

CARD 7

Adults who lack capacity

1. Temporary or permanent mental incapacity

Patients with mental disorders or learning disabilities should not automatically be regarded as lacking the capacity to give or withhold their consent to disclosure of confidential information. Unless unconscious, most people suffering from a mental impairment can make valid decisions about some matters that affect them. An individual's mental capacity must be judged in relation to the particular decision being made. If therefore a patient has the requisite capacity, disclosure of information to relatives or third parties requires patient consent. One of the most difficult dilemmas for health professionals occurs where the extent of the patient's mental capacity is in doubt. In such cases health professionals must assess the information which is available from the patient's health record and from third parties. They should attempt to discuss with patients their needs and preferences as well as assess their ability to understand their condition and prognosis. If there is still doubt about a patient's competence to give or withhold consent, health professionals should seek a second opinion.

2. Relatives, carers and friends

If a patient lacks capacity, health professionals may need to share information with relatives, friends or carers to enable them to assess the patient's best interests. Where a patient is seriously ill and lacks

capacity, it would be unreasonable always to refuse to provide any information to those close to the patient on the basis that the patient has not given explicit consent. This does not, however, mean that all information should be routinely shared, and where the information is sensitive, a judgement will be needed about how much information the patient is likely to want to be shared, and with whom. Where there is evidence that the patient did not want information shared, this must be respected.

3. Next of kin

Although widely used, the phrase 'next of kin' has no legal definition or status. If a person is nominated by a patient as next of kin and given authority to discuss the patient's condition, such a person may provide valuable information about the patient's wishes to staff caring for the patient. However, the nominated person cannot give or withhold consent to the sharing of information about the patient and has no rights of access to the patient's medical records. The patient may nominate anyone as next of kin – spouse, partner, family member or friend. In the absence of such a nomination, no-one can claim to be next of kin.

4. Proxy decision-makers

In England and Wales, the Mental Capacity Act 2005 allows people over 18 years of age who have capacity to appoint a welfare attorney to make health and personal welfare decisions once capacity is lost. The Court of Protection may also appoint a deputy to make these decisions. Where a patient lacks capacity and has no relatives or

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friends to be consulted, the Mental Capacity Act requires an Independent Mental Capacity Advocate (IMCA) to be appointed and consulted about all decisions about 'serious medical treatment', or place of residence. An attorney or deputy can also be appointed to make decisions relating to the management of property and financial affairs. In the case of health information, health professionals may only disclose information on the basis of the patient's best interests. While it will be necessary for attorneys, deputies and IMCAs to have some information to enable them to act or make decisions on behalf of the patient, that does not mean that they will always need to have access to the whole of the patient's records, but only what is necessary to deal with the issue in question. Where there is no attorney, deputy or IMCA, information should only be disclosed in the patient's best interests.

In Scotland the Adults with Incapacity (Scotland) Act 2000 allows people over the age of 16 who have capacity to appoint a welfare attorney to make health and personal welfare decisions once capacity is lost. The Court of Session may also appoint a deputy to make these decisions. An attorney or deputy can also be appointed to make decisions relating to the management of property and financial affairs. In the case of health information, health professionals may only disclose information when it is of benefit to the patient. While it will be necessary for attorneys and deputies to have some information to enable them to act or make decisions on behalf of the patient, that does not mean that they will always need to

have access to the whole of all the patient's records, only what is necessary to deal with the issue in question. Where there is no attorney or deputy, information should only be disclosed where it is of benefit to the patient.

In Northern Ireland, there is no mental capacity legislation. Information should therefore only be disclosed in accordance with the common law and in the patient's best interests.

5. Abuse and neglect

Where health professionals have concerns about a patient lacking capacity who may be at risk of abuse or neglect, it is essential that these concerns are acted upon and information is given promptly to an appropriate person or statutory body, in order to prevent further harm. Where there is any doubt as to whether disclosure is considered to be in the patient's best interests, it is recommended that the health professional discusses the matter on an anonymised basis with a senior colleague, the Caldicott guardian, their professional body or defence organisation. Health professionals must ensure that their concerns and the actions they have taken or intend to take, including any discussion with the patient, colleagues or professionals in other agencies, are clearly recorded in the patient's medical records.

(See also Card 6 on Assessment of Capacity and Determining 'Best Interests' and Card 10 Public Interest and Card 1: 'Capacity', 'MCA' and 'Scotland Incapacity'.)

CARD 8

Children and young people

1. Competent children

There is no presumption of capacity for people under 16 in England, Wales and Northern Ireland and those under that age must demonstrate they have sufficient understanding of what is proposed. However, children who are aged 12 or over are generally expected to have to have capacity to give or withhold their consent to the release of information. In Scotland, anyone aged 12 or over is legally presumed to have such capacity. Younger children may also have sufficient capacity. When assessing a child's capacity it is important to explain the issues in a way that is suitable for their age. If the child is competent to understand what is involved in the proposed treatment, the health professional should, unless there are convincing reasons to the contrary, for instance abuse is suspected, respect the child's wishes if they do not want parents or guardians to know. However, every reasonable effort must be made to persuade the child to involve parents or guardians particularly for important or life-changing decisions.

2. Children who lack capacity

The duty of confidentiality owed to a child who lacks capacity is the same as that owed to any other person. Occasionally, young people seek medical treatment, for example, contraception, but are judged to lack the capacity to give consent. An explicit request by a child that information should