuller information anyone considering making a LPA should take expert advice.

## **What sort of decisions can an attorney make?**

### **Personal welfare LPAs**

Donors can authorise their attorney to act in relation to all matters concerning their personal welfare or they can list specific matters they wish the attorney(s) to have power to act. So the type of decisions the attorney might be authorised to take could include:

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

However, the donor might want to be specific about what powers the attorney has, or to exclude particular types of decisions.

Mrs H has recently been diagnosed as being in the early stages of Alzheimer's disease. She is anxious to get all her affairs in order while she is still able to do so. She decides to make a personal welfare LPA, appointing her daughter as attorney so that when she lacks capacity, her daughter can make decisions on her behalf concerning the care she receives, including deciding if residential or nursing home care is necessary (in other words where Mrs H will live). However, Mrs H has always believed quite strongly that doctors should be the ones who should decide whether a person receives particular medical treatments if that person lacks capacity to make those decisions themselves. She does not think it is right for her daughter to be able to make such decisions on her behalf and so she states in the LPA that her daughter's authority as her personal welfare attorney does not extend to making decisions on her behalf relating to medical treatment.

When there is a Personal Welfare LPA which either gives a general authority or includes specific authority to the attorney to give or refuse consent for medical treatment then healthcare professionals must consult with the

attorney and seek his/her consent in the same way as they would with a patient who had the capacity to consent.

An LPA relating to personal welfare will not authorise the attorney to give or refuse treatment in the following circumstances;

When the donor has the capacity to make his/her own treatment decisions;

- When there is an advance decision (more on these later) refusing treatment (unless the LPA was made later and gave the attorney specific authority to give or refuse treatment specified in the advance decision);
- When the treatment is life-sustaining, unless the LPA document expressly authorises this.

As always decisions have to be taken in the person's best interests. If there is disagreement between the attorney and the doctor, then the doctor should get a second opinion and discuss the matter further with the attorney. If agreement can not be reached then the matter may have to go to the Court of Protection for a ruling.

It is also important to remember that, in the same way that a person with capacity cannot demand a particular treatment, LPAs cannot give attorneys the power to demand specific forms of medical treatment.

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

### **Property and affairs LPAs**

As stated before attorneys authorised to take decisions under a property and affairs LPAs can, unlike the personal welfare LPAs, make decisions on behalf of the donor before the donor loses capacity to make their own decisions. Naturally the donor would have to agree to this. Alternatively the donor can stipulate that the LPA can only be used when s/he lacks capacity.

The donor may have fluctuating or partial capacity and therefore be able to make some decisions (or at some times) but needs the attorney to make

others (or at other times). The attorney should allow and encourage the donor to do as much as possible, and only act when the donor requests or needs it.

**It should be fully understood that this is simply a guide and anyone considering making a LPA or of becoming a donee should seek more informed advice.**

### **What is the Court of Protection?**

At present the Court of Protection's role and function is for the management of property and financial affairs of people lacking capacity. The new Court of Protection will take on these roles and functions as well as serious decisions affecting healthcare and personal welfare matters, that are presently dealt with by the High Court.

The Court of Protection will have powers to:

- Make a declaration or ruling about such matters as whether a person does have capacity when there is a dispute between professionals, or about the provision of medical treatment;
- Appoint a deputy, where a single decision of the Court is not sufficient and there is no LPA, but there is a need for on-going decision making. The deputy would then have the authority to make decisions on the person who lacks capacity's behalf;
- Adjudicate on matters concerning LPAs, such as where there are concerns about the validity of an LPA.

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

A young woman receives a significant award of damages following an accident at work, which resulted in serious brain damages and other disabilities. Her parents have recently divorced and are arguing about how the money should be used and where their daughter should live. She has always been close to her sister, who is keen to be involved but is anxious about dealing with such a large amount of money. The Court decides to appoint the sister and a solicitor as joint and several deputies (which means they can act together but may also act independently if they wish, so that any decision taken by any attorney alone would be as valid a if s/he were he sole attorney)

to decide where the young woman will live and how to manage her property and affairs.

### **Can someone make an advanced decision to refuse treatment?**

It is a general principle of law and medical practice that people have a right to consent to or refuse treatment. Valid consent must be obtained before giving medical treatment, carrying out physical investigations or providing personal care. As we have seen people lacking capacity to consent may be treated only if it is their best interests.

The Courts have decided that that competent and informed adults who are capable of understanding the implications of their decisions have the established right to refuse specified medical procedures and treatments in advance, intending that refusal to take effect when they no longer have the capacity to refuse procedures or treatments.

An advance refusal of treatment made by a person over 18 years of age is as valid as a decision made at the time the treatment is offered if an advance decision exists and is valid and applicable in the particular circumstances. The Act makes statutory provision for this.

An advance decision to refuse treatment (except life sustaining treatment)

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

An advance decision will only apply at a time when the person lacks capacity to consent to the specified treatment. It is advised that anyone making an advance decision to refuse treatment should speak to their doctor, or a patients' group. For most people who make an advance decision their capacity to make such a decision would not be questioned. However, in some circumstances it might be helpful to obtain evidence to confirm the person's capacity to make an advance decision, for example if there is a possibility that the advance decision may be challenged in the future.

Mrs L, a 38-year-old woman, has been suffering from serious lower abdominal pain. During discussions her doctor informs her that it is possible that there may be a problem with her ovaries and that he wants her to undergo an exploratory operation. His advice is that if her ovaries have a non-cancerous cyst it may be necessary to remove it and this may lead to the removal of one or more of her ovaries. Mrs L is concerned that this may affect her fertility and therefore draws up an advance decision stating that under no circumstances should the ovaries be removed. She asks her doctor to witness the advance decision. If during the exploratory operation the doctor found a non-cancerous

cyst the doctor would not be able to remove Mrs L's ovaries because of the advance decision. He would need to discuss the matter with Mrs L once she regained consciousness and had capacity to make the relevant decisions after the exploratory operation.

There are no specific formalities that have to be completed, but it would be advisable if it were recorded somewhere where it can be activated should the need arise, which could be their health record. It would be preferable for the advance decision to be in writing as this would provide proof that an advance decision to refuse treatment actually exists. Again there is no required format for the advance decision; however it would be helpful for the following information to be included:

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

However, there are more strict formalities and safeguards on the making of an advance decision **to refuse life-sustaining treatment**. Life-sustaining treatment is defined as treatment which a person providing health care regards as necessary to sustain life. Whether a treatment is life-sustaining depends on the type of treatment, but also on the particular circumstances in which it may be prescribed. For example, in some situations giving antibiotics may be life-sustaining, whereas in other circumstances antibiotics are used to treat non-life-sustaining conditions. The important factor here is that the treatment is necessary to sustain life at that time. It is for the doctor to assess whether a treatment is life-sustaining in each particular situation.

An advance decision refusing life-sustaining treatment must fulfil the following requirements in order to be applicable:

- The advance decision must be in writing;
- The written document must be signed by the maker. Where the maker is unable to sign, (for example because of a physical disability),

arrangements may be made for the advance decision to be signed by someone else at the maker's direction and in his/her presence;

- The maker must sign the advance decision in the presence of a witness to the signature, who must also sign the document in the maker's presence. If the maker is unable to sign the advance decision may be signed by someone else at the maker's direction, also in the presence of a witness;
- The written document must be verified by a specific statement made by the maker, either included in the document or a separate statement, expressing and explicitly stating that the advance decision is to apply to the specified treatment "even if life is at risk";
- This statement must be signed by the maker (or by someone else at his/her direction), in the presence of a witness, who must also sign the statement. This is in addition to the need to sign and witness the advance decision itself.

A clear exception where an advance decision to refuse treatment is not applicable is when someone is detained under the Mental Health Act 1983. For people who are being treated on a voluntary basis for a mental disorder, an advance decision refusing specific types of treatment should be respected. However, where a patient is liable to be detained under the Mental Health Act, the content of an advance decision refusing treatment for mental disorder may be overridden by the compulsory treatment provision of Part 4 of that Act. It is important to remember that only treatment for mental disorder is regulated by the Mental Health Act. Where a patient is also having treatment for a physical disorder an advance decision to refuse treatment could still be valid and applicable, regardless of the fact that s/he was also being treated for a mental disorder.

### **What about getting access to personal information about the person who lacks capacity so as to be able to make a decision on their behalf?**

People making decisions on behalf of those who lack capacity will often need to share personal information relating to the person so that they can determine, and act in, that person's best interests.

### **Disclosure of, and access to, information can be complex, so this guide should not in any way be treated as a definite statement of law.**

If an attorney is acting within the scope of the LPA they are entitled to ask for information as if 'stepping into the shoes' of the person who lacks capacity. They can therefore ask for information under the Data Protection Act 1998. However, in practice an attorney or deputy may only require limited information and may not need to do this through the Data Protection Act. In such circumstances, an informal approach to the person holding or controlling the data can be made. Once satisfied that the request comes from an attorney or deputy (having seen appropriate authority) the person holding the information should be able to provide the information requested.

Mr Y is an elderly man in the later stages of Alzheimer's. Mr Y's son is responsible for his care and welfare under a LPA. Mr Y has been in residential care for a number of years, but his son has become concerned about the ability of the current home to meet his needs, given an apparent recent deterioration of his condition. He asks for specific information from his father's file in respect of the care provided so that he may make an informed decision in the best interest of his father. But the manager of the care home refuses, saying that he is prevented from disclosing personal information in respect of his father because of the Data Protection Act. Mr Y's son points out that as a personal welfare attorney under the LPA he is, legally, his father's agent and that the LPA gives him authority to look after his father's welfare. He needs to access specific personal data in order to ensure proper care is provided to Mr Y. With the power of the LPA, the Data Protection Act 1998 requires the care home manager to provide access to personal data held on MR Y in this respect.

The attorney or deputy is, of course, placed under a duty of confidentiality as regards the information released to him/her and should be extremely careful to protect it. Any failure to do so may result in the LPA or deputyship being revoked.

### **What about when the carer is not an attorney or deputy?**

Health and social care professionals have always disclosed information about people who lack capacity to, for example, family carers and other relatives, when it is clearly in the interests of the person lacking capacity. Obviously there needs to be some constraints on the information given, and the NHS Code of Confidentiality says 'Where a patient is incapacitated and unable to consent, information should only be disclosed in the patient's best interests and then only as much information as is needed to support their care'.

Under the Act the need for professionals to consult people who know the person who lacks capacity when determining best interests will further encourage them to share information to make the consultation meaningful. However, at the same time, a person disclosing information concerning a person lacking capacity must be assured that they are acting lawfully and that the disclosure is justified. They need to balance the right to privacy of the person who lacks capacity against what is in his/her best interest.

A doctor might disclose to a carer what drugs need to be administered to someone lacking capacity: or a social worker might decide to reveal information about someone's past when discussing with a close family member what would be best for his/her future. In both these cases the doctor and the social worker would only disclose as much information as was relevant to the act to be carried out or the question to be decided.

A bank manager, on the other hand, is less likely to know the person lacking capacity and less likely to be aware of the carer's relationship to the person lacking capacity. This means that s/he is less likely to be able to judge that it would be in the person's best interests to release the information than say a doctor or social worker. It is likely that anyone seeking information on the



finances of someone lacking capacity will need to apply to the Court of Protection for a single order or a financial deputyship authorising access to that information.

The following simple checklist set out some of the most important considerations when information is requested. The person requesting information should ask:

- Am I acting under a LPA or as a deputy with specific authority?
- What information do I need?
- Why do I need it?
- Who has this information?
- Can I show that I need the information for me to make a decision that is in the best interests of the person on whose behalf I am acting and that that person lacks capacity to act for him/herself?
- Does the person concerned have the capacity to consent to disclosure of information, or has s/her previously given consent?
- Do I need to share the information with anyone else to make a decision that is in the best interests of the person lacking capacity?
- Should I keep a record of my decision or action?
- How long should I keep information for?
- If so, should I request the information under the formal subject access provisions of the Data Protection Act 1998?

### **Is there anything else in the Act that would affect carers?**

#### **The Independent Mental Capacity Advocacy Service**

There will be a new service provided under the Act, the Independent Mental Capacity Advocacy (IMCA) service. Its purpose is to provide representation and support for particularly vulnerable people who lack capacity who are facing important decisions about certain serious, potentially life-changing situations. However, they will only be required when the person lacking capacity has no friends or family to support them.

#### **A new criminal offence**

The Act introduces a new criminal offence of ill treatment or wilful neglect which applies to the following individuals:

- A person who has the care of a person who lacks capacity or is reasonably believed to lack capacity; or
- A person who is the attorney appointed under a LPA or Enduring Power of Attorney(EPA); or
- A person who is a deputy appointed for the person by the court.

The penalty for such an offence is a fine and/or a sentence of imprisonment of up to 5 years.

Norma is 95 and suffering from Alzheimer's disease. She lives with her son, Brendan, who is her principle carer and who also has been appointed as her personal welfare attorney under a LPA. A district nurse regularly visits Norma at home to give her medication for arthritis. She is concerned that recently Norma is displaying bruises and other injuries. She also suspects that Brendan may be assaulting his mother when drunk. She alerts the police and the local Adult Protection Committee. Following this, a number of things happen: following a criminal investigation, Brendan is charged with ill treatment of his mother. In addition, the court, in conjunction with the Public Guardian, also takes steps to revoke the LPA. Lastly, local Social Services are alerted and procedures are set in motion to put in place alternative care arrangements for Norma. The local Authority could also involve an Independent Mental Capacity Advocate to support Norma.

### **Resolving disagreements**

Despite efforts to determine what a person who lacks capacity would want in relation to a particular decision and what would be in their best interests, sometimes disagreements may arise in the course of taking a decision for or acting for a person lacking capacity. It is generally in the interest of all involved to resolve the problem in a way that is quick, effective, involves minimal stress and is cost effective.

While the Act establishes a new, dedicated Court of Protection to settle serious and complex disputes, it may often be appropriate to explore alternative solutions to solving problems. Moreover in some cases it would be inappropriate to take the matter to court.

In respect of disputes arising between family carers or other carers and expert advisers, many disputes may be avoided through effective communication and taking time to listen and address concerns and issues. Some initial steps that might therefore be taken are:

- Outline the options fully in terms that are easy to understand;
- Invite a colleague to talk to the family;
- Offer recourse to independent expert advice;
- Listen to, acknowledge and address the concerns raised;
- Where the situation is not urgent allow time for reflection.

There may be a role for an independent advocate to be involved to act in the interests of the person who lacks capacity. The advocate would be independent of any statutory agency or other party involved. Or it might that there is a role for mediation through an experienced mediator.

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