

ADVANCE DIRECTIVES / ADVANCE DECISIONS (LIVING WILLS) POLICY

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THIS DOCUMENT REPLACES	<p>This document replaces the Advance Directive (Living Wills) policy issued in June 2006.</p> <p>The Policy has been updated in line with the Mental Capacity Act (2005) by the PCT's solicitors. Some minor changes have been made throughout the document but the major change is the insertion of Section 10: Advance Directives/Decisions – Impact of the Mental Capacity Act 2005.</p> <p>The title of the Policy has also been amended to take account of the fact that under the Act, Advance Directives/Decisions (Living Wills) are broadly to be known as Advance Decisions or Advance Refusals.</p>
NOTES	<p>For access to legal advice from the PCT's solicitors contact your Director; Sheila Gardner, Asst Director of Finance and Claims Manager (01225 831876) or Sarah Leggett (contact details above)</p> <p>In an emergency situation out of hours contact the Director on-call.</p> <p>Contact details for the Independent Mental Capacity Advocate service (IMCA) for BANES: Bath Mind: tel: 01225 316330; e-mail bathmindimca@btconnect.com; website: www.bathmindimca.org.uk</p>
IMPLEMENTATION PLAN	<p>Local cascade by managers. Key points for implementation:</p> <ul style="list-style-type: none"> • Ensure all staff working in a clinical area are aware of the existence of the Policy and how to access it • Ensure all managerial and clinical staff are aware of their responsibilities as detailed in the Policy (section 7.1, pages 9-11) • Ensure all managerial and clinical staff are aware of the contents of Section 10 on the impact of the Mental Capacity Act 2005 • Ensure that within each clinical team staff are given the opportunity to raise concerns that they may have in relation to their responsibilities or other aspects of this Policy and that these are discussed either as part of a team or with the individual concerned as appropriate.

Section	INDEX	Page
1	Summary	3
2	Policy Statement	4
3	Aim & Scope of the Policy	5
4	Legal Status	5
5	Consent	7
6	Individuals wishing to make an Advance Directive	7
7	Implementation of Advance Directives and Responsibilities	
	7.1 Staff responsibilities	8
	7.2 Method of Implementation	11
	7.3 Training Requirements	11
	7.4 Internal documentation system	12
	7.5 Internal management system	12
	7.6 Identifying patients with an Advance Directive	12
	7.7 Disputes	13
8	Withdrawal of or amendment to an Advance Directive	13
9	Refusal of Medical Treatment (where no Advance Directive exists)	14
10	Advance Directives/Decisions – Impact of the Mental Capacity Act 2005	14
11	References	16
Appendices		
	1 Definition of Terms	17
	2 Criteria for Valid Application of an Advance Directives	19
	3 When to use an Independent Mental Capacity Advisor	20
	4 PCT Patient Information Leaflet on Advance Directives/Decisions	21

1. SUMMARY

- 1.1 The PCT strongly supports the principle of Advance Directives commonly known as a Living Will. Through Advance Directives, 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 Directives must be followed.
- 1.2 Although oral Advance Directives are valid if supported by appropriate evidence, there are obvious advantages to a patient recording their views and decisions in writing.

The principle of Advance Directives was codified in law from 1st October 2007. Under this legislation some Advance Directives will need to be written. For a full explanation of this and the law applicable from 1st October 2007, please in particular consider Section 10 of this policy document. Generally Advance Directives will also be termed "Advance Decisions" under this legislation.

Health professionals should not become involved in the drafting of any advance directive for a patient. If asked, medical personnel should ask patients to obtain independent help with their advance directive. However, where a patient makes a verbal advance directive this should be recorded in the patient's notes, witnessed, signed and dated.

- 1.3 Drafting an Advance Directive 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 Directives should take all reasonable steps to provide accurate factual information about treatment options and their implications. The PCT's information leaflet on Advance Directives should also be given to the patient.
- 1.4 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 Directive. Patients should also be encouraged to discuss their intentions with their GP, with family and friends.
- 1.5 In principal, no person has a legal right to accept or decline treatment on behalf of another adult. However, the Mental Capacity Act 2005 does introduce the concept of substituted healthcare decision making via a Lasting Power of Attorney ("LPA"). A person can be nominated to take healthcare decisions on behalf of that individual under an LPA. An Advance Decision "outranks" an LPA and person nominated under it, unless the LPA was created after the Advance Decision, and is valid/applicable. Nonetheless, the PCT 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.
- 1.6 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 Lasting Power of Attorney and the LPA was created after the Advance Decision.
- 1.7 It is strongly recommended that authors of Advance Directives review them at regular intervals (maximum 5 years) and destroy rather than amend them if they feel unsure about any previously expressed choices.
- 1.8 An advance directive can be revoked by a competent patient 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.

- 1.9 In all cases, it is vital to check that the Advance Directive 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 Directive still represents the patient's wishes.
- 1.10 If a health professional is informed by a patient that an advance directive is withdrawn, the clinician must clearly record this in the patient's records, including the date, time and circumstances. Any advance directive is superseded by a further clear and competent decision by the individual concerned to this effect. Any copies of the advance directive should be destroyed with the date and time of destruction noted.
- 1.11 If the situation faced by the staff is not identical to that described by the patient in their Advance Directive, then the general spirit of the Directive may still guide treatment if this is clearly described. 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. If there is doubt as to what the patient intended, the law supports the presumption that appropriate life prolonging measures should be given. Health professionals should use their own professional judgement about the appropriateness of a Directive in these situations.
- 1.12 The PCT encourages health professionals to raise the subject of Advance Directives 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 directive, they cannot demand care which the healthcare team considers to be inappropriate or illegal, or demand 'positive' steps to be taken to accelerate death i.e. euthanasia.
- 1.13 The PCT 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 Directive. Those with a conscientious objection are not obliged to comply with an Advance Directive **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 Directive. 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.
- 1.14 Late discovery of an Advance Directive after life-prolonging treatment has been initiated is not sufficient grounds for ignoring it.
- 1.15 There is a significant ethical and legal difference between the concept of an Advance Directive and the issue of euthanasia. In Advance Directives, the PCT 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.
(Adapted from BMA Code of Practice on Advance Statements 1995)
- 1.16 This Policy should be read in conjunction with the PCT's Consent to Treatment and Examination and 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.

2. POLICY STATEMENT

- 2.1 The Policy aims to ensure that wherever possible, patients in receipt of care from the PCT will have their expressed wishes and legal rights that are contained in Advance Directives

respected and upheld where valid and applicable, and that care given will be in the best interests of individual patients at all times.

3. AIM AND SCOPE OF THE POLICY

3.1 The aim and scope of this Policy is to provide instructions on the management of Advance Directives/Advance Decisions within the PCT. This includes:

- Following the process outlined by the Department of Health's Reference Guide: Consent for Examination or Treatment and the BMA/GMC Code of Practice for Advance Statements about Medical Treatment. Principles outlined in the Mental Capacity Act 2005 should also be followed.
- Identifying those clinical staff responsible for following the above process and managing Advance Directives.
- Identifying the skills & training required of clinical and non-clinical staff.
- Communication channels
- Reporting structures.
- Documentation guidelines
- Storage of Advance Directives
- Information to be given to the public on Advance Directives

4. LEGAL STATUS

4.1 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).

Advance refusal of treatment, which is valid and applicable to subsequent circumstances in which the patient later lacks capacity, is **legally binding**. An advanced refusal is valid if made voluntarily by an appropriately informed person. Failure to respect such an advanced refusal can result in legal action against the practitioner (DOH 2001). Advance Directives/Decisions **are** advance refusals of treatment.

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 2001).

4.2 Patients are not able to refuse "basic care" and hygiene through an Advance Directive 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 refusal/directive.

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

- 4.4 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.
- 4.5 Criteria for valid application of Advance Directives/Decisions: please see Appendix 2. This should be read in conjunction with section 10 of this policy document from 1 October 2007
- 4.6 For criteria for valid application of Advance Decisions/Directives following the implementation of the Mental Capacity Act from 1 October 2007, please see section 10 of this policy document.

4.7 Mental Health:

A patient detained under the Mental Health Act 1983 can make an Advance Directive if they are competent at the time of making the particular decision. However, Advance Directives can be overridden by the provisions in Sections 58, 62 and 63 of the Mental Health Act 1983. In these particular circumstances, patient consent is not required by the Act and therefore the Advance Directive will not be applicable. However, if possible, a patient's advance directive or preferences should be considered as part of the treatment plan.

4.8 Verbal Advance Directives/Decisions:

While a witnessed verbal advance directive 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 directive this Directive 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 directive has been made to a patient's relative or friend, it must be supported by appropriate evidence to be valid. The treating health professional should be happy that this evidence is satisfactory. 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 10).

4.9 Children and young people:

Advance Directives are not legal for children and young people under 18. Similarly 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 treatment 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 Directive 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.

4.10 Pregnant women:

An Advance Directive will only apply where the woman has explicitly referred to the fact that the refusal should continue to apply despite her pregnancy and following the Advance Directive will not endanger a viable foetus. However if an incapacitated pregnant woman presents with an apparently valid Advance Directive then legal advice should be sought to clarify the position. The courts may consider the Advance Directive ineffective if withholding treatment risks the life of a viable foetus (BMA, 1995). An application to court can be made in these circumstances.

5. **CONSENT**

Refer to the PCT's Consent to Examination or Treatment Policy.

6. **INDIVIDUALS WISHING TO MAKE AN ADVANCE DIRECTIVE**

6.1 When responding to requests for assistance with Advance Directives, health professionals should consider:

- Is the patient over 18 years of age?
- Is the patient mentally competent? (see 6.5)
- 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 Directive with a health professional?
- Does the patient know and understand the risks of not having treatment?

(Adapted from BMA guidance, 1995)

6.2 Individuals seeking advice must be given the PCT Patient Information Leaflet on Advance Directives (Appendix 4) which is also available on the PCT website. Those who require information in another format or assistance of an advocate should be given information on to how to obtain this.

6.3 Patients should be encouraged to discuss their intention to make an Advanced Directive 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.

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

6.5 **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 (DOH, 2001).

An apparent lack of capacity to give or withhold consent to explore end of life issues may in fact be the result of communication difficulties rather than genuine incapacity. Appropriate colleagues should be involved in making assessments of capacity, such as specialist learning difficulties teams, speech and language therapists, other specialists as required, unless the urgency of the patient's situation prevents this.

If at all possible, the patient should be assisted 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.

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. The level of understanding required to make decisions must be commensurate with the gravity of the decision being made.

In a legal context, a person is deemed to have capacity if he/she can understand and retain the information relevant to the decision in question, can believe that information, and can assess it to arrive at a choice. In order for the advance directive to be valid, a patient must, at the time it was made, have had the capacity to understand and weigh the implications and consequences of that choice. As stated, the level of understanding must be commensurate with the gravity of the decision being made. The Mental Capacity Act 2005 also 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?

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, and an application to court should be made for this purpose. All assessments of capacity should be recorded in the health professional's records. Information on how to access legal advice is provided in the Notes section in the table on Page 1 of this Policy.

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 PCT Consent to Examination or Treatment Policy for guidance concerning lack of capacity. Please also consider the Mental Capacity Act 2005 from 1 October 2007. Contact details for the Independent Mental Capacity Advocate service (IMCA) for BANES are given on Page 1 of the Policy

7. IMPLEMENTATION OF ADVANCE DIRECTIVES/ADVANCE DECISIONS AND RESPONSIBILITIES:

7.1 STAFF RESPONSIBILITIES

7.1.1 Directors, Assistant Directors and Managers will ensure that:

- the Policy is made available to all staff
- all internal procedures regarding the management and following of Advance Directives are adhered to and recorded.
- Advance Directives are considered and followed where the circumstances indicate that this is valid and applicable

- clinical staff are appropriately skilled in ensuring that Advance Directives 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 Directives are provided.

7.1.2 All Clinical Staff will ensure that they

- understand and follow the PCT's policies and procedures regarding the management of Advance Directives and Consent to Treatment or Examination
- understand the legal status and professional issues concerning Advance Directives
- 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 Directives 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 Directives
- having knowledge of an Advance Directive, 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.

7.1.3 Nurses' responsibilities:

Please refer to NMC Code of Professional Conduct (2001).

This states that when patients or clients no longer have capacity to consent or refuse treatment nurses must try to establish if previously indicated treatment preferences in an Advance Directive are still valid and must;

Respect any refusal of treatment or care outlined when the individual was "legally competent, provided that the decision is clearly applicable to the present circumstances and that there is no reason to believe that they have changed their minds." (NMC Code of Professional Conduct 2001 p 5)

Nurses with a conscientious objection to limiting treatment at a patient's request should make their views known via their line manager. The PCT 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.

7.1.4 Doctors' responsibilities and Liabilities of Health Professionals:

- Medical personnel can only act on an advance directive 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 directive documentation. It is solely the burden of the patient that the directive has been brought to the attention of the medical professionals.
- The validity of an advance directive should be considered by treating clinicians.

- Staff must also ensure that the clinical situation in question has actually arisen. The directive 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 directive apply to the clinical circumstances in hand, it is better for staff to proceed as they would have in the absence of the directive. The Courts are most unlikely to criticise staff in this situation.
- Clinicians must take note of an advance directive, and having been notified that an advance directive 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 directive. If a person is now incapacitated but is known to have objections to all or some of the treatment, healthcare professionals may not be justified in proceeding, even in an emergency. They will need to consider the available evidence about the patient's views and how convincing it seems. In the absence of evidence of refusal, treatment which is in the interests of that individual can be given.
- Questions arise about the ethical status of discontinuing treatment, which was already initiated prior to the discovery of an advance directive. The BMA considers that late discovery of an Advance Directive after treatment has been initiated does not mean that the directive cannot be implemented. Treatment should therefore be discontinued in accordance with the directive once it is known, unless there is doubt as to the document's validity.
- Clinicians should consider their own views and inform patients at the outset of any absolute objection to the principle of the advance directive. The patient then has the opportunity to consult another doctor. Doctors who are unexpectedly faced with an advance directive, 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 directive.
- Clinicians may be legally liable if they disregard the terms of a valid advance directive (i.e. refusal of treatment), if the directive is known of, and applicable to the circumstances.
- Health professionals following the terms of a clear advance directive 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 directive to a patient other than the one who made it would raise issues of negligence.
- If the situation is not identical to that described in the advance directive, it is still possible to act, if possible, in the general spirit of the directive. If any individuals are named in the directive for contact, they, as well as the patient's GP may be able to clarify the patient's wishes.
- 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. Health professionals must use their own professional judgement about the appropriateness of the advance directive.
- If an advance directive 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 directive cannot demand that treatment is provided. Therefore, if an advance directive does consent to certain treatment options, the health team will have to assess whether the treatment is medically appropriate or advisable for the patient at that time.
- Health professionals faced with questions from their patients about Advance Directives, or who are required to consider the implementation of an advance directive should consult the BMA's Code of Practice 1995 as well as this policy document. Staff should also be aware of the Mental Capacity Act 2005 and the impact that this has.
- Requests for further information by medical professionals which cannot be obtained from the PCT should be directed to:
 - Medical Ethics Committee Secretariat
 - Medical Ethics Department
 - BMA House
 - Tavistock Square
 - London, WC2H 9JP
 - Tel: 020 7383 6286
- Health professionals should be reminded that the provision of the Mental Capacity Act 2005, took full effect from 1 October 2007, and that there are changes to this area of practice both from a legal and clinical perspective. The law as it applies from 1 October 2007 is outlined at Section 10 of this policy document.

7.2 Method of Implementation

Follow the recommendations in the Department of Health Reference Guide to Consent for Examination and Treatment (March 2001 – or any updated versions), and the BMA Code of Practice (April 1995 – or any updated versions) and NMC Codes of Conduct.

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

- a) assess that current circumstances are valid and applicable (see appendix 2 and Section 10).
- b) check that the Advance Directive remains valid if the patient can be communicated with
- c) discuss any implications of following the directive and document the discussion (this discussion will ideally be witnessed)
- d) involve any nominated individual, family or the patient's general practitioner, to assess validity and applicability where there is any element of doubt
- e) exercise judgement regarding the best interests of the patient.

7.3 Training requirements

All health professionals who may be expected to support an individual's request concerning an Advance Directive should have undertaken training appropriate to their role. Training in Consent, the Mental Capacity Act 2005 and Advance Directives will be provided by the PCT.

7.4 Internal documentation systems for the management of Advance Directives must be established as follows:

Clinical records must record the following:-

- a) The presence of an Advance Directive and the content of it. Contact details of the health care proxy should also be recorded (Appendix 1), as well as the patient's GP. Please also consider whether a Lasting Power of Attorney with substituted healthcare decision making has been created since The Advance Directive/Decision was made (see 1.5)
- b) The assessment of the validity and applicability of that Directive 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.
- c) Any discussions with the patient regarding the implications of the Advance Directive.
- d) Any decisions made regarding care/treatment given which is considered to be in the best interests of the patient.
- e) Withdrawal of or alteration to the Advance Directive (see section 8.0).

7.5 Internal management systems must be established as follows: -

- a) systems must be developed and implemented to enable all clinical staff to discuss issues regarding the management and following of Advance Directives 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 the PCT 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 Directive.
- b) the GP and community staff must be informed of the presence of an Advance Directive/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
- c) the Clinical Governance Lead or Assistant Director of Quality and Risk will provide advice and support for complex issues relating to Advance Directives
- d) issues will be reported to the Clinical Governance Committee.

7.6 Identifying patients who have made an Advance Directive

- a) It is the patient's responsibility to let relevant professionals know of the existence of the document, where it is stored 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, or could not find, the Advanced Directive although they will need to consider available **evidence** about the patient's views.
- b) Storage of documentation regarding an Advance Directive 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 directive 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 directive should be filed with the patient's hospital medical records. Again, please consider whether a Lasting Power of Attorney with substituted healthcare decision making has been created since the Advance Directive/Decision was made (see 1.5)

- c) Although not a legal requirement, the existence of an advance directive 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 directive, and the circumstances in which it will be appropriate.

7.7 Disputes

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 the common law doctrine of necessity (now codified in Section 5 of the Mental Capacity Act 2005) until such issues are resolved. If the dispute cannot be resolved following these measures then legal advice should be sought.

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 Directive 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).

8. WITHDRAWAL OF OR AMENDMENT TO AN ADVANCE DIRECTIVE

- 8.1 If a person wishes to withdraw their Advance Directive 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.
- 8.2 If a health professional is informed by the author of an Advance Directive 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 Directive 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.
- 8.3 Where an advance directive no longer reflects a competent person's wishes it becomes invalid. Ideally where there are changes to an advance directive, a new document should be produced and the old document destroyed. However, if an advance directive 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.
- 8.4 **Photocopying of Advance Directives 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.**

9. REFUSAL OF MEDICAL TREATMENT (WHERE NO ADVANCE DIRECTIVE EXISTS)

Adults have the right under common law to refuse medical treatment in the absence of a formal Advance Directive. 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.

10. ADVANCE DIRECTIVES/DECISIONS – IMPACT OF THE MENTAL CAPACITY ACT 2005

The Mental Capacity Act 2005 (“the Act”) principally took effect on 1st October 2007.

Under the Act, Advance Directives (Living Wills) are broadly to be known as Advance Decisions or Advance Refusals.

The Act itself has codified but not substantially changed the law in this area.

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.

Is the Advance Decision Binding?

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

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.

Validity

- 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 the Advance Decision is overridden by a later and applicable Lasting Power of Attorney (which entitles those appointed to take healthcare decisions on behalf of the individual in the current situation).

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.

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 Mental Health Act cannot always make an Advance Decision in respect of treatment to be provided as part of that detention. Please see section 4.7 for further details.

Impact of the Advance Directive/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.

11. **REFERENCES & BIBLIOGRAPHY**

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DEFINITION OF TERMS

ADVANCE DIRECTIVES/ADVANCE DECISIONS (LIVING WILLS/ REFUSALS)

An Advance Directive (living will) 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 Directive 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 Directives/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 (DOH 2001). 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 do not have the same rights at law as an adult.

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, depending on the gravity of the decision to be made.

Please refer to PCT 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 the patient's medical, nursing and other appropriate notes.

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 to take healthcare decisions, from 1 October 2007).

Please refer to PCT 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

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 Directive 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. An Advance Decision "outranks" a Lasting Power of Attorney and person nominated under it, unless the Lasting Power of Attorney was created after the Advance Directive/Decision and is valid/applicable.

A healthcare proxy not appointed under a Lasting Power of Attorney 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 Directive/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 Directive. **PCT employees should not act as independent witnesses.**

CRITERIA FOR VALID APPLICATION OF ADVANCE DIRECTIVES

- a) The subject of the Advance Directive must be 18 or over at the time the document was prepared and signed.
- b) The subject of the Advance Directive must have been mentally competent and not suffering from any mental distress at the time the directive was drawn up.
- c) The subject of the Advance Directive must not have been influenced or harassed by anyone else whilst preparing it.
- d) The subject of the Advance Directive must have been fully informed about the treatment options and their implications when the Advance Directive was made.
- e) The advance directive should be current reflecting the up-to-date views/wishes of the individual
- f) 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, PCT employee or anyone who stands to benefit from the subject's Last Will and Testament or the death of the patient.
- g) The document must have anticipated the particular circumstances that in fact arise and intended the Directive to apply in those circumstances.

From 1 October 2007, please consider Section 10 for additional factors regarding a valid and applicable Advance Directive/Decision as a result of the Mental Capacity Act.

In addition please note:

- In all circumstances, a contemporaneous decision by a competent individual overrides previously expressed statements or an advance directive made by that person (BMA 1995)
- Any provisions of Advance Directives refusing treatment for mental illness are rendered **invalid** in circumstances where the patient is legally detained for treatment.(BMA 1995)
- Health professionals may be legally liable if they disregard the terms of an Advance Directive if the Directive is known of and applicable to the circumstances (BMA 1995)

Source: Age Concern 2003: Advance Statements, Advance Directives and Living Wills BMA 1995 Advance Statements about medical treatment –code of practice.

WHEN TO INVOLVE AN INDEPENDENT MENTAL CAPACITY ADVOCATE (IMCA)

Independent Mental Capacity Advocates (IMCA)

You must involve an IMCA in the following situations and where the person you are representing lacks capacity and has no relative, friend or unpaid carer to support them.

Professionals should make a referral to an IMCA when the **NHS** body is proposing:

- Serious medical treatment
- A stay of more than 28 days in hospital or 8 weeks in a care home
- A change to a person's accommodation to another hospital for more than 28 days or more than 8 weeks in a care home

Professionals should consider whether it would be appropriate to make a referral to an IMCA when the **Local Authority** is proposing:

- To change, or to provide, residential or supported accommodation for more than 8 weeks

An IMCA may also be instructed to support a person who lacks capacity to make a decision concerning:

- Care reviews, where no-one else is available to be consulted
- Protection of Vulnerable Adult Procedures, whether or not family and friends are involved, and when the person who lacks capacity is abusing another person

An IMCA would not be involved if:

- The treatment needed to be provided as a matter of urgency
- If the person lacking capacity would be made homeless unless they were admitted to a care home

For further information on the IMCA service contact:

Sue Sherrin, Bath Mind, 13 Abbey Church Yard, Bath. BA1 1LY

Tel. 01225 316330

E-mail: bathmindimca@btconnect.com

Website: www.bathmindimca.org.uk

For further information on the Mental Capacity Act refer to the PCT's Guidance on Mental Capacity Act.

Where can I get more information?

Several health and social care related organizations provide these forms including:

Age Concern – Bath & NE Somerset

18, Kingsmead Square, Bath BA2 2AE

Telephone: 01225 466135

Email: age@concernbnes.freemove.co.uk

Website: 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

website www.alzheimers.org.uk

produces a free information sheet and guidance on preparing an advance directive – *Future medical treatment: advance statements and advanced directives or living wills*. This information sheet together with a sample advance directive 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

website: www.patients-association.com

produces a booklet: *Living Wills – a guide for patients*. This booklet is free to download as a pdf file from their website.

Bath and North East Somerset 
Primary Care Trust

ADVANCE DIRECTIVE/DECISION (LIVING WILL)

September 2007 (v2)

What is An Advance Decision or Living Will?

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 and Living Wills

A general principle of law and medical practice is that all adults have a right to consent to treatment or to refuse medical treatment.

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 nominate a person to take healthcare decisions on your behalf under a Lasting Power of Attorney. An Advance Directive/Decision will still be valid however unless the Lasting Power of Attorney was created after the Advance Decision, and is valid/applicable in the circumstances. The views of a person appointed under a Lasting Power of Attorney with regard to healthcare decisions will have legal effect.

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 a Living Will?

Anyone over the age of 18 can make a Living Will. It is a way of ensuring doctors do not give you certain medical treatments against your wishes.

Why make a Living Will?

You can choose in advance the circumstances in which you would want to discontinue medical treatment. You can use a Living Will

to specify which organs, if any, you would like to donate after your death.

Who should I tell?

Although not obligatory, it is advisable to discuss your intention to make a Living Will with a Healthcare professional in the first instance. The existence of a Living Will and contact person should be recorded in your medical records. If possible a copy of the document should be kept with the medical records. It is, however, your responsibility to let all the health professionals treating you know about your Living Will, 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 a Living Will used?

It is important to remember that a Living Will 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 Living Will 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 a Living Will?

You can put your requirements in writing or use a specially pre-printed form. You can ask for help from an advocacy organization such as Age Concern or the Alzheimer's Society. This is important since new legislation takes/took effect on 1 October 2007.

It is important that your Living Will is updated at least every 5 years.