ADVANCE DECISIONS TO REFUSE TREATMENT
GUIDANCE FOR STAFF:

Including specific instructions for accepting and recording Advanced Directives and checking and using Advanced Directives.

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ASHFORD & ST. PETER’S HOSPITAL NHS FOUNDATION TRUST

ADVANCE DECISIONS TO REFUSE TREATMENT
GUIDANCE FOR STAFF

See also: Mental Capacity Act 2005 at www.opsi.gov.uk
Mental Capacity Act 2005 Code of Practice at www.dca.gov.uk

Trust Policies
Assessing a Patient’s Mental Capacity to Make Decisions
Do not Attempt Resuscitation (DNAR)
Mental Capacity Policy
Witnessing Documents for Patients

1 INTRODUCTION

This guidance is based on the guidance set out in the Mental Capacity Act Code of Practice (the Code) which provides guidance and information about how the Mental Capacity Act 2005 works in practice.

The Code has statutory force which means that certain categories of people (including those with a duty to care) have a legal duty to have regard to it when working with or caring for adults who may lack capacity to make decisions for themselves.

Guidance with regard to assessing a patient’s mental capacity can be found in the Mental Capacity Act Code of Practice and the Trust’s guidelines “Assessing a Patient’s Mental Capacity to make Decisions”.

2 AN ADVANCE DECISION TO REFUSE TREATMENT

It is a general principle of law and medical practice that people have a right to consent to or refuse treatment. The Courts have recognised that adults have the right to say in advance that they want to refuse treatment if they lose capacity in the future – even if this results in their death. A valid and applicable advance decision to refuse treatment has the same force as a contemporaneous decision. This has been a fundamental principle of Common Law for many years and now has statutory force through the Mental Capacity Act 2005 (the Act).

Sections 24 – 26 of the Act set out when a person can make an advance decision to refuse treatment. This applies if:

- The person is 18 years or older, and
- They have capacity to make an advance decision about treatment.

*Healthcare professionals must follow an advance decision if it is valid and applies to the particular circumstances.*

Advance decisions can have serious consequences for the people who make them. They can also have an important impact on family and friends, and professionals.
involved in their care. Before healthcare professionals can apply an advance decision, there must be proof that the decision:

- Exists
- Is valid, and
- Is applicable to the current circumstances.

People can only make advance decisions to refuse treatment. Nobody has the right to demand specific treatment, either at the time or in advance. So, no one can insist on being given treatments that healthcare professionals consider to be clinically unnecessary, futile or inappropriate. However, people can make a request or state their wishes and preferences in advance. Healthcare professionals should then consider the request when deciding what is in the patient’s best interests if the patient lacks capacity.

3 CAPACITY TO MAKE AN ADVANCE DECISION

For most people, there will be no doubt about their capacity to make an advance decision. Even those who lack capacity to make some decisions may have the capacity to make an advance decision. In some cases, it would be helpful to have evidence of a person’s capacity to make the advance decision (e.g. if there is a risk that it may be challenged in the future). It is also important to remember that capacity can change over time and a person who lacks capacity to make a decision now might be able to make it in the future. Capacity assessment is decision specific.

4 WHAT SHOULD BE INCLUDED IN AN ADVANCE DECISION

There are no particular requirements about the format of an advance decision. It can be written or verbal unless it deals with life sustaining treatment in which case it must be written and specific rules apply. (Please see Section 7).

An advance decision to refuse treatment:

- Must state precisely what treatment is to be refused – a statement giving a general desire not to be treated is not enough.
- May set out the circumstances when the refusal should apply.
- Will only apply at a time when the person lacks capacity to consent to or refuse specific treatment.

People can use medical language or everyday language in their advance decision. However, they must make clear what their wishes are and what treatment they would like to refuse.

An advance decision refusing all treatment in any situation (for example, where a person explains that their decision is based on their religion or personal beliefs) may be valid or applicable, but again, please note specific rules apply to life sustaining treatment.
5 WRITTEN ADVANCE DECISIONS

There is not a set form for written advance decisions. Content will vary depending on a person’s wishes and situation. However, it should include the following information:

• Full details of the person making the advance decision including date of birth, home address.

• The name and address of the person’s G.P and whether they have a copy of the document.

• A statement that the document should be used if the person ever lacks capacity to make treatment decisions.

• A clear statement of the decision, the treatment to be refused and the circumstances in which the decision will apply.

• The date the document was written (or reviewed).

• The person’s signature (or the signature of someone that the person has asked to sign on their behalf and in their presence).

• The signature of the person witnessing the signature, if there is one, (or a statement directing somebody to sign on the person’s behalf).

The Mental Capacity Act Code of Practice states that “witnessing the person’s signature is not essential, except in cases where the person is making an advance decision to refuse life sustaining treatment”. ¹

The Mental Capacity Act Code of Practice also states that:

“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”. ²

If a healthcare professional is witnessing the person’s signature, it is good practice for the professional to make a record of their assessment of the person’s capacity to make the advance decision. (Please see Trust Policy: Witnessing Documents for Patients).

¹ Department of Constitutional Affairs Mental Capacity Act 2005 Code of Practice (2005 London TSO) page 165

² Department of Constitutional Affairs Mental Capacity Act 2005 Code of Practice (2005 London TSO) page 165
6  VERBAL ADVANCE DECISIONS

There is no set format for verbal advance decisions. When treating a patient who lacks capacity, healthcare professionals will need to consider whether a verbal advance decision exists and whether it is valid and applicable.

Where possible, Healthcare professionals must record a verbal advance decision to refuse treatment in the person's medical records. The record must include:

- A note that the decision should apply if the person lacks capacity to make treatment decisions.
- A clear note of the decision, the treatment to be refused and the circumstances in which the decision will apply.
- Details of someone who was present when the oral advance decision was recorded and the role in which they were present (e.g. healthcare professional or family member), and
- Whether they heard the decision, took part in it or are just aware that it exists.

7  ADVANCE DECISIONS TO REFUSE LIFE SUSTAINING TREATMENT

The Act imposes particular legal requirements and safeguards on the making of advance decisions to refuse life sustaining treatment. These must meet the following specific requirements:

- They must be put in writing. If the person is unable to write, someone else should write it down for them (e.g. a family member can write the decision on their behalf, or the healthcare professional can document in the person's medical records).
- The person must sign the advance decision. If they are unable to sign, they can direct someone to sign on their behalf.
- The person making the decision must sign in the presence of a witness to the signature. The witness must then sign the document in the presence of the person making the advance decision. If the person making the decision is unable to sign they can direct someone else, in the presence of the witness, to sign on their behalf. The witness must then sign to indicate that they have witnessed the nominated person signing the document in front of the person making the advance decision.
- The advance decision must include a clear, specific written statement from the person making the advance decision that the advance decision is to apply to the specific treatment even if life is at risk.

Section 4(10) of the Act states that life sustaining treatment is treatment which a healthcare professional who is providing care to the person regards as necessary to sustain life. The decision will not just depend on the type of treatment, but also the circumstances in which it is given (e.g. in some situations antibiotics may be life
sustaining, but in others they can be used to treat conditions that do not threaten life).

Artificial nutrition and hydration (ANH) has been recognised as a form of treatment. ANH involves using tubes to provide nutrition and fluids to someone who cannot take them by mouth. An advance decision can refuse ANH. It is recognised that such an advance decision is likely to result in the person’s death if followed.

An advance decision cannot refuse actions that are needed to keep a person comfortable. (Examples include warmth, shelter, actions to keep a person clean and the offer of food and water by mouth). Section 5 of the Act allows Healthcare professionals to carry out these actions in the best interests of the person who lacks capacity.

8 WITHDRAWAL OF AN ADVANCE DECISION

Section 24(3) of the Act allows a person to cancel or alter an advance decision at any time while they still have the capacity to do so. There are no formal processes to follow. People can cancel their decision verbally and in writing. It is the responsibility of the person to inform Health professionals of any changes.

9 CHANGING AN ADVANCE DECISION

People can make changes to an advance decision verbally and in writing whether or not the advance decision was made in writing. It is good practice for the healthcare professional to record any changes in the medical records. However, if a person wants to change an advance decision to include a refusal of life sustaining treatment, the steps detailed in Section 7 must be followed.

10 ADVANCE DECISIONS AND OTHER RULES ABOUT DECISION MAKING

Sometimes a patient may have both a ‘lasting power of attorney’ (LPA) and also an ‘advance decision to refuse treatment.’ The date of the documents guides which takes precedence.

A valid and applicable advance decision to refuse treatment can be upheld once capacity is lost.

An advance decision made when a person had capacity overrides:
- The decision of a Court appointed deputy
- The provision of Section 4 of the Act which would otherwise allow healthcare professionals to give treatment

They believe is in the person’s best interests.

A Lasting Power of Attorney (LPA) for personal welfare must be dated after the ‘advance decision to refuse treatment’ or else the advance decision takes precedence.
(For more information of the validity of LPAs, please see Section 10 of the Trust’s Guidance for Staff: Assessing a Patient’s Mental Capacity to Make Decisions or the Mental Health Act 2005 Code of Practice).

11 DECIDING ON THE EXISTENCE, VALIDITY AND APPLICABILITY OF AN ADVANCE DECISION

11.1 DECIDING WHETHER AN ADVANCE DECISION EXISTS

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 needed. The decision may be recorded in the medical records. Some people may carry a card or wear a bracelet.

It is important to be able to establish that the person making the advance decision was over 18 when they made their decision and that they had capacity to do so. However, healthcare professionals should always start from the assumption that the person had the capacity to make the advance decision.

11.2 DECIDING WHETHER THE ADVANCE DECISION IS VALID

An existing advance decision must still be valid at the time it needs to be put into effect. Events that would make the advance decision invalid include those where:

- The person withdrew the decision while they still had capacity to do so.
- After making the advance decision, the person made a Lasting Power of Attorney (LPA), giving an attorney authority to make treatment decisions that are the same as those covered by the advance decision.
- The person has done something that clearly goes against the advance decision which suggests they have changed their mind.

11.3 DECIDING WHETHER THE ADVANCE DECISION IS APPLICABLE

To be applicable, an advance decision must apply to the situation in question and in the current circumstances. Healthcare professionals must first determine if the person still has capacity to accept or refuse treatment at the relevant time. If they have capacity, they can refuse treatment there and then. Or, they can change their decision and accept treatment. The advance decision is not applicable in such situations.

The advance decision must apply to the proposed treatment. It is not applicable to the treatment in question if:

- The proposed treatment is not the treatment specified in the advance decision.
- The circumstances are different from those that have been set out in the advance decision, or
• There are reasonable grounds for believing that there have been changes in circumstances which would have affected the decision if the person had known about them at the time they made the advance decision.

In deciding whether an advance decision applies to the proposed treatment, healthcare professionals must consider:

• How long ago the advance decision was made, and

• Whether there have been any changes in the patient’s personal life (e.g. the person is pregnant and this was not anticipated at the time of the advance decision) that might affect the validity of the advance decision, and

• Whether there have been any developments in medical treatment that the person did not foresee (e.g. new medications, treatment or therapies).

*For an advance decision to apply to life sustaining treatment it must meet the requirements set out in Section 7.*

12 WHAT YOU SHOULD DO IF AN ADVANCE DECISION IS NOT VALID OR APPLICABLE

If an advance decision is not valid or applicable to current circumstances:

• Healthcare professionals must consider the advance decision as part of their assessment of the person’s best interests if they have reasonable grounds to believe it is a true expression of the person’s wishes, and

• They must not assume that because an advance decision is either invalid or not applicable, they should always provide the specified treatment (including life sustaining treatment) – they must base this decision on the person’s best interests.

13 HEALTHCARE PROFESSIONALS’ RESPONSIBILITIES

Healthcare professionals should be aware that:

• A patient they propose to treat may have refused treatment in advance, and

• Valid and applicable advance decisions to refuse treatment have the same legal status as decisions made by people with capacity at the time of treatment.

• A hard copy of the Advanced Directive must be stored in the notes of the patient. It is the responsibility of the Physician to place a copy of the Advanced Directive (Advanced Decision) into the notes.

• The existence of the document must be recorded as an alert in Patient Centre. A copy of the Advanced Directive must be forwarded to the PAS office by the in charge Physician. An alert will be placed against the PMI record.
• It is recommended that a copy is scanned to the Pas/Clinical Systems Manager/Health informatics. Ext 3817/3235. Alternatively a hard copy can be delivered to the department. The sensitivity of the information held in the document must have the highest regard.

• The PAS office will scan the Advanced Directive so an electronic copy is stored on T:\ Advanced Directive which nominated clinicians will have access to. Nominated clinicians include the Accident and Emergency Consultants and Senior Nurses.

Where appropriate, when discussing treatment options with people who have capacity, healthcare professionals should ask if there are any specific types of treatment they do not wish to receive if ever they lack capacity to consent.

If somebody tells a healthcare professional that an advance decision exists for a patient who now lacks capacity to consent, they should make reasonable efforts to find out what the decision is. This might include having discussions with relatives, reviewing medical records or discussing with the patient’s G.P.

Once they know a verbal or written decision exists, healthcare professionals must determine whether it is:

• Valid.
• Applicable to the proposed treatment.

(Please see Section 11).

If Healthcare professionals are satisfied that an advance decision exists, is valid and applicable, they must follow it and not provide the treatment refused in the advance decision.

If the Healthcare professional is not satisfied that an advance decision exists, is valid and applicable, they can treat the person, but the treatment must be in the person’s best interests. They should document a clear record as to why they have not followed the advance decision which they consider to be invalid or not applicable.

Healthcare professionals can give or continue to give treatment while doubts are resolved over an advance decision. If required, the Court of Protection can settle disagreements about the existence, validity or applicability of an advance decision. In this situation, healthcare professionals are able to give necessary treatment while the situation is resolved.

14 TREATMENT IN EMERGENCIES

A healthcare professional must provide treatment in a patient’s best interests, unless they are satisfied that an advance decision is:

• Valid, and
• Applicable in the circumstances.

Healthcare professionals should not delay emergency treatment to look for an advance decision if there is no clear indication that one exists. However, if it is clear
that a person has made an advance decision that is likely to be relevant, healthcare professionals should assess the validity and applicability as soon as possible.

15 HELP & ADVICE

Further information, help and advice can be obtained via:

- Head of Patient Experience Extension 3185
- Safeguarding Adult Lead Bleep 8213
- BMA Ethics Department 0300 123 1233 open 08.30-18.00

16 REFERENCES & BIBLIOGRAPHY

Mental Capacity Act 2005 London: HMSO 2005
Department of Constitutional Affairs  Mental Capacity Act 2005 Code of Practice (2005 London TSO)

17 Useful Websites

www.opsi.gov.uk
www.dca.gov.uk

APPENDIX ONE

Equality Impact Assessment Summary

Name: Head of Customer Affairs
Policy/Service: Advance Decisions to Refuse Treatment

Background

- Description of the aims of the policy
- Context in which the policy operates
- Who was involved in the Equality Impact Assessment

This guidance is based on the guidance set out in the Mental Capacity Act Code of Practice (the Code) which provides guidance and information about how the Mental Capacity Act 2005 works in practice.

The Code has statutory force which means that certain categories of people (including those with a duty to care) have a legal duty to have regard to it when working with or caring for adults who may lack capacity to make decisions for themselves.
It is a general principle of law and medical practice that people have a right to consent to or refuse treatment. The Courts have recognised that adults have the right to say in advance that they want to refuse treatment if they lose capacity in the future – even if this results in their death. A valid and applicable advance decision to refuse treatment has the same force as a contemporaneous decision. This has been a fundamental principle of Common Law for many years and now has statutory force through the Mental Capacity Act 2005 (the Act).

Methodology

- A brief account of how the likely effects of the policy was assessed (to include race and ethnic origin, disability, gender, culture, religion or belief, sexual orientation, age)
- The data sources and any other information used
- The consultation that was carried out (who, why and how?)

This Policy reflects the statutory framework for patients wishing to make an advance decision to refuse treatment.

The effects of the Policy were fully assessed as part of the legislative process.

The Trust has a legal duty to have regard for the legislation and Code of Practice.

Key Findings

- Describe the results of the assessment
- Identify if there is adverse or a potentially adverse impacts for any equalities groups

No adverse or potentially adverse impacts for any equalities groups noted.

The Trust has a legal duty to have regard for the Mental Capacity Act Code of Practice and a healthcare professional must follow an advance decision if it is valid and applies to the particular circumstances of the patient at a given time.

Conclusion

- Provide a summary of the overall conclusions

The Policy summarises the statutory framework and requirements of the Mental Capacity Act Code of Practice.

Healthcare professionals must follow an advance decision if it is valid (as defined by the Code of Practice) and applies to the particular circumstances of the patient.

Recommendations

- State recommended changes to the proposed policy as a result of the impact assessment
- Where it has not been possible to amend the policy, provide the detail of any actions that have been identified
- Describe the plans for reviewing the assessment

No recommendations made.
Guidance on Equalities Groups

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<td>Sexual orientation including lesbian, gay and bisexual people (consider whether the policy/service promotes a culture of openness and takes account of individual needs)</td>
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<td>Age (consider any barriers to accessing services or employment, identify and remove or justify terms which could be ageist, for example, using titles of senior or junior)</td>
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<tr>
<td>Culture (consider dietary requirements, family relationships and individual care needs)</td>
<td>Social class (consider ability to access services and information, for example, is information provided in plain English?)</td>
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