Advance decisions to refuse treatment

Please be aware that this printed version of the Policy may NOT be the latest version. Staff are reminded that they should always refer to the Intranet for the latest version.

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<tr>
<th>Purpose of Agreement</th>
<th>This policy enables staff to follow the principles of the Mental Capacity Act 2005 in dealings with people who have expressed a decision to refuse medical treatment.</th>
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<tr>
<td>Document Type</td>
<td>Policy</td>
</tr>
<tr>
<td>Reference Number</td>
<td>Solent/Policy/CLS/001</td>
</tr>
<tr>
<td>Version</td>
<td>2</td>
</tr>
<tr>
<td>Name of Approving Committees/Groups</td>
<td>Assurance Committee</td>
</tr>
<tr>
<td>Operational Date</td>
<td>June 2012</td>
</tr>
<tr>
<td>Document Review Date</td>
<td>June 2014</td>
</tr>
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<td>Document Sponsor (Name &amp; Job Title)</td>
<td>Judy Hillier, Nursing and Quality</td>
</tr>
<tr>
<td>Document Manager (Name &amp; Job Title)</td>
<td>Richard Murphy, Mental Capacity Act lead</td>
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| Document developed in consultation with | This policy has been consulted on with the Mental Capacity Act Implementation Group, SIF, Acute Care Forums. The original policy (2008) had been subject to scrutiny by Portsmouth City tPCT legal advisors Bevan Britten LLP. This Policy has been subject to the following consultation:  
  - Mental Capacity Implementation Group  
  - Service Clinical Governance groups  
  - Sent to Associate Directors for all services  
  - Consultant Safeguarding lead  
  - End of Life Care Team |
| Intranet Location    | Joint Policies                                                                                   |
| Website Location     |                                                                                                  |
| Keywords (for website/intranet uploading) | Mental capacity, advance decision, best interest, end of life care |

One year extension to this policy as agreed at Assurance Committee on 28 March 2012
Appendices

The following appendices form part of this policy document:

Appendix 1: Definition of Terms
Appendix 2: Criteria for Valid Application of an Advance Decisions
Appendix 3: Solent NHS Trust Information Leaflet on Advance Decisions
Appendix 4: Equality and Human Rights and Mental Capacity Act impact Assessment
# ADVANCE DECISIONS TO REFUSE TREATMENT

<table>
<thead>
<tr>
<th>Section</th>
<th>CONTENTS</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Introduction and Purpose</td>
<td>4</td>
</tr>
<tr>
<td>2</td>
<td>Scope and Definitions</td>
<td>7</td>
</tr>
<tr>
<td>3</td>
<td>Process / Requirements &amp; Legal Status</td>
<td>7</td>
</tr>
<tr>
<td>4</td>
<td>Consent</td>
<td>9</td>
</tr>
<tr>
<td>5</td>
<td>Individuals wishing to make an Advance Decision</td>
<td>9</td>
</tr>
<tr>
<td>6</td>
<td>Roles &amp; Responsibilities</td>
<td>12</td>
</tr>
<tr>
<td>6.1</td>
<td>Staff responsibilities</td>
<td>12</td>
</tr>
<tr>
<td>6.2</td>
<td>Method of Implementation</td>
<td>14</td>
</tr>
<tr>
<td>6.3</td>
<td>Internal documentation system</td>
<td>15</td>
</tr>
<tr>
<td>6.4</td>
<td>Internal management system</td>
<td>15</td>
</tr>
<tr>
<td>6.5</td>
<td>Identifying patients with an Advance Decision</td>
<td>16</td>
</tr>
<tr>
<td>6.6</td>
<td>Disputes</td>
<td>16</td>
</tr>
<tr>
<td>7</td>
<td>Withdrawal of or amendment to an Advance Decision</td>
<td>17</td>
</tr>
<tr>
<td>8</td>
<td>Refusal of Medical Treatment (where no Advance Decision exists)</td>
<td>17</td>
</tr>
<tr>
<td>9</td>
<td>The Mental Capacity Act 2005</td>
<td>17</td>
</tr>
<tr>
<td>10</td>
<td>Training</td>
<td>20</td>
</tr>
<tr>
<td>11</td>
<td>Equality, Diversity &amp; Mental Capacity</td>
<td>20</td>
</tr>
<tr>
<td>12</td>
<td>Success Criteria</td>
<td>20</td>
</tr>
<tr>
<td>13</td>
<td>Policy Review</td>
<td>21</td>
</tr>
<tr>
<td>14</td>
<td>References</td>
<td>21</td>
</tr>
<tr>
<td>15</td>
<td>Appendices</td>
<td>22</td>
</tr>
<tr>
<td>1</td>
<td>Definition of Terms</td>
<td>23</td>
</tr>
<tr>
<td>2</td>
<td>Criteria for Valid Application of an Advance Decisions</td>
<td>26</td>
</tr>
<tr>
<td>3</td>
<td>PCT Patient Information Leaflet on Advance Decisions</td>
<td>27</td>
</tr>
<tr>
<td>4</td>
<td>Equality Impact Assessment</td>
<td>29</td>
</tr>
</tbody>
</table>
1. INTRODUCTION & PURPOSE

1.1. This policy has been created to assist Solent NHS Trust staff with the care of patients that have an Advance Decision to Refuse Treatment (Advance Decision) or wish to make an Advance Decision. The Policy aims to ensure that wherever possible, patients in receipt of care from Solent NHS Trust will have their expressed wishes and legal rights that are contained in Advance Decisions respected and upheld where valid and applicable, and that care given will be in the best interests of individual patients at all times.

1.2. Solent NHS Trust strongly supports the principle of Advance Decisions. Through Advance Decisions, patients have a legal right to make choices regarding medical treatment should they suffer loss of mental capacity in the future and to decline specific treatment, including life-prolonging treatment. Where valid and applicable, Advance Decisions must be followed.

1.3. Although oral Advance Decisions are valid, there are obvious advantages to a patient recording their views and decisions in writing. References to “documents” in this policy relate either to notes made by healthcare staff or by documents written by patients. Please note that if the Advance Decision relates to “life sustaining treatment” it must be written down, signed, witnessed and contain a statement that its contents remain in force “even if life is at risk”. The Code of Practice should be referred to for further guidance.

1.4. The principle of Advance Decisions was codified in law in the Mental Capacity Act 2005, fully enacted from 1st October 2007. Under this legislation some Advance Directives or living wills will need to be written. For a full explanation of this and the law applicable from 1st October 2007, please in particular consider Section 9 of this policy document.

1.5. Health professionals should not become involved in the drafting of any Advance Decision for a patient unless they have specific training to do this (for example members of The Specialist Palliative care team). If asked, medical personnel should ask patients to obtain independent help with their Advance Decision. However, where a patient makes a verbal Advance Decision this should be recorded in the patient’s notes, witnessed, signed and dated.

1.6. If a member of The Specialist Palliative care team is involved in an Advance Decision then it is best practice that they do not sign as witness, especially when being involved in the writing of the document. However there are occasions when there is no other available person to witness the patient sign the form. On these rare occasions the member of staff should consider their role carefully and clearly record reasons if they do act as a witness.

1.7. Drafting an Advance Decision is the patient’s responsibility. It is recommended that this be done with advice and counselling as part of a continuing health professional-patient dialogue. Health professionals consulted by people wishing to make Advance Decisions should take all reasonable steps to provide accurate factual information about treatment options and their implications. Solent NHS Trust’s information leaflet on Advance Decisions should also be given to the patient.
1.8. It is the responsibility of the patient to ensure that those who may be asked to comply with its provisions know of the existence of an Advance Decision. Patients should also be encouraged to discuss their intentions with their GP, with family and friends.

1.9. Unless appointed as a deputy by a court to make a specific decision or under the following authority, no person has a legal right to accept or decline treatment on behalf of another adult. The Mental Capacity Act 2005 introduces the concept of substituted healthcare decision making via a Lasting Power of Attorney: Personal Welfare (LPA: PW). A person can be nominated to take healthcare decisions on behalf of that individual under an LPA: PW. An Advance Decision “outranks” an LPA: PW and person nominated under it, unless the LPA: PW was created after the Advance Decision, and is valid/applicable. Nonetheless, Solent NHS Trust also recognises that the nomination of a healthcare proxy by the patient may be another helpful development in communicating the patient’s views when the individual is no longer capable of expressing these. Medical personnel are able to give consideration to the views of the healthcare proxy. This may provide some clarification to medical professionals.

1.10. Similarly the views of relatives may help in clarifying a patient’s wishes but relatives’ opinions cannot over-rule those of the patient or supplant the health professionals' duty to assess the patient’s best interest. Their views should be taken into account although they are not legally binding, unless an individual is nominated to take healthcare decisions under a LPA:PW that was created after the Advance Decision.

1.11. It is strongly recommended that authors of Advance Decisions review them at regular intervals (maximum 5 years) and destroy rather than amend them if they feel unsure about any previously expressed choices.

1.12. A competent patient can revoke an Advance Decision at any time and for any reason. Therefore the treating clinician or GP should undertake a regular review with the patient while he or she still has capacity to ensure that the patient’s wishes have not changed in any way. Any review should be recorded in the patient’s notes and should be signed and dated.

1.13. In all cases, it is vital to check that the Advance Decision being presented is that of the patient being treated and has not been withdrawn and that, if communication with the patient is possible, to check the decision still represents the patient’s wishes.

1.14. If a health professional is informed by a patient that an Advance Decision is withdrawn, the clinician must clearly record this in the patient’s records, including the date, time and circumstances. Any Advance Decision is superseded by a further clear and competent decision by the individual concerned to this effect. Any copies of the Advance Decision should be destroyed with the date and time of destruction noted.

1.15. If the situation faced by the staff is not identical to that described by the patient in their Advance Decision and this means the advance decision is not applicable, then the general spirit of the decision may be evidence of the person’s wishes and feelings and still be a relevant fact to be considered in deciding what is in the person’s best interest. In these situations staff should
contact any person nominated by a patient as well as the patient’s GP and family to clarify the patient’s wishes.

1.16. Solent NHS Trust encourages health professionals to raise the subject of Advance Decisions in a sensitive manner with patients who are anxious about the possible administration of unwanted treatments at a later stage. However, health professionals should be clear that although an individual can refuse treatment or stipulate that treatment can be withheld using an Advance Decision, they cannot compel the provision of care which the healthcare team considers to be inappropriate or illegal, or demand ‘positive’ steps to be taken to accelerate death i.e. euthanasia.

1.17. Solent NHS Trust supports practitioners in considering their own views and informing patients at the outset of any objection they may have to the principle of an Advance Decision. Those with a conscientious objection are not obliged to comply with an Advance Decision except in an emergency or when delegation is not possible. In an emergency if no other health professional is available there is a legal duty to comply with an appropriate and valid Advance Decision. If a health professional is involved in the management of a case and cannot for reasons of conscience accede to a patient’s request i.e. for limitation of treatment, management of that patient must be passed to a colleague.

Late discovery of an Advance Decision after life-prolonging treatment has been initiated is not sufficient grounds for ignoring it. Any ongoing treatment which is specified in the Advance Decision must be stopped.

1.18. In 1995 the BMA Code of Practice on Advance Statements highlighted that there is a significant ethical and legal difference between the concept of an Advance Decision and the issue of euthanasia. After the Mental Capacity Act 2005 became statute the difference was further emphasised by the BMA dealing with the issues under separate guidance. The issue of Advance Decisions is dealt with in BMA Advance decisions and proxy decision-making in medical treatment and research (2007). In Advance Decisions, Solent NHS Trust confirms its commitment to the fundamental and legitimate right of patients to accept or reject treatment options. This is in contrast to euthanasia or assisted suicide, where the primary purpose is to actively cause or hasten death. Euthanasia is illegal and this Policy should not be seen as supporting it.

1.19. This Policy should be read in conjunction with Solent NHS Trust’s Consent to Treatment and (DNA) Cardiopulmonary Resuscitation (CPR) Policies as well as the Professional Codes of Conduct pertaining to specific professional groups. Staff should also be familiar with the principles of the Mental Capacity Act 2005.

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1 see BMA (2010) Responding to patient requests relating to assisted suicide: guidance for doctors in England, Wales and Northern Ireland
1.20. If there are concerns about the validity or applicability of an Advance Decision then life sustaining treatment can be given whilst further advice and/or the Court of Protection are asked to decide on the matter.

1.21. The NHS South of England have supported the use of the ‘message in a bottle’ scheme as a means of communicating the existence and whereabouts of an advance decision. The information is kept in a clearly marked plastic container in the person’s refrigerator and there are stickers to place on the front door to indicate its presence. Staff in relevant areas should be aware of this scheme.

2. **SCOPE & DEFINITIONS**

This document applies to all directly and indirectly employed staff within Solent NHS Trust and other persons working within the organisation in line with Southampton City PCT’s Equal Opportunities Document. Solent NHS Trust is the community and mental health provider arm of Southampton City Primary Care Trust.

The scope of this Policy is to provide instructions on the management of Advance Decisions within Solent NHS Trust. This includes:

- Following the process outlined by the Department of Health’s Reference Guide: Consent for Examination or Treatment 2nd edition, principles and the requirements of statute outlined in the Mental Capacity Act 2005 and the other guidance documents listed under references.
- Identifying those clinical staff responsible for following the above process and managing Advance Decisions.
- Identifying the skills & training required of clinical and non-clinical staff.
- Communication channels
- Reporting structures.
- Documentation guidelines
- Storage of Advance Decisions
- Information to be given to the public on Advance Decisions

3 **PROCESS/REQUIREMENTS**

3.1 Prior to the Mental Capacity Act 2005 the BMA expressed the strong view that where an informed, competent person has made an anticipatory choice, which is "clearly established and applicable in the circumstances", doctors are bound by it. (BMA 1995)\(^2\). This principle is reflected in the Mental Capacity Act 2005 Advance Decisions.

An advance refusal of treatment, which is valid and applicable to subsequent circumstances in which the patient later lacks capacity, is **legally binding.** Failure to respect such an advanced refusal can result in legal action against

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\(^2\) This guidance has since been updated: BMA Advance decisions and proxy decision-making in medical treatment and research (2007)

A valid and applicable advance refusal is a legal document and, as such, must never be overridden or ignored by health professionals on the grounds of the professional’s personal conscientious objection to such a refusal (DOH 2009/MCA 2005).

3.2 Patients are not able to refuse “basic care” and hygiene through an Advance Decision although they can legally refuse specific medical procedures. Basic care means those procedures, which are essential to keep an individual comfortable.

The administration of medicine, or the performance of any procedure, which is solely or primarily designed to provide comfort to the patient or alleviate that person’s pain or symptoms of distress, are elements of basic care.

It is generally accepted that “basic care” includes warmth, shelter, pain relief, management of distressing symptoms such as vomiting and hygiene measures. However, nutrition and hydration should not be given to a person who indicates opposition, and invasive measures such as tube feeding should not be instituted contrary to a clear Advance Decision.

3.3 Individuals cannot make legally enforceable demands about specific treatments they wish to receive.

3.4 Health care providers cannot be required to act contrary to the law and so a current or advance request for active euthanasia would be invalid.

3.5 Criteria for valid application of Advance Decisions: please see Appendix 2. This should be read in conjunction with section 9 of this policy document.

3.6 Mental Health

A patient being treated for a mental health issue can make an Advance Decision if they have capacity with regard to the issue at the time of making the particular decision. However, if they are subsequently detained under the Mental Health Act 1983, their Advance Decision can be overridden by the provisions in Sections 58, 62 and 63 of the Mental Health Act 1983 if that Advance Decision relates to treatment for mental disorder. In these particular circumstances, patient consent is not required by the Act and therefore the Advance Decision will not be applicable. However, if possible, a patient’s preferences should be considered as part of the treatment plan.

The Mental Health Act 1983 Code of Practice should be referred to for further information on advance decisions and these sections. It should also be referred to in regard of advance decisions for; patients under community treatment orders and where electro convulsive therapy for detained patients is being considered.

3.7 Verbal Advance Decisions

While a verbal Advance Decision of a clear refusal of treatment by an adult does have legal force, by contrast general statements of preferences should be respected, if appropriate, but are not legally binding. However, whilst a
witnessed verbal refusal of treatment is an acceptable type of Advance Decision, this Decision should be made to a clinician wherever possible who should make a comprehensive record. A copy of that record should be kept in the patient’s file. If a verbal Advance Decision has been made to a patient’s relative or friend, the treating health professional should ensure that the Advance Decision exists and is valid and applicable to the situation. From 1 October 2007 where an Advance Decision is to apply to life sustaining treatment it must be verified by a written statement to that effect, signed and witnessed (see Section 9).

3.8 **Children and young people**

Advance Decisions are not legal for children and young people under 18. Similarly most of the Mental Capacity Act 2005 does not apply to individuals under the age of 18.

People who understand the implications of their choices can state in advance how they wish to be treated if they suffer loss of mental capacity. Young people under the age of 18 are entitled to have their views taken into account, and these should be accommodated if possible. It is widely recognised that medical decisions relating to children should be a partnership involving patients, their families and the healthcare team. However the refusal of certain treatments by a young person is not necessarily binding on doctors, and can be overridden by persons with parental responsibility, or if necessary the court.

An Advance Decision must be made by an adult in order to have legal effect. The European Court of Human Rights has taken the view that parents have the right under Article 8 of the European Convention to be involved in important decisions concerning their children.

3.9 **Pregnant women**

An Advance Decision’s validity may be questioned if it is not clear that the person knew they were pregnant when they made the advance decision or clearly stated that it should continue to apply even if they became pregnant (Code 2007, para 9.43). If an incapacitated pregnant woman presents with an apparently valid Advance Decision then legal advice should be sought to clarify the position. An application to court can be made in these circumstances.

4. **CONSENT**

Please refer to Solent NHS Trust’s Consent to Examination or Treatment Policy.

5. **INDIVIDUALS WISHING TO MAKE AN ADVANCE DECISION**

5.1 **When responding to requests for assistance with Advance Decisions, The BMA 2005 guidance stated that health professionals should consider:**

   - Is the patient over 18 years of age?
Does the person have mental capacity to make the advance decision? (See 5.5)

Is it clear that the patient is reflecting his or her own views and is not being influenced by others?

If there is a known illness does the patient have sufficient knowledge of the medical condition and possible treatment options?

Has the patient discussed the specific conditions of their Advance Decision with a health professional?

Does the patient know and understand the risks of not having treatment?

This remains good practical advice and will be helpful for professionals to bear in mind despite the guidance being updated by the BMA 2007 guidance. For further guidance on capacity and capacity, undue influence and vulnerability see the Deprivation of Liberty Safeguards and Mental Capacity Act 2005 policy. For guidance on safeguarding issues see Solent NHS Trust’s safeguarding policy. Finally, for further guidance on sharing appropriate information to support patients make decisions see the consent to treatment policy.

5.2 Individuals seeking advice must be given Solent NHS Trust Patient Information Leaflet on Advance Decisions (Appendix 3). Those who require information in another format or assistance of an advocate should be given information on how to obtain this.

5.3 Patients should be encouraged to discuss their intention to make an Advanced Decision with a health professional and also with their family, close friends and relevant health and social care professionals. The matter should be fully discussed in the presence of a witness. Detailed contemporaneous notes of the matter discussed must be made and a copy retained in the patient’s record.

The original note must be retained securely. The note should be legible, unambiguous and not contain any abbreviations. The note should be clearly signed by the author and witnessed. It should be dated and a note made of the time of the discussion and circumstances whenever possible. A significant event should be put on RIO, the equivalent computer system an appropriate paper form needs to be completed identifying the whereabouts of these documents.

5.4 Those that have made Advance Decision should be encouraged to review and update it at least every 5 years (minimum).

5.5 Assessment of mental capacity

Adults are presumed to have capacity but where doubt exists the health professional should seek appropriate assessment of the capacity of the patient to make the decision in question using the two-stage test of capacity as described in the Mental Capacity Act 2005 Code of Practice. See Solent NHS Trust Deprivation of Liberty and Mental Capacity Act 2005 for further information.

Every effort should be made to enable the patient to make and communicate their own decision, for example by providing information in non-verbal ways
where appropriate. Those requiring information in another format or assistance of an advocate should be given information or assistance in obtaining this.

The Mental Capacity Act 2005 codifies the assessment of capacity. When assessing capacity, the starting position should be that an individual does indeed have it. Under the Act consider:-

Is there an impairment of, or disturbance in, the functioning of the person's mind or brain?

Does the impairment make the person unable to make the decision? Can the person:-
  - Understand the information relevant to that decision?
  - Retain that information?
  - Use or weigh that information as part of the process of making the decision?
  - Communicate their decision?

The BMA give the following pointers when considering this test and what a person should be able to do in the context of advance decisions:

- be capable of choosing and understand why a choice is needed
- have information about risks, benefits and alternatives
- understand and retain enough basic information to make the choice
- be aware of how it is relevant to him/herself
- know there is a right to consent or refuse (except for compulsory treatment under mental health legislation)
- know how to refuse
- be capable of communicating a choice (BMA 2007)

Try different ways of communicating and consider using professionals with specialist skills.

Where doubt continues to exist about a patient’s mental capacity, the correct person to make the decision is a Judge from the Court of Protection, and an application to court should be made for this purpose. All assessments of capacity should be recorded in the health professional’s records.

If the incapacity is temporary because of anaesthesia, sedation, intoxication or temporary unconsciousness, health professionals should not proceed beyond what is essential to preserve the patient’s life or prevent deterioration in health.

Please refer to Solent NHS Trust Consent to Examination or Treatment Policy for guidance concerning lack of capacity.
6. ROLES & RESPONSIBILITIES

IMPLEMENTATION OF ADVANCE DECISIONS AND RESPONSIBILITIES:

6.1 STAFF RESPONSIBILITIES

6.1.1 Directors, Associate Directors and Managers will ensure that:

- the Policy is made available to all staff,
- all internal procedures regarding the management and following of Advance Decisions are adhered to and recorded, and
- Advance Decisions are considered and followed where the circumstances indicate that this is valid and applicable
- clinical staff are appropriately skilled in ensuring that Advance Decisions are fully discussed with the patient and their family and that they are fully aware of any implications arising from following it
- clinical staff understand the issue of providing care in the best interests of the patient
- Periodic reports on issues regarding the management of Advance Decisions are provided.

6.1.2 All Clinical Staff will ensure that they:

- understand and follow Solent NHS Trust’s policies and procedures regarding the management of Advance Decisions and Consent to Treatment or Examination
- understand the legal status and professional issues concerning Advance Decisions
- comply with the standards set by Professional Bodies regarding their professional and legal duty of care
- complete all necessary documentation regarding the management and following of Advance Decisions and provision of care in the best interests of the patient
- work within limits of own clinical competence
- seek advice where necessary regarding the following of Advance Decisions
- have knowledge of an Advance Decision, will inform others involved in that patient’s care on a ‘need to know’ basis
- Encourage discussion between individual patients and their families/carers regarding their care preferences.

6.1.3 Nurses’ responsibilities:

The NMC code was updated in 2008 and states that nurses must be aware of the mental capacity legislation in their country. For the purpose of Solent NHS Trust staff this is the Mental Capacity Act 2005 and includes knowledge of advance decisions to refuse treatment. The guidance also confirms nursing staff’s duty to have regard to the Code of Practice.

Nurses with a conscientious objection to limiting treatment at a patient’s request should make their views known via their line manager. Solent NHS Trust will endeavour to respect their beliefs and pass the management of the
patient to a colleague. However if delegation is impossible the NMC’s view is that nurses cannot refuse to care for patients in these circumstances. If this difficult situation arose then the staff member would be supported by their line manager and provided with appropriate clinical supervision.

6.1.4 **Doctors' responsibilities and Liabilities of Health Professionals:**

- Medical personnel can only act on an Advance Decision if it is brought to their attention. Under no circumstances should any delay or deviation to normal medical management occur whilst the document is being located.

- Staff are under no duty to undertake searches specifically for Advance Decision documentation. It is solely the burden of the patient that the decision has been brought to the attention of the medical professionals.

- The validity of an Advance Decision should be considered by treating clinicians.

- Staff must also assure themselves that the clinical situation in question has actually arisen. The decision must accurately reflect the clinical circumstances in which it is to be applied. Often there is no difficulty, however, where there is reasonable doubt that the conditions of the decision apply to the clinical circumstances in hand, it is better for staff to proceed as they would have in the absence of the decision. The Courts are most unlikely to criticise staff in this situation.

- Clinicians must take note of an Advance Decision, and having been notified that an Advance Decision exists, should make all reasonable efforts to acquaint themselves with its content. In cases of emergency however, necessary treatment should not normally be delayed to look for an Advance Decision.

- If a person is now incapacitated but is known to have objections to all or some of the treatment, it should be considered if these constitute an advance decision. If they do not then it should be decided what is in the best interest of the person and this should be followed.

- Questions arise about the ethical status of discontinuing treatment, which was already initiated prior to the discovery of an Advance Decision. The BMA, concurring with the law, considers that late discovery of an Advance Decision after treatment has been initiated does not mean that the decision cannot be implemented. Treatment should therefore be discontinued in accordance with the decision once it is known, unless there is doubt as to the document’s validity (BMA 2007).

- Clinicians should consider their own views and inform patients at the outset of any absolute objection to the principle of the Advance Decision. The patient then has the opportunity to consult another doctor. Doctors who are unexpectedly faced with an Advance Decision, who feel unable to comply, should relinquish the patient's management to colleagues. However, if there is no other doctor available, there is a legal duty to comply with an appropriate and valid Advance Decision.
Clinicians may be legally liable if they disregard the terms of a valid Advance Decision if the decision is known of, and applicable to the circumstances.

Health professionals following the terms of a clear Advance Decision and exercising due care and attention are unlikely to face any legal objections. However, basic care (measures necessary to keep a patient comfortable) should be given.

Health professionals must always act with due care and attention. The mistaken application of an Advance Decision to a patient other than the one who made it would raise issues of negligence.

If there is doubt as to what a patient intended, the law supports a presumption that appropriate life prolonging measures and treatment should be given whilst the issue is resolved. Health professionals must use their own professional judgement about the applicability and validity of the Advance Decision.

If an Advance Decision is not applicable to the circumstances, it is not legally binding, although it may give a valuable indication of the general treatment options the patient would prefer.

An Advance Decision cannot compel treatment to be provided.

Health professionals faced with questions from their patients about Advance Decisions, or who are required to consider the implementation of an Advance Decision should consult the BMA’s 2007 document as well as be aware of the impact of the Mental Capacity Act 2005 and this policy document.

Requests for further information by medical professionals which cannot be obtained from Solent NHS Trust should be directed to:
Medical Ethics Committee Secretariat
Medical Ethics Department
BMA House
Tavistock Square
London, WC2H 9JP
Tel: 020 7383 6286

6.2 Method of Implementation


Identify those senior clinical staff with first line responsibility and agree responsibilities. Clinical Staff must be able to:

- Assess that current circumstances are valid and applicable (see appendix 2 and Section 9).
check that the Advance Decision remains valid if the patient can be
communicated with
- discuss any implications of following the decision and document the
discussion (this discussion will ideally be witnessed)
- involve any nominated individual, family or the patient’s general
practitioner, to assess validity and applicability where there is any element
doubt
- Exercise judgement regarding the best interests of the patient.

6.3 **Internal documentation systems for the management of Advance
Decisions must be established as follows:**

Clinical records must record the following:

- The presence of an Advance Decision and the content of it. Contact
details of any healthcare proxy should also be recorded (Appendix 1), as
well as the patient’s GP. Please also consider whether a LPA:PW has
been created since the Advance Decision was made (see 1.8)

- The assessment of the validity and applicability of that decision in the
current circumstances including any discussions with the
patient/nominated individual / GP regarding validity if the patient is unable
to provide this information for themselves.

- Any discussions with the patient regarding the implications of the Advance
Decision.

- Any decisions made regarding care/treatment given which is considered
to be in the best interests of the patient.

- Withdrawal of or alteration to the Advance Decision (see section 7.0).

6.4 **Internal management systems must be established as follows:** -

- Systems must be developed and implemented to enable all clinical staff to
discuss issues regarding the management and following of Advance
Decisions with GP colleagues and other members of the Primary Health Care
Team (PHCT) in partnership with the patient (if possible) and carer.
It is acknowledged that in reality it is unlikely that the patient, their GP and
Solent NHS Trust staff will be available to meet and talk at the same time;
however, this should not prevent the discussions being held. Discussions
between these individuals should be encouraged as it is extremely
important in providing clarity and effective management in relation to any
Advance Decision.

- The GP and community staff must be informed of the presence of an
Advance Decision for patients being discharged to the care of the Primary
Healthcare Team. Where possible, community staff will be informed of
this at multi-disciplinary care planning meetings and case reviews

- the Clinical Governance Lead or Associate Director of Quality and Risk
will provide advice and support for complex issues relating to Advance
Decisions

- Issues will be reported to the Clinical Governance Committee.
6.5 **Identifying patients who have made an Advance Decision**

- It is the patient’s responsibility to let relevant professionals know of the existence of the decision, where it is stored if in written form and whom they would like consulted about its implementation. This is particularly important when changing doctors or attending different hospitals. Health professionals will not incur liability if proceeding with medical treatment where they did not know of the Advanced Decision although they will need to consider available evidence about the patient’s views.

- Storage of documentation regarding an Advance Decision and notification of its existence are the responsibility of the individual. Those close to the patient should be made aware of its existence, be told where it is and, where appropriate, state who the health care proxy is. Some individuals carry a card, bracelet or other measure indicating the existence of an Advance Decision and where it is kept. A copy is also best lodged with their general practitioner if possible, which will allow the GP to provide the information to other health professionals on referral or, in emergency situations, to provide the information on request. For patients who are treated by a specialist team over a prolonged period, a copy of the Advance Decision should be filed with the patient’s hospital medical records. Again, please consider whether a LPA:PW has been created since the Advance Decision was made (see 1.6)

- Although not a legal requirement, the existence of an Advance Decision should be marked clearly on the patient’s records and ideally, if possible, a copy should be kept with the records. Staff involved in the patient’s care should also be informed of the existence of an Advance Decision, and the circumstances in which it will be appropriate.

- The NHS South of England have supported the use of the ‘message in a bottle’ scheme as a means of communicating the existence and whereabouts of an advance decision. The information is kept in a clearly marked plastic container in the person’s refrigerator and there are stickers to place on the front door to indicate its presence. Staff in relevant areas should be aware of this scheme.

6.6 **Disputes**

6.6.1 In the event of a disagreement between health professionals or between relatives about the patient’s previously expressed wishes, opinions should be sought from relevant colleagues and others who are familiar with the patient. In the interim the patient should be treated in their best interests under Section 5 of the Mental Capacity Act 2005 until such issues are resolved. For further guidance on resolving disputes see Solent NHS Trust’s policy, Deprivation of Liberty Safeguards and the Mental Capacity Act Policy.

6.6.2 All staff involved in a patient’s care should have the opportunity of presenting their views. This includes community staff who may have known the patient over a longer period. Views of family members and close friends of the patient should also be considered. Ultimately, the senior professional managing the particular episode of the patient’s care must consider the available evidence of the patient’s wishes before reaching a decision on issues raised by the Advance Decision but they may need to seek advice from the courts if the
matter cannot be resolved. In cases of dispute emergency treatment should be given until resolution (BMA 1995 and 2007/MCA 2005).

7. WITHDRAWAL OF OR AMENDMENT TO AN ADVANCE DECISION

7.1 If a person wishes to withdraw their Advance Decision they should destroy their copy and inform their GP and everyone else who has a copy or knows of its existence that it is no longer valid.

7.2 If a health professional is informed by the author of an Advance Decision that it is being withdrawn, the health professional is responsible for recording this in the clinical record including the date, time and circumstances. It is important to meet with the individual to discuss the required issues and changes. Any Advance Decision is superseded by a further clear and competent decision to this effect by the individual concerned whether written or verbal. Any copies held should be destroyed with the date and time of the destruction noted.

7.3 Where an Advance Decision no longer reflects a competent person’s wishes it becomes invalid. Ideally where there are changes to an Advance Decision, a new document should be produced and the old document destroyed. However, if an Advance Decision is to be altered, any alteration should be dated and signed with an independent witness (see Appendix 1). Holders of any copies should be alerted to the fact that the original has been amended and given a copy of the amended document. If a copy is held by any health professional it is the responsibility of the author to ensure that they are aware of the alterations and that an altered copy is available. The procedure for destruction of the original should then be followed.

7.4 Photocopying of Advance Decisions should not be undertaken by health professionals because of the difficulties in keeping a record of copies that may later need to be amended or destroyed. The exception to this is The Specialist Palliative care team who have a protocol to ensure any out of date Advance Decisions are destroyed and up to date copies of the advance decision are sent to relevant people.

8. REFUSAL OF MEDICAL TREATMENT (WHERE NO ADVANCE DECISION EXISTS)

Adults have the right under common law to refuse medical treatment in the absence of a formal Advance Decision. If a patient no longer has capacity and has not clearly indicated their wishes in the past, the decision to provide or withhold life-prolonging treatment must be based on an assessment of their best interests.

9. THE MENTAL CAPACITY ACT 2005

The Act itself has codified but not substantially changed the law in this area. For further information see Solent NHS Trust’s policy, Deprivation of Liberty Safeguards and the Mental Capacity Act Policy.

Under the Act:-

An “Advance Decision” is a decision made by an adult with capacity that if:
- at a later time a specified treatment is proposed to be carried out by a person providing healthcare and
- at the time he or she lacks capacity to consent to that treatment, then
- the specified treatment is not to be carried out or continued.

Key Points – Advance Decisions and Mental Capacity Act:-

- An Advance Decision only applies to refusals of treatment.
- An Advance Decision does not apply to the provision of basic care to keep a patient comfortable.
- The individual must have been 18 years old or more to make an Advance Decision.
- The individual must have had capacity at the time of making the Advance Decision.
- The Advance Decision must clearly specify the treatment to be refused.
- The Advance Decision must clearly specify the circumstances in which a refusal of treatment will apply (although non scientific language will be acceptable).
- Any Advance Decision can be withdrawn or altered at any time if the individual has capacity.

Incapacity

The Advance Decision will not be binding or come into effect if at the material time the person who made it still has capacity to give or refuse consent.

Is the Advance Decision Binding?

To be binding the Advance Decision must be VALID and APPLICABLE.

Validity

The Advance Decision is:

- Not valid if the individual withdrew the Advance Decision at any time when he or she had capacity.
- Not valid if the individual has subsequently acted in a way clearly inconsistent with the Advance Decision.
- Not valid if a later and applicable Lasting Power of Attorney: Personal Welfare overrides the Advance Decision.

Applicability – The Advance Decision is not applicable if:-

- Treatment is not that specified in the Advance Decision.
- Any circumstances specified in the Advance Decision are absent.
- There are reasonable grounds for believing that circumstances exist which the patient did not anticipate and which would have been likely to have affected the decision.
The BMA advises professionals to consider the following in determining if an advance decision is still valid and whether:

- Whether the current circumstances match those the patient envisaged;
- Whether the decision is relevant to the patient’s current health care needs;
- Whether there is any evidence that the patient had a change of heart while still competent;
- Whether the decision, if old, has been reviewed;
- Whether, since the decision was last updated, new medical developments would have affected the patient’s decision;
- Whether the patient subsequently acted in a manner inconsistent with the decision made in the advance decision or subsequently appointed a proxy decision-maker to make the decision in question. (BMA 2007)

**Life Sustaining Treatment**

- An Advance Decision will not be applicable to life sustaining treatment unless it is verified by a statement to the effect that it is to apply to that treatment even if life is at risk.
- This must be in writing, signed and witnessed.

**Patients Detained under the Mental Health Act 1983**

- Patients who are formally detained under the Mental Health Act 1983 cannot always make an Advance Decision in respect of treatment to be provided as part of that detention. Please see section 3.6 for further details.

**Impact of the Advance Decision**

If an Advance Decision is valid and applicable, it has the effect of a contemporaneous refusal of treatment by an adult with capacity.

It is for healthcare professionals to decide if an Advance Decision is valid and applicable. If there are concerns, there is a duty to make enquiries of those who may know – i.e. family, carers, the GP, etc. Similarly if healthcare professionals suspect that an Advance Decision exists, reasonable efforts, time permitting, should be made to find out what it says, although healthcare professionals can act in an emergency.

If there is uncertainty about whether an Advance Decision exists or the medical professional is not satisfied that it is valid or applicable in the current circumstances, there will be no liability incurred by medical professionals for providing treatment.

Likewise if a doctor reasonably believes that a valid and applicable Advance Decision exists, there will be no liability for withholding treatment.

In an emergency where there is doubt about an Advance Decision, treatment can be provided. However if there is time, cases of doubt can be referred to Court, and in the meantime treatment necessary to preserve life or prevent
serious deterioration may be given. It is anticipated with the new “Court of Protection” that decisions can be turned around extremely quickly if the situation so requires.

10. TRAINING

Solent NHS Trust recognises the importance of appropriate training for staff. For training requirements and refresher frequencies in relation to this policy subject matter, please refer to the Training Needs Analysis (TNA) on the intranet.

‘All training undertaken must be recorded on the Organisational Learning Module (OLM) of the Electronic Staff Record (ESR) taken from signing in sheets. Monitoring of training attendance will be carried out by the Learning & Development Department. Please refer to the Induction & Mandatory Training Policy section 5.7.4. Non attendance will be managed according to the procedure detailed in the Learning and Development Policy at section 3.9’

An introduction to the Mental Capacity Act 2005 lasting for 45 minutes, will be provided, either via the corporate induction programme for new staff or via the half day ‘Safeguarding’ session developed by the Learning and Development team. In this way, all staff will be given a basic understanding of the Act.

Level 3 training aimed at clinical staff will be provided on via a full days training. Staff will have to have attended an introductory session before applying for a place on the level 3 sessions. This training will investigate the Act in more detail and will include use of this policy as a tool. Amongst other things the training will incorporate consent and decision making for people who lack mental capacity.

‘The Specialist Palliative care team receive training from the Specialist Palliative Care services in conjunction with the Hampshire CNS’s and the Rowans hospice consultants. This enables them to support patients in making advance decisions.

11. EQUALITY & DIVERSITY AND MENTAL CAPACITY ACT

An Impact Needs Requirements Assessment (INRA) has been completed for this policy and no significant adverse effects have been noted. As the policy relates to people lacking capacity making their own decisions wherever possible it contributes positively towards equality and inclusion.

This policy has been assessed and meets the requirements of the Mental Capacity Act 2005.

12. SUCCESS CRITERIA / MONITORING THE EFFECTIVENESS OF THE DOCUMENT

On an annual basis this policy will be audited against the auditing standard (continued in appendix 2) by Solent NHS Trust Senior Manager responsible for the Mental Capacity Act 2005 to ensure that staff working within the Organisation are following the principles enshrined in the Act.
13. POLICY REVIEW

This policy will be reviewed on an annual basis by the Mental Capacity Act Implementation Group.

This document may be reviewed at any time at the request of either staff side or management, but will automatically be reviewed on a bi-annual basis.

14. REFERENCES AND LINKS TO OTHER DOCUMENTS


BMA (2007) Advance Decision and Proxy Decision Making in Medical Treatment and Research London BMA

Data Protection Act (1998) HMSO

Dept of Health 2007 Mental Capacity Act 2005 Code of Practice London TSO

Dept of Health (2003) Building on the Best London; Dept of Health


Dept of Health (2001) Seeking consent: working with older people London; Dept of Health

GMC (2006) Withholding and Withdrawing Life-prolonging Treatments: Good Practice in Decision-making

Human Rights Act (1998) HMSO


Advance Decisions to Refuse Treatment website http://www.adrtnhs.co.uk/
15. **APPENDICES**

Appendix 1: Definition of Terms

Appendix 2: Criteria for valid application of an Advance Directive

Appendix 3: Solent NHS Trust Patient Information Leaflet on Advance Directives/Decisions

Appendix 4: Equality and Human Rights and Mental Capacity Act impact Assessment
DEFINITION OF TERMS

ADVANCE DECISIONS TO REFUSE TREATMENT

An Advance Decision is a mechanism whereby competent people give clear instructions about what is to be done if they subsequently lose the capacity to decide or to communicate. An Advance Decision is intended to be a binding refusal of treatment. Withholding or withdrawing treatment in the future made by an informed competent adult in contemplation of the specific circumstances, which arise. It is legally binding.

ADVANCE STATEMENT

Note: this policy does not relate to advance statements in general. The only advance statement it relates to is “Advance Decisions”. This definition is included for clarification purposes only.

An advance statement is the general term for an act whereby a person, whilst mentally competent, specifically makes arrangements about their future health care should they become unable to do this. In essence, people who understand the implications of their choices can state in advance how they wish to be treated if they suffer loss of mental capacity.

An advance statement is broader in scope, and can, for example be:

- a clear instruction refusing some or all medical procedures. This is known as an Advance Directive.
- a statement reflecting an individual’s aspirations and preferences which can help professionals identify how the person would like to be treated without binding them to that course of action if it conflicts with professional duty of care or judgement.
- a statement of general beliefs and aspirations of life which an individual values. It makes no specific request or refusal but aims to indicate what he / she would want.
- a statement which names another person who should be consulted at the time a decision has to be made. The views expressed by that named person should reflect what the person would want. This can supplement and clarify the intended scope of a written statement but the named person’s views are presently not legally binding in England, Wales and Northern Ireland. In Scotland, the powers of a tutor dative may cover such eventualities.
- a combination of the above. Those sections expressing clear refusal may have legal force in the case of adult patients.

CAPACITY/COMPETENCE

The ability to understand the implications of a decision. A person may be deemed to have capacity or competence if he/she:

- can comprehend and retain the information relevant to the decision in question
- can understand its principle benefits, risks and alternatives
• can understand in broad terms what will be the consequences of not receiving the proposed treatment
• make a free choice (i.e. free from undue pressure)
• retain the information long enough to make an effective decision
• can weigh that information in the balance to arrive at a choice.
The Mental Capacity Act 2005 reinforces the above principles of capacity and assessment of capacity.

Adults are presumed to have capacity, but where any doubt exists the health professional should seek the appropriate assessment of the capacity of the patient to take the decision in question. Ultimately, this may need to be a legal decision and where doubt exists concerning mental capacity; an application to the Court can be made. Although they may understand and weigh the implications, young people under the age of 18 generally do not have the same rights at law as an adult. However; they are entitled to have their views taken into account but can be overruled by a court or a person with parental responsibility.

Note: the degree of capacity needed to make a decision will vary with the circumstances; in other words, a person may have the capacity needed to make certain decisions but not others. Please refer to Solent NHS Trust Consent Policy / Dept of Health guidance / BMA Code of Practice and the Mental Capacity Act 2005 for further information.

Note: All assessments of an individual's capacity should be recorded in line with Solent NHS Trust's policies.

**CONSENT**

Consent is a patient’s agreement for a health professional to provide care. It may be given non-verbally, verbally or in writing. For consent to be valid, the patient must:

• be competent to make the particular decision
• have received sufficient information to take it and make an informed choice
• not be acting under duress.

When a patient lacks the mental capacity to give or withhold consent for him or herself, no one else can give it on their behalf (unless a person has been appointed under a Lasting Power of Attorney: Personal Welfare to take healthcare decisions).

Please refer to Solent NHS Trust Consent to Examination or Treatment Policy / Dept of Health guidance for further information.

**HEALTH CARE PROXY OR PERSONS APPOINTED UNDER A LASTING POWER OF ATTORNEY: PERSONAL WELFARE**

A health care proxy is someone who is chosen to play a part in decisions about an individual's health care when they are no longer able to do this for themselves. It can be a family member, partner, friend or carer. The person chosen should be someone who will best represent the individual’s interests relating to health decisions and should be written
on the Advance Decision form with the contact details. The proxy will be a helpful person in acting as an interpreter of the individual's values and wishes.

Under the Mental Capacity Act 2005 a person can be nominated to take healthcare decisions on behalf of that individual under a lasting Power of Attorney: Personal Welfare. An Advance Decision “outranks” a LPA: PW and person nominated under it, unless the LPA: PW was created after the Advance Decision and is valid/applicable.

A healthcare proxy not appointed under a Lasting Power of Attorney: Personal Welfare can offer a view as to treatment, but that view is not legally binding.

INDEPENDENT WITNESS

This is a person who is to witness the signature on the Advance Decision. A witness should be over the age of 18 years and should not be anyone who stands to benefit from the Last Will and Testament of the person drafting the Advance Decision. Solent NHS Trust employees should not act as independent witnesses.
APPENDIX 2

CRITERIA FOR VALID APPLICATION OF ADVANCE DECISIONS

1. Advance decisions can be verbal or written, although please see 7 below. Each is legally binding.

2. The subject of the Advance Decision must be 18 or over at the time the document was prepared and signed.

3. The subject of the Advance Decision must have had mental capacity in relation to the decision being made at that time.

4. The subject of the Advance Decision must not have been under undue influence by anyone else whilst preparing it.

5. The subject of the Advance Decision must have been fully informed about the treatment options and their implications when the Advance Decision was made.

6. The Advance Decision should be current reflecting the up-to-date views/wishes of the individual

7. In consideration of life-sustaining treatment the Advance Decision must be in written form with a statement that the decision applies even if life is at risk. The document should be signed and dated by at least one witness over the age of 18. This person should not be a spouse, partner, relative, or anyone who stands to benefit from the subject’s Last Will and Testament or the death of the patient. The Code of Practice should be consulted for further guidance

8. The document must have anticipated the particular circumstances that in fact arise and intended the decision to apply in those circumstances. Please consider section 9 of this document for additional factors regarding a valid and applicable Advance Decision as a result of the MCA.

Please note:

- In all circumstances, a contemporaneous decision by a competent individual overrides previously expressed statements or an Advance Decision made by that person (MCA 2005)

- Any provisions of Advance Decisions refusing treatment for mental illness are rendered invalid in circumstances where the patient is legally detained for treatment. (MCA 2005)

- Health professionals may be legally liable if they disregard the terms of an Advance Decision if the decision is known of and applicable to the circumstances (MCA 2005)
Where can I get more information?

Several health and social care related organisations provide advice, information and specimen forms including:

**Age UK Portsmouth**
Portsmouth: 16-18, Kingston Road, Portsmouth PO1 5RZ
Telephone: 023 9286 2121

**AGE Concern Southampton:** 1 Saxon Gate, Back of the Walls, Southampton, SO14 3HA
Tel: 023 8036 8636
Website: [www.ageconcern.org.uk](http://www.ageconcern.org.uk) and then click on ‘Information & Advice’

**Alzheimer’s Society**
Gordon House, 10 Greencoat Place, London SW1P 1PH Helpline 0845 300 0336
produces a free information sheet and guidance on preparing an Advance Decision. This information sheet together with a sample Advance Decision form can also be downloaded as a pdf file from their website.

**Patients Association**
P.O. Box 935 Harrow Middx HA1 3YJ.
Helpline 0845 608 4455

**SEAP Portsmouth**
The Oasis Centre, 1a Upper Arundel street, Portsmouth Hampshire, PO1 1NP, T: 02392 837777: SEAP is an advocacy service
What is An Advance Decision?
A practical way of planning ahead to ensure that a person’s wishes are respected at a time when they are no longer capable of making decisions or conveying their wishes about treatment.

The Law
The Mental Capacity Act 2005 allows you to set out what treatments you would not wish to have should you lose capacity to make those decisions at some point in the future.

You can nominate someone who should be consulted at the time a decision has to be made. The views expressed by that person will be considered by medical professionals although do not have legal force. Under the Mental Capacity Act 2005 you can also give someone the power to take healthcare decisions on your behalf under a Lasting Power of Attorney: Personal Welfare (LPA: PW). An Advance Decision will still be valid however unless the LPA: PW was created after the Advance Decision, and is valid/applicable in the circumstances. The views of a person appointed under a LPA: PW with regard to healthcare decisions will have legal effect.

In general, people under 18 are entitled to have their views taken into account but can be overruled by a court or a person with parental responsibility.

Who can make an Advance Decision?
Anyone over the age of 18 can make an Advance Decision as long as they have the capacity to do so. It is a way of ensuring doctors do not give you certain medical treatments against your wishes.

Why make an Advance Decision?
You can choose in advance the circumstances in which you would want to discontinue medical treatment.

Who should I tell?
Although not obligatory, it is advisable to discuss your intention to make an Advance Decision with a Healthcare professional in the first instance. The existence of an Advance Decision and contact person (if any) should be recorded in your medical records. If possible a copy of any document should be kept with the medical records. It is, however, your responsibility to let all the health professionals treating you know about your Advance Decision, where it is stored and who you would like them to consult if the time comes for it to be used or revised. You should also share this information with your family.

When is an Advance Decision used?
It is important to remember that an Advance Decision can only be executed or your nominated person consulted if you are incapacitated and are unable to communicate your views.

You can alter or cancel your Advance Decision at any time but it is your responsibility to let your GP and anyone else concerned know that you have done this.

How can I make an Advance Decision?
You can do this orally or you can put your requirements in writing or use a specially pre-printed form. If you intend to refuse life-sustaining treatment this has to be in writing. You can ask for help from an advocacy organization such as Age Concern or the
Alzheimer's Society. This is important since new legislation took effect on 1 October 2007.

It is important that your Advance Decision is updated at least every 5 years.
### Step 1 – Scoping; identify the policies aims

<table>
<thead>
<tr>
<th>Question</th>
<th>Answer</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. What are the main aims and objectives of the document?</td>
<td>To ensure the organisation’s compliance with the Mental Capacity Act 2005 in relation to advance decisions</td>
</tr>
<tr>
<td>2. Who will be affected by it?</td>
<td>All staff across the organisation and potentially all service users</td>
</tr>
<tr>
<td>3. What are the existing performance indicators/measures for this?</td>
<td>There is currently a consent audit and evidence for essential standards 2</td>
</tr>
<tr>
<td>4. What information do you already have on the equality impact of this document?</td>
<td>The policy ensures ECHR article rights are upheld for people who wish to make an advance decision to refuse treatment and sets how to determine when an advance decision is applicable and valid. Providing the person has capacity when completing an advance decision; the status of the advance decision will not be affected by the person’s characteristics in relation to any of the six areas of equality. People’s rights under the MCA will be upheld by this policy. The principles of the policy and the capacity and best interest process ensure discrimination is not occurring in the process. This policy will set the standards and allow this to be monitored.</td>
</tr>
<tr>
<td>5. Are there demographic changes or trends locally to be considered?</td>
<td>Ensure there are suitable communication means for providing information to service user groups whose first language is not English or have other means of communicating.</td>
</tr>
<tr>
<td>6. What other information do you need?</td>
<td>None</td>
</tr>
</tbody>
</table>

### Step 2 - Assessing the Impact; consider the data and research

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
<th>Answer (Evidence)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Could the document unlawfully against any group?</td>
<td></td>
<td>no</td>
<td>The document complies with the statute and ensures the organisation's compliance</td>
</tr>
<tr>
<td>2. Can any group benefit or be excluded?</td>
<td></td>
<td>yes</td>
<td>The document, if complied with, will ensure the rights are upheld for all individuals, and their carers, who have made a valid and applicable advance decision and ensures that teams are able to appropriately support those who wish to make an advance decision.</td>
</tr>
<tr>
<td>3. Can any group be denied fair &amp; equal access to or treatment as a result of this document?</td>
<td></td>
<td>no</td>
<td>As above</td>
</tr>
<tr>
<td>4. Can this actively promote good relations with and between different groups?</td>
<td></td>
<td>no</td>
<td>Not its aim</td>
</tr>
<tr>
<td>5. Have you carried out any consultation internally/externally with relevant individual groups?</td>
<td></td>
<td>no</td>
<td>The MCA and its code of practice was developed in consultation with a wide variety of service user groups. The policy will be monitored via feedback from the patient experience service and risk events, which will be considered at the MCA and DOLS.</td>
</tr>
</tbody>
</table>
6. Have you used a variety of different methods of consultation/involvement  
no  
See above

7. Will this document require a decision to be made by or about a service user? (Refer to the Mental Capacity Act document for further information)  
yes  
See above: It is a key purpose of the document.

If there is no negative impact – end the Impact Assessment here.

**Step 3 - Recommendations and Action Plans**

1. Is the impact low, medium or high?

2. What action/modification needs to be taken to minimise or eliminate the negative impact?

3. Are there likely to be different outcomes with any modifications? Explain these?

**Step 4 - Implementation, Monitoring and Review**

1. What are the implementation and monitoring arrangements, including timescales?

2. Who within the Department/Team will be responsible for monitoring and regular review of the document?

**Step 5 - Publishing the Results**

How will the results of this assessment be published and where? (It is essential that there is documented evidence of why decisions were made).

**Retain a copy and also include as an appendix to the document**