

Advance Decision to Refuse Treatment Policy

Version number:	5.0
Consultation Groups	Mental Health Law Department
Approved by (Sponsor Group)	Mental Health Law Monitoring Group
Ratified by:	Quality Committee
Date ratified:	24 th July 2024
Name of originator/author:	Maxine Bennett
Executive Director lead:	Chief Medical Officer
Implementation Date:	July 2024
Last Review Date	May 2024
Next Review date:	May 2027

Services	Applicable
Trust wide	Yes
Mental Health and LD	Yes
Community Health Services	Yes

Version Control Summary

Version	Date	Status	Comment/Changes
1.0	14/12/05	Draft	
1.0	02/02/06	Final	
2.0		Draft Review	Addition of references to the Mental Capacity Act 2005 and its Code of Practice.
2.0	14/11/07	Draft Review	Additions from Pat Clow - MCA Project Lead Newham PCT
3.0	08/01/18	Draft Review	Amended the term 'competent' to 'capacitous' throughout the document Addition of reference to community services Addition to section 2 of a paragraph differentiating between advance decisions to refuse treatment and Advance Directives
4.0	08/03/21	Final	
5.0	20/05/24	Final	Additional information regarding when a witness would be required. Information added in relation to responsibly of person making advance decision to make professionals aware of it. References added to refer professionals to template of advance decision to refuse treatment.

Executive Summary

- The policy sets out what practitioners should do when somebody has made an advance decision to refuse treatment and gives guidance on action to be taken where it is proposed to administer treatment to a person lacking capacity to consent to such treatment.
- It also sets out how to check whether an advance decision exists and is valid and applicable in the circumstances; the responsibilities of healthcare professionals when an advance decision exists; and how to handle disagreements about advance decisions.
- The Mental Capacity Act 2005 enables anyone over the age of 18, who has capacity, to refuse specified medical treatment for a time in the future when they may lack the capacity to consent to or refuse that treatment. This applies to all persons irrespective of whether they are in receipt of health services or not.
- A person's treatment decision can be overridden in some circumstances, for example when a patient is detained under the Mental Health Act 1983, the contents of any advance decision may be overridden by virtue of the provisions in Part IV of that Act.
- Other than for life-sustaining treatment, there is no legal requirement as to the format of an advance decision. Both written and oral formats are capable of being legally effective.
- There is nothing to stop a person withdrawing or destroying a written advance decision at any time while he/she has the capacity to do so.

CONTENTS

Paragraph	Page
1.0 Introduction	5
2.0 Definition of Advance Decision To Refuse Treatment	5
3.0 Duty of care and respect for capacitous patients' autonomy	6
4.0 Format of advance decisions	7
5.0 Life sustaining treatment	8
6.0 Withdrawing and amending an advance decision	9
7.0 Validity and applicability of an advance decision	9
8.0 Advance decisions re patients detained under the MHA 1983	11
9.0 Responsibility of healthcare professionals	11
10.0 Emergency situations	13
11.0 Court of Protection	13
12.0 References	13-14

1. INTRODUCTION

The purpose of this policy is to provide clear instruction and guidance for practitioners on the subject of advance decisions to refuse medical treatment.

Statutory provisions of advance decisions to refuse treatment can be found in s24 –s26 of the Mental Capacity Act 2005. Further guidance on good practice for practitioners can be found in Chapter 9 of the Mental Capacity Act Code of Practice.

Subject to the limitations set out below, persons with capacity to make decisions for themselves about their medical treatment are legally entitled to accept or refuse any treatment that is offered to them whether it is for a physical or mental disorder. In the event that a person loses capacity, a valid¹ advance decision to refuse treatment should be respected as if that person were able to make that refusal at the material time. Healthcare professionals must follow an advance decision if it is valid and applies to the particular circumstances. If they do not, they could face criminal prosecution (be charged with committing a crime) or civil liability (somebody could sue them).

Advance decision to refuse treatment for mental disorder can be overruled if the person is detained in hospital under the Mental Health Act 1983, when treatment could be given compulsorily under Part 4 of that Act. However, where practicable, they should try to comply with the patient's wishes as expressed in an advance decision in considering whether it is possible to use a different form of treatment not refused by the advance decision.

Exceptions to this principle are where statutory authority exists which allows a clinician to override a person's treatment decision, e.g. under the Mental Health Act 1983, and if a person loses capacity and becomes subject to the various provisions of the Mental Capacity Act 2005, e.g. where under a personal welfare Lasting Power of Attorney, a person can consent to medical treatment on behalf of another.

Under the Mental Capacity Act, medical treatment can be given to someone who does not have the capacity to make a treatment decision, as long as such treatment is in his or her best interests and as long as it has not been refused in advance in a valid and applicable advance decision to refuse treatment (an advance decision).

2. DEFINITION OF AN ADVANCE DECISION TO REFUSE TREATMENT (Section 24 and 9.1 – 9.3 of the Code of Practice)

Section 24(1) of the Mental Capacity Act 2005 defines an advance decision to refuse treatment as:

“...a decision made by a person after s/he has reached the age of 18 and when s/he has capacity to do so, that if –

¹ Made when a person has capacity

- (a) at a later time and in such circumstances as s/he may specify, a specified treatment is proposed to be carried out or continued by a person providing health care for P, and
- (b) at that time s/he lacks capacity to consent to the carrying out or continuation of the treatment,

the specified treatment is not to be carried out or continued.”

The Code of Practice at 9.11 states that an advance decision to refuse treatment:

- must state precisely what treatment is to be refused – this can be expressed in medical language or lay terms, as long as it is clear what is meant, but a statement giving a general desire not to be treated is not enough;
- may set out the circumstances when the refusal should apply. It is helpful to include as much detail as possible;
- Will only apply at a time when the person lacks capacity to consent to or refuse the specific treatment.
- Other terms such as Advance Directives, Advance Statements or Advance Care Planning are sometimes misused as an alternative to Advance Decisions to Refuse Treatment. It is very important that health care professionals are clear when using these terms as to what they are referring to and how they document future planning discussions with patients as the completion of an Advance Directive or an Advance Statement may not necessarily contain an advance decision to refuse treatment; it may only set out a person’s preferences or wishes in the event they lose capacity. It is therefore vital that the correct terminology is used to differentiate as to whether a document which set out a person’s future health care requirements relates to preferences and wishes or to a refusal of treatment.

3. DUTY OF CARE AND RESPECT FOR CAPACITOUS PATIENTS’ AUTONOMY (9.4 – 9.9 of the Code of Practice)

Healthcare professionals have a duty to provide a good standard of care and treatment, to show respect for human life and to exercise their duties in a fair, unprejudiced and non-discriminatory way.

All patients, whether or not they lack capacity, have the right to expect the same standards of care, and the duties and responsibilities placed on health professionals apply equally in their care of both capable people and people who may lack capacity. No assumption should be made that life and health have any less value for those who lack capacity.

One particular duty of health professionals is to respect a capacitous patients’ autonomy to make decisions in relation to their treatment. Capacitous and informed adults who are capable of understanding the implications of their decisions have an established legal right to refuse medical procedures or treatment.

Although such statements should be given due consideration, it should be remembered that no patient, whether having or lacking capacity, has the right in law to demand specific forms of medical treatment and therefore no-one can insist, either at the time or in advance, on being given treatments that doctors consider to be clinically unnecessary, futile or inappropriate. Neither can any person insist on an unlawful procedure such as a health professional assisting in their suicide.

It is entirely a matter for individual choice as to whether or not a person wishes to make plans for possible future lack of capacity by making an advance refusal of treatment. There is no obligation to make such a decision. Many people prefer to leave treatment decisions to their doctors at the time any treatment might need to be considered. Individuals who choose to make advance refusals of treatment must do so voluntarily while they have capacity to make such a decision. This means, among other things, that they must be able to understand and retain the information relevant to the decision, be able to use and weigh details of benefits and burdens of the different options, and not be subject to any form of undue pressure from others.

4. FORMAT OF ADVANCE DECISIONS TO REFUSE TREATMENT (9.10 – 9.23 of the Code of Practice)

Unless it deals with life-sustaining treatment, there is no legal requirement as to the format of an advance decision to refuse treatment. Both written and oral formats are capable of being legally effective.

However, the Code of Practice sets out the following information as being helpful to include in any written advance decision:

- Full details of maker, including date of birth, home address, and any distinguishing features (so that an unconscious person, for example, might be identified).
- Name and address of General Practitioner and whether they have a copy of the document.
- [Where relevant] information on where the advance decision is stored and list of people who are aware of its existence and should be contacted.
- A clear statement of the decision, specifying the treatment to be refused and the circumstances in which the decision will apply or which will trigger a particular course of action.
- Date the document was written (or reviewed) and, if appropriate, the time interval between creation and review.
- The signature of the witness who witnessed the maker's signature, if there is one.

The role of the witness does not involve certifying the capacity of the person making the advance decision even though in some situations, a professional such as a doctor may be

asked to act as a witness. Witnessing the person's signature is not essential, except in cases where the person is making an advance decision to refuse life-sustaining treatment. But if there is a witness, they are witnessing the signature and the fact that it confirms the wishes set out in the advance decision. It may be helpful to give a description of the relationship between the witness and person making the advance decision. The role of the witness is to witness the person's signature, it is not to certify that the person has the capacity to make the advance decision – even if the witness is a healthcare professional or knows the person.

This policy dictates that Trust employees directly involved in, or closely associated with the care of an individual receiving mental health or community services from this Trust, should not act as an independent witness to an advance decision to refuse medical treatment.

There is no prescribed statutory style for how oral advance decisions to refuse treatment should be made, because the contents of the advance decision will vary considerably according to the situations of the individual decision maker. For example, the nature of an oral advance decision of a person made shortly before going into the operating theatre, who verbally informs his healthcare team that he wants to impose limitations on the surgery he is facing, may differ from that of a person who makes an oral advance decision during ongoing medical treatment. Such oral advance decisions must be documented in the patient's medical notes, which will then form a written record of the oral advance decision. The following information should be included in such a written record:

- A note that the decision is intended to have effect if the maker lacks capacity to make treatment decisions in the future;
- A clear note of the decision, specifying the treatment to be refused and the circumstances in which the decision will apply;
- Details of a witness to the decision;

5. LIFE-SUSTAINING TREATMENT (9.24 – 9.28 of the Code of Practice)

Subsections (5) and (6) of section 25 deal with life-sustaining treatment and are reproduced here:

- (5) An advance decision is not applicable to life-sustaining treatment unless –
 - (a) the decision is verified by a statement by P² to the effect that it is to apply to that treatment even if life is at risk, and
 - (b) the decision and statement comply with subsection (6).
- (6) A decision or statement complies with this subsection only if –
 - (a) it is in writing,
 - (b) it is signed by P or by another person in P's presence and by P's direction
 - (c) the signature is made or acknowledged by P in the presence of a witness, and

² The Person

(d) the witness signs it, or acknowledges his signature, in P's presence.

The Code of Practice at 9.24 also states that the advance decision must include a clear, specific statement that the decision is to apply to the specific statement even if life is at risk.

Transitional arrangements

(Mental Capacity Act 2005 - information about the transitional provisions for existing advance decisions to refuse life-sustaining treatment. Department of Health)

Prior to the Mental Capacity Act coming into force, some people will have made advanced decisions that were valid under common law, but which will not comply with the new requirements in the Mental Capacity Act that apply to life-saving treatment. Where a person has made an advanced decision in accordance with common law, they will have an expectation that it will be acted upon. However, if that person has lacked capacity to amend their advanced decision since the act came into force the advance decision may not comply with the new requirements in the Act.

The transitional provision gives effect to such an advance decision even though it does not comply with all the provisions relating to life-sustaining treatment in the Mental Capacity Act (i.e. signed in front of a witness and including a statement that the decision applies even if life is at risk) provided that it meets the particular conditions set out in article 5 of the transitional order.

The particular conditions are that there is a reasonable belief that the advance decision was made before October 2007, a reasonable belief that the person has lacked capacity to amend their advance decision since 1 October 2007 and the advance decision is in writing.

If it appears that a person has made an advance decision prior to the commencement of the Mental Capacity Act, the matter **MUST** be referred to the Mental Health Law department for further advice.

6. WITHDRAWING OR AMENDING AN ADVANCE DECISION (9.29 – 9.32 of the Code of Practice)

The person's views may well change to such an extent that s/he wishes to withdraw the advance decision altogether. There is nothing to stop the person withdrawing or destroying a written advance decision at any time while s/he has capacity to do so. No formal procedures are required. Whether or not advance decisions are set out in writing, they can be altered or withdrawn either orally or in writing, as the person's particular situation requires. For example, someone who becomes severely disabled after they have made an advance decision may change their views on what treatments they would be prepared to have, and what they see as a good quality of life. They might therefore decide to change or withdraw an advance decision they have already made. See 9.29 – 9.32 of the Code of Practice.

7. VALIDITY AND APPLICABILITY OF ADVANCE DECISIONS (Section 25 of the Act and 9.33 – 9.46 of the Code of Practice)

An advance decision to refuse treatment is a major step and could have serious and significant consequences for the maker. It could also have a significant impact on their family and friends and for professionals involved in their care and treatment. Upon the patient being assessed as lacking the capacity to make a treatment decision, in order for the refusal to be legally effective at the time when it is proposed to carry out or continue medical treatment, an advance decision must be both valid and applicable to the proposed treatment.

Events that would make an advance decision invalid are:

- a) The person has withdrawn the decision while s/he still had capacity to do so;
- b) The person has, under a Lasting Power of Attorney created AFTER the advance decision to refuse treatment, conferred authority on the donee to give or refuse consent to the treatment to which the advance decision relates;
- c) The person has done something, which is clearly inconsistent with the advance decision that implies s/he has had a change of mind.

Circumstances where the advance decision would not be applicable are:

- The person has capacity to give or refuse consent to the treatment it relates to;
- The proposed treatment is not the treatment specified in the advance decision;
- The circumstances are absent from those set out in the advance decision;
- There are reasonable grounds for believing that circumstances have arisen which were not anticipated by the person when making the advance decision and which would have affected their advance decision had s/he anticipated them at the time.

Where there are disputes as to the validity of an advance decision, or there is ambiguity about the patient's intention or capacity at the time the decision was made, then consideration should be given to treating the patient in what is considered to be their best interests under the Mental Capacity Act, until such time as the issues can be resolved. The matter must also be raised with the Mental Health Law Department as soon as possible for further advice.

If a patient's advance directive is not followed for any reason, there should be a clear entry in the clinical notes explaining the reasons.

An advance decision in respect of life-sustaining treatment is not applicable if any of the points referred to in paragraph 5 above are absent.

Any advance decision made prior to the Mental Capacity Act 2005 coming into force on 1st October 2007, may still be valid and applicable due to their legal recognition in case law³ since 1994 (see section 5 above).

8. ADVANCE DECISIONS REGARDING TREATMENT FOR MENTAL DISORDER FOR PATIENTS DETAINED UNDER THE MENTAL HEALTH ACT (1983)

Where a patient is liable to be detained under the Mental Health Act (1983), the contents of any advance decision to refuse treatment for mental disorder may be overridden by the compulsory treatment provisions of The MHA. Treatment for mental disorder may therefore be given under the 1983 Act without the patient's consent in most circumstances and even where the patient is making or has made a decision to refuse a particular treatment for that particular condition. However, even where clinicians may lawfully treat a patient compulsorily under the Mental Health Act, they should, where practicable, try to comply with the patient's wishes as expressed in an advance decision. They should, for example, consider whether it is possible to use a different form of treatment not refused by the advance decision. If it is not, they should explain why to the patient.

An advance decision to refuse treatment for a condition, that does not fall within the application of the 1983 Act, could still be valid and effective regardless of whether the patient was liable to be detained or compulsorily treated under mental health legislation. Also, except for emergencies:

- Treatment to which S58A applies (ECT) cannot be given contrary to a valid and applicable advance decision
- Treatment cannot be given to CTO patients who have not been recalled to hospital contrary to a valid and applicable advance decision

In case of doubt, it is advisable to seek advice from colleagues and/or Mental Health Law offices in these situations

9. RESPONSIBILITIES OF HEALTH CARE PROFESSIONALS (Section 26 and 9.47 – 9.66 of the Code of Practice)

It is the responsibility of the person making the advance decision to make sure their decision will be drawn to the attention of healthcare professionals when it is needed. Some people will want their decision to be recorded on their healthcare records. Those who do not will need to find other ways of alerting people that they have made an advance decision and where somebody will find any written document and supporting evidence. Some people carry a card or wear a bracelet. It is also useful to share this information with family and friends, who may alert healthcare professionals to the existence of an advance decision. But it is not compulsory. Providing the person's GP with a copy of the written document will allow them to record the decision in the person's healthcare records.

³ *C (Adult: Refusal of Medical Treatment), Re* [1994] 1 All E.R. 819, *AK (Adult Patient) (Medical Treatment: Consent), Re* [2001] 1 FLR 12, *HE v A Hospital NHS Trust* [2003] EWHC 1017 (Fam. Div.)

Health care professionals should be aware of the possibility that a patient may have made an advance decision. If, during the course of diagnosing and treating their patient, a health care professional has reasonable grounds to believe or is alerted to the existence of a relevant written or oral advance decision they should, if time permits, make all practicable efforts to find out what that decision was. This might include having discussions with relatives of the patient (in a way that the patient's confidentiality won't be breached), looking in the patient's clinical notes held in the hospital or contacting the patient's GP. Any confirmed and valid and applicable Advanced Decision must be either uploaded to the patient's clinical records if a copy has been obtained or an alert should be made on the clinical records of its existence and where it is stored.

Once health care professionals who are considering treatment have been informed of the existence of an oral advance decision or presented with a written advance decision, they need to consider:

- (1) whether it is an advance decision within the meaning of the Mental Capacity Act,
- (2) whether it is valid, and
- (3) whether it is applicable to the treatment.

Health care professionals must also consider whether the advance decision is applicable (see paragraph 6 above) in the circumstances that have now arisen.

Particular care will need to be taken for advance decisions that do not appear to have been reviewed or updated, for instance, in the light of changes in personal circumstances or developments in medical treatment. If the current situation does not involve circumstances identical to those specified in the advance decision, the decision may not be applicable. If any individuals have been named in the advance decision as people to contact or be consulted, they may be able to clarify the patient's wishes or help in determining his/her best interests.

In circumstances where the existence of a valid and applicable advance decision is known, failure to follow that decision could lead to a claim for damages for battery or a criminal charge of assault.

If healthcare professionals have genuine doubts, and are therefore not satisfied about the existence, validity or applicability of the advance decision, then treatment can be provided without incurring liability.

Healthcare professionals will be protected from liability if they fail to provide treatment if they reasonably believe that a valid and applicable advance decision exists.

In situations where there is a conscientious objection to providing or stopping life-sustaining treatment, the healthcare professional should not allow this to impact on the legal position of the patient and if necessary, they should refer the patient's case to the Mental Health Law department.

In situations where there is disagreement as to validity or applicability of any advance decision, and discussions and consultations with colleagues, family and other carers has

failed to resolve the dispute, it remains the ultimate responsibility of the healthcare professional who is in charge of the person's care to decide following advice from the Mental Health Law department. All discussions should be recorded.

10. EMERGENCY SITUATIONS (9.55 – 9.56 of the Code of Practice)

A health care professional may safely treat unless satisfied that there is

- (1) A qualifying advance decision which is
- (2) Valid and
- (3) Applicable in the circumstances.

Emergency treatment should not be delayed in order to look for an advance decision to refuse treatment if there is no clear indication that one exists.

11. COURT OF PROTECTION (9.67 – 9.69 of the Code of Practice)

The Court of Protection cannot overturn a valid and applicable advance decision to refuse treatment.

It can make a decision when there is genuine doubt or disagreement about existence, validity or applicability of an advance decision.

It can decide whether:

- A person has capacity to accept or refuse treatment at the time it is proposed;
- The advance decision is valid;
- The advance decision is applicable to the proposed treatment in the circumstances

Pending the Court's decision, healthcare professionals can provide life-sustaining treatment or treatment to prevent a serious deterioration in the condition.

The Court has procedures which operate 24 hours a day to deal with urgent cases; guidance can be found in chapter 8 of the Code of Practice.

12. REFERENCES (and relevant intranet location)

Mental Capacity Act 2005 - <http://www.legislation.gov.uk/ukpga/2005/9/contents>

Mental Capacity Act 2005 Code of Practice –
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/921428/Mental-capacity-act-code-of-practice.pdf

Mental Health Act 1983 Code of Practice -
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/435512/MHA_Code_of_Practice.PDF

Consent to Examination and Treatment Policy

European Convention on Human Rights - <http://www.echr.coe.int/echr>

The Mental Capacity Act 2005 (Transitional and Consequential Provisions) Order 2007
<http://www.opsi.gov.uk/si/si2007/20071898.htm>

Department of Health Mental Capacity Act 2005 –information about the transitional arrangements for existing advance decisions to refuse life-sustaining treatment.
http://www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/Consent/DH_076863

Advance decision to refuse treatment template can be found at:
<https://www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/11/Advance-Decisions-to-Refuse-Treatment-Guide.pdf>