

Making decisions : helping people who have difficulty deciding for themselves : a guide for social care professionals.

Contributors

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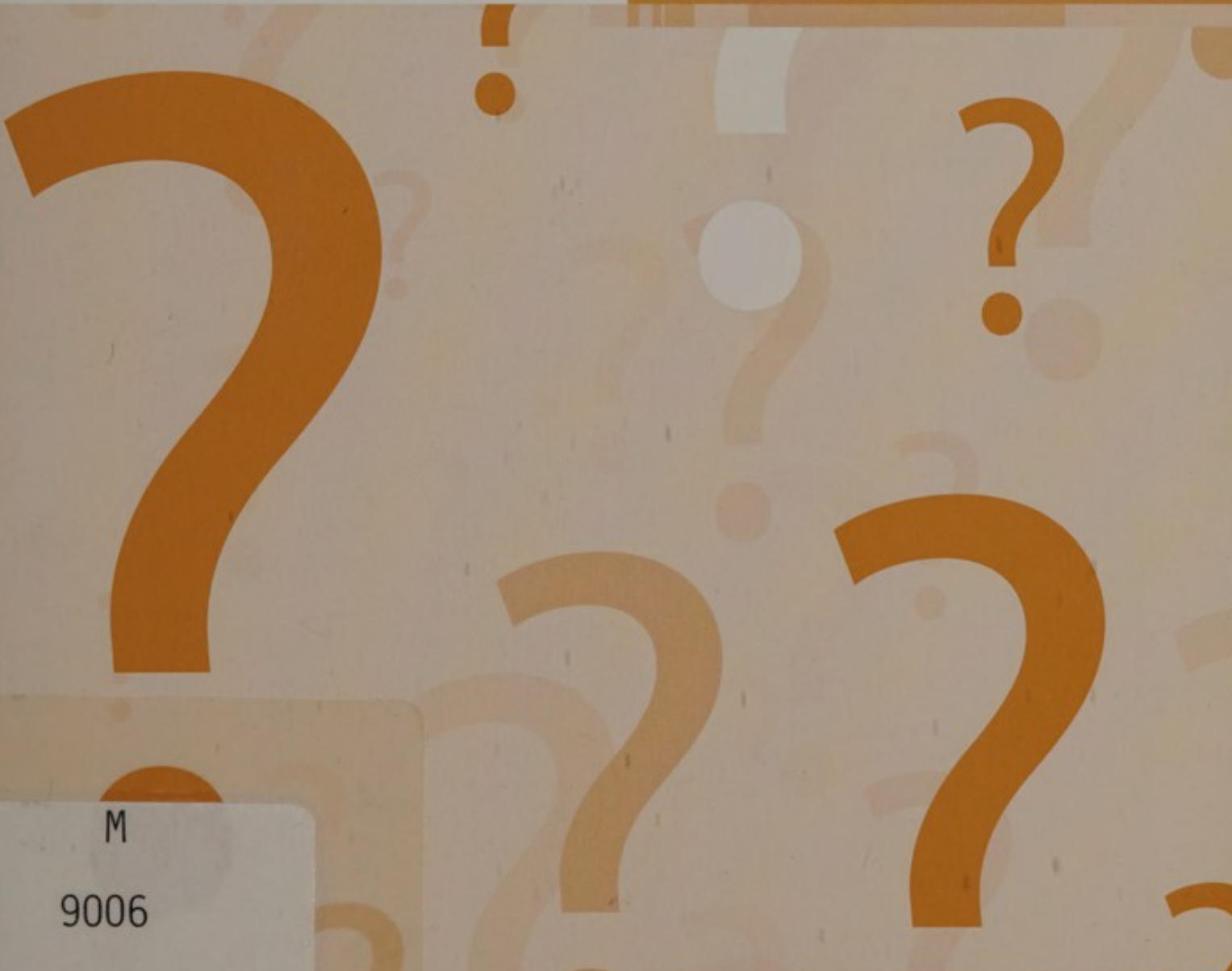
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Making decisions

Helping people who have difficulty deciding for themselves

A guide for social care professionals



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About this booklet

This booklet has been produced by the Lord Chancellor's Department to help social workers, residential and home care workers and other care professionals and volunteers involved in the care of adults who need support to make decisions. That support may be needed because of learning difficulty, brain injury, dementia, mental health problems or any other illness or disability which affects the person's mental capacity.

The booklet explains the current legal position and lists sources of professional guidance and relevant organisations.

The booklet does *not* cover:

- ▶ the care of children and young people (aged up to 18), although some of the issues discussed here may be relevant; or
- ▶ the assessment, admission to hospital and compulsory treatment of patients for mental disorder or guardianship of clients under the Mental Health Act 1983.

The information contained in this booklet relates only to England and Wales.

1. The role of the social care professional

In law, every adult has the right to make their own decisions and is assumed to have capacity to do so unless it is proved that they do not. For example, people with learning disabilities or difficulties have the same rights as other citizens and should be given the help and support they need to maximise their independence and control their own lives. Everyone has a right to determine what happens to their own bodies and (if they are able to give it) valid consent must be obtained from an elderly or disabled person before providing personal care, such as bathing and dressing.

Social care professionals have a key role to play in helping and supporting people with impaired mental functioning to understand what decisions need to be made and why, and what the consequences might be.

Through their work, they will be in a good position to know the most effective way of communicating with the people they care for and how to explain things, such as the use of simple language, pictures or photographs. Social workers, residential or home care workers may have developed a trusting relationship with their clients, which may enable them to find better ways of communicating.

Social care professionals may therefore be involved in:

- ▶ providing information to their clients on the options that may be available to them, decisions that need to be made and on other sources of help or advice

- ▶ helping with communication, or calling in other professionals (such as speech therapists) where needed
- ▶ providing support for carers or other family members, particularly helping them to recognise when the person being cared for is capable of making their own decisions or where expert help may help them to do so
- ▶ giving an opinion on the social functioning and interactive abilities of the person in their care and how this might affect their capacity to make a particular decision; or
- ▶ observing the person's behaviour with the aim of identifying their needs and wishes.

Speech and language therapists, occupational therapists or an independent advocate may be able to help with communication or suggest alternative methods to convey information. An independent advocate is someone who is unpaid and acts on a voluntary basis; he or she can help the person express their wishes and aspirations and make choices.

Some organisations have produced publications, tapes and other materials to help people who need support to make decisions, or to help the people who support them. They are: Values Into Action, Motor Neurone Disease Association, Speakability, National Autistic Society. (See **Useful organisations** pages 24–30).

2. Defining and assessing mental incapacity

Even with help and support, however, some people lack capacity to make some decisions and those decisions may need to be taken for them. An assessment must be made in each case, for each particular decision. For more serious or complicated decisions, a more formal assessment of capacity may be needed.

Capacity is a legal concept. For a few activities, such as competence to act as a witness in court, the legal test of capacity is set out in legislation. For others, such as making a will or drawing up an Enduring Power of Attorney (EPA), the requirements to establish capacity have been set out in case law.

The courts have decided that in many circumstances 'capacity' means being able to *understand and retain relevant information and weigh it in the balance so that a choice can be made*. Even if someone has a medical condition or disability, a person may have capacity to make some decisions but not others.

For some people, for example those with dementia, the loss of ability to cope worsens over a long period of time, so the point at which they are no longer able to make a particular decision is hard to pinpoint. The mental capacity of others, such as those with mental health problems, may fluctuate.

In cases of fluctuating or temporary incapacity (as in any other case) the person's capacity to make a particular decision must be assessed at the time the decision has to be made. It may be possible to put off the decision until such time as the person has recovered, and regained capacity to make their own decision.

Who can assess capacity?

There are different tests for assessing capacity depending on the decision or action that needs to be made or taken.

The person (this could be a healthcare or other professional, relative or carer) who needs consent will be the first to consider whether the person concerned has the necessary capacity to give it. For example, in legal matters or transactions such as making a will or an Enduring Power of Attorney, the solicitor dealing with the case will need to be satisfied that the person has capacity before any documents are signed. If he or she thinks it is necessary, the solicitor will get an opinion from a doctor or psychiatrist.

Where consent to medical examination or treatment is needed, the doctor or other healthcare professional proposing the treatment will need to decide whether the patient has capacity to consent to or refuse treatment, for example dental treatment or routine operations.

The family doctor will often be able to give an opinion on the person's general condition and their capacity to make particular decisions. If they are unable to make the assessment, they will be able to advise on who is best placed to do so.

Advice agencies or voluntary organisations may have relevant information or be able to suggest sources of expert help or advice. For example, the National Autistic Society can advise on the best way to help and support someone with an autistic spectrum disorder. Similarly the Alzheimer's Society can advise where someone suffers from Alzheimer's Disease. (See **Useful organisations** on pages 24–30).

Further guidance

See page 21 under:

- ▶ **Assessing Capacity.**

3. Best interests

Generally the law will allow basic day-to-day actions to be performed by another person, such as a family member, carer or social care professional, for the welfare of someone who lacks capacity. This could include dressing, bathing or feeding someone who is in residential care or living at home, or handing out tablets prescribed by a doctor. This is called the *doctrine of necessity*.

In all cases the person performing these basic day-to-day actions should act in the *best interests* of the person who lacks capacity. Social care professionals should also comply with the National Minimum Standards (NMS) in relation to both care homes and domiciliary care.

What is 'best interests'?

Best interests means that the person's known wishes and beliefs and their general well being *must* be taken into account. In relation to medical treatment, the courts have said that '*the patient's values and preferences when competent, their well-being and quality of life, relationships with family or other carers, spiritual and religious welfare and their own financial interests*' must be taken into account – not just what might be best for their physical health.

These principles are often adopted for other types of decisions that need to be made, or actions taken, on the person's behalf in areas other than healthcare.

Social care professionals have an important role in helping to determine what may be in the best interests of the person being cared for (*see **Hints for determining best interests**, pages 18–20*).

There are special rules governing financial and healthcare decisions, and the person may have made arrangements for some decisions in advance. Control over someone else's property can *only* be taken with specific legal authority to do so, for example under an Enduring Power of Attorney or an order of the Court of Protection (*see pages 10–12*).

4. Financial decisions

An employee of Social Services or a social or residential care worker should never become involved with a person's property or finances unless they have the approval of their manager or prior authority from their employing department. Social care professionals should also comply with the requirements of the National Minimum Standards (NMS) in relation to both care homes and domiciliary care.

Where social care professionals are involved in carrying out financial assessments, or are involved in any way in handling money for the person being cared for, it is essential to check:

- ▶ whether anyone has been given legal authority to deal with the person's finances; and



- ▶ if that authority continues to be valid once the person has lost capacity to manage their own affairs.

If the affairs of the person being cared for are at all complicated, legal advice should be obtained.

Arrangements to manage a person's financial affairs

A person can put arrangements in place to manage their financial affairs *as long as they have the mental capacity to do so.*

For example, he or she can arrange for a trusted relative or friend to be a signatory to a bank or building society account, to enable that person to draw out money or pay bills on their behalf. Or he or she can arrange for an 'agent' to collect social security benefits and, if authorised, to use the money on their behalf.

Such arrangements allow someone to choose whom they wish to authorise and how much authority they want to give them. This authorisation *must* be given while the person concerned has mental capacity and must be in writing. These arrangements will not be legally valid once the person has lost capacity to manage their own affairs. They can, however, be used as an indication of the person's wishes about whom they would like to take over.

The *only* arrangement that can continue after loss of capacity is an Enduring Power of Attorney.

What is an Enduring Power of Attorney?

An Enduring Power of Attorney (EPA) is a form of deed that allows someone (called the *donor*), while they have capacity, to appoint another person or persons of their choice (called the *attorney(s)*) to manage their financial affairs and property. Forms are available from:

- ▶ stationers who sell legal forms; or
- ▶ solicitors or other advisers.

The attorney can be a friend, relative or a member of the professions, such as a solicitor.

The donor can choose for the attorney(s) *either* to:

- ▶ take over the financial affairs at once while the donor still has capacity. The attorney(s) can then continue to act after the donor becomes mentally incapable so long as the power is registered with the PGO; *or*
- ▶ take over the financial affairs *only* when the donor is no longer mentally capable of managing his/her own financial affairs, again after the power has been registered with the PGO.

An EPA can be general, covering all the donor's property and affairs, or the donor can set limits on what the attorney can do.

Free information and advice about EPAs can be obtained from the Public Guardianship Office (*see **Useful organisations**, page 28*).



What if arrangements for financial decisions have not been made in advance?

If no prior arrangements have been put in place and financial decisions need to be made for a person who has lost capacity, action should be taken immediately to safeguard their financial position and procedures started to appoint someone to act on their behalf.

Where the person's only source of income is social security benefits or pensions, the Department of Work and Pensions (DWP) should be asked to choose an appointee. This will generally be a relative or other carer, or sometimes a solicitor. If the person is in residential care, and there is no-one else able or willing to act as appointee, the manager or proprietor of the care home could be appointed as a last resort. However, this is to be avoided if at all possible, because of possible conflicts of interest.

If the person owns property or has more extensive assets, an application must be made to the Court of Protection for a receiver to be appointed. The Court protects and manages the property and financial affairs of people with impaired mental capacity. If the person has no family, or there is no one else suitable to act as receiver, the court may decide to appoint the local director of Social Services, who can then delegate the management of the person's affairs to a member of his or her staff. The court order will set out the receiver's duties. More information about receivership can be obtained from the PGO.

What about healthcare decisions?

An attorney acting under an EPA, a receiver or anyone else appointed by the Court of Protection has *no power to make personal or healthcare decisions* on behalf of the person they act for. Since they are in control of the donor's money, however, they will often need to be involved in or consulted about these decisions.

5. Healthcare decisions

No one – husbands or wives, partners, close relatives, professional carers or independent advocates – can legally give or withhold consent to medical treatment on behalf of another adult.

Healthcare professionals can and should provide treatment without consent for people who lack capacity if they consider it to be clinically necessary and in the best interests of the person. They should always consult those close to the person to agree the best course of action or treatment, unless the person has made clear in the past that they would not want a particular individual involved. *No one* should be asked to sign a consent form on behalf of the person, though they may be asked to sign a form to say that they have been consulted about the person's best interests.

Making arrangements about future health care in advance

While he or she still has capacity, a person can state their wishes about the forms of medical treatment that they would (or would not) be prepared



to consent to if they should subsequently lose capacity to decide for themselves. This is known as an *advance statement*, *advance directive* or *living will*.

What can an advance statement include?

There are various types of advance statements:

- ▶ a requesting statement giving someone's aspirations and preferences
- ▶ a statement of general beliefs and aspects of life which someone values
- ▶ a statement naming someone who should be consulted at the time a decision needs to be made
- ▶ a statement requesting certain types of treatment which someone would want to receive in certain circumstances
- ▶ a statement setting out a degree of irreversible deterioration after which no life sustaining treatment should be given
- ▶ a clear instruction refusing some or all medical treatments. This is often called an *advance directive*.

Advance statements can be a combination of any or all of the above. They cannot require a doctor to do anything which is unlawful, including action taken with the purpose of ending the patient's life.

If it is known that the person being cared for has made an advance statement in the past, healthcare professionals involved in their care and treatment should be told.

Are advance statements legally binding?

Requesting statements and general statements of preference should be respected by healthcare professionals, if appropriate, and taken into account in deciding what is in someone's best interests, but they are *not* legally binding.

However, advance directives *refusing* treatment *are* legally binding, even if carers and relatives or healthcare professionals disagree with the decision made by the patient, as long as:

- ▶ the refusal was made while the person still had mental capacity and he or she understood the implications of their decision
- ▶ it is clear and applicable in the particular circumstances in which treatment is proposed; and
- ▶ it was made without undue pressure from other people and there is no reason to believe that the person has changed their mind.

However, these apply only where the person has lost capacity: a contemporaneous, competent decision *always* overrides an advance directive. In cases where there is genuine doubt or ambiguity about the person's intention or capacity at the time the statement was made, healthcare professionals should adopt a best-interests approach until clarification is obtained.

6. Resolving disagreements

Where decisions are being made on behalf of people who have difficulty deciding for themselves, it is usually possible for everyone involved to reach agreement on what is best and what should be done. Sometimes, however, this is not possible.



If the dispute is about a serious matter affecting the basic freedoms of the person concerned, anyone involved – a relative, partner, carer or any other person with a legitimate interest – can ask the High Court to decide what is in the person's best interests.

For example, the Court can be asked to decide about healthcare, such as whether the person should have certain types of medical treatment. The Court can also be asked to decide about the person's personal welfare, such as where he or she should live or whether they should have contact with other family members.

Where the person lacks capacity to be able to instruct their own solicitor, the Official Solicitor will usually be appointed to act on the person's behalf. If it seems that court procedures may be necessary, the social care professionals should contact their legal advisors. Professional or regulatory bodies may also be able to offer advice.

In some cases, the Court may request a report from a social care professional giving an opinion about the person's social functioning and their relationship with family members, or any other information which may help the Court to reach a decision.

Disputes about the management of financial affairs

If the dispute concerns the management of the person's *financial* affairs, for example, the validity of an EPA or concerns about the suitability or actions of an attorney or receiver, an application can be made to the Court of Protection. Advice can be sought from the PGO on to how to proceed before the application is made.

7. Recovering capacity

A person who has previously lost capacity to make their own decisions can sometimes recover sufficiently to manage their own affairs again. If no formal arrangements have been made to delegate decisions to someone else, such as an Enduring Power of Attorney, the person can simply start making their own decisions again.

If the person has made an advance statement about health and wishes to change their mind, they can simply destroy the written document and inform everyone who knew about it that it is no longer valid. A person may also withdraw an advance directive verbally, and this should be noted by the clinician on the person's records. While the person still has capacity, they can make a new statement at any time.

If the person has made an EPA that has been registered, or has had a receiver appointed by the Court of Protection, an application must be made to the Court of Protection for an order to revoke the EPA or to discharge the receivership. The Court will need medical evidence that the person no longer has a mental disorder which affects their capacity to manage their own affairs. Once the Court of Protection is satisfied that the person has recovered, other organisations dealing with the person's money or property (for example, banks or solicitors) will need to be told.

If the Department of Work and Pensions has appointed an appointee, the person will need to inform the DWP of their recovery and make a new application for benefits.

8. Combating abuse, exploitation and neglect

Social care professionals, perhaps more than any other professional group, are most acutely aware of the risks of abuse to vulnerable people and of the need to be keenly alert to any possible signs of abuse. For example, they may see unexplained bruising or other evidence of physical abuse on older clients. A person with severe learning difficulties may become distressed or start to display inappropriate sexual behaviour, which could be an indication of sexual abuse. Inappropriate gifts of money or property or unexpected changes in a person's financial circumstances may suggest exploitation or financial mismanagement.

Local authority Social Services have responsibility, jointly with other relevant agencies, to put in place effective local strategies for preventing, detecting and dealing with incidents of abuse.

Social care professionals must be aware of local procedures and joint protocols, including relevant contact details, so that immediate action can be taken if abuse is suspected.

As a basic guide, the following steps should be considered if abuse is suspected:

- ▶ if there is concern about the collection or use of social security benefits, contact the local Job Centre Plus. (For those over the age of 60, Pension Services)
- ▶ if there are suspicions about the actions of an attorney or receiver, discuss your concerns with the Public Guardianship Office

- ▶ if it is suspected that a criminal act has been committed (such as theft or physical assault) against a vulnerable person, contact the police; or
- ▶ if there is concern about the care or treatment given to a vulnerable person in a hospital or residential care home, discuss your concerns with the managers of the relevant NHS trust or Social Services.

An advice agency or a solicitor can help in pursuing a complaint.

9. Useful information and organisations

Hints for determining best interests

Find out the past and present wishes and feelings of the person and the factors which the person would consider if he or she were able to do so.

Try to find out the person's own wishes and values and any views which they may have held before they lost capacity. Check the person's case notes to see if any record has been made of their views or wishes. These may have been set out in a document, such as an advance statement, or expressed informally to relatives or other people involved in their care.

Care should be taken that these are their true wishes. Check that the person has not been unduly influenced by others or that their wishes or views have not changed over time or because of changes in circumstance.



Try to consider everything that may be important to the person, even though it may not be directly relevant to the particular decision which needs to be made. For example, religious, ethnic or cultural values, particular hobbies or interests and likes or dislikes, may all be important in helping to decide what may be in the person's best interests.

Enable and encourage the person to participate, or improve his or her ability to participate, as fully as possible in the decision-making process.

Always try to consult the person and find out his or her current views. Take time to explain what is happening and the decision that needs to be made. Even if they are unable to make the decision itself, they may have views on issues that affect the decision, and on what is best for them.

Try to find out the best way to communicate with the person. Again, family members, an independent advocate, speech and language therapists or other professionals may be able to help.

Consult relatives and others, where appropriate and practical, about the person's wishes and feelings and what would be in his or her best interests.

Try to consider the views of people close to the person, especially close relatives, partners or professional carers. Close relatives or friends may have a better knowledge of the person's views and wishes or may have a different but equally valid view of what may be best for them. Family members could have other records or documents which may be useful to refer to.

However, the person has a right to confidentiality and may not want certain people to be involved in the decision-making process.

Consider whether the proposed action or decision can be achieved in any other way such that the outcome would be less restrictive of the person's freedom of action.

Explore all the other possible options or alternatives available, and consider which option would allow most freedom for the person's future choices.

Further guidance

Subject	Title	Available from
Abuse	<i>No Secrets: Guidance on developing/ implementing multi-agency policies and procedures to protect vulnerable adults from abuse</i>	DH Publications Tel: 09701 555 455 www.doh.gov.uk/scg/nosecrets.htm
Abuse	<i>Confidentiality: Protecting and Providing Information</i> (2000)	General Medical Council Tel: 020 7915 3507/3685 www.gmc-uk.org/standards/default.htm
Abuse	<i>Confidentiality and Disclosure of Health Information</i> (1999) (section 9.1)	British Medical Association Tel: 020 7383 6286 www.bma.org.uk
Advance Statements	<i>Advance Statements about Medical Treatment</i> (1995)	British Medical Association Tel: 020 7383 6286 www.bma.org.uk/ap.nsf/Content/codeofpractice
Advance statements	<i>Advance Statements? BMA Views in Healthcare</i>	British Medical Association Tel: 020 7383 6286 www.bma.org.uk/ap.nsf/Content/advancestatements
Applications to the court in medical decisions	<i>Ms B and NHS Hospital Trust 2002</i> (High Court Judgment)	www.courtservice.gov.uk/judgmentsfiles/j1075/B_v_NHS.htm
Applications to the High Court in medical and welfare decisions	<i>Declaratory Proceedings: Medical & Welfare Decisions for Adults who Lack Capacity.</i> (Fam Law 351, July 2001)	Official Solicitor Tel: 020 7911 7127 www.offsol.demon.co.uk/adultdeclarations.htm
Assessing capacity	<i>Assessment of Mental Capacity: Guidance for Doctors and Lawyers.</i> (BMA and Law Society, 1995 – second edition due 2003)	Available from BMJ Bookshop Tel: 020 7383 6286 www.bma.org.uk/ethics

Subject	Title	Available from
Assessment, admission and compulsory treatment of patients with a mental disorder	<i>Mental Health Act: Code of Practice</i> (1999) (Second edition due 2003)	Department of Health www.doh.gov.uk/pub/docs/doh/mhcop.pdf
Best interests	<i>Consent Tool Kit</i> – BMA	British Medical Association Tel: 020 7383 6286 www.bma.org.uk/ap.nsf/Content/consenttoolkit+m
Best interests	<i>Assessment of Mental Capacity: Guidance for Doctors and Lawyers</i> (BMA and Law Society, 1995 – second edition due 2003)	Available from BMJ Bookshop Tel: 020 7383 6244 www.bma.org.uk/ethics
Confidentiality	<i>Confidentiality: Protecting and Providing Information</i>	General Medical Council Tel: 020 7915 3507/3685 www.gmc-uk.org/standards/default.htm
Confidentiality	<i>Assessment of Mental Capacity: Guidance for Doctors and Lawyers</i> (BMA and Law Society, 1995 – second edition due 2003)	British Medical Association www.bma.org.uk/ap.nsf/content/consenttoolkit+m
Confidentiality	<i>Confidentiality and Disclosure of Health Information</i> (1999)	British Medical Association www.bma.org.uk/ethics
Consent to examination and treatment	<i>Reference Guide to Consent for Examination and Treatment 2001</i> ; and free booklets for patients, carers and relatives	DH Publications Tel: 09701 555 455 www.doh.gov.uk/consent/guidance.htm
Consent to examination and treatment	<i>Consent Tool Kit</i> – BMA	British Medical Association www.bma.org.uk/ap.nsf/content/consenttoolkit+m
Consent to examination and treatment	<i>Seeking Patients' Consent: the Ethical Considerations</i>	General Medical Council www.gmc-uk.org/standards/default.htm



Subject	Title	Available from
Reform of the law for people with mental incapacity	<i>Mental Incapacity</i> (Law Commission Report No 231 (1995))	The Stationery Office Tel: 0870 600 55 22 www.lawcom.gov.uk/549.htm
Reform of the law for people with mental incapacity	<i>Making Decisions – the Government's proposals for making decisions on behalf of mentally incapacitated adults</i> (1999)	Lord Chancellor's Department www.lcd.gov.uk/consult/family/decision.htm
Reform of the law for people with mental incapacity	<i>Campaign Pack</i>	Making Decisions Alliance Tel: 020 7306 0807 www.makingdecisions.org.uk
Withdrawing treatment	<i>Withholding and Withdrawing Life Prolonging Medical Treatment</i> (2001)	Available from BMJ Bookshop Tel: 020 7383 6244 www.bmjpg.com/withwith/ww.htm
Withdrawing treatment	<i>Withholding and Withdrawing Life Prolonging Treatments: Good practice in decision-making</i>	General Medical Council www.gmc-uk.org/standards/default.htm

Useful organisations

Organisation	What it is/does	Contact
Action on Elder Abuse	Provides a confidential helpline service for anyone concerned with the abuse of older people and emotional support for those involved.	Astral House 1268 London Road London SW16 4ER Freephone Helpline: 0880 8808 8042 www.elderabuse.org.uk
Age Concern	Provides national information line for older people and their concerns.	Age Concern England Astral House 1268 London Road London SW16 4ER Tel: 020 8765 7200 www.ageconcern.org.uk
Alert	Campaigns against legalised euthanasia. Provides information on matters relating to Living Wills, Advance Directives and Motor Neurone Disease.	27 Walpole Street London SW3 4QS Tel: 020 7730 2800 www.donoharm.org.uk
Alzheimer's Society	Care and research charity for people with all forms of dementia, their families and carers.	Gordon House 10 Green Coat Place London SW1P 1PH Helpline: 0845 300 0336 www.alzheimers.org.uk
British Medical Association	Professional body and trade union representing doctors from all branches of medicines in the UK.	Medical Ethics Department British Medical Association BMA House Tavistock Square London WC1H 9JP Tel: 020 7383 6286 www.bma.org.uk



Organisation	What it is/does	Contact
CARERS UK	Looks after family, partners or friends in need of help because they are ill, frail or have a disability.	Ruth Pitter House 20/25 Glasshouse Yard London EC1A 4JT CarersLine: 0808 808 7777 020 7490 8824 www.carersonline.org.uk
Citizen Advocacy Information and Training	Provides advice about citizen advocacy groups in the initial stages of setting up schemes. Runs training days and gives support to existing schemes.	Unit 164 Lee Valley Technopark Ashley Road London N17 9LN Tel: 020 8880 4545 www.citizenadvocacy.org.uk
Counsel and Care	Provides a confidential and free advisory service for people over 60. Gives advice about welfare benefits and provides financial help towards essential care.	Twyman House 16 Bonny Street London NW1 9PG Helpline: 0845 300 7585 www.counselandcare.org.uk
Down's Syndrome Association	Offers help for people with Down's Syndrome.	155 Mitcham Road London SW17 9PG Tel: 020 8682 4001 www.downs-syndrome.org.uk
Foundation for People with Learning Disabilities	Works with people with learning disabilities to improve the quality of their lives.	7th Floor 83 Victoria Street London SW1H 0HW Tel: 020 7802 0300 www.learningdisabilities.org.uk
General Medical Council	Statutory body which sets and monitors professional standards for doctors. Charity whose purpose is the protection, promotion and maintenance of the health and safety of the community.	178 Great Portland Street London W1W 5JE General Enquiries Desk: 020 7580 7642 www.gmc-uk.org

Organisation	What it is/does	Contact
Headway – brain injuries association	Sets up self-help and support groups; provides information, publicity and booklets on patients' problems, and help for families.	4 King Edward Court King Edward Street Nottingham NG1 1EW Helpline: 0808 800 2244 Tel: 0115 924 0800 (Nottingham) 020 7841 0240 (London) www.headway.org.uk
Help the Aged	Promotes and develops practical programmes. Offers free advice through Senior Line and via information leaflets.	St James's Walk Clerkenwell Green London EC1R 0BE Welfare Rights Adviceline: 0808 800 6565 www.helptheaged.org.uk
Linacre Centre for Healthcare Ethics	Catholic bioethics centre. Produces academic and other material on a range of issues in healthcare, including euthanasia and the withholding and withdrawing of treatment and care. Also provides advice to health practitioners on ethical aspects of their work.	60 Grove End Road London NW8 9NH Tel: 020 7806 4088 www.linacre.org
Medical Defence Union	Provides 24 hour access to advice and assistance with medico-legal and ethical problems to its members.	3 Devonshire Place London W1M 5PE General Enquiries: 020 7202 1500 Membership Helpline: 0800 716376 www.the-mdu.com
Medical Protection Society	Mutual society of doctors and other healthcare workers providing advice and assistance on any legal issue stemming from professional practice.	33 Cavendish Square London W1G 0PS Tel: 0845 605 4000 020 7399 1301 www.mps.org.uk



Organisation	What it is/does	Contact
MedicAlert Foundation	Non-profit-making registered charity providing a life-saving identification system for individuals with hidden medical conditions and allergies.	1 Bridge Wharf 156 Caledonian Road London N1 9UU Tel: 0800 581 420 www.medicalert.org.uk
MENCAP	Offers support for people with a learning disability and their families. Provides specialist information, homes, leisure activities and further education.	123 Golden Lane London EC1Y 0RT Helpline: 0808 808 1111 Tel: 020 7454 0454 www.mencap.org.uk
Mind (National Association for Mental Health)	Mental health charity in England and Wales – works for a better life for everyone with experience of mental distress.	15-19 Broadway Stratford London E15 4BQ Tel: 020 8519 2122 Mindinfo: 08457 660 163 www.mind.org.uk
Motor Neurone Disease Association	Independent charity that offers support to people with Motor Neurone Disease and those who care for them.	PO Box 246 Northampton NN1 2P2 Tel: 01604 250505 Helpline: 08457 626262 www.mndassociation.org.uk
National Autistic Society	UK charity providing information and support for people with autism spectrum disorders and their families. Also provides information for professionals.	393 City Road London EC1V 1NG Tel: 020 7833 2299 Helpline: 0870 600 85 85 www.nas.org.uk
Official Solicitor	Provides representation for minors or adults under legal disability in county court or High Court proceedings in England and Wales. Protects the best interests and human rights of those who are unable to represent themselves in the legal process.	81 Chancery Lane London WC2A 1DD Tel: 020 7911 7127 www.offsol.demon.co.uk

Organisation	What it is/does	Contact
Patient Concern	Committed to promoting choice and empowerment for all Health Service users.	PO Box 23732 London SW5 9FY Tel: 020 7373 0794 www.patientconcern.org.uk
The Prevention of Professional Abuse Network POPAN	Helps people abused by health or social care professionals. Provides information, support, and advocacy. Prevents abuse through training and awareness raising.	1 Wyvil Court Wyvil Road London SW8 2TG Tel: 020 7622 6334 Support Line: 0845 4 500 300 www.popan.org.uk
Public Guardianship Office	Provides financial protection services for clients who are not able to manage their financial affairs because of mental incapacity. Supports the families and advisers of the person who is incapable.	Archway Tower 2 Junction Road London N19 5SZ Customer Service Helpline 0845 330 2900 Enquiry Line: 0845 330 2900 www.guardianship.gov.uk
Relatives and Residents Association	Helps with finding the right care home and with costs. Gives practical advice to anyone with an elderly relative or friend living in a home or long-stay hospital.	5 Tavistock Place London WC1H 9SW Adviceline: 020 7916 6055 www.relres.org.uk
RESCARE (The National Society for mentally disabled people in residential care)	Provides information, advice and support to families including legal advice.	Rayner House 23 Higher Hillgate Stockport SK1 3ER Tel: 0161 474 7323 www.rescare.org.uk
Respond	Runs a national helpline for people with learning disabilities, professionals and carers, dealing with the issues of abuse and abusing.	Third Floor 24-32 Stephenson Way London NW1 2HD Helpline: 0808 808 0700 www.respond.org.uk

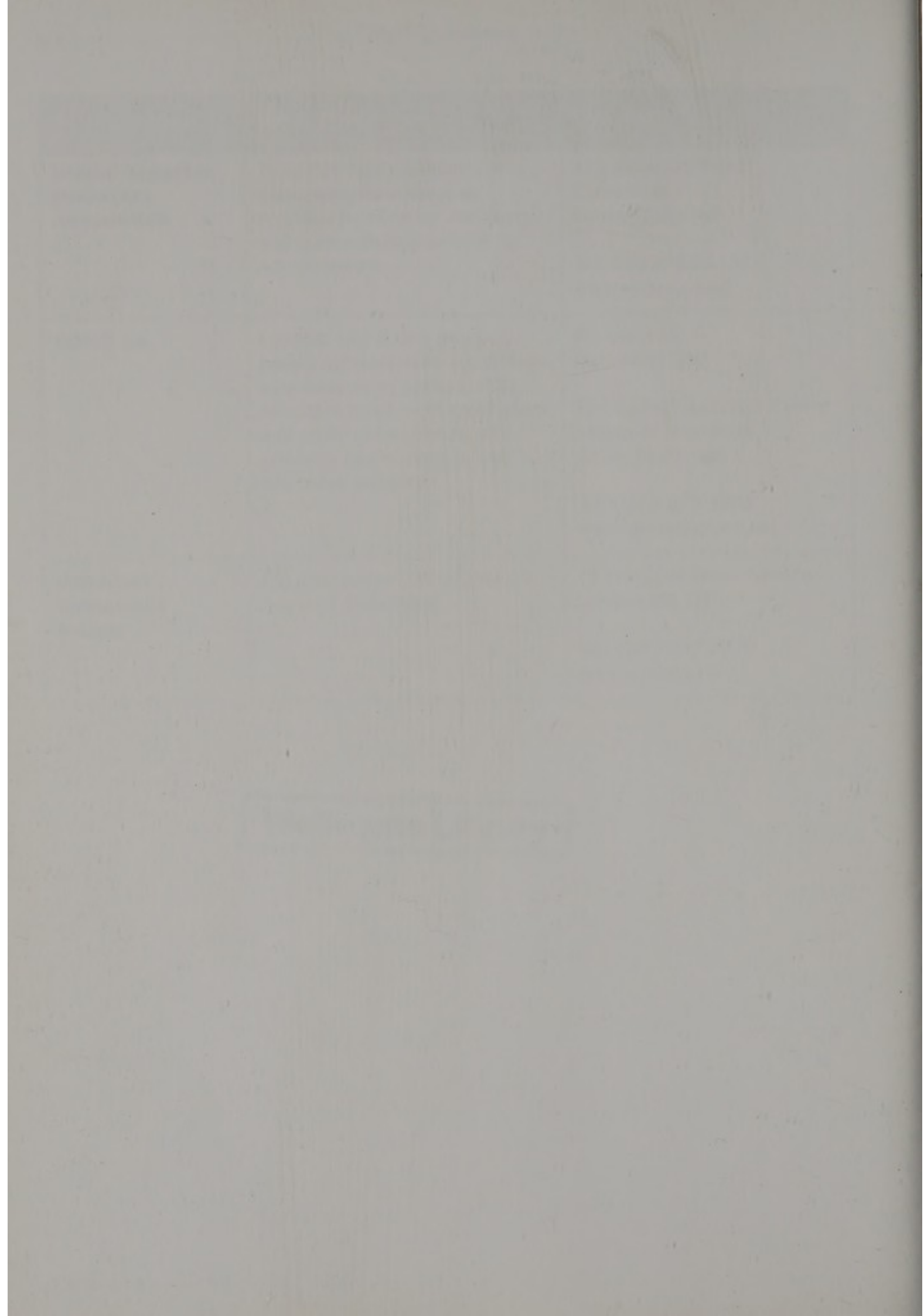


Organisation	What it is/does	Contact
Rethink (formerly National Schizophrenia Fellowship)	Charity for people who experience severe mental illness and for those who care for them.	17 Oxford Street Southampton SO14 3DJ General Enquiries: 0845 456 0455 Advice Line: 020 8974 6814 www.rethink.org
SANE	Runs a phone helpline giving advice on all forms of mental illness and offering support to sufferers, their friends, families and professionals.	1st Floor Cityside House 40 Adler Street London E1 1EE Helpline: 0845 767 8000 www.sane.org.uk
Scope (Major disability charity with a focus on cerebral palsy)	Provides a wide variety of services for disabled people including accommodation, educational and training facilities, and fieldwork support for disabled people and their families.	6 Market Road London N7 9PW Tel: 020 7619 7257 Cerebral Palsy Helpline: 0808 800 3333 www.scope.org.uk
Speakability	Supports people living with aphasia and their carers.	1 Royal Street London SE1 7LL Tel: 020 7261 9572 Helpline: 080 8808 9572 www.speakability.org.uk
Stroke Association	Provides practical support for people who have had strokes, their families and carers.	Stroke House 240 City Road London EC1V 2PR Tel: 020 7566 0300 Helpline: 0845 30 33 100 www.stroke.org.uk

Organisation	What it is/does	Contact
<p>United Kingdom Homecare Association</p>	<p>Promotes high standards in domiciliary care services. Provides helpline for members and a consultancy service for non-members.</p>	<p>42b Banstead Road Carshalton Surrey SM5 3NW</p> <p>Tel: 020 8288 1551 www.ukhca.co.uk</p>
<p>VOICE UK</p>	<p>Support and action group for people with learning disabilities who have been abused. Puts people in touch with counsellors and other professionals and provides counselling, advice and other services.</p>	<p>PO Box 238 Derby DE1 9NJ</p> <p>The College Business Centre Uttoxeter New Road Derby DE22 3WZ</p> <p>Tel: 0870 013 3965 www.voiceuk.clara.net</p>
<p>Voluntary Euthanasia Society</p>	<p>Provides advice on making an Advance Statement.</p>	<p>13 Prince of Wales Terrace London W8 5PG</p> <p>Tel: 020 7937 7770 www.ves.org.uk</p>

Wellcome Library







Other booklets in this series:

Making Decisions: A guide for legal practitioners
Making Decisions: A guide for healthcare professionals
Making Decisions: A guide for family and friends
Making Decisions: Planning for future incapacity
Making Decisions: A guide for people with learning difficulties

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Copies of these booklets are available from:

Mental Incapacity Branch

Family Policy Division 1

Lord Chancellor's Department

4th Floor, Selborne House

56-60 Victoria Street

London SW1E 6QW

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