

Policy For Advance Decisions (Living Wills)

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Approved by:	Patient Views Committee	
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Target Organisation(s)	Worcestershire Acute Hospitals NHS Trust	
Target Departments	All	
Target staff categories	All	

Purpose of this document:

An Advance Decision enables someone aged 18 years and over, while still capable, 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 document provides information and guidance for healthcare professionals for when a patient enquires about or presents with an Advance Decision and to ensure that patients are made fully aware of the implications of making an Advance Decision, and to avoid any misunderstandings in the implementation of an Advance Decision in connection with treatment decisions.

This policy takes into account the Mental Capacity Act 2005 and the European Convention on Human Rights (ECHR).

Acknowledgements:

Northern Lincolnshire & Goole Hospitals NHS Foundation Trust

Key amendments to this Document:

Date	Amendment	By:
Nov 08	Document creation	J Clavey
14 October 2008	Approved at Patient Views Committee	
Dec 11	Minor amendments to reflect change in assurance committee structure	J Clavey
June 2015	Document reviewed – no changes made	J Clavey
August	Document extended for 6 months as per TMC paper approved	TMC

Policy for Advance Decisions (Living Wills)

2017	on 22 nd July 2015	
December 2017	Document extended for 3 months as per TLG recommendation	TLG
March 2018	Document extended for 3 months as approved by TLG	TLG
June 2018	Document reviewed and approved with no changes made	J Clavey
June 2020	Document extended for 6 months during COVID period	
February 2021	Document extended for 6 months as per Trust agreement 11.02.2021	Trust agreement
August 23	Document extended for 3 months whilst review is undertaken by Avril Adams	A Adams

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ADVANCE DECISIONS

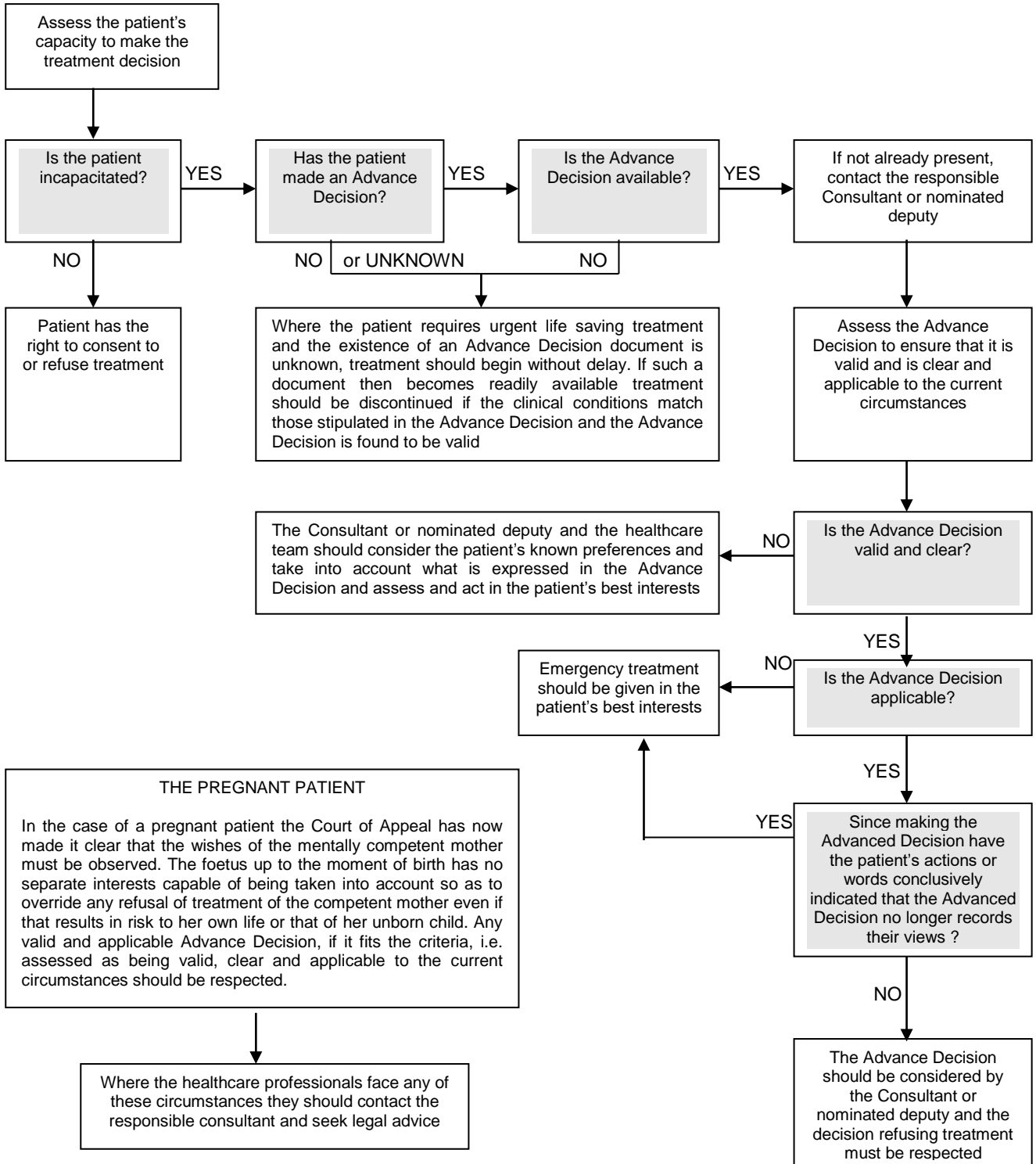
The following 'quick summary' and flowcharts are intended to provide 'at a glance' information and advice for staff on the actions to take when a patient presents with an Advance Decision. It should be stressed that the summary and flowcharts are a guide only.

More detailed information on Advance Decisions is given in the full body of this document and staff are advised to ensure that they are familiar with its contents and adhere at all times to the principles contained therein.

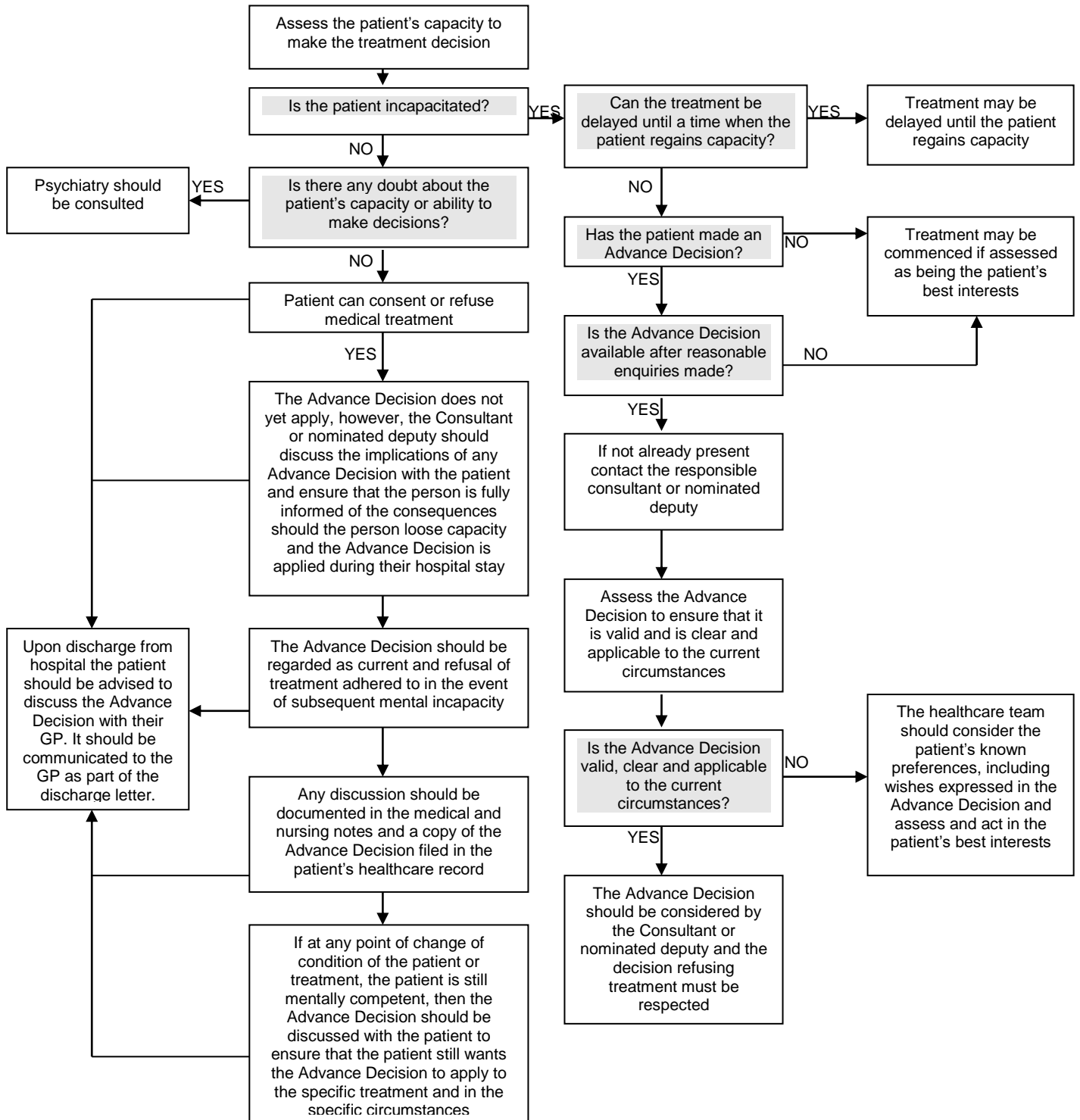
'Quick Summary'

- An Advance Decision enables someone aged 18 years and over, while still capable, to refuse specified medical treatment for a time in the future when they may lack the capacity to consent to or refuse that treatment.
- An Advance Decision to refuse treatment must be valid and applicable to current circumstances. If it is, it has the same effect as a decision that is made by a person with capacity and healthcare professionals must follow the decision.
- Healthcare professionals will be protected from liability if they:
 - stop or withhold treatment because they reasonably believe that an Advance Decision exists, and that it is valid and applicable;
 - treat a person because, having taken all practical and appropriate steps to find out if the person has made an Advance Decision to refuse treatment, they do not know or are not satisfied that a valid and applicable Advance Decision exists.
- People can only make an Advance Decision under the Act if they are 18 years or over and have the capacity to make the decision. They must also say what treatment they want to refuse. They can cancel their decision – or part of it – at any time.
- If the Advance Decision refuses life-sustaining treatment, it must:
 - be in writing (it can be written by someone else or recorded in the healthcare records);
 - be signed and witnessed, and
 - state clearly that the decision applies even if life is at risk.
- To establish whether an Advance Decision is valid and applicable, healthcare professionals must try to find out if the person:
 - has done anything that clearly goes against their Advance Decision;
 - has withdrawn their decision;
 - has subsequently conferred the power to make that decision on an Attorney, or;
 - would have changed their decision if they had known more about the current circumstances.
- Sometimes healthcare professionals will conclude that an Advance Decision does not exist, is not valid and/or applicable – but that it is an expression of the person's wishes. The healthcare professional must then consider what is set out in the Advance Decision as an expression of previous wishes when working out the person's best interests.
- Some healthcare professionals may disagree in principle with patients' decisions to refuse life-sustaining treatment. They do not have to act against their beliefs, but they must not simply abandon patients or act in a way that affects their care.
- Advance Decisions to refuse treatment for a mental disorder may not apply if the person who made the Advance Decision is or is liable to be detained under the Mental Health Act 1983.

ADVANCE DECISIONS FLOWCHART – EMERGENCY SITUATION

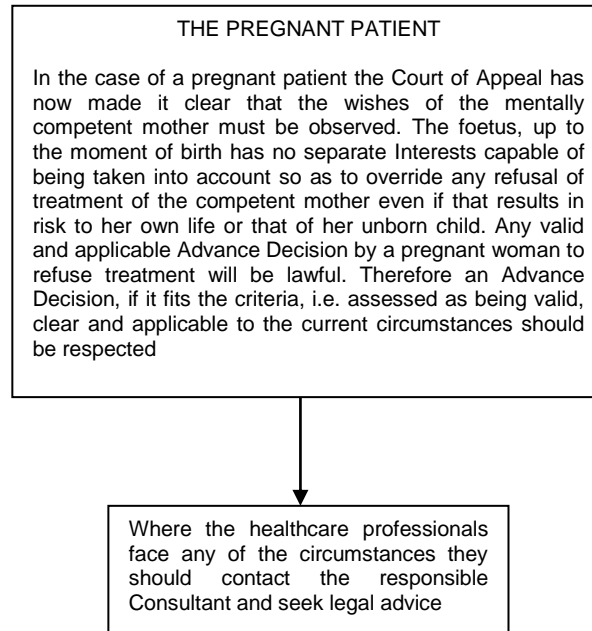


ADVANCE DECISIONS FLOWCHART – NON-EMERGENCY SITUATION



ADVANCE DECISIONS FLOWCHART – NON-EMERGENCY SITUATION

Continued



1. INTRODUCTION

Worcestershire Acute Hospitals NHS Trust is supportive of patients who present with an Advance Decision and its staff are readily open to discussion with patients regarding their future medical care and treatment.

The principles reflected in this policy are enshrined in the European Convention on Human Rights (ECHR) as fundamental individual rights with specific reference to Article 2 – right to life, Article 3 – freedom from inhuman or degrading treatment, Article 8 – respect for private and family life and Article 14 – the right not to be discriminated against.

This policy also takes into account the Mental Capacity Act 2005 and the Mental Capacity Act Code of Practice (Chapter 9) which gives guidance on Advance Decisions which healthcare professionals must “have regard to”.

This policy applies to all adult patients aged 18 years and over under the care of the Trust who may enquire about or present with an Advance Decision. This policy does not apply to children under the age of 18 years.

2. PURPOSE

For the purpose of this document, where the wording ‘Advance Decision’ appears this should also be taken to mean Living Will, Advance Directive or Advance Statement. For information on other definitions used within this document refer to Appendix A.

This policy has been designed to provide information and guidance for healthcare professionals to enable them to recognise and respond effectively to adult patients enquiring about or presenting with an Advance Decision and also to ensure that patients are made fully aware of the implications of making an Advance Decision and to avoid any misunderstanding in the implementation of an Advance Decision in connection with treatment decisions.

3. ADVANCE DECISIONS

3.1 What is an Advance Decision (Living Will)?

Advance Decisions have been previously known as Advance Directives, Advance Statements or Living Wills. However good practice is now to refer to all advance statements to refuse treatment at a future date as Advance Decisions in line with the terminology of the Mental Capacity Act 2005:

“An Advance Decision means a decision made by a person after he has reached 18 years of age and when he has capacity to do so, that if:

- a) at a later time and in such circumstances as he may specify, a specified treatment is proposed to be carried out or continued by a person providing healthcare for him; and*
- b) at that time 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”.* (Section 24, Mental Capacity Act 2005)

“An Advance Decision enables someone aged 18 and over, while still capable, to refuse specified medical treatment for a time in the future when they may lack the capacity to consent to or refuse that treatment”. (Mental Capacity Act Code of Practice, Chapter 9)

An Advance Decision can also be defined as:

“An expression of views and preferences concerning medical treatment if the patient became incapacitated. An alternative term in common law is ‘Living Will’. (Law Commission 2006)

“A clear instruction refusing some or all medical procedures and the authority for that instruction is derived from the established legal right of competent, informed adults to refuse treatment irrespective of the wisdom of their judgment” (BMA 1995).

Advance Decisions may cover any matter upon which the individual has decided views but is most often quoted in connection with decisions about medical treatment, particularly the treatment that might be provided as the patient approaches death.

Importantly only refusals of treatment are legally binding on healthcare professionals providing the advance decision is valid and applicable (see also Section 3.2) although the document may contain information about a person’s wishes which should be taken into account when making any decision in best interests.

The fundamental aim of the Advance Decision is to provide a means for the patient to continue to exercise autonomy in decision making about refusal of future treatment at a time when he/she is no longer able to make the decision themselves due to incapacity, and shape the end of his or her life. The Advance Decision must make clear the refusal of the individual to accept specified treatment in the event of incapacity.

The Advance Decision may be part of a broader discussion where a person expresses their views about care and treatment in a more formal way and can be seen as part of a broader willingness to discuss death openly and to deal with anxieties patients have about what might happen to them if they become mentally incapacitated. Although Advance Decisions only relate to refusals of treatments which might be available, a person may also identify, through an advance statement within the same document, their agreement to anticipated treatments or procedures. Such advance statements are not legally binding but are evidence of a person’s stated wishes and feelings which must be taken into account by a decision maker when making a decision in a person’s best interests.

The legal force of Advance Decisions is based on the principle of the autonomy of competent adults (aged 18 years or over) to decide amongst other things what medical treatment they consent to and refuse. It is established that a “mentally competent patient has an absolute right to refuse to consent to medical treatment for any reason, rational or irrational, or for no reason at all, even where that decision may lead to his or her own death” (Re MB 1997). An Advance Decision which is valid and applicable is legally binding and must be complied with even if it conflicts with an objective evaluation of the patient’s best interests. In other words, where an Advance Decision is being followed the best interest’s principle does not apply. If there is doubt about the validity or applicability of an Advance Decision then treatment should be given to sustain life or prevent a serious deterioration until the doubt is resolved.

The Courts have made it clear that competent adult patients can consent to or refuse any medical treatment, (except compulsory treatment for mental disorder under the Mental Health Act 1983). However, a person cannot make legally enforceable demands about specific treatments they want to receive. Doctors and health professionals cannot be required to provide treatment which they consider clinically inappropriate. Similarly a request for active euthanasia or assisted suicide would be unlawful. Any actions whose primary purpose is to bring about or hasten death are illegal and could result in criminal charges being brought.

An Advance Decision to refuse treatment cannot preclude the provision of ‘basic care’ namely care to maintain bodily cleanliness and to alleviate severe pain, as well as the provision of direct oral nutrition and hydration (Law Commission 1995). ‘Basic care’ does not include artificial nutrition and hydration (ANH) which is classed as a medical treatment and can be refused in an Advance Decision. Healthcare professionals can therefore provide ‘basic care’ in the best interests of patients who lack capacity to consent.

An Advance Decision can be in written form or made as a witnessed oral statement, and as long as the patient is competent to make the Advance Decision, both forms will be legally binding and must be followed. Importantly though, a refusal of treatment that is necessary to sustain life requires that strict formalities are complied with in order for the Advance Decision to be valid and applicable – it must be in writing, signed and witnessed, which is a requirement of the MCA 2005 from 1 October 2007 (see also Section 3.3). The healthcare professional in receipt of any oral Advance Decision should make every effort that at least one other member of staff is witness to it, and should immediately document clearly in the patient’s notes any comments falling in the remit of an Advance Decision about treatment. If possible the patient should sign the entry in the notes.

Children – A person must be over the age of consent, currently 18 years of age, for an Advance Decision to be accepted as a legally binding decision. An Advance Decision made by a child is not regarded as having the same legal status as one made by an adult. The Children Act 1989 emphasises that the views of children should be sought and taken into account in matters which touch their welfare. Where appropriate, they should be advised to take decisions jointly with those involved in their care, especially family members and health care professionals.

For further information on the legal background to Advance Decisions including appropriate case law and the stance of the various professional bodies on this issue refer to Appendix B.

3.2 Valid Advance Decisions

To be valid the Advance Decision must be made at a time when the person making it had the requisite mental capacity to make a decision on the particular treatment decision. (For further details on assessing capacity please refer to Appendix A of this policy, Worcestershire Statutory and Non Statutory Organisations Mental Capacity Act 2005 - Summary and Guidance for Staff, the Trust’s Policy for Consent to Examination or Treatment and Chapter 4 of the Mental Capacity Act 2005 Code of Practice.)

If possible discussion in advance regarding the Advance Decision with the patient concerned is always the best option. However, where this is not possible, and the healthcare professional is presented with an Advance Decision then, before applying it, there must be proof that the decision exists, is valid and is applicable in the current circumstances:

- Does the Advance Decision set out precisely the treatment being refused? Does it apply to the current medical condition of the patient?
- Are medical and nursing staff satisfied that the Advance Decision was made when the patient was in a state of adequate mental health, i.e. that the person had capacity to make the decision? If this is in doubt, the validity of the Advance Decision can be challenged through the courts.
- Does the Advance Decision refuse life sustaining treatment? If yes, is it signed, dated and witnessed? Does it state clearly that the decision applies even if life is at risk?

An Advance Decision will not be valid if:

- 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 refuse consent to the treatment covered by the Advance Decision;
- the person has done something that clearly goes against the Advance Decision which suggests that they have changed their mind.

The healthcare professional in charge of the patient's care when treatment is required should try to establish whether an Advance Decision exists which is valid and applicable in the circumstances of the specified treatment. They should try and find out if the person has done something clearly going against their Advance Decision, has withdrawn their decision, has subsequently given the power to make the decision to someone else (under a Lasting Power of Attorney (LPA)) or would have made a different decision if they had known more about the current circumstances.

The Advance Decision will only apply to treatment which is specified in the Advance Decision and which is only to be given in the circumstances described.

The Advance Decision will not be applicable if there are reasonable grounds for believing that the current circumstances were not anticipated by the person when making it. A classic example is where new drugs are available to treat the patient's condition which would have altered the patient's decision had he known. Changes in personal circumstances may also affect the applicability of the decision.

Where there is doubt about the validity or applicability of an Advance Decision, legal advice should be sought and an application to Court for a declaration of what is lawful may be necessary. The Legal Services team can be contacted both in and out-of-hours for further information and advice.

Advance Decisions can refuse treatment for either a physical disorder or a mental disorder. However, if a person is detained in hospital under the Mental Health Act (MHA) 1983 then generally an Advance Decision to refuse treatment for the mental disorder for which they are detained for treatment can be overruled and treatment given under Part IV of the 1983 Act. Advance Decisions to refuse treatment for other illnesses and conditions that they are not detained for remain unaffected by the fact that the individual is in hospital under the provisions of the MHA 1983.

An Advance Decision should be reviewed and updated at regular periods. Decisions made a long time in advance are not automatically invalid, but are more likely to give rise to doubt and uncertainty when deciding whether they are valid and applicable. No guidance exists as to how frequently the review should be but a period of one to three years appears reasonable. If clinical circumstances are changing quickly however, then more frequent review is recommended.

It is vital to remember that an Advance Decision will NOT be applicable to the treatment in question (even if validly executed) if at the material time the patient still has capacity to give or refuse consent to the treatment.

3.3 Advance Decisions relating to Life Sustaining Treatment

An Advance Decision is only applicable to life sustaining treatment if specific legal requirements have been complied with.

An Advance Decision relating to life sustaining treatment **MUST**:

- be in writing (it can be written by someone else or recorded in the health records);
- be signed by the patient, OR by another person in the patient's presence and at the patient's direction (if the patient is unable to sign);
- the patient's signature must be witnessed, and the witness must then sign in the presence of the patient;
- if the patient is unable to sign, they can be witnessed directing someone else to sign on their behalf, and the witness must then also sign.

It must explicitly state that the Advance Decision is to apply to the specific treatment even if life is at risk.

'Life sustaining treatment' is a treatment which the clinician treating the patient regards as necessary to sustain life, and so will vary from case to case. For example, in certain situations, antibiotics may be life-sustaining but in others they may be a treatment for a condition that is not threatening life.

Artificial hydration and nutrition (ANH) has been recognised as a form of medical treatment, and a validly executed Advance Decision can refuse ANH. However, even a valid Advance Decision to refuse life sustaining treatment cannot refuse basic medical care to keep someone comfortable.

No health care professional is allowed to initiate a treatment which contravenes a valid advanced decision. However where a treatment has been initiated prior to the health care team becoming aware of a valid advanced decision which refuses this treatment then a healthcare professional who has a conscientious objection to the withdrawal of the treatment is not obliged to do so. The healthcare professional must however not obstruct other healthcare professionals from withdrawing the treatment.

The healthcare professional should make their views known to the patient and other professionals involved in the patient's care as soon as possible to allow patients with capacity the option of transferring their care to another healthcare professional. If the patient has made a valid and applicable Advance Decision but is now lacking capacity, arrangements should be made for the management of the patient's care to be transferred to another healthcare professional who is willing to carry out the terms of the Advance Decision.

3.4 Advance Decisions and Lasting Power of Attorney (LPA)

Under the Mental Capacity Act 2005, an individual will be able to grant a LPA in relation to personal welfare, which can include consenting to or refusing consent to medical treatment. Such decision making powers can extend to giving or refusing consent for life sustaining treatment, but only if that provision is expressly authorised within the LPA. Such treatment can only be made by the attorney in circumstances where the individual lacks, or the donee of the LPA reasonably believes that the individual lacks, capacity to make the decision.

A valid and applicable Advance Decision however overrules the decision of any personal welfare LPA made before the Advance Decision was made. Before the donee of a power under an LPA has authority to make a decision under the LPA it must be registered with the Public Guardian's Office. The decision that the donee of the LPA makes must be authorised by the LPA. A person may choose to limit the powers of the donee and this will be set out in the LPA which the healthcare professional will need to check.

If however an LPA giving the attorney power to make decisions about medical treatment is made after an Advance Decision about the same treatment, this will invalidate the Advance Decision, and give the attorney the power to make decisions about the specified treatment in that person's best interests.

3.5 Disputes regarding Advance Decisions

The patient's representative has to show that the Advance Decision is applicable. However if disagreements occur about the existence, validity or applicability of an Advance Decision either between healthcare professionals themselves or between healthcare professionals and those close to the patient, the Consultant (or in their absence the senior clinician or deputy) responsible for the patient's care must consider all available evidence of the patient's wishes. Nothing in an apparent Advance Decision stops a person providing life sustaining treatment or doing an act which the person reasonably believes will prevent a serious deterioration in the patient's condition whilst guidance is sought from the court or until the dispute is resolved.

All staff involved in the patient's care should have the opportunity to express their views. All discussions should aim to resolve issues surrounding the validity of the Advance Decision and confirm its applicability to the current circumstances, not be an attempt to overrule the patient's Advance Decision.

Every effort should be made to clarify the dispute, and this may involve case conferences, discussions and seeking the views of an independent colleague. If no agreement can be reached then legal advice should be sought from the Legal Services Team. If necessary, the Court of Protection can make a ruling concerning the validity and applicability of an Advance Decision. Whilst this ruling is sought, healthcare professionals can provide life sustaining treatment or treatment to prevent a serious deterioration in the patient's condition, without incurring liability.

3.6 Minimum Content of an Advance Decision

There are no particular formalities for the format of an Advance Decision, unless it concerns life sustaining treatment, in which case it must be written and specific rules apply (see Section 3.3 above).

An Advance Decision **MUST** state precisely what treatment is to be refused – a general desire not to be treated is not enough. An Advance Decision that refuses specified treatment in any situation can be valid and applicable, and whilst an individual is not required to give reasons for their decision, it can be helpful if they can do, as this gives further evidence of capacity (e.g. if their decision is based on religious grounds or personal beliefs).

An Advance Decision may set out circumstances when the refusal should apply, and as much detail as possible should be included.

There is no requirement for the Advance Decision to be expressed using medical terminology, and layman's terms are perfectly acceptable as long as it is clear what treatments or interventions are being referred to.

As indicated above, whilst there is no set format for written Advance Decisions, it is helpful to include:

- full details of the person making the decision – full name, date of birth, home address, and any distinguishing features in case healthcare professionals need to identify an unconscious person;
- name and address of GP and whether they have a copy of the document;
- a clear statement that the document should be used if the individual 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;
- where relevant, a clear statement that the decision is intended to apply even if the treatment in question is to sustain life;
- the date the document was written or reviewed;
- the signature of the individual (or the person who has been asked to sign on behalf of the individual) and any witness to signature (including relationship to the maker).

NB. There is no requirement to certify on the document that the individual has the capacity to make the Advance Decision.

There is also no set format for oral Advance Decisions. If possible healthcare professionals should record an oral Advance Decision in the healthcare record, including:

- a clear statement that the decision should apply if the person lacks capacity to make treatment decisions in the future, and a note of the decision, the treatment to be refused and the circumstances in which the decision will apply;
- the details of someone who was present and witnessed the oral Advance Decision and their role.

3.7 Advance Decisions and Emergency Treatment

If a patient is unconscious but not in imminent danger, wherever possible relatives and/or carers should be contacted and consulted as to the existence of an Advance Decision. If no valid and applicable Advance Decision is in existence treatment should be provided in the patient's best interests.

Where a patient requires urgent life saving treatment and the existence of an Advance Decision is unknown medical treatment should be commenced without delay in the patient's best interests to sustain life or prevent deterioration. Healthcare professionals should never delay emergency treatment to look for an Advance Decision if there is no clear indication that one exists.

If at a later stage evidence of a valid and applicable Advance Decision comes to light treatment should be immediately given in line with the Advance Decision. This may mean discontinuing treatment.

3.8 Withdrawal or alteration of an Advance Decision

The patient may withdraw or alter an Advance Decision at any time when he has capacity to do so. There is no formal process to follow.

A withdrawal (including a partial withdrawal) need not be in writing and can be made verbally. Any verbal withdrawal should be recorded in the patient's healthcare records and the patient should be encouraged to tell people who were previously aware of their Advance Decision that it has been withdrawn. In addition to a written or verbal withdrawal of an Advance Decision if a patient does an act which is clearly inconsistent with the Advance Decision then this should be treated as a

withdrawal of the decision e.g. a decision to refuse blood products followed by a decision to accept blood products would invalidate the Advance Decision.

An alteration of an Advance Decision need not be in writing and can be made verbally, even if the Advance Decision was made in writing. Any changes of decision should be recorded in the patient's healthcare record and health professionals should ensure that all those involved in the patient's care are aware of the alteration.

If a patient wishes to alter an Advance Decision to include a refusal of life sustaining treatment they must follow the specific legal requirements (see Section 3.3 above).

3.9 Storage of an Advance Decision

The primary responsibility for this lies with the patient and it is the patient's responsibility to ensure that the existence and content of an Advance Decision is brought to the attention of the relevant healthcare professionals on attendance or admission to hospital.

It is recommended that a copy of any written Advance Decision should be given to the patient's general practitioner who can then also record the Decision in the patient's primary healthcare records.

In the case of chronically ill patients, who are treated by a specialist team over a prolonged period a copy of the Advance Decision should be stored in the patient's healthcare records and form part of the care plan.

Any Advance Decision presented on admission or attendance to hospital should be recorded and stored in the front of the healthcare record. The alert sheet inside the front cover of the patient's health care record should also be endorsed to ensure that all clinicians involved in the patient's care are aware of the existence of the Advance Decision.

It is the responsibility of the admitting nurse to ensure that all members of the multi-disciplinary team are aware of the existence of an Advance Decision where an Advance Decision is brought to their attention.

Any Advance Decision is confidential, and remains confidential if recorded in the patient's healthcare records. Some patients will inform their friends and family of their Advance Decision, but others will not, and healthcare professionals must obtain the patient's consent before discussing the existence or content of an Advance Decision with relatives or carers.

From time to time, requests may be received from individuals who are not currently receiving treatment and/or who have no active Trust healthcare records, for a copy of an Advance Decision to be retained by the Trust. Such requests should be responded to by the Head of Health Records. Where requests are received by other Trust staff, these should be forwarded to the Head of Health Records. Template letters for responding to such requests are provided at Appendices C and D.

3.10 Supporting Patients Who Wish to Make an Advance Decision

If a patient expresses their wish to make an Advance Decision, they should be encouraged and strongly advised to consult their own GP and/or hospital based medical staff most closely involved in their treatment to discuss the implications of making an Advance Decision. They should be advised to discuss matters with their families or persons involved in their care and recommended to seek legal advice from a Solicitor, Citizens Advice Bureau or an organisation that can provide advice on specific conditions or situations.

It is good practice to ensure that whether oral or written, the patient's Advance Decision is appropriately witnessed.

The patient should be made aware of the importance of regularly reviewing their Advance Decision to ensure that it remains valid and applicable. The frequency of review will depend upon the patient's clinical circumstances. A decision that is regularly reviewed is more likely to be valid and applicable to current circumstances than decisions made long ago, which, although not automatically invalid or inapplicable may raise doubts.

The patient should be made aware that the responsibility for the consequences of the Advance Decisions are entirely their own.

The patient **MUST** be made aware that unless they withdraw their Advance Decision and make healthcare professionals aware of this (e.g. where the patient may change his/her mind) it **WILL** be implemented by NHS healthcare professionals where the person lacks capacity to make their own treatment decision, and that they are legally bound to follow a valid and applicable Advance Decision as though the patient was capable of refusing the specified treatment. Refer to Appendix E for an Information Leaflet for Patients on Advance Decisions.

3.11 Liability of Healthcare Professionals in relation to Advance Decisions

Healthcare professionals must follow the terms of an Advance Decision if they are satisfied that the Advance Decision exists, is valid, and is applicable to the situation. Any failure to do so could result in a criminal charge of assault or a civil claim for damages for battery.

There is protection from liability for not following an Advance Decision if healthcare professionals are either:

- not aware of an Advance Decision; or
- the treatment proposed is not the treatment specified in the Advance Decision;
- any circumstances specified in the Advance Decision are absent; or
- there are reasonable grounds for believing circumstances exist which the person did not anticipate at the time of the Advance Decision, which would have affected the decision had they been anticipated.

If there are reasonable grounds for questioning the existence, validity or applicability of the Advance Decision treatment can be provided without incurring liability. Treatment should be provided in the patient's best interests, and this will involve considering the Advance Decision as part of the expression of the patient's past wishes and feelings in the assessment of 'best interests' if there are reasonable grounds for thinking it is a true expression of the patient's wishes. The healthcare professional should clearly document in the patient's medical records why they have not followed the Advance Decision – i.e. why they consider it to be invalid or not applicable.

There is protection from liability for healthcare professionals for failing to provide treatment if they 'reasonably believe' that a valid and applicable Advance Decision refusing the treatment in question exists. However there must be reasonable grounds for coming to this conclusion based on what was known to the healthcare professional at the time.

If a healthcare professional is told that an Advance Decision exists for a patient who now lacks capacity, they should make reasonable efforts to find out what the Advance Decision is – this may involve contacting the GP or having discussions with relatives and/or carers of the patient.

In situations where there is serious doubt about the existence, validity or applicability of an Advance Decision that cannot be resolved it will be necessary to seek a declaration from the Court. Whilst this decision is being sought, a healthcare professional should provide life sustaining treatment or carry out any act he reasonably believes to be necessary to prevent a serious deterioration in the patient's condition without incurring liability.

4. DUTIES AND RESPONSIBILITIES

The Chief Executive has overall responsibility for ensuring that a policy of Advance Decisions is in place.

The Medical Director on behalf of the Chief Executive is responsible for ensuring the development, implementation and regular review of the policy on Advance Decisions. Clinical Directors and General Managers are responsible for ensuring that this policy is implemented and adhered to as appropriate within their respective areas. Clinical Directors and General Managers will also be responsible for ensuring that this policy is available in all wards and departments and is covered in relevant training programmes/mandatory updates.

Medical and nursing staff responding to patients who may present with or enquire about an Advance Decision are required to do so in accordance with this policy. All relevant staff must therefore ensure that they are familiar with the contents of this policy and adhere at all times to the principles contained therein. Where problems or deviations occur, staff should report these in accordance with the Trust's Incident Reporting Policy.

Legal Services staff will be responsible for providing advice and assistance, including seeking legal advice where this is felt to be necessary where there is any doubt or concern about the validity of an Advance Decision.

The Head of Health Records will be responsible for responding to requests from patients for Advance Decisions to be filed in their healthcare records (see Appendices C and D for template letters).

The Patient Safety Committee will be responsible for monitoring compliance with this policy.

The Patient Safety Committee will be responsible for the ratification of this policy.

5. APPROVAL AND RATIFICATION PROCESS

Comments on the policy and any subsequent amendments will be sought from relevant clinical staff and Directorates prior to ratification by the Clinical Assurance Committee.

Staff consulted in the development of the policy:

- Medical Director
- Director of Nursing
- Associate Medical Directors
- Clinical Directors
- General Managers
- Deputy Directors of Nursing
- Matrons
- Consultants in Palliative Medicine
- Head of Health Records
- Head of Legal Services
- Assistant Legal Services Manager

6. REVIEW AND REVISION

This policy will be reviewed and revised, as appropriate, every three years, or sooner should the need arise.

7. IMPLEMENTATION AND DISSEMINATION

This policy will be posted on the Trust's Intranet and its existence made known to all relevant staff. Hard copies will also be sent, for retention and reference, to all General Managers and Clinical Directors.

Amendments to the Policy will be communicated by the Head of Legal Services as and when they occur.

Directorates will be responsible for ensuring that this policy is implemented and adhered to as appropriate within their respective areas and is covered in relevant training programmes and mandatory updates.

8. MONITORING COMPLIANCE AND EFFECTIVENESS

Monitoring of compliance with and effectiveness of this policy will be undertaken as follows:

- review of incident trends as part of the overall Incident Analysis Reports;
- monitoring of requests for information and advice received by the Legal Services Team.

Where issues are identified, these will be raised via the relevant Directorate Governance Leads / Group for follow-up action as appropriate.

9. FURTHER READING AND ASSOCIATED DOCUMENTS

This policy should be considered alongside other relevant Trust policies including the Do Not Attempt Resuscitation (DNAR) Policy and the Policy for Consent to Examination or Treatment.

References:	Code:
Worcestershire Statutory & Non Statutory Organisations Mental Capacity Act 2005 - Summary & Guidance for Staff (January 2008)	Via intranet
WAHT Do Not Attempt Resuscitation (DNAR) Policy (2007)	WAHT-ANA-006a
WAHT Policy for Consent to Examination or Treatment (2007)	Via intranet
WAHT Incident Reporting Policy (2007)	Via intranet
GMC Consent: patients & doctors making decisions together 2008	www.gmc-uk.org
Public Guardianship Office	www.guardianship.gov.uk
Mental Capacity Act 2005	www.justice.gov.uk
Mental Capacity Act Code of Practice	www.guardianship.gov.uk
Mental Capacity – Department of Constitutional Affairs 2005	www.justice.gov.uk
Advance Directives under the Mental Capacity Bill	www.mind.org.uk
Guidance on the Mental Capacity Act 2005. National Council for Palliative Care 2005	www.ncpc.org.uk
European Convention on Human Rights (Articles 2, 3, 8 and 14)	
Law Commission 2006	www.lawcom.gov.uk
Nursing & Midwifery Council Code of Professional Practice 2004	www.nmc-uk.org
Autonomy and the legal status of Advance Directives, Healthcare	

Risk, October 2004, pg 21	
The Department of Constitutional Affairs (2003) Making Decisions: helping people who have difficulty deciding for themselves	www.dca.gov.uk/menincap/intro.htm
Seeking patient's consent: the ethical considerations. GMC 1999	www.gmc-uk.org
The Children Act 1989	www.opsi.gov.uk/acts
BMA Code of Practice 1995	www.bma.org.uk
BMA Advance Statements about medical treatment 1995	www.bma.org.uk
Report on Mental Incapacity (1995) Law Com No 231, HMSO	www.lawcom.gov.uk
Mental Health Act 1983	www.dh.gov.uk/en
Re MB (An Adult: Medical Treatment) [1997] 2FLR 426	
Re T [1992] 4All ER 649	
Re C [1994] 1 All ER 819	
Airedale NHS Trust v Bland [1993] 1 All ER 589	

APPENDIX A Definitions

Advance Decision: This is a decision made by a person after he has reached the age of 18 years and when he has capacity to do so that if:

- a) at a later time and in such circumstances as he may specify, a specified treatment is proposed to be carried out or continued by a person providing healthcare for him; and
- b) at that time 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.

Basic Care: This has been defined by the BMA as “Those procedures essential to keep an individual comfortable. The administration of medication or the performance of any procedure which is solely or primarily designed to provide comfort to the patient or alleviate the person’s pain, symptoms or distress are facets of basic care”.

It is generally accepted that ‘basic care’ includes warmth, shelter, pain relief, management of distressing symptoms such as nausea, vomiting, breathlessness and psychological distress, and also hygiene measures such as management of incontinence. The BMA’s Code of Practice states that food and drink should be offered to the patient but not forced upon them.

Best Interests: Healthcare professionals have an ethical obligation to make their patient’s best interests their first concern. The Mental Capacity Act does not actually define ‘best interests’ but is clear that in deciding what is in the best interest of a person lacking capacity decision makers must take account of all relevant factors it would be reasonable to consider. As a starting point the Mental Capacity Act sets out a checklist of common factors that must be considered. These include:

- Considering all relevant circumstances and making every effort to encourage and enable the person lacking capacity to take part in making the decision.
- Taking into account any evidence of the patient’s current and previously expressed preferences and wishes, including an Advance Decision.
- Consider the beliefs and values that would be likely to influence the individual’s decision if he had capacity, and any other factors he would be likely to consider if able to do so.
- If practical and appropriate, taking into consideration the views of anyone named by an individual as someone to be consulted on matters of this kind, any carers or other people interested in the individual’s welfare, any donee of a LPA appointed by the individual or any Deputy appointed by the Court, as to what would be in the individual’s best interests.
- What is in a person’s best interest may change over time and a proper and objective assessment must always be carried out, even in an emergency situation.

Mental Capacity: This is the ability to make a decision, and the starting point must always be to assume that an individual has capacity unless it is established that he lacks capacity. Difficulty communicating a decision is not the same as a lack of capacity to make the decision.

The test for capacity has been codified by the Mental Capacity Act, and is a 2 stage test which is decision and time specific. The test is:

- 1) Does the patient have an impairment of, or a disturbance in the functioning of, their mind or brain?
- 2) If yes, does this mean that the patient is unable to make a specific decision when they need to?

A person is unable to make a decision if they are unable:

- a) to understand the information relevant to the decision
- b) to retain that information
- c) to use or weigh that information as part of the process of making the decision balancing risks and benefits
- d) to communicate the decision

Lack of Capacity: A person lacks capacity in relation to the matter if at the material time he is unable to make a particular decision for himself in relation to the matter because of an impairment of, or a disturbance in the functioning of the mind or brain. This is a decision specific test, and so a person may lack capacity to make some decisions themselves but may have capacity to make other decisions.

Donee: A person authorised under a personal welfare LPA to make decisions for another person when they lack capacity or can be a Deputy appointed by the Court to make treatment decisions for the person when the person is unable to make decisions for themselves.

APPENDIX B

Principle Legislation and Guidance

1. Patient's Rights

It is a general principle of law and medical practice that all mentally competent adults aged 18 years and over have the right to consent to or refuse medical treatment, including resuscitation.

The principles reflected in this policy are enshrined in Article 2 (right to life), Article 3 (freedom from inhuman or degrading treatment), Article 8 (respect for private and family life) and Article 14 (the right not to be discriminated against) of the European Convention on Human Rights (ECHR) as fundamental individual rights.

Under the Mental Capacity Act 2005, from October 2007 patients will be able to make a Lasting Power of Attorney (LPA) to individuals who they choose. Under the legislation a LPA in relation to the patient's personal welfare can extend to giving or refusing consent to the carrying out or continuation of treatment but will only extend to life-sustaining treatment if that is expressly contained in the LPA.

2. Legal Position

In England and Wales an Advance Decision to refuse treatment is legally binding as long as the following conditions apply:

- i) The Advance Decision was made when the patient was mentally capable of making that decision.
- ii) The patient meant their refusal to apply to the specific treatment refused in the specific situation which later arises and they understand the consequences of their decision in that situation, including any risk to life.
- iii) The decision was the patient's and was not made under pressure or under a third party's influence.
- iv) The patient was 18 years or over at the time at which the Advance Decision was made. (A patient under 18 years is still entitled to have their views taken into account but cannot refuse treatment which is in their best interests. A child aged 16 years and over can consent to treatment as though they were an adult. A child under 16 years who is competent can also consent to treatment. A parent or someone with parental responsibility can also consent and refuse treatment in best interests).

The legality of Advance Decisions is backed by case law including the case of Re T [1992] 4 All ER 649. In 1992, the Appeal Court indicated that when an informed and competent patient had made an anticipatory choice which is "clearly established and applicable in the circumstances" doctors should be bound by it. This view was confirmed by later cases (Airedale NHS Trust v Bland [1993] 1 All ER 589 and Re C [1994] 1 All ER 819. In these cases discussion revolved around the legally binding nature of an informed refusal of specific treatment(s). Therefore a doctor who knowingly acted in disregard of such a competent advance refusal would be likely to be held guilty of assault. Conversely a doctor who acts in good faith in accordance with an apparently valid Advance Decision would not be considered negligent.

In the case of NHS Trust V Ms T (May 2004) a Court called into question the applicability of an Advance Decision. The treating NHS Trust had sought an interim declaration authorising the treatment of Ms T by way of blood transfusion as her haemoglobin level required it. Ms T had a propensity for self harm that manifested itself in blood letting. This required the Trust to challenge an Advance Decision signed by Ms T stating that she no longer wished to receive blood transfusions as she believed her blood was evil and contaminated the transfused blood. The applicability of her Advance Decision was called in to question because the letter from Ms T's GP,

reportedly in support of it, was somewhat ambiguous about the circumstances to which it should apply. However, the Court did not ultimately have to decide the point as Ms T was found to lack capacity at the time she made the Advance Decision.

It is important to note that if an individual is detained under a section of the Mental Health Act 1983, to which the provisions of Part IV (Consent to Treatment) apply, this overrules any Advance Decision which they might have made pertaining to the treatment of the mental disorder for which they are detained. An Advance Decision refusing treatment for any other physical or mental illness remains unaffected by the fact that the individual is detained under the provisions of the MHA 1983.

In *Re T (adult: refusal of treatment)* [1992] the court considered what doctors should do when circumstances change. “What the doctors cannot do is to conclude that if the patient still had the necessary capacity in the changed situation he would have reversed his decision. This would be simple to deny his right of decision. What they can do is consider whether at the time the decision was made it was intended by the patient to apply in the changed situation. If the factual situation falls outside the scope of the refusal or if the assumption on which it is based is falsified, the refusal ceases to be effective. The doctors are then faced with a situation in which the patient has made no decision and by then being unable to decide for himself, they have both the right and the duty to treat him in accordance with what in the exercise of their clinical judgment they consider to be best interest.”

3. Professional Guidance

In 1995, the British Medical Association (BMA) published a Code of Practice which provides advice and guidance to health professionals on issues surrounding Advance Decisions. It “very strongly recommends that patients who draft advance decisions should do so with the benefit of medical advice” and that patients should be encouraged to review their advance decisions at regular intervals as part of doctor and patient dialogue.

GMC Guidance on seeking patients’ consent provides that doctors must respect any refusal of treatment that was given when the patient was competent, as long as the decision in the Advance Decision is clearly applicable to the present circumstances and there is no reason to think that the patient has changed their mind. If no Advance Decision of this kind is available then the patient’s known wishes should be taken into account.

The Nursing and Midwifery Council Code of Professional Practice 2004 gives guidance on issues surrounding Advance Decisions and provides that if patients have lost capacity to consent to or refuse treatment an Advance Decision given when they were legally competent must be respected if the decision is applicable to the current circumstances and there is no reason to think the patient has changed their mind. If there is no statement available, any known wishes of the patient should be taken into account and treatment provided in their best interests.

APPENDIX C

Standard Letter Where Active Trust Healthcare Records Exist

Dear

Re: Advance Decision/Living Will

Thank you for providing your Advance Decision/Living Will for inclusion in your healthcare record held by this Trust.

It is the Policy of the Trust to note only the existence of a person's Advance Decision and so we return the original to you. Because of the wishes of people, and the circumstances in their lives, can change over time we feel it important that you retain the original Decision and ensure you update it as circumstances change in your life.

It is your responsibility to bring any Advance Decision you make to the attention of the healthcare professionals caring for you at a time and in circumstances where it may apply. We suggest that you let a relative or friend know of its existence and whereabouts so that if you are unable to bring the Advance Decision to the attention of the healthcare professionals in the future then someone else nominated by you can do so on your behalf. In addition we would ask that you ensure that your General Practitioner (GP) knows you have completed an Advance Decision and that you inform anyone else who may be involved in your treatment.

In the event of your being admitted to hospital it is important that you inform staff that you have an Advance Decision, or your family do so if you are unable to communicate, and produce the Advance Decision.

In an emergency you will usually be taken to the nearest hospital with the appropriate facilities to care for you. That hospital may not be aware of your wishes and your family or GP would need to inform staff, if possible, that you have an Advance Decision.

If healthcare professionals are presented with an Advance Decision that is valid and applicable to the circumstances and to the treatment in question, they are duty bound to abide by it. It is therefore imperative that you ensure that you immediately inform your GP and any healthcare professionals treating you if you change or withdraw your Advance Decision or ensure that a family member does so if you are unable to communicate.

If you have any queries regarding this please do not hesitate to contact me.

Yours sincerely

Head of Health Records

APPENDIX D

Standard Letter Where No Active Trust Health Records Exist

Dear

Re: Advance Decision/Living Will

Thank you for sending us a copy of your Advance Decision/Living Will.

Unfortunately we do not have any active healthcare records on file for you. This may be because it is more than X[insert number] years since you were last treated in the hospital and your records have been archived, or because you have never been treated at this hospital. In either case this means that we will be unable to register that you have made an Advance Decision.

You should, therefore, notify the existence of your Advance Decision to your GP who may wish to retain a copy.

In the event of your being admitted to this hospital you should inform staff you have an Advance Decision or you should ask a family member to do so if you are unable to communicate. You should take steps to ensure that a copy of it can be made available to the clinical team treating you in the event of an emergency. In an emergency you will usually be taken to the nearest hospital with facilities to care for you. That hospital will not be aware of your wishes unless the existence of your Advance Decision is drawn to staff's attention.

If medical staff are presented with a valid Advance Decision that is applicable to the situation in question, they are duty bound to abide by it, and it is therefore imperative that you ensure that you immediately inform your GP or any medical staff treating you if you change or withdraw your Advance Decision, or ensure that a family member does so if you are unable to communicate.

If you have any queries regarding this please do not hesitate to contact me.

Yours sincerely

Head of Health Records

APPENDIX E

Information for Patients on Advance Decisions / Living Wills

What is an Advance Decision to refuse treatment?

Some people have views about what type of treatment they do not want to have should they become ill in the future when they no longer have the mental capacity to consent to or refuse treatment. An Advance Decision allows people aged 18 years and over to set out their refusal to specific medical treatment in circumstances where the treatment would otherwise be provided, before they lose capacity.

An Advance Decision to refuse treatment allows adults to state what particular kinds of treatment they would NOT want to have if at any time in the future they lose the capacity to decide this for themselves. It can relate to any kind of treatment, even if refusal could result in death. Only Advance Decisions relating to refusal of life saving treatment need to be in writing (other Advance Decisions can be made orally) but to avoid confusion it is always helpful if an Advance Decision is in writing.

What are the Rules about Advance Decisions?

The Mental Capacity Act 2005 came into force in October 2007. It sets out exactly what is required for an Advance Decision to be valid and applicable. Advance Decisions were possible before (when they have been known as advance directives or living wills) but the Mental Capacity Act clarifies the situation and also provides safeguards to prevent the misuse of Advance Decisions.

If you have a valid and applicable Advance Decision in place, the doctors treating you must follow this Advance Decision, even if it results in your death. However, the doctors must be sure that:

1. the Advance Decision EXISTS – it is your responsibility to ensure that the medical staff are aware of any Advance Decision that you have made; and
2. the Advance Decision is VALID – at the time of making the Advance Decision you must have had the mental capacity to do so and since this time you have not withdrawn it or acted in a way that is inconsistent with what you have specified in the Advance Decision (e.g. by agreeing to treatment that the Advance Decision refuses) or overridden it by making a Lasting Power Attorney (LPA) that relates to the treatment in the Advance Decision; and
3. the Advance Decision is APPLICABLE – it must make clear which treatment is being refused and it should explain exactly what the circumstances are that the refusal refers to – a general desire not to be treated is not sufficient. There is no need to use medical terminology and layman's terms are perfectly acceptable, as long as it is clear what the refusal relates to.

If there is any confusion as to whether you have a valid and applicable Advance Decision in existence medical staff will treat you in what they consider to be your best interests taking into account any of your previous expressed wishes and views, whilst this issue is resolved. It is therefore advisable to update your Advance Decision at regular intervals (between 1 and 3 years) to ensure that it is current and to attempt to minimise any confusion as to its validity.

What are the rules for Advance Decisions to refuse Life-sustaining treatment?

Life sustaining treatment is any treatment which is needed to keep you alive, and without which you might die. Advance Decisions refusing life sustaining treatment must be in a particular format. They must:

1. Be in writing
2. Be signed and witnessed (either by yourself or by a nominated witness if you are unable to sign).
3. The Advance Decision must specifically state that the decision is still to apply even if life is at risk (if this statement is separate to the Advance Decision, this must also be signed and witnessed).

What can an Advance Decision NOT do?

An Advance Decision cannot be used to demand certain medical treatments if this goes against the clinical judgment of the doctor, it can only state what treatments a person would refuse. Similarly, an Advance Decision cannot ask for a person's life to be ended – any actions whose primary purpose is to bring about or hasten death are illegal in this country.

Advance Decisions can also be overruled and are invalid if a person is detained under the Mental Health Act 1983 and has an Advance Decision refusing treatment for the mental disorder for which they are detained. However, Advance Decisions to refuse treatment for other illness and conditions that the person is not detained for remain unaffected by the fact that the individual is in hospital under the provisions of the MHA 1983 and so will still be valid.

If you would like more information on the Mental Capacity Act and Advance Decisions please see below for a list of useful contacts. You can also call 0845 330 2900 or email the Public Guardianship Office at custserv@guardianship.gov.uk for further information on the Mental Capacity Act 2005.

Useful organisations and websites:

Citizens Advice Bureau – www.citizensadvice.org.uk

Patients Association – www.patients-association.com

Making Decisions Alliance – www.makingdecisions.org.uk

Patient Concern – www.patientconcern.org.uk

Carers UK – www.carersuk.org Tel: 020 7566 7637

Age Concern England – www.ageconcern.org.uk Information Line 0800 00 99 66

The Terence Higgins Trust – www.tht.org.uk

Mental Health Foundation – www.mentalhealth.org.uk Tel: 020 7803 1100

MIND – www.mind.org.uk Information Line 0845 766 0163

Supporting Document 1 - Equality Impact Assessment Tool

To be completed by the key document author and attached to key document when submitted to the appropriate committee for consideration and approval.

		Yes/No	Comments
1.	Does the policy/guidance affect one group less or more favourably than another on the basis of:		
	Race	No	
	Ethnic origins	No	
	Nationality	No	
	Gender	No	
	Transgender	No	
	Religion or belief	No	
	Sexual orientation	No	
	Age	No	
	Disability - learning disabilities, physical disability, sensory impairment & mental health problems	No	
2.	Is there any evidence that some groups are affected differently?	No	
3.	If you have identified potential discrimination, are any exceptions valid, legal and/or justifiable?	n/a	
4.	Is the impact of the policy/guidance likely to be negative?	No	
5.	If so can the impact be avoided?	n/a	
6.	What alternatives are there to achieving the policy/guidance without the impact?	n/a	
7.	Can we reduce the impact by taking different action?	n/a	

If you have identified a potential discriminatory impact of this key document, please refer it to Assistant Manager of Human Resources, together with any suggestions as to the action required to avoid/reduce this impact.

For advice in respect of answering the above questions, please contact Assistant Manager of Human Resources.

Supporting Document 2 – Financial Impact Assessment

To be completed by the key document author and attached to key document when submitted to the appropriate committee for consideration and approval.

	Title of document:	Yes/No
1.	Does the implementation of this document require any additional Capital resources	No
2.	Does the implementation of this document require additional revenue	No
3.	Does the implementation of this document require additional manpower	No
4.	Does the implementation of this document release any manpower costs through a change in practice	No
5.	Are there additional staff training costs associated with implementing this document which cannot be delivered through current training programmes or allocated training times for staff	No
	Other comments:	

If the response to any of the above is yes, please complete a business case which is signed by your Finance Manager and Directorate Manager for consideration by the Accountable Director before progressing to the relevant committee for approval