

**East Midlands**

**Health and Social Care Community**

**Advance Decisions to Refuse Treatment**

**Specialist Guidance  
(Adult)**

**April 2007**

## CONTENTS

<b>Contents</b>	Page 2
<b>Documentation Control</b>	Page 3
<b>Preface</b>	Page 4
<b>Executive Summary</b>	Page 5
<b>1 Introduction</b>	Page 8
<b>2 What is an Advance Decision to Refuse Treatment?</b>	Page 9
<b>3 Are Advance Decision to Refuse Treatment Legally Binding?</b>	Page 10
<b>4 Determining Best Interests</b>	Page 12
<b>5 Assessment of Capacity</b>	Page 13
<b>6 Making written and verbal Advance Decision to Refuse Treatment</b>	Page 15
<b>7 Storage and Distribution of an Advance Decision to Refuse Treatment</b>	Page 18
<b>8 Dealing with an Advance Decision to Refuse Treatment</b>	Page 19
<b>9 Education and training</b>	Page 20
<b>10 References</b>	Page 21
<b>Appendix 1 – Example Advance Decision to Refuse Treatment Proforma</b>	Page 22
<b>Appendix 2 – Advance Decision to Refuse Treatment Patient Information Leaflet</b>	Page 24
<b>Appendix 3 – Glossary</b>	Page 27

## Documentation Control

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### Organisations to receive ratified Policy:

NHS Primary Care Trusts	Acute Trusts	NHS Trusts – Mental Health and Learning Disabilities	NHS Trusts	County Council / Social Services
Nottingham City PCT	Chesterfield Royal Hospital NHS Foundation Trust	Derbyshire Mental Health Services NHS Trust	East Midlands Ambulance Service NHS Trust	Nottinghamshire County and Nottingham City
Nottinghamshire County tPCT	Derby Hospitals NHS Foundation Trust	Leicestershire Partnership NHS Trust	NHS Direct	Derbyshire and Derby City
Bassetlaw PCT	Doncaster and Bassetlaw Hospitals NHS Foundation Trust	Lincolnshire Partnership NHS Trust		Leicestershire County and Leicester City
Lincolnshire tPCT	Kettering General Hospital NHS Trust	Northamptonshire Healthcare NHS Trust		Lincolnshire County Social Services
Derby City PCT	Northampton General Hospital NHS Trust	Nottinghamshire Healthcare NHS Trust		Northants County Council
Derbyshire PCT (excluding Glossop)	Nottingham University Hospitals NHS Trust	Derbyshire Mental Health Services NHS Trust		
Leicester City PCT	Sherwood Forest Hospitals NHS Foundation Trust			
Leicestershire County and Rutland PCT	United Lincolnshire Hospitals NHS Trust			
Northamptonshire PCT	University Hospitals of Leicester NHS Trust			

## Preface

It is a matter of individual choice as to whether or not a person wishes to make an Advance Decision to Refuse Treatment (ADRT). This is entirely voluntary. An Advance Decision to Refuse Treatment can be made at any time but if capacity is lost this decision has to pass the requirements to be valid and applicable.

The East Midlands Health and Social Care Community wish to ensure that patients are freely able to express their wishes and that those wishes are respected in all areas of healthcare as well as during transport between them.

The objective of this specialist guidance is to raise awareness of all health and social care professionals on the nature and implications of an Advance Decision to Refuse Treatment including: -

- The potential advantages and disadvantages of making an Advance Decision to Refuse Treatment
- The legal issues surrounding Advance Decision to Refuse Treatment
- Dealing with requests from patients wishing to make an Advance Decision to Refuse Treatment
- Where to obtain help and guidance in cases of uncertainty (detailed guidance is given in Dealing with an ADRT)

**This specialist guidance is intended for adults (aged 18 and over) with capacity. Legal advice is necessary for people wishing to make advance decisions below that age.**

**Consideration is necessary for women of childbearing age who may be or are actually pregnant. An ADRT may affect an unborn child, who does not have legal status until born. The pregnant mother is still permitted to make an ADRT. It is necessary to clarify with your organisation or with a legal opinion whether any advance decision made would still be valid.**

**It is not the intention of this guidance to replace Do Not Attempt Resuscitation (DNAR) policies per se. The implementation of the Mental Capacity Act will require a full review of all such policies. Specialist guidance is currently being considered by the General Medical Council and other professional bodies. Refer to your local DNAR policies for current practice within your organisation.**

## Advance Decisions to Refuse Treatment: Executive Summary

The Mental Capacity Act 2005 will be implemented in two phases. Advance Decisions to Refuse Treatment (ADRT) will become into force in October 2007. ADRT should be viewed as part of Advance Care Planning, underpinned by Good Clinical Practice. The Code of Practice tells us how to implement this Act. There must be compliance at every level; failure to do so may be a criminal offence.

**An ADRT enables someone aged 18 and over while still able to refuse specified medical treatment for a time in the future when they may lack the capacity to consent or refuse that treatment.**

### What is mental capacity?

In a day-to-day context, mental capacity means the ability to make decisions or take actions affecting daily life. This can change over time due to illness

**Assessing Capacity: The Mental Capacity Act asks us to use a 2-stage test of capacity**

- 1. Is there an impairment of, or disturbance in, the functioning of the person's mind or brain?**
- 2. Is the impairment or disturbance sufficient that the person lacks the capacity to make that particular decision at a particular time?**

This 2-stage test must be used and your records must show it has been used. Stage 2 often requires the assessor to explore if the person can:

- a) Understand in broad terms and simple language what decision they need to make and why they need to make it?
- b) Understand the consequence of making or not making this decision?
- c) Understand, retain and weigh up the relevant information related to this decision
- d) Communicate the decision by any means including the help of an appropriate specialist.

In some circumstances the ability to make a decision can be unfairly influenced by others including coercion by healthcare professionals or family / carers

### **Five key principles are contained within in the Act**

1. A person must be assumed to have capacity
2. A person is not to be treated as unable to make a decision **unless all practicable steps to help him/her to do so have been taken without success**
3. A person is not to be treated as unable to make a decision **merely because he makes an unwise decision.**
4. An act done or decision made, for or on behalf of a person who lack capacity **must be done, or made, in his/her best interests.**
5. Before the act is done or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is **less restrictive** of the person's rights and freedom of action

### **Basic Rules to clarify that an Advance Decision to Refuse Treatment is legal**

An Advance decision to Refuse Treatment **must Exist, be Valid and Apply** to the circumstances outlined e.g. refuse a specific treatment in the event of a predicted and described situation. Anyone involved with people with Advance Decisions should always test any situation against these 3 criteria.

**What format does an Advance Decisions to Refuse Treatment have to be in?**

1. In writing (best practice)
2. Full details of maker
3. Name and address of General Practitioner and whether they have a copy
4. Statement that decision is intended when capacity is lost
5. Must specify the treatment that is to be refused
6. Must specify the circumstances in which the refusal will apply
7. Date written (and reviewed)
8. Maker's signature (or nominated individual)
9. Witness signature (signed in the maker's presence)

**Please note that if the decision is the Refusal of Life-Sustaining Treatment**

The format must (by law) be in writing, include distinguishing features to help confirm identity, be specific to the circumstances and which treatments are being refused and include the words "even at risk of life"

**What is life-sustaining treatment?**

Depends on type and circumstances of intervention. Artificial Hydration and Nutrition is a clinical intervention and is considered treatment. Basic care is not treatment eg hygiene, warmth, the offer of food and water (by normal routes). It is essential this is clarified to people at the time of decision.

**What should the maker of an ADRT do?**

It is the responsibility and (good practice) for the maker of an ADRT to **discuss, create distribute, review, withdraw/ amend** their decision. Professionals might be asked to offer support.

**Telling people of the ADRT - Copies should be distributed to:**

1. Stay at the person's home / residence
2. Other / relevant family or preferred person
3. Care Home (if a resident)
4. General Practitioner / Health Centre
5. Key Worker, Specialist Health, Social or Care Professional
6. Ambulance service, local Acute Hospital Trust, NHS Direct, Out of Hours Provider
7. To consider informing the person's solicitor (if relevant)

**When acting in persons' "Best interests" the following must be considered:**

1. Is the lack of capacity temporary or permanent?
2. Respect patient's past and present views
3. Refer to any relevant written statement made when the individual had capacity
4. Consult opinions of family or appropriate others, especially those holding lasting power of attorney
5. Encourage participation of the patient in decision making process
6. Any decision must be the less restrictive alternative e.g. effect on liberty
7. Avoid discrimination

**What is Lasting Power of Attorney?**

A Lasting Power of Attorney (LPA) is a formal document, which indicates that a person has chosen to nominate an individual to make decisions regarding their personal or medical care, which can include life-sustaining treatment. Once the LPA has been properly registered with the Office of the Public Guardian any previous ADRT is invalidated.

## **Is the Mental Capacity Act anything to do with mental illness?**

It must be clearly understood that the Mental Capacity Act 2005 does not replace the Mental Health Act 1983. These Acts refer to different circumstances. The Mental Health Act 1983 applies to the assessment, admission, and treatment of patients with a mental disorder, or guardianship of clients under the Act.

If the person retains capacity and is not under compulsory treatment (Part IV) for their mental disorder they still have the right to make an ADRT. If the person is detained under Part IV of the Mental Health Act treatment of the mental disorder cannot be refused even if it is mentioned in the ADRT. An ADRT for a physical disorder could still be valid and applicable despite being detained under Part IV of the Mental Health Act. A person subject to detention under other components of the Mental Health Act cannot have their ADRT for any reasons overridden.

## **Emergency Situations**

A doctor may safely provide treatment, which is considered to be in the patient's best interest unless there is a qualifying, valid and applicable ADRT. Emergency treatment should not be delayed in order to look for an Advance Decision if there is no clear indication that one exists.

## **Liability of Healthcare professionals**

In the presence of a valid and applicable Advance Decision, actions contrary to this Advance Decision may be liable to civil or criminal proceedings. If there are genuine doubts about the existence, validity or applicability, treatment can be provided (if they can demonstrate that this belief was reasonable)

### **How professionals should deal with an Advance Decision to Refuse Treatment**

The first member of staff who becomes aware of a patient's advance decision to refuse treatment for the first time should:

1. Acknowledge its existence to the patient
2. The patient or nominated individual should provide, a copy of the written document and it should be placed prominently in the records
3. Inform the senior medical practitioner responsible for the patient current team
4. The team should clarify its validity and applicability
5. Inform the multidisciplinary team and ensure that the information is mentioned at team handovers
6. When possible, clarify with relatives and carers that they have been advised of the existence of the ADRT (if it is clear that advising the relatives and carers would be in the patient's best interests, as the Advance Decision is a confidential document)
7. If a written document has not yet been made, encourage the patient to complete one if possible, offering the available proforma
8. Any team member must declare their conscientious objections to carrying out the instructions in the ADRT as soon as possible

**The person who retains capacity always has the right to change their ADRT. Remember, this ADRT only applies when a person loses capacity.**

***Avoid mistakes by clear communication and documentation***

## 1 Introduction

Advance Decisions to Refuse Treatment (ADRT) is one of the important areas covered by the Mental Capacity Act 2005, which will become law in a phased way in April 2007 and October 2007. ADRT will become subject to statutory law in October 2007, which must be followed, rather than case law, by which they are currently governed. Adults with capacity have always had the right to refuse treatment for a physical illness by withholding their consent to treatment. The Mental Capacity Act formalises in statute the potential of individuals making refusals in **advance** for those that subsequently lose capacity.

Patients' autonomy can be challenged by professionals or systems in several ways. There are many possible reasons why staff / systems of organisations fail to recognise, communicate and ensure patient choice is respected. ADRT should be viewed as an integral part of Advance Care Planning, underpinned by Good Clinical Practice (GMC 2006).

**The purpose of the Mental Capacity Act and the accompanying Code of Practice** is to provide both the statute and framework for acting and making decisions on behalf of individuals who lack mental capacity.

**Everyone working with and / or caring for adults who lack capacity, whether they are dealing with everyday matters or life-changing events in the lives of people who lack capacity must comply with the Act.**

Individuals with capacity already have the right to refuse or withdraw their consent to medical treatment. The Mental Capacity Act enshrines the right of people with capacity to be able to define, **in advance**, which medical treatments they will not consent to, at a time when that individual has lost capacity. Treatment and care preferences should be considered as part of Advance Care Planning (National End of Life Care Programme 2007).

### **Five key principles are contained within the Act**

1. A person must be assumed to have capacity unless it is established that he lacks capacity
2. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success
3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
5. Before the act is done or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is **less restrictive** of the person's rights and freedom of action

The East Midlands Health and Social Care Community wishes to ensure that all patients are able to express their decisions and that all staff are familiar with the methods of ensuring those decisions are respected.

**Emergency treatment will not be delayed in order to look for an ADRT decision if there is no clear indication that a valid and applicable one exists.**



## 2 What is an Advance Decision to Refuse Treatment?

People may have heard of terms such as “Living Will”, “Advance Statement” or “Advance Directive”. The Mental Capacity Act 2005 now refers exclusively to an **‘Advance Decision to Refuse Treatment’ (ADRT)**.

**An ADRT enables a person, aged 18 and over, whilst still capable, to refuse specified medical treatment for a time in the future when they may lack the capacity to consent to or refuse that treatment.**

**An ADRT must be valid and applicable to the circumstances when the ADRT becomes active. If it is, it has the same effect as a current decision that is made by a person with capacity: healthcare professionals must follow the decision.**

This is explicit in meaning and clearly requires the person making such a decision to ensure that it is valid, applicable, and specific to the treatments the person wishes to refuse. The decision must specify the circumstances in which the refusal will apply at the point when capacity is lost.

These provisions apply only to advance decisions to refuse treatment. No patient, whether or not he has capacity, has the right, in law, to **demand** specific forms of medical treatment, either at the time or in advance, if professionals consider the treatment to be clinically unnecessary, futile or inappropriate.

An ADRT cannot require a doctor to do anything that is unlawful, including any action taken with the intent of ending a person's life. A valid and applicable ADRT previously made by a person who had capacity at the time cannot be considered suicide. The adherence of a health or social care professional to a valid and applicable ADRT cannot be regarded as assisted suicide. If the ADRT is potentially not valid or applicable, a comprehensive review of the situation must occur.

**ADRT only apply to treatment and cannot: -**

- Give guidance on disposal of property
- Appoint executors of Last Will and Testament
- Replace a Last Will and Testament
- Refer to an event after a persons death e.g. post mortem examination that might be directed by a Coroner

### **3 Are Advance Decisions to Refuse Treatment legally binding?**

If an ADRT exists and is valid and applicable, it has to be followed by everyone, as it is a legal document. An ADRT becomes active when a person loses capacity. A person who has capacity continues to make their own decisions and the ADRT they have made is inactive.

**In order for the ADRT to be valid and applicable the following must apply.**

#### **1) Existence**

If an ADRT exists all health and social care professionals must make reasonable efforts to confirm its existence e.g. check care records, ask relatives / carers. In the context of decisions to refuse life-sustaining treatment this must be in written format. It is the responsibility of the maker of an ADRT to have taken actions to alert people to this decision.

#### **2) Validity**

To be valid the maker of the ADRT fully understood the implications of the ADRT when it was made.

Events that would make an Advance Decision invalid are

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

#### **3) Applicability**

Once the ADRT is established as valid it must be determined that it is applicable to the situation in question.

An ADRT is not applicable to the treatment if:

- The proposed treatment is not the treatment specified in the ADRT
- The circumstances are different from any specified in the ADRT
- There are reasonable grounds for believing that circumstances have now arisen, which were not anticipated by the person when making the ADRT and which would have affected the ADRT on had he anticipated them at the time.

In the assessment of the validity and applicability of an ADRT consideration should be given to an ADRT made at a significant time in the past, as there may have been changes in the patient's personal life, or developments in available medical treatments. Professional judgement needs to be exercised.

## **Liability of Healthcare Professionals**

In the presence of a valid and applicable ADRT actions contrary to this ADRT may be liable to civil or criminal proceedings. If there are genuine doubts about the existence, validity or applicability, treatment can be provided (if it can be demonstrated that this belief was reasonable). These doubts should be documented.

## **Conscientious Objection**

Wherever possible, health and social care professionals with a conscientious objection to managing a patient declining a life saving treatment in line with their valid ADRT should make their views clear when the matter is initially raised.

An option to transfer care of the patient must be offered, if feasible. Beliefs of health and social care professionals should be respected, but they cannot abandon their duty of care to patients. The Court of Protection can direct actions if no agreement can be made.

Health and social professionals are not legally bound to provide treatment, requested in advance, if it conflicts with their professional judgement on what is clinically necessary or appropriate for the patient. Nevertheless, they should take into account the persons preferences in an Advance Statement when deciding what is in their Best Interests. They are however legally bound by a valid and applicable ADRT, even if relatives or carers disagree with it.

## **What is life-sustaining treatment?**

ADRT can incorporate a decision specific to life sustaining treatment. This is often regarded as a treatment, which a person providing the healthcare regards as necessary to sustain life. Whether a treatment is 'life sustaining' depends not only on the type of treatment, but also on the particular circumstances it is prescribed

There is often concern about whether the provision of food and water is a life sustaining treatment in this context. Artificial Hydration and Nutrition is legally considered as a treatment because it requires clinical intervention beyond the normal mechanisms of the body. The provision of basic care to make people comfortable including the offer of food, water, warmth, shelter, hygiene cannot be refused in an ADRT and are allowed. Patients require reassurance that ongoing support will be provided. **It is essential this is clarified to people at the time of decision**

## **ADRT and Mental Disorders**

It must be clearly understood that the Mental Capacity Act 2005 does not replace the Mental Health Act 1983. These Acts refer to different circumstances. The Mental Health Act 1983 applies to the assessment, admission, and treatment of patients with a mental disorder, or guardianship of clients under the Act.

If the person retains capacity and is not under compulsory treatment (Part IV) for their mental disorder they still have the right to make an ADRT. If the person is detained under Part IV of the Mental Health Act treatment of the mental disorder cannot be refused even if it is mentioned in the ADRT. An ADRT for a physical disorder could still be valid and applicable despite being detained under Part IV of the Mental Health Act. A person subject to detention under other components of the Mental Health Act cannot have their ADRT for any reasons overridden.

In cases of doubt it is advisable to obtain an independent clinical and or legal opinion. Ethics of Clinical Practice Committees may be a helpful source of advice.

#### **4. Determining Best Interests**

If no valid or applicable ADRT exists and the patient has lost capacity it is a requirement to establish “Best Interests” of the patient.

##### **Best Interests assessment must:**

- Encourage participation of the individual to improve their ability to take part in a decision.
- Identify all relevant circumstances that the person who lacks capacity would take into account if they were making the decision themselves.
- Find out the persons views, including past and present wishes and feelings that have been expressed verbally, in writing, through behaviour or habits; any beliefs or values that might be likely to influence the decision.
- Avoid discrimination e.g. age, appearance, condition or behaviour.
- Assess whether the person might regain capacity e.g. after receiving medical treatment. If so can the decision be delayed?
- If the decision concerns life sustaining treatment it must not be motivated by a desire to bring about the person's death
- Consult others including anyone previously named by the person e.g. carers, close family and friends, any appointed Lasting Power of Attorney, or Enduring Power of Attorney or Court Appointed Deputy. If decisions about major issues or treatments are to be made when none of the above are available an Independent Mental Capacity Advocate must be consulted. Professional standards of confidentiality must be maintained.
- Avoid restricting the person's rights by considering other options that may be less restrictive e.g. limiting liberty.

The multidisciplinary team and relatives / carers may be able to provide some information about the patient. In cases of ongoing uncertainty about what constitute the patient's “Best Interests” and where there are unresolved differences of opinion especially with the patient's family / carer it may be necessary to refer to the Court of Protection. This should only be necessary if timely negotiations at a local level with the relevant health and social care professional in charge of the person's care have failed to resolve the problem. The Senior Clinician (GP or Consultant) in charge of the patient's care must not, in the interim, stop / withdraw treatment.

All of the above must be taken into account when making the decision in “best interests and the outcome documented.

## 5 Assessment of Capacity

The presumption of capacity: "A person must be assumed to have capacity unless it is established that he lacks capacity"

### **The Mental Capacity Act requires the use of a 2-stage test of capacity for a specific decision**

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

**If so**

2. Is the impairment or disturbance sufficient that the person lacks the capacity to make that particular decision at that time?

Stage 2 often requires the assessor to explore if the person can:

- Understand in broad terms and simple language what decision they need to make and why they need to make it?
- General understanding of the consequence of making or not making this decision?
- Understand, retain and weigh up the relevant information relevant to this decision
- Can communicate the decision by any means including the help of an appropriate specialist (e.g. speech therapist, interpreter) and or equipment.

In some circumstances the ability to make a decision can be unfairly influenced by others including coercion by health and social care professionals or relatives / carers. This influence must be considered as it may affect the assessment process.

This 2-stage test must be used and documented in the patients appropriate care records.

### **Maximising decision-making capacity:**

**A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.**

**A person is not to be treated as being unable to make a decision merely because he makes an unwise decision.**

It must be remembered that: -

- There is a presumption of capacity until demonstrated otherwise
- Any assessment of capacity has to be made in relation to a particular decision (e.g. choice of treatment) at a particular time.
- An individual's capacity can vary over time, so health and social care professionals should identify the time and manner most suitable to the patient to discuss treatment options. It may be necessary to call upon expert assessment of the patient's capacity e.g. psychiatrist, clinical psychologist
- Capacity may be temporarily impaired by toxic conditions or temporary illness

- All assessments of a person's capacity should be documented in the patient's medical, nursing and other appropriate care records.

Determining capacity should be conducted using a multi-professional approach. This may reduce the burden of the decision onto a single professional; however, the final responsibility remains with the senior professional for the patient.

In cases of doubt it is advisable to obtain an independent clinical and or legal opinion. Ethics of Clinical Practice Committees may be a helpful source of advice.

## 6 Making an Advance Decision to Refuse Treatment

### Written Statements

ADRT should use clear statements in unambiguous language. The Mental Capacity Act does not impose any particular format except that it requires that certain criteria are met for ADRT relating to life-sustaining treatment.

### Format of an ADRT

Good practice guides the maker of an ADRT to include the following information

- In writing
- Details of maker including full name, date of birth, home address and any distinguishing features – in case health and social care professionals need to identify the maker if unconsciousness
- Name and address of GP and preferably whether they have a copy of the ADRT
- Statement that the ADRT should be used if the person lacks capacity to make treatment decisions
- Must specify the particular treatment that is to be refused and the circumstances in which the ADRT will apply
- Date written (and dates if reviewed)
- Maker's signature (or the signature of someone the person has asked to sign on their behalf and in their presence)
- Witness signature, name and contact details, if there is one. Signed in the presence of the above person at the same time as their signature

### If the ADRT incorporates the refusal of life sustaining treatment the following must:

1. **Be in writing.** If the person is unable to write, someone else must write it down for them e.g. a family member or a health social care professional.
2. **Be signed by the maker.** If they are unable to sign they can direct someone to sign on their behalf in their presence.
3. **Be signed in the presence of the witness.** The witness must then sign in the presence of the person making the ADRT. If the person making the ADRT cannot sign, the person can direct someone to sign on his or her behalf in front of the person making the ADRT.
4. **Include a clear, specific written statement** that the ADRT is to apply to a specific treatment **"even if life is at risk"**. If this part of the ADRT is made at a separate time it must be signed and witnessed as previously stated.

The witness is to the maker's signature and confirms the ADRT only. Just by witnessing the signature does not imply the witness has assessed the capacity of the maker.

It is possible that this health and social care professional acting, as a witness will also be the person who may assess the maker's capacity. If so this professional should also make a record of the assessment of capacity.

It is good practice to also include in the care record the details of the named professional who supported the person making this ADRT and whether the information can be shared with relatives / carers or other non professional associates / contacts.

It is recommended that a careful record of the number and distribution of the document is kept and updated, as this is extremely important when revalidating,

modifying or withdrawing the ADRT. The contact details of these recipients could be included as well, to facilitate communication

A sample ADRT proforma is included in Appendix 1, which describes the key information suggested by the Mental Capacity Act Code of Practice. Many alternatives exist and as long as the basic requirements are included, it can be valid.

**When responding to requests for assistance to make ADRT professionals should consider: -**

- Does the patient have sufficient knowledge of their medical condition and possible treatment options available, if there is a known illness?
- The patient is presumed to have mental capacity.
- Is the patient reflecting their own views and whether there is any outside pressure from other people?
- Has the patient had adequate time to consider and opportunity to discuss their decision?
- Is the patient aware of the potential drawbacks of making an ADRT? These might include misinterpretation of the decisions that have been documented and the loss of an opportunity to change one's mind once the patient loses capacity
- Has the patient advised his relatives / carers of the ADRT? Patients do not have to tell their relatives and carers. Professionals have to respect such a decision. It is usually helpful for all parties if there has been an open discussion and clear communication of the maker's ADRT. It should be recorded if the patient stipulates who they do not wish to be informed.

It may be appropriate for patients considering making an ADRT to be given a specific Patient Information Leaflet (see appendix 2). Support from a trained professional in conjunction with such leaflet may help to truly inform the patient of their choices.

**Verbal ADRT**

**These are valid for refusal of non life-sustaining treatment.** There is also no set format for how a verbal (non written) ADRT should be made. Remember that if the person retains capacity it is necessary to obtain informed consent at that time of the proposed treatment (ADRT is not active). Health and social care professionals will need to judge if this verbal ADRT to be used after loss of capacity is valid and applicable. This ADRT should be clearly documented in the patient's care record.

The entry to the care record in response to the oral statement should:

- State that the verbal ADRT shall take effect if the maker loses capacity to make decisions in the future
- Clearly note the decision, specifying the treatment to be refused and the circumstances in which the decision will apply
- Detail who was present when the verbal ADRT was made (name and dated signatures of the professionals should be included in the medical records)
- Distribute the ADRT as below ADRT



Opportunistic or casual remarks by a healthy person reflecting distaste for life-prolonging treatment in the hypothetical event of incapacity are unlikely to be considered as a valid and applicable ADRT as insufficient detail is given about specificity of the treatment being refused and in which circumstances it will apply.

**The patient should also be strongly encouraged to convert the verbal ADRT into a written form where feasible and appropriate.**

### **Reviewing, Withdrawing or Amending an ADRT**

This can be done at any time by the maker, if they have capacity. It can be done in any form including verbally unless an ADRT refusing life sustaining treatment is being added. It is best practice to do this in writing and clearly communicate changes to others involved. This should be done in a timely fashion. These contacts should have already been identified at the time of writing of the original ADRT.

If the ADRT is to be withdrawn completely all copies of the original document must be marked as no longer active. The date of cancellation and who cancelled the document should be indicated.

## **7 Storage and Distribution of an Advance Decision to Refuse Treatment**

Storage and notification of an ADRT is primarily the responsibility of the maker of the ADRT.

Patients may wish to accept support in the communication and distribution of their ADRT to the relevant people including those health and social care professionals / organisations. Some patients might have the support in a Key Worker role (a named professional who is 'best placed' to ensure the person receives co-ordinated, holistic care or timely end of life care). It is anticipated that with training the Key Worker is enabled and empowered to do this.

It is advised

- The maker should keep their own copy of the ADRT and ensure that its existence is readily identified e.g. with a Medic Alert Bracelet, prominent place in the home.
- The maker should be encouraged to give his or her own General Practitioner and other responsible health + social care providers a copy of the ADRT. The existence of this ADRT should be recorded in paper and electronic records.

Suggested list of key people, agencies / organisations who might be informed of the existence of an ADRT

- Relative / Carer
- Key Worker (health, mental health, social services etc)
- General Practitioner
- Care Home (if the person/patient is a resident)
- Ambulance Services (please see appendix for contact details)
- Out of Hours Services including NHS Direct
- Local Hospital (especially if a known / current patient)

The maker may wish to discuss this process with a solicitor and ask them to store a copy of their ADRT, but it is not essential.

Each organisation is responsible for ensuring that they have appropriate systems in place to record and respect a valid and applicable ADRT.

Clearly other services or agencies might need to be informed depending on circumstances, for example if the maker was receiving care from independent providers or charity / voluntary organisations including hospice care.

**It is expected that GP practices will have a supportive care register that identifies patients who have life limiting disease. This register might include details of advance care planning supported by other tools such as Gold Standards Framework or Liverpool Care Pathway. There should be appropriate recognition of such ADRT's or statements of preference in-patient care plans and actions to ensure the patient achieves a dignified death. An ADRT should be included in the care plan / patient record.**

## **8 Dealing with an Advance Decision to Refuse Treatment**

When staff become aware of a patient's ADRT for the first time they should: -

- Acknowledge its existence to the patient
- The maker or nominated individual must provide, a copy of the written ADRT (if life sustaining treatment is being refused)
- Inform the senior medical practitioner responsible for the patient's current care
- The team should clarify its validity and applicability and it should be placed prominently in the care records.
- Inform the multi-professional team and ensure that the information is mentioned at team handovers
- When allowed, clarify with relatives and carers that they have been advised of the existence of the ADRT. The maker may have stated that the ADRT remain confidential and not be discussed with anyone other than those providing healthcare.
- Following a verbal ADRT the maker should be encouraged to complete in a written format – staff may offer the available proforma (Appendix 1)
- Any team member with conscientious objections to carrying out the instructions in the ADRT should inform their line manager so that appropriate staffing arrangements can be made.

### **Ensuring the Advance Decision to Refuse Treatment is respected**

This is especially important in emergency situations. Please see section 3.1 Best Interests for more detail. It is vital that by proper communication and documentation that all relevant services including ambulance or other emergency services are already informed of the ADRT. In rare circumstances where a valid and applicable ADRT had been made and its existence is not known or identified by such services, treatment may be given until the existence, validity and applicability can be verified.

## **9 Education and Training**

It is expected that each organisation will develop a training and education programme with an accompanying competency framework to support members of staff. There might be advanced levels of knowledge and skills required by certain members of staff especially if they are in a senior role and have responsibility for the care of the person.

As part of this specialist guidance there will be an accompanying Training Programme. This resource contains a self-directed modular approach to the learning need and is augmented by case examples, self-assessment questions and video scenarios.

The scenarios will include examples of:

- Breaking bad news linked to introducing the concept of ADRT as part of Advance care Planning
- Assessing capacity
- Making an ADRT
- Dealing with an ADRT when presented in a clinical environment

Clinical effectiveness / audit tools have been written to support this guidance. These tools will be forwarded to health and social care organisations at the time full dissemination. These tools are examples of how staff or organisations might evaluate the implementation of a local ADRT Policy.

## 10 References

Mental Capacity Act. April 2005 [Accessed 30<sup>th</sup> April 2005]  
<http://www.opsi.gov.uk/acts/acts2005/20050009.htm>

Mental Capacity Act, Code of Practice 2007

Good Medical Practice. General Medical Council 2006  
[http://www.gmc-uk.org/guidance/good\\_medical\\_practice](http://www.gmc-uk.org/guidance/good_medical_practice)

Advance Care Planning: A Guide for Health and Social Care Staff  
<http://www.endoflifecare.nhs.uk/eolc/acp/>

### Useful Links

**CSIP - Care Services Improvement Partnership.** For more information go to [www.csip.org.uk](http://www.csip.org.uk)

**DCA - Department for Constitutional Affairs.** For more information go to [www.dca.gov.uk](http://www.dca.gov.uk)

**DH - Department of Health.** For more information go to [www.dh.gov.uk](http://www.dh.gov.uk)

**MCIP - Mental Capacity Implementation Programme** - a joint Programme between the DCA, DH, the PGO and WAG, established to implement the organisation, process and procedures to launch the Mental Capacity Act in 2007. For more information go to [www.dca.gov.uk/legal-policy/mental-capacity/index.htm](http://www.dca.gov.uk/legal-policy/mental-capacity/index.htm)

**PGO-Public Guardianship Office.** For more information to [www.guardianship.gov.uk](http://www.guardianship.gov.uk)

## Advance Decision to Refuse Treatment

<b>Name (Maker)</b> <b>John Smith</b>	<b>Any distinguishing features in the event of unconsciousness</b> <b>Bald, Tattoo of dagger on right forearm</b>
<b>Address</b> <b>Some Close, Nottingham, NGX XXX</b>	<b>Date of Birth</b> <b>13/05/34</b>
	<b>Telephone Number</b> <b>0115 7777777</b>
<p>These are my advance decisions, about my health care, in the event that I cannot consent to treatment and replace any previous decisions I have made.</p> <p><i>In these specific circumstances:</i></p> <p><b><i>When my Motor Neurone Disease has deteriorated to the point that I cannot swallow safely and I develop chest infections</i></b></p> <p><i>I wish to refuse the following treatments:</i></p> <p><b><i>Any Antibiotic treatment, help with my breathing by machine and artificial feeding including a “drip”.</i></b></p> <p><i>I would also wish to refuse life sustaining treatment, “even if my life is at risk” such as</i></p> <div style="display: flex; justify-content: space-between; align-items: flex-end;"> <div><b><i>Cardio-Pulmonary Resuscitation (restarting my heart or breathing)</i></b></div> <div style="border: 1px solid black; padding: 2px 10px; text-align: center;"><b>x</b></div> </div> <div style="display: flex; justify-content: space-between; align-items: flex-end; margin-top: 10px;"> <div><b><i>Assisted Ventilation (breathing), including by use of a machine</i></b></div> <div style="border: 1px solid black; padding: 2px 10px; text-align: center;"><b>x</b></div> </div> <div style="display: flex; justify-content: space-between; align-items: flex-end; margin-top: 10px;"> <div><b><i>Artificial Nutrition and Hydration (giving food or water by any other route than by my mouth)</i></b></div> <div style="border: 1px solid black; padding: 2px 10px; text-align: center;"><b>x</b></div> </div> <p><i>I have marked the boxes to show that these are specific treatments I do not want. I am aware that I will be provided basic care, support and comfort</i></p>	
<b>Maker’s Signature</b> <b>J Smith</b>	<b>Date of Signature</b> <b>15/05/07</b>
<b>Witness</b>	
<b>Name</b> <b>Mr A Friend</b>	<b>Witness Signature</b> <b>A Friend</b>
<b>Address</b> <b>11 Good Rd Nottingham</b>	<b>Telephone</b> <b>0115 1726354</b>
	<b>Date</b> <b>15/05/07</b>

**Person to be contacted to discuss my wishes:**

**Name**            **Mr Richard Smith**                      **Relationship**    **Son**  
**Address**        **43 Another Rd**  
                      **Leicester**                                      **Telephone**        **0116 5672341**

I have discussed this with (eg name of Healthcare Professional) **Dr W Coat**

**Profession / Job Title**            **Consultant Neurologist**  
**Contact Details**                    **Dept of Neurology, Nice Hospital, Nottingham**  
    **Tel No: 0115 1234567**

**Date**        **13/05/07**

I give permission for this document to be discussed with my relatives / carers

**YES**

NO

(please circle one)

**My General Practitioner is: (name)** **Dr Flower**

**Address**                                      **The Surgery, Daisy Rd, Nottingham**  
**Telephone Number**                      **0115 7654321**

**Review 1: Date/Time of review**                      **Valid until**

**Maker's Signature**                                      **Witness Signature**

**Review 2: Date/Time of review**                      **Valid until**

**Maker's Signature**                                      **Witness Signature**

The following list identifies which people have a copy and have been told about this Advance Decision to Refuse Treatment (and their contact details)

Name	Relationship	Telephone number
<b>Dr W Coat</b>	<b>Hospital Consultant</b>	
<b>Dr Flower</b>	<b>GP</b>	
<b>Richard Smith</b>	<b>Son</b>	
<b>Alan Friend</b>	<b>Friend</b>	
<b>L Brittan</b>	<b>Specialist Nurse</b>	
<b>Ambulance Service</b>		

Should you wish to inform East Midlands Ambulance Service please send a copy of this form by fax or post.....

## Patient Information Leaflet

(Example of core information that organisations might include)

- **Do you want to decide NOW what treatment you want to refuse in the FUTURE ? Advance Decisions to Refuse Treatment explained**
- **Advance Decisions to Refuse Treatment..... What are they?**

There may be times in the future when you may need to receive medical treatment. At these times, the health and social care professionals that treat you will always try to give you the best treatment possible.

But, in some cases, you may have strong feelings about treatment you decide not to have in particular circumstances in the future. An Advance Decision to Refuse Treatment is how you record such decisions
- **So, what goes in an Advance Decision to Refuse Treatment?**

Any treatment that you **DO NOT** wish to have in the future. There is no set format unless your decision includes refusing treatment that sustains life when it must be written. Making an ADRT is entirely voluntary.
- **Are Advance Decisions to Refuse Treatment legally binding?**

**Yes**

This is a precise way of expressing a decision NOT to have a specific treatment in specific circumstances in the future and is binding providing the ADRT is valid and applicable. These decisions **MUST** also be your OWN decisions.
- **What does an Advance Decision to Refuse Treatment form look like?**

It can be a simple form, which you fill in yourself. An example can be provided although you are free to write your own (following a certain format if you are refusing life sustaining treatment).
- **Where can I get hold of an Advance Decision to Refuse Treatment form?**

By asking a health or social care professional. Often it is best to ask your GP or Hospital team who may already be involved in your care.
- **Special Circumstances**

There may be a number of circumstances that might make such an ADRT more complicated to write and for professions to follow. This



might include women who may become or is pregnant. You should seek help if you have any doubts before making an ADRT

➤ **Communicating your Advance Decision to Refuse Treatment**

If you have made an Advance Decision to Refuse Treatment you must ensure that the key people / organisations know this. Guidance and support can be given to help you do this.

This will help to avoid difficult situations especially when an emergency happens.

➤ **Can I name someone to make my decisions about treatments I don't want if I become unable to?**

Yes. A Lasting Power of Attorney can be appointed by you to make healthcare decisions should you become unable to make your own decisions. Appointing a Lasting Power of Attorney can be done through your solicitor.

➤ **Does my Advance Decision to Refuse Treatment need to be witnessed?**

Any ADRT should be witnessed. If you are writing an ADRT the witness must sign in your presence. If you cannot sign you can direct someone to sign for you, in front of you and the witness. If possible consider asking someone to witness who is independent and has nothing to gain as a consequence to the ADRT.

➤ **Who should I discuss the types of treatment I don't want with?**

We advise you to talk your advance decisions through with your close family, the doctor, nurse or GP who are involved in your care – though you are not obliged to do so. If you have a family solicitor, it may be useful to talk your wishes through with them.

➤ **Who writes my Advance Decision to Refuse Treatment form?**

You do. Once you have discussed and decided on what treatment you don't want, you can complete the Advance Decision to Refuse Treatment form.

➤ **Does a Doctor or Nurse have to sign my Advance Decision to Refuse Treatment?**

No. We advise you to discuss what you have put in (or want to put in) your ADRT with a Doctor. This can be your GP or another Doctor involved in your care. If at any point you do speak to a Doctor about your decisions, please ask if their details can be included in your

Advance Decision to Refuse Treatment form as a point of contact for the future.

➤ **Who should know about my wishes?**

Once you have made your ADRT and preferably written, signed and witnessed your document, we advise you give a copy of it to your close family members, your GP, any other Doctor, Nurse and social worker involved in your care and potentially your family solicitor but this is not essential.

Don't forget to keep a copy of your document in an easy to access, visible place within your home and record how many copies exist, in case you change your mind.

➤ **What should I do if I want to use my Advance Decision to Refuse Treatment document?**

Tell the Health Professional involved in your care that you have an Advance Decision. Tell them **where to find it**, and who can support your decisions.

Remember a time may come when you cannot tell a health professional about your ADRT. This is why you should let people know about it as soon as possible

➤ **Can I Change My Mind?**

Yes at any time. If you change your mind then simply inform all your healthcare and social care professionals straightaway. It is important that you inform all those individuals who have a copy of the previous Advance Decision as this is now invalid.

➤ **Where can I go for further advice and support?**

The staff responsible for your care, including your doctors and nurses, will be able to discuss this with you. A sample form is available at your request. Additionally the Patient Advice and Liaison Service (phone number.....) can be of particular help. Your local solicitor can give advice and potential guidance on types of forms to complete to produce an Advance Decision.

Useful websites include:

Department of Constitutional Affairs [www.dca.gov.uk](http://www.dca.gov.uk)

Department of Health [www.dh.gov.uk](http://www.dh.gov.uk)

Help the Aged [www.helptheaged.org.uk](http://www.helptheaged.org.uk)

## Glossary

### Key Worker

This is a named professional who is 'best placed' to ensure the person receives co-ordinated, holistic and timely end of life care. This professional could be a specialist nurse or social worker. Although this person may offer advocacy this worker is not an Independent Mental Capacity Advocate.

### Independent Mental Capacity Advocate (IMCA)

An IMCA is a professional appointed to give added protection to "unbefriended" people currently without capacity when an NHS or Local Authority is planning to make a decision. This is only necessary when there is no previously nominated representative eg LPA or court appointed deputy.

### Lasting Power of Attorney (LPA)

A person can appoint an LPA (whilst retaining capacity) to make decisions about their personal welfare and / or property at the point the person loses capacity. An LPA will have to be in prescribed fashion and registered with the Office of the Public Guardian. Those with a LPA are duty bound to act in the best interests of the person who appointed them

### Cardio – Pulmonary Arrest / Resuscitation

This is an event when the heart and / or breathing stops. Resuscitation is designed to temporarily replace this natural function by use of cardiac massage or artificial respiration whilst efforts are made to reverse the process that lead to the arrest.

### Gold Standards Framework (GSF) [www.goldstandardsframework.nhs.uk](http://www.goldstandardsframework.nhs.uk)

The aim is to improve palliative care provided by the whole primary care team by optimising continuity of care, teamwork, advance planning (including out of hours), symptom control and patient carer and staff support

### Liverpool Care Pathway for the Dying Patient (LCP)

[www.lcp-mariecurie.org.uk](http://www.lcp-mariecurie.org.uk)

The LCP empowers health and social care professionals to deliver high quality proactive care to dying patients and their relatives regardless of diagnosis. LCP is often used in the final phase, often days to last few weeks.

### Ambulance Services

These services include specialist staff and vehicles equipped to provide life-supporting treatment. Other components of such services may be more orientated to transporting people without such specialist resources or providing immediate care in the community.