General Medical Council

Professional standards

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Decision making and consent

Summary

This guidance will support you in your conversations with your patients and help you to be confident you're sharing the information they need to make decisions. By following it, it will help you make sure that you have informed consent from your patient.

It covers:

- What you should tell a patient when talking about risks.
- What to do if your patient doesn't want to hear information you think is relevant.
- What to do if your patient may lack capacity to make a decision
- What you should record.

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About our Decision making and consent guidance

Consent is a fundamental legal and ethical principle. All patients have the right to be involved in decisions about their treatment and care and to make informed decisions if they can. The exchange of information between medical professionals and patients is essential to good decision making. Serious harm can result if patients are not listened to, or if they are not given the information they need - and time and support to understand it - so they can make informed decisions about their care.

Doctors, physician associates and anaesthesia associates (collectively referred to as medical professionals) must be satisfied that they have a patient's consent or other valid authority before providing treatment or care. The purpose of this guidance is to help medical professionals to meet this standard. It reflects the ethical principles that underpin good practice.

While the law relating to decision making varies across the UK, this guidance is consistent with the law in all four countries and supports medical professionals acting within it. Key legislation and case law relating to decision making and consent is summarised in a factsheet available on our website. Medical professionals are expected to keep up to date with the law and follow our guidance and other regulations that are relevant to their work. *Available online at *Decision making and consent*

The guidance is addressed to doctors, physician associates and anaesthesia associates but may also be of interest to others.

How to use this guidance

This is guidance, which forms part of the professional standards, on good practice. It sets out a framework for decision making that will help you practise ethically and in line with the law. If you're not sure how the law applies in a given situation, seek advice through local procedures, consult your defence body or professional association, or seek independent legal advice.

The standards of good practice apply to doctors, physician associates and anaesthesia associates (collectively referred to as medical professionals and whom we address directly as 'you' throughout the guidance). As with all our professional standards, this guidance applies to all our registrants to the extent it is relevant to the individual's practice.

The professional standards describe good practice, and not every departure from them will be considered serious. You must use your professional judgement to apply the standards to your day-to-day practice. If you do this, act in good faith and in the interests of patients, you will be able to explain and justify your decisions and actions. We say more about professional judgement, and how the professional standards relate to our fitness to practise processes, appraisal and revalidation, at the beginning of *Good medical practice*.

Terminology

We use the terms ‘must’ and ‘should’ in the following ways.

- ‘You must’ is used for a legal or ethical duty you’re expected to meet (or be able to justify why you didn’t).
- 'You should’ is used for duties or principles that either:
  - may not apply to you or to the situation you’re currently in, or
  - you may not be able to comply with because of factors outside your control

The seven principles of decision making and consent

One

All patients have the right to be involved in decisions about their treatment and care and be supported to make informed decisions if they are able.

Two

Decision making is an ongoing process focused on meaningful dialogue: the exchange of relevant information specific to the individual patient.

Three

All patients have the right to be listened to, and to be given the information they need to make a decision and the time and support they need to understand it.

Four

Medical professionals must try to find out what matters to patients so they can share relevant information about the benefits and harms of proposed options and reasonable alternatives, including the option to take no action.

Five

Medical professionals must start from the presumption that all adult patients have capacity to

make decisions about their treatment and care. A patient can only be judged to lack capacity to make a specific decision at a specific time, and only after assessment in line with legal requirements.

Six

The choice of treatment or care for patients who lack capacity must be of overall benefit to them, and decisions should be made in consultation with those who are close to them or advocating for them.

Seven

Patients whose right to consent is affected by law should be supported to be involved in the decision-making process, and to exercise choice if possible.

The scope of this guidance

1. This guidance is relevant to every health and care decision that you make with every patient. This includes decisions about treatments, procedures, interventions, investigations, screenings, examinations and referrals.
2. Decisions about consent to disclosure of information are covered in our guidance on confidentiality. Decisions about providing innovative treatments or approaches are covered by this guidance.
3. This guidance applies equally to decisions about mental and physical health, and in whatever setting your interaction with a patient takes place, including remote consultations.
4. For patients under 18 this guidance should be read alongside *0–18 years*.

Taking a proportionate approach

5. Not every paragraph of this guidance will be relevant to every decision that you make with or about a patient. Your judgement about how to apply the guidance will depend on the specific circumstances of each decision, including:
    a. the nature and severity of the patient's condition and how quickly the decision must be made. See also paragraphs 62–64 on Treatment in emergencies.
    b. the complexity of the decision, the number of available options and the level of risk or degree of uncertainty associated with any of them
    c. the impact of the potential outcome on the patient's individual circumstances
    d. what you already know about the patient, and what they already know about their condition and the potential options for treating or managing it

e. the nature of the consultation.

6. Obtaining a patient's consent needn't always be a formal, time-consuming process. While some interventions require a patient's signature on a form, for most healthcare decisions you can rely on a patient's verbal consent, as long as you are satisfied they've had the opportunity to consider any relevant information (see paragraph 10) and decided to go ahead.

Although a patient can give consent verbally (or non-verbally) you should make sure this is recorded in their notes. * Although a patient can give consent verbally (or non-verbally) you should make sure this is recorded in their notes. See also paragraphs 50–53 on *Recording decisions for more information**.

7. For some quick, minimally or non-invasive interventions – particularly examinations – it would be reasonable to rely on a patient's non-verbal consent. Examinations are a necessary part of diagnosis, and it's reasonable to believe that a patient presenting for a consultation wants to be diagnosed.

However, even for such routine procedures you should:

a. explain what you're going to do and why

b. make clear the patient can say no, and stop immediately if they do

c. be alert for any sign that they may be confused or unhappy about what you are doing.

The dialogue leading to a decision

8. The exchange of information between medical professionals and patients is central to good decision making. It's during this process that you can find out what's important to a patient, so you can identify the information they will need to make the decision.

9. The purpose of the dialogue is:

a. to help the patient understand their role in the process, and their right to choose whether or not to have treatment or care

b. to make sure the patient has the opportunity to consider relevant information that might influence their choice between the available options

c. to try and reach a shared understanding of the expectations and limitations of the available options.

The information you give patients

10. You must give patients the information they want or need to make a decision.

This will usually include:

a. diagnosis and prognosis

b. uncertainties about the diagnosis or prognosis, including options for further investigation. See also paragraphs 25–26 on Dealing with uncertainties.

c. options for treating or managing the condition, including the option to take no action

d. the nature of each option, what would be involved, and the desired outcome

e. the potential benefits, risks of harm, uncertainties about and likelihood of success for each option, including the option to take no action.
By 'harm' we mean any potential negative outcome, including a side effect or complication. *By 'harm' we mean any potential negative outcome, including a side effect or complication. See also paragraphs 21–24.

11. You must try to make sure the information you share with patients about the options is objective. You should be aware of how your own preferences might influence the advice you give and the language you use. When recommending an option for treatment or care to a patient you must explain your reasons for doing so, and share information about reasonable alternatives, including the option to take no action. You must not put pressure on a patient to accept your advice.

12. You should not rely on assumptions about:

a. the information a patient might want or need

b. the factors a patient might consider significant

c. the importance a patient might attach to different outcomes.

13. Other examples of information that might be relevant and, if so, should be shared with patients include:

a. whether an option is an innovative treatment designed specifically for their benefit

b. whether there is a time limit on making their decision and what the implications of delaying might be

c. the names and roles of key people who will be involved in their care, and who they can contact (and how) if they have questions or concerns

d. their right to refuse to take part in teaching or research

e. their right to seek a second opinion

f. any bills they will have to pay

g. any conflicts of interest that you or your organisation may have

h. any treatments that you believe have greater potential benefit for the patient than those you or your organisation can offer.

Exceptional circumstances in which you may decide not to share all relevant information

14. There may be circumstances in which you decide not to share all relevant information with a patient straight away. If you delay sharing information necessary for making a decision, you should let the patient know there's more to discuss and make sure arrangements are made to share the information as soon as it's appropriate to do so. You must make a record of the information you still need to share, your reasons for not sharing it now, and when it can be shared.

15. You should not withhold information a patient needs to make a decision for any other reason, including if someone close to the patient asks you to. In very exceptional circumstances you may feel that sharing information with a patient would cause them serious harm and, if so, it may be appropriate to withhold it. In this context 'serious harm' means more than that the patient might become upset, decide to refuse treatment, or choose an alternative. This is a limited exception and you should seek legal advice if you are considering withholding information from a patient.

Finding out what matters to a patient

16. You must listen to patients and encourage them to ask questions.

17. You should try to find out what matters to patients about their health – their wishes and fears, what activities are important to their quality of life, both personally and professionally – so you can support them to assess the likely impact of the potential outcomes for each option.

18. You must seek to explore your patient's needs, values and priorities that influence their decision making, their concerns and preferences about the options and their expectations about what treatment or care could achieve.

19. You should ask questions to encourage patients to express what matters to them, so you can identify what information about the options might influence their choice.

20. You should explore with patients what risks they would and wouldn't be prepared to take to achieve a desired outcome, and how the likelihood of a particular outcome might influence their choice. * For 'risks' we mean the risk of a harm occurring, where a harm is any negative outcome, including a side effect or complication. See also paragraphs 21–24.*

Discussing benefits and harms

21. You must give patients clear, accurate and up-to-date information, based on the best available evidence, about the potential benefits and risks of harm of each option, including the option to take no action.

22. It wouldn't be reasonable to share every possible risk of harm, potential complication or side effect. Instead, you should tailor the discussion to each individual patient, guided by what matters to them, and share information in a way they can understand. See paragraphs 16–20 on Finding out what matters to a patient.

23. You should usually include the following information when discussing benefits and harms.

a. Recognised risks of harm that you believe anyone in the patient's position would want to know. You'll know these already from your professional knowledge and experience.

b. The effect of the patient's individual clinical circumstances on the probability of a benefit or harm occurring. If you know the patient's medical history, you'll know some of what you need to share already, but the dialogue could reveal more.

c. Risks of harm and potential benefits that the patient would consider significant for any reason. These will be revealed during your discussion with the patient about what matters to them.

d. Any risk of serious harm, however unlikely it is to occur. This is likely to be easier to discuss in advance if possible, see paragraphs 32–39 on *Looking ahead to future decisions*. See paragraph 5 on *Taking a proportionate approach.*

e. Expected harms, including common side effects and what to do if they occur.

24. You should consider using visual or other explanatory aids to support patients to understand their personalised risk, taking account of their individual clinical and personal circumstances, compared with population level risk.

25. You must answer patients' questions honestly and accurately, and as fully as is practical in the circumstances. You must be clear about the limits of your knowledge and, if you can't answer a question, explain whether it is something you are uncertain of or something that is inherently uncertain.

26. If you are uncertain about the diagnosis, or the clinical effect a particular treatment might have, or if the available evidence of benefits and harms of an option is unclear, you should explain this to the patient. Some things will become clearer after treatment starts, so you should discuss in advance what the arrangements will be for monitoring the effect of the treatment and reviewing the decision to provide it. You should also explore in advance what options the patient might prefer in the future, depending on how treatment progresses, and the factors that might influence their choice. See paragraphs 16–20 on Finding out what matters to a patient and paragraphs 21–24 on Discussing benefits and harms.*

The dialogue leading to a decision continued

Supporting patients' decision making

27. Patients need relevant information (see paragraph 10) to be shared in a way they can understand and retain, so they can use it to make a decision. To help patients understand and retain relevant information you should:

a. share it in a place and at a time when they are most likely to understand and retain it

b. anticipate whether they are likely to find any of it distressing and, if so, be considerate when sharing it

c. accommodate a patient's wishes if they would like to record the discussion. See paragraph 53 on Visual and audio recordings.

d. accommodate a patient's wishes if they would like anyone else – a relative, partner, friend, carer or advocate – to be involved in discussions and/or help them make decisions

e. use an interpreter or translation[1]service if they have difficulty understanding spoken English

f. share it in a format they prefer - written, audio, translated, pictures or other media or methods

g. give them time and opportunity to consider it before and after making a decision.

28. You should be alert to signs that patients may need support to understand and retain the relevant information, use it to make a decision, or communicate that decision to you.

29. You should make sure that reasonable adjustments[2] are made so that patients with additional needs have enough time and support to understand relevant information and make a decision. In all cases, you must treat patients fairly and not discriminate against them.

30. You must check whether patients have understood the information they have been given, and if they would like more information before making a decision.

The scope of decisions

31. You must be clear about the scope of decisions so that patients understand exactly what they are consenting to. You must not exceed the scope of a patient's consent, except in an emergency. See also paragraphs 62–64 on Treatment in emergencies.

Agreeing the scope of a patient's consent with them in advance is particularly important if:

a. treatment or care will be provided in stages with opportunities to review and adjust in between

b. different healthcare professionals will provide different parts of the treatment or care

c. there may be opportunity, once an intervention is underway and the patient's decision-making ability is compromised, to carry out another intervention

d. there is significant risk of a specific harm occurring during an intervention, which would present more than one way to proceed. See paragraphs 21–24 on Discussing benefits and harms.

Looking ahead to future decisions

32. For some patients, there are foreseeable circumstances when they will have a choice of options at a time when they might find it more difficult to make decisions – for example because:

a. they may be in pain, confused or afraid

b. their capacity or insight may be impaired by their condition or the effects of an intervention

c. a decision may need to be made quickly so there will be less time for dialogue.

33. You should anticipate such circumstances and discuss them with patients in advance if practical, so that when a decision needs to be made patients have already had time and opportunity to consider the relevant information (see paragraph 10). Discussing a risk of serious harm will be easier to do in advance than in a time-pressured situation when the patient might be in pain, confused or afraid, and the mention of potential serious harm for the first time could be distressing.

34. Discussing options in advance doesn't remove the need to have a further dialogue immediately before providing treatment, and at regular intervals as treatment or care progresses. Even if there's a care plan in place, or the patient's made an advance decision, you should still talk to them about the options available in case the options have changed or the patient has changed their mind.

35. If a patient has a condition that is likely to impair their capacity as it progresses, you should sensitively encourage them to think about what they might want to happen if they become unable to make healthcare decisions. You should bear in mind that some patients may not be ready to talk about these issues. Such discussions might include:

a. the patient's wishes and fears, their preferences about future options for care, and the values and priorities that influence their decision making

b. any treatment or care the patient might want to refuse, and in what circumstances

c. any interventions that might become necessary in an emergency, such as cardiopulmonary resuscitation (CPR)[3].

d. whether the patient would like anyone else – relatives, friends, carers or representatives – to be involved in decisions about their care.

36. A patient may want to nominate someone to make decisions on their behalf if they lose capacity or they may want to make an advance statement about refusing or requesting a particular treatment. In these circumstances, you should let patients know that there are ways to formalise their wishes and suggest that they seek support and independent advice about this. See paragraphs 77–80 on The legal framework.

37. You must record a summary of your discussion with the patient about their future care and any decisions they make, including as much detail as practical about the patient's wishes and fears, their preferences about future options for care, and the values and priorities that influence their decision making. If possible, you should make this record while the patient has capacity to review and understand it.

38. You should make sure the record of this discussion is flagged and made available to the patient and others involved in their care, so everyone is clear about what has been agreed. Any decision or preference should be easy to access and regularly reviewed.

39. If you are giving treatment or care to a patient who is nearing the end of their life, you must follow the guidance in *Treatment and care towards the end of life: decision making*.

The dialogue leading to a decision continued

Support from other members of the healthcare team

40. As decision making is a dynamic, ongoing process, a team-based approach can be helpful in fulfilling patients' information needs, which may change as their treatment or care progresses.

41. There may be members of your healthcare team who are expert in certain conditions and their treatment, who are skilled communicators, or who have developed a trusting relationship with the patient. You should consider the role these team members could play in contributing to the dialogue that leads to a decision, while following paragraphs 42–47 on responsibility and delegation.

Responsibility and delegation

42. You may decide to delegate part of the decision-making process, such as sharing detailed information with a patient about a specific intervention. This type of delegation is routinely used in some multidisciplinary teams for specific interventions.

43. When deciding whether it is appropriate to delegate, you should consider:

a. the nature of the intervention and the complexity of the information about it

b. the level of uncertainty surrounding the outcome

c. whether the patient has already developed a trusting relationship with you or the person you would delegate to

d. anything unusual about the patient's condition(s) and any concerns that you anticipate the patient may have.

44. You must make sure the person you delegate to:

a. is suitably trained and competent

b. has sufficient knowledge of the intervention and its associated benefits and harms, as well as alternative options for treatment and care

c. has the skills to have a dialogue with the patient that's in line with this guidance

d. feels competent to carry out the delegated task and understands and agrees that they will refer to you (or another appropriate colleague) for further information, advice or support if necessary.

45. If part of the decision-making process has been delegated, you are still responsible for making sure that the patient has been given the information they need to make the decision (see paragraph 10), has had time and support to consider it, and has given their consent before you provide treatment or care. You should also check that the patient has a realistic expectation of the outcome.

46. If a colleague who is sharing information with a patient on your behalf raises concerns about their competence to do this, you should offer support, supervision or training and/or make alternative arrangements.

47. If a colleague asks you to share information with a patient or seek a patient's consent on their behalf, you must be satisfied you have the necessary knowledge and skills to do so in line with this guidance. If you're not, you should explain this and seek support. If you believe you're being asked to practise outside your competence, or you are insufficiently supported you must consider raising a concern. [4]

The dialogue leading to a decision continued

If you disagree with a patient's choice of option

48. You must respect your patient's right to decide. If their choice of option (or decision to take no action) seems out of character or inconsistent with their beliefs and values, it may be reasonable to check their understanding of the relevant information (see paragraph 10) and their expectations about the likely outcome of this option and reasonable alternatives. If it's not clear whether a patient understands the consequences of their decision, you should offer more support to help them understand the relevant information. But you must not assume a patient lacks capacity simply because they make

a decision that you consider unwise. See paragraphs 27–30 for ways of Supporting patients' decision making.

49. If a patient asks for treatment or care that you don't think would be in their clinical interests, you should explore their reasons for requesting it, their understanding of what it would involve, and their expectations about the likely outcome. This discussion will help you take account of factors that are significant to the patient and assess whether providing the treatment or care could serve the patient's needs. If after discussion you still consider that the treatment or care would not serve the patient's needs, then you should not provide it. But, you should explain your reasons to the patient and explore other options that might be available, including their right to seek a second opinion. See paragraphs 16–20 on Finding out what matters to a patient.

Recording decisions

Patients' medical records

50. Keeping patients' medical records up to date with key information is important for continuity of care. Keeping an accurate record of the exchange of information leading to a decision in a patient's record will inform their future care and help you to explain and justify your decisions and actions.

51. You should take a proportionate approach to the level of detail you record. *Good medical practice* states that you must include the decisions made and actions agreed - and who is making the decisions and agreeing the actions - in the patient's clinical records. This includes decisions to take no action.

Visual and audio recordings

52. If you make a recording as part of a patient's care you must follow our guidance on *Making and using visual and audio recordings of patients*. Such recordings form part of the medical record and should be treated in the same way as other records.

53. Recordings made by patients are owned by them and do not have to be stored with their medical records.

Consent forms

54. Consent forms can be a helpful prompt to share key information, as well as a standard way to record a decision that can make regular review easier. They can also be used to review decisions made at an earlier stage, and the relevant information they were based

on.

55. But, filling in a consent form isn't a substitute for a meaningful dialogue tailored to the individual patient's needs.

Reviewing decisions

56. Unless treatment or care begins immediately after a patient has given consent, there will be opportunity for a decision to be reviewed.

57. You should review a patient's decision immediately before providing treatment or care and, if treatment is ongoing, make sure there are clear arrangements in place to review decisions regularly, allowing patients opportunity to ask questions and discuss any concerns. You should also consider regularly reviewing a decision to take no action.

58. Reviewing a decision is particularly important:

a. if you haven't personally had a discussion with the patient because they were initially seen by a colleague

b. if significant time has passed since the decision was made

c. if the patient's condition has changed

d. if you have reason to believe the patient might have changed their mind

e. if any aspect of the chosen treatment or care has changed

f. if new information has become available about the potential benefits or risks of harm of any of the options that might make the patient choose differently.

59. You must make sure that patients are kept informed about the progress of their treatment, and you should let patients know that they can change their mind at any time.

Circumstances that affect the decision-making process

Time and resource constraints

60. Being able to meet a patient's individual needs for information and support depends, in part, on the time and resources available to you and your colleagues in the organisations where you work. Where there are pressures on your time or resources are limited, you should consider:

a. the role other members of the health and care team might play. See paragraphs 40–41 on Support from other members of the healthcare team.

b. what other sources of information and support are available to the patient, such as patient information leaflets, advocacy services, expert patient programmes, or support

groups for people with specific conditions.

61. If factors outside your control mean that patients aren't given the time or support they need to understand relevant information (see paragraph 10), and this seriously compromises their ability to make informed decisions, you must consider raising a concern.[4] You should also consider if it is appropriate to proceed, bearing in mind that you must be satisfied that you have a patient's consent or other valid authority before providing treatment or care.

Treatment in emergencies

62. In an emergency, decisions may have to be made quickly so there'll be less time to apply this guidance in detail, but the principles remain the same. You must presume a conscious patient has capacity to make decisions and seek consent before providing treatment or care.

63. In an emergency, if a patient is unconscious or you otherwise conclude that they lack capacity and it's not possible to find out their wishes, you can provide treatment that is immediately necessary to save their life or to prevent a serious deterioration of their condition. If there is more than one option, the treatment you provide should be the least restrictive of the patient's rights and freedoms, including their future choices. See paragraphs 81–84 on Presuming and assessing capacity.

64. For as long as the patient lacks capacity, you should provide ongoing care following the guidance in paragraphs 87–91. If the patient regains capacity while in your care, you must tell them what has been done and why, as soon as they are sufficiently recovered to understand. And you must discuss with them the options for any ongoing treatment.

Circumstances that affect the decision-making process continued

If a patient doesn't want to be involved in making a decision

65. No one else can make a decision on behalf of an adult who has capacity. If a patient who has capacity asks you or someone else to make a decision on their behalf, you should tell them this. You should explain that it's important they understand some basic information so that you can proceed with treatment or care. This would usually include what the options are and what they aim to achieve.

66. If a patient has chosen an option but doesn't want to discuss the details, you should explain they will need to have some information about what it would involve before you can proceed, such as:

a. whether the procedure is invasive

b. what level of pain or discomfort they might experience and what can be done to minimise this

c. anything they should do to prepare for the intervention

d. if it involves any risk of serious harm.

67. You should try to find out why they don't want to be involved in decision making and explore whether you can do anything to reassure and support them. They might be anxious about the decision or overwhelmed by the information and need time or support to process it.

68. If, after trying to discuss options with them along the lines set out above, your patient insists that they don't want even this basic information, you will need to judge whether their consent is valid so that you can proceed. This is more likely to be the case if the proposed option is a well-established intervention commonly used for treating the condition they have, and there's reason to believe the patient wants to be treated or cared for rather than take no action. You should consider seeking advice from your supervisor, medical defence body or professional association in these circumstances.

If you're concerned a patient can't make a decision freely

69. Many factors influence patients' decision making, but it's important that nothing influences a patient to such an extent that they can't exercise free will. If a patient can't make a decision freely, they won't be able to consent.

70. Patients may feel pressure to have particular treatment or care. Pressure can come from others – partners, relatives or carers, employers or insurers – or from patients' beliefs about themselves and society's expectations.

71. You should be aware of this possibility and of other situations in which patients may be particularly vulnerable or susceptible to pressure, for example, if they are:

a. experiencing domestic or other forms of abuse

b. resident in a care home

c. cared for or supported by others because of a disability

d. detained by the police or immigration services, or in prison

e. subject to compulsory treatment or assessment orders, or at risk of becoming so. See paragraphs 94–96 on Making decisions about treatment and care when a patient's right to consent is affected by law.

72. If you suspect a patient's rights have been abused or denied, you must follow local safeguarding procedures and consider raising a concern.

73. You should do your best to make sure patients reach their own decision, having considered relevant information (see paragraph 10) about the available options, including the option to take no action. You should support them to make a decision,

following the steps in paragraphs 27–30 as well as:

a. giving them more time and a safe, quiet space to consider the options

b. making sure you have an opportunity to talk to them on their own

c. signposting them to specialist support services.

74. You must make sure your patient is aware that they have the right to choose whether or not to have treatment. You should not proceed with treatment or care if you don't think it will serve the patient's needs. See paragraphs 48–49 if you disagree with a patient's choice of option.

75. If, after following the guidance in paragraphs 72–74, you still believe a patient is under such extreme pressure to agree to or refuse a particular intervention that they can't exercise free will, you should seek advice through local procedures, consult your medical defence body or professional association or seek independent legal advice. The Court may be able to make declarations and orders to protect adults where they are not able to freely make a decision.

Circumstances that affect the decision-making process continued

If your patient may lack capacity to make the decision

Mental capacity

76. Capacity is the ability to make a decision. This ability can vary depending on a patient's condition and how it changes over time, and on the nature of the decision to be made. For this reason, capacity is described as decision-specific and time-specific; so, a person can only have capacity or lack capacity to make a specific decision at a specific time.

The legal framework

77. Each jurisdiction of the UK has its own mental capacity legislation which, together with accompanying codes of practice, provides a framework for making decisions when patients lack the capacity to decide for themselves.

78. You must be aware of your duties under the relevant legislation, and have regard to the relevant code of practice, wherever you practise in the UK.

79. The Key legislation and case law factsheet provides a summary of capacity legislation and some of the relevant case law across the UK, and the impact these have on decision making for people who lack (or may lack) capacity to make healthcare decisions, and for those who treat them.

80. The guidance that follows doesn't explain the detail or use the specific language of the legislation, but it is consistent with the law across the UK.

Presuming capacity

81. You must start from the presumption that every adult patient has capacity to make decisions about their treatment and care. You must not assume a patient lacks capacity to make a decision solely because of their age, disability, appearance, behaviour, medical condition (including mental illness), beliefs, their apparent inability to communicate, or because they choose an option that you consider unwise.

Assessing capacity

82. Assessing capacity is a core clinical skill and doesn't necessarily require specialist input (eg by a psychiatrist). You should be able to draw reasonable conclusions about your patient's capacity during your dialogue with them. You should be alert to signs that patients may lack capacity and must give them all reasonable help and support to make a decision. See paragraphs 27–30 for ways of Supporting patients' decision making.

83. A person has capacity if they can do all the following:

a. understand information relevant to the decision in question

b. retain that information

c. use the information to make their decision

d. communicate a decision.

84. If you believe that a patient may lack capacity to make a decision, you must assess their capacity using the test set out in the relevant legislation, taking account of the advice in the relevant guidance. If you find it difficult to judge whether a patient has capacity to make a decision, you should seek support from someone who knows the patient well, for example, another member of the healthcare team or someone close to the patient.

85. In complex cases where you believe you're unable to make a judgement, you should seek specialist input from psychiatrists, neurologists, speech and language therapists or liaison nurses, or discuss with your supervisor. You should also seek specialist input if the patient or someone close to them disagrees with your judgement.

86. If the patient may regain capacity and the decision can be delayed, you must consider this.

Circumstances that affect the decision-making process continued

Making a decision when the patient lacks capacity: overall benefit

87. We use the term 'overall benefit' to describe the ethical basis on which decisions are made about treatment and care for adult patients who lack capacity to decide for themselves. This involves weighing up the risks of harm and potential benefits for the individual patient of each of the available options, including the option of taking no action. The concept of overall benefit is consistent with the legal requirements to consider whether treatment 'benefits' a patient (Scotland), or is in the patient's 'best interests' (England, Wales and Northern Ireland).

88. If you are the person with lead responsibility for the patient's treatment and care, before concluding that it is your responsibility to decide which option(s) would be of overall benefit to a patient who lacks capacity, you should take reasonable steps to find out:

a. whether there's evidence of the patient's previously expressed values and preferences that may be legally binding, such as an advance statement or decision

b. whether someone else has the legal authority to make the decision on the patient's behalf or has been appointed to represent them. Or in Scotland if someone is applying to be granted such authority (see s49 Adults with Incapacity (Scotland) Act 2000)

89 If there is no evidence of a legally binding advance refusal of treatment, and no one has legal authority to make this decision for them, if you are the person with lead responsibility for the patient's treatment and care, then you are responsible for deciding what would be of overall benefit to your patient.[5] In doing this you must:

a. consult with those close to the patient and other members of the healthcare team, take account of their views about what the patient would want, and aim to reach agreement with them

b. consider which option aligns most closely with the patient's needs, preferences, values and priorities

c. consider which option would be the least restrictive of the patient's future options.

90 If a proposed option for treatment or care will restrict a patient's right to personal freedom, you must consider whether you need legal authorisation to proceed with it in the circumstances.[7]

91 You should allow enough time, if possible, for discussions with those who have an interest in the patient's welfare, and you should aim to reach agreement about how to proceed.

Resolving disagreements

92 Sometimes members of the healthcare team disagree about what would be of overall benefit to the patient, or those close to the patient disagree with you and the healthcare team. It is preferable, and usually possible, to resolve disagreements about a patient's treatment and care through local processes.

For example, by:

a. involving an independent advocate or local mediation service

b. consulting a more experienced colleague and/or an independent expert

c. holding a case conference or seeking advice from a clinical ethics committee.

93 If, having taken these steps, there is still disagreement about a significant decision, you must follow any formal steps to resolve the disagreement that are required by law or set out in the relevant code of practice. You must make sure you are aware of the different people you must consult, their different decision-making roles and the weight you must attach to their views. You should consider seeking legal advice and may need to apply to an appropriate court or statutory body for review or for an independent ruling. Your patient, those close to them and anyone appointed to act for them should be informed as early as possible of any decision to start legal proceedings, so they have the opportunity to participate or be represented.

Making decisions about treatment and care when a patient's right to consent is affected by law

94 A patient's right to make a healthcare decision for themselves can be affected by mental health or other[6] legislation and by common law powers of the courts. Patients may be required by law to comply with assessment or treatment because they present a risk to themselves, to their health or to others. There are strict safeguards around using these legal powers to restrict or restrain individuals, and these determine what is permitted without consent. You should be aware of what treatment is, and is not, legally permissible.

95 If you consider it necessary to use these legal powers to treat or assess a patient without consent, you must follow the procedures set out in the relevant legislation and statutory guidance and in paragraph 96 of this guidance. If you need advice or support, you should contact your defence body or professional association or seek independent legal advice.

Taking a patient-centred approach

96 You must take a patient-centred approach even if the law allows you to assess or treat a patient without their consent. For example, you must:

a. be polite and considerate and respect your patient's dignity and privacy

b. protect your patient's rights and freedoms and, if restriction or restraint is necessary, use it for the minimum time and in the least restrictive way possible
c. support your patient to be involved in decisions about their care, let them know if they can exercise choice about any aspect of their treatment, and respect their choices if possible
d. keep your patient informed about the progress of their treatment and regularly review decisions.

Endnotes

1. If a patient is a Welsh language speaker, this may be a legal requirement.

2. Good medical practice paragraph 33 states; 'You must consider and respond to the needs of patients with impairments or disabilities. Not all impairments and disabilities are easy to identify so you should ask patients what support they need, and offer reasonable adjustments that are proportionate to the circumstances.'..' 'Reasonable adjustments' does not only mean changes to the physical environment. It can include, for example, being flexible about appointment time or length, and making arrangements for those with communication difficulties, such as impaired hearing. For more information, see the Equality and Human Rights Commission's website.

3. See paragraphs 128–146 on CPR in *Treatment and care towards the end of life*.

4. See *Raising and acting on concerns about patient safety*

5. In these circumstances you will have legal authority to make decisions about treatment under the *Mental Capacity Act 2005 (England and Wales)* or the common law in Northern Ireland. In Scotland under the *Adults with Incapacity (Scotland) Act 2000* (the 2000 Act) you will have legal authority to make decisions about treatment if you are the treating medical practitioner with lead responsibility for the patient's treatment and care, subject to issuing a certificate of incapacity. In this context 'medical practitioner' is taken to mean 'doctor' given its use in The Medical Act 1983. It should be noted that this legal authority is not restricted to doctors in Scotland as section 47(1A) of the 2000 Act states that in addition to medical practitioners, dental practitioners, ophthalmic opticians, registered nurses and any individual who falls within such description of persons as may be prescribed by the Scottish Ministers also has this authority. This list does not include physician associates or anaesthsia associates so on this basis physician associates and anaesthesia associates do not have this legal authority. See also the Key legislation and caselaw factsheet.

. 6. For example, the Public Health (Control of Disease) Act 1984; the Public Health etc. (Scotland) Act 2008; the Public Health Act (Northern Ireland) 1967.

7. Please note there are some circumstances in which a patient who lacks capacity under the relevant UK mental capacity legislation is nonetheless able to consent to what would otherwise constitute a deprivation of their liberty entailed by their care arrangements. Please see the Key legislation and caselaw factsheet for further information.

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You are welcome to contact us in Welsh. We will respond in Welsh, without this causing additional delay.

Mae croeso i chi gysylltu â ni yn Gymraeg. Byddwn yn ymateb yn Gymraeg, heb i hyn achosi oedi ychwanegol.

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