Name of Policy: “Advance Decisions to Refuse Treatment by Patients” Specialist Guidance (Adult)

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This policy supersedes all previous issues

“Advance Decisions to Refuse Treatment by Patients” Specialist Guidance (Adult) v6
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“Advance Decisions to Refuse Treatment by Patients” Specialist Guidance (Adult)

Preface

It is a matter of individual choice 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 meet certain requirements to be valid and applicable.

Gateshead Health NHS Foundation Trust wishes 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 transfers between them. Making decisions in advance may help to ensure that the care a patient receives is what they would want in given circumstances, but there are disadvantages. Obviously preconceptions healthy people have about illness may be quite different from how they feel when it occurs and they are actually experiencing those circumstances.

The objective of this specialist guidance is to raise the awareness of all health professionals on the nature and implications of an Advance Decision to Refuse Treatment including (ADRT); -

- The potential advantages and disadvantages of making an Advance Decision to Refuse Treatment
- The legal issues surrounding an Advance Decision to Refuse Treatment
- Dealing with requests from patients wishing to make an Advance Decision to Refuse Treatment
- Where to obtain the help and guidance provided for dealing with an Advance Decision to Refuse Treatment

This specialist guidance is applicable to adults (aged 18 and over) with the mental capacity to make an informed decision. Legal advice is necessary for people wishing to make advance decisions below that age.

Young people under the age of majority (18 years in England) do not have the same rights in law as adults. However, there is an unclear position for those aged between 16 and 18. It is therefore good practice for children and young people to be kept as fully informed as possible about their care and treatment.

Health professionals should always seek the views of children and young people on issues that relate to their welfare

Consideration is necessary for women of childbearing age who could be or could become or are already pregnant; an ADRT may affect an unborn child who does not have legal status until born. The pregnant mother is permitted to make an ADRT if she knows she is pregnant but difficulties may arise if the pregnancy was unknown and / or confirmed after mental capacity is lost.
Advance Decisions to Refuse Treatment:

Executive Summary

The Trust acknowledges that it is the right of every competent adult patient to determine whether or not to accept medical treatment. Courts have made it clear that patients can authorize or refuse treatment and ADRT’s are legally binding in certain circumstances. An ADRT can not make a patient’s request for specific treatment legally binding. Requests for euthanasia in all forms, or assisted suicide, are not recognized by law and are therefore, not legally binding. No ADRT may preclude the giving of basic care.

An ADRT should be viewed as part of advance care planning and underpinned by good clinical practice. The Mental Capacity’s Code of Practice tells us how to implement the Mental Capacity Act 2005. There must be compliance at every level; failure to adhere to the Act’s principles may be a criminal offence.

An ADRT enables someone aged 18 and over, while they are still competent, to refuse specified medical treatment in specific circumstances, to plan for a time in the future when they may lack the mental capacity to make an informed decision about their health care.

The policy will give guidance to staff when a patient wishes to make or has made an ADRT.
1 Introduction

Advance Decision 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. ADRTs will become subject to statutory law in October 2007 (which means they must be implemented), rather than to 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.

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.

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

There are many possible reasons why staff / organisational systems fail to recognise, communicate and ensure patient choice is respected.

An ADRT should be viewed as an integral part of Advance Care Planning, underpinned by Good Clinical Practice’ (GMC 2006; National End of Life Care Programme 2007)).

Five statutory principles are contained within in 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/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 under this Act for or on behalf of a person who lacks 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 least restrictive of the person’s rights and freedom of action

Gateshead Health NHS Foundation Trust 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.
2 Policy scope

The policy explains the legal status of Advance Decisions to Refuse Treatment, what they are and what they are not and describes the processes involved in creating and implementing an Advance Decision.

The guidance offered in this document applies to all Health Professionals in the event that they are approached by or made aware that a patient either has an Advance Decision to Refuse Treatment or requests to write one. The legal and ethical aspects of ADRTs are addressed in the main body of the document.

In the event that the patient is unable to make an informed decision because of a pre-existing condition that impacts on cognitive abilities such as some learning disabilities, an independent advocate may be requested to represent the patient and ensure his/her views are incorporated whenever possible and appropriate. A PALS Officer can offer advice and guide the patient in sourcing such an advocate to act on his/her behalf. This may be via Lasting Power of Attorney (LPA) or, in mental health cases, an Independent Mental Capacity Advocate (IMCA) may be appointed (see glossary) to provide support and representation. In the cases of wishes expressed by children under the age of sixteen, a parent will advocate in the child’s best interests. Where there is unresolved conflict with clinical opinion, the Trusts corporate risk department should be consulted for advice on further actions. This might include escalating the conflict through the legal process when necessary.

This policy does not address euthanasia or assisted suicide.

The policy should be read in conjunction with the following:
- The Mental Capacity Act 2005
- The Mental Capacity Act Code of Conduct 2005
- Policy for Specimen Collection
- Policies for Consent to Treatment
- Policy for ‘Do Not Resuscitate’

3 Aim of policy

An understanding of the term “Advanced Decision to Refuse Treatment’ (ADRT) is key in enabling staff to respond to patients’ requests to withhold treatment and the processes to confirm its currency and legitimacy. The policy defines what constitutes an ADRT: this term replaces previous references to ‘Advance Directives’ and ‘Living Wills’ which are now obsolete.

The policy explains the roles and responsibilities of clinical staff, Senior Managers and the Executive Team when the issue of ADRTs is raised by a patient. Using best practice guidelines, it describes the processes required to implement an ADRT on behalf of a patient, acknowledging that Advanced Decisions can be a contentious issue and that staff need to feel supported and protected in what represents a new practice for most of them.
The policy acknowledges that there are some occasions where the implementation of an Advance Decision conflicts with the cultural, religious or personal beliefs of individual practitioners and management of these situations is identified within the document.

A definition is given of the new role of ‘Lasting Power of Attorney’ and its place within the process described. A glossary is included at appendix 8.

4 Duties (roles and responsibilities)
HealthCare professionals.

Healthcare professionals should be aware that:
• A patient they propose to treat may have refused treatment in advance
• Valid and applicable ADRT’s have the same legal status as decisions made by patients with capacity at the time of treatment.

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

If somebody tells a healthcare professional that an ADRT exists for a patient for a patient who now lacks capacity to consent, they should make reasonable efforts to find out what the decision is. Reasonable efforts might include having conversations with the relatives of the patient, viewing medical records or contacting the patients GP.

Once a healthcare professional knows a verbal or written ADRT exists, they must determine whether it is valid and it is applicable to the proposed treatment (this will be explained further in the policy detail)

Court of protection.

The court of protection can make a decision where there is genuine or doubt or disagreement about an ADRT’s existence, validity or applicability. But the court does not have the power to overturn a valid and applicable ADRT.

Patients.

Patients have responsibility to make sure their ADRT will be drawn to the attention of healthcare professionals when it is needed. They may provide their GP with a copy, ask for this to be held within their medical records or alert family or friends to where this could be found when needed.

5 Definitions

What is an ADRT?
An Advanced Decision is a general principal of law and medical practice that people have a right to consent or to refuse treatment. This applies if
• The person is 18 or older
• He / she has the capacity to make a decision about treatment
No patient has the legal right to demand specific treatment, either at the time or in advance that a healthcare professional would deem clinically unnecessary, futile or inappropriate.

**Capacity to make and ADRT**
A patient must have capacity to make the decision in respect of which he/she wishes to make and ADRT. All patients must be assumed to have capacity unless it is established that they lack capacity.

**Refusing life sustaining treatment**
ADRT’s to refuse life sustaining treatment must be in writing.

**Recording the presence of an ADRT**
The presence of ADRT is recorded in the patients medical notes.

**Guidance on making, updating and cancelling ADRT’s**
It is the patients responsibility to ensure that their ADRT is reviewed and updated and that the Trust is provided with an update document to retain on its systems. If healthcare professionals are satisfied that and ADRT exists, is valid and is applicable they must follow it and not provide the treatment refused in the ADRT.

**How to handle disagreements about ADRT**
It is ultimately the responsibility of the healthcare professional who is in charge of the patient’s care when the treatment is required to decide whether there is and ADRT which is valid and applicable in the circumstances. In the event of disagreement about an ADRT between health care professionals, or between health care professionals and family members or others close to the the patient, the senior clinician must consider all the available evidence.

**Court of Protection**
The court of protection can make a decision where there is genuine doubt or disagreement about an ADRT existance, validity or applicability. But the court does not have power to overturn a valid and applicable ADRT.

6 **Main Body of the policy**

6.1 **What is an Advance Decision to Refuse Treatment?**

People may have heard of terms such as “Living Will”, “Advance Statement” or “Advance Directive”. These terms are now redundant: the Mental Capacity Act 2005 now refers exclusively to an ‘Advance Decision to Refuse Treatment’ (ADRT) to encompass refusal of treatments in a planned way in both life- and non life-threatening situations.

An ADRT enables a person aged 18 and over and whilst still capable, to refuse specified medical treatment for a time in the future when he / she 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 and healthcare professionals must adhere to the decision.

An ADRT 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 health care staff 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 and 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, clearly documenting the process and outcomes.

An ADRT only applies to treatment and cannot:
- Give guidance on disposal of property
- Appoint executors of Last Wills and Testaments
- Replace Last Wills and Testaments
- Refer to an event after a person’s death e.g. post mortem examination that might be directed by a Coroner

6.2 Are Advance Decisions to Refuse Treatment Legally Binding?

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

In order for the ADRT to be valid, specific 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, discuss with relatives/carers (unless confidentiality issues would be compromised). It is the responsibility of the maker of an ADRT to have taken actions to alert people to this decision and he / she should either retain the original copy of the ADRT or place it with a nominated Health Care Proxy (see glossary) or solicitor.
In the context of decisions to refuse ‘life-sustaining treatment’ the ADRT must be in written format and meet specific criteria

2) Validity

For the ADRT 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 he/she still had capacity to do so
- After making the ADRT the person made a Lasting Power of Attorney (LPAPW) giving an ‘attorney’ the authority to make treatment decisions that are the same as those covered by the ADRT
- The person has said or done something, which clearly contradicts the ADRT, suggesting that they have changed their mind

An Advance Decision to Refuse Treatment over-rules:

1. An Attorney acting under the Lasting Power of Attorney (LPAPW); provided that the ADRT was made after the LPA was signed

2. The decision of a court-appointed deputy provided that the ADRT is valid and applicable

3. Health care professionals’ provision of treatment that they would otherwise believe to be in the person’s best interests, provided that the ADRT is valid and applicable

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 had he/she 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 judgment needs to be exercised.

In instances when applicability of an Advance Decision is unclear for whatever reason, a declaration can be obtained from the court as to whether the ADRT is valid or not and whether it should be implemented or
The Senior Manager on Call should contact the Trust’s Legal Services Department for advice in the first instance.

It is essential that legal advice be obtained in the event of any difficulties, conflict or uncertainty associated with ADRTs

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 is genuine doubt about the existence, validity or applicability of an ADRT, treatment can be provided (if it can be demonstrated that this doubt was reasonable). Any doubts should be documented.

Advance Decisions to Refuse Treatment that request actions such as the administration of a lethal injection are not lawful

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 action if no agreement can be made.

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

Health professionals should be aware that they could face legal action if they knowingly ignore a valid Advance Decision to Refuse Treatment

What is ‘life-sustaining treatment’?
An ADRT can incorporate a decision specific to life-sustaining treatment if certain criteria are met. Life-sustaining treatment is defined as a treatment that the healthcare professional 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 in which it is prescribed.

There is often debate about whether the provision of food and water is a life-sustaining treatment in this context. Artificial hydration and nutrition are legally considered to be treatments because they require 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 and hygiene cannot be refused in an ADRT and is allowed. Patients require reassurance that ongoing support will be provided. It is essential this is clarified to people at the time of the 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.

**N.B.**

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 overridden for any reasons.*

In cases of doubt it is advisable to obtain an independent clinical and/or legal opinion. The Trust’s Legal Services Department and Safeguarding team will provide advice when necessary.

### 6.3 Determining Best Interests

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

**Best Interests assessment must:**

- Encourage participation of the individual to improve their ability to take part in a decision if they have capacity
- Identify all relevant circumstances that the person who lacks capacity would take into account if they were making the decision themselves
- Find out the person’s views, including past and present wishes and feelings that have been expressed verbally, in writing, through behaviour or habits or 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?
- Be aware that 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. their carers, close family and friends, any appointed Lasting 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 (IMCA) must be consulted.

**Professional standards of confidentiality must be maintained**
Avoid restricting the person’s rights by considering options that may be least restrictive of 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 / carers, it may be necessary to refer to the Court of Protection (refer to the Trust’s Legal Services Department). 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 process and outcomes documented.

If the patient is competent, his or her agreement should be sought to involve relatives or carers. It may also be helpful to ask competent patients whom they want, or do not want, to be generally involved in decision-making if they do become incapacitated. Refusal by a competent patient to allow information to be disclosed to family or friends must be respected.

### 6.4 Assessment of Mental 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:

**Stage 1:**

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?

**IF YES:**

**Stage 2** 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 (e.g. interpreter and/or equipment)

This 2-stage test must be used and its use and outcomes documented in the patient’s care records

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.

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 and he should not 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 as well as unconsciousness
- All assessments of a person’s capacity should be clearly and contemporaneously 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 on 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 via the Trust’s Legal Services Department or safeguarding team.

6.5 Making Written and Verbal Advance Decisions to Refuse Treatment

A) Written Statements

In creating a written Advance Decision to Refuse Treatment, the following must be implemented:
- The patient, at or prior to the time the Decision was agreed, must have been informed in broad terms of the nature and effect of the treatment that was being refused, i.e. the consequences of non-treatment
- It must be clear that the ADRT is applicable to the current circumstances i.e. the patient had contemplated the situation that later arose and was made fully aware of probable treatment and its repercussions
• The patient must not have been unduly influenced or coerced by anyone, i.e. the decision was an autonomous one.
• A check must be made that the patient has not rescinded the ADRT either verbally or in writing since it was drawn up.
• A check must be made that the patient was mentally competent at the time the ADRT was prepared.
• In the event of an ‘end of life’ situation, the written Decision must meet all of the criteria identified (see below) in order to ensure validity.

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

Format of an ADRT

Good practice guides the maker of an ADRT to include the following information in written documentation of an ADRT:

• 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 whether they have a copy of the ADRT.
• Statement that the ADRT should be used if the person lacks capacity to make treatment decisions.
• Specification that 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. The ADRT is signed in the presence of the patient at the same time that he / she signs.

If the ADRT incorporates the refusal of life-sustaining treatment the following criteria must be met. The ADRT MUST:

1. **Be in writing.** If the person is unable to write, someone else must write it for them e.g. a family member, health social care professional or a solicitor.

2. **Be signed by the maker.** If they are unable to sign they can direct someone to sign on their behalf in their presence and in the presence of a witness.

3. **Be signed in the presence of the witness.** The witness must then sign in the presence of the person making the ADRT. The witness is to the maker’s signature only and does not require knowledge of the contents of 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.
Witnessing the signature does not imply the witness has assessed the capacity of the maker. It is possible that a health or social care professional acting as a witness will also be the person who might 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 any named professionals who supported the person making this ADRT and whether or not 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. Any new versions of the document should include the date of review and the version number. The contact details of recipients of the document should be included if possible to facilitate communication.

An example ADRT proforma is included at Appendix 4, which includes the statutory components recommended by the Mental Capacity Act’s Code of Practice. Many alternative pro formas exist and as long as the basic requirements are included, they are valid.

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

- Whether the patient has sufficient knowledge of his / her medical condition and possible treatments available if there is a known illness

- Whether, given that the patient is presumed to have mental capacity, he / she is reflecting his / her own views, whether there are any outside pressures from other people and whether the patient has had adequate time to consider and the opportunity to discuss his / her decision

- Whether the patient is 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 capacity is lost

- Whether the patient has advised his relatives / carers of the ADRT. Patients do not have to tell their relatives and carers about their ADRT and 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 must be recorded if the patient stipulates whom they do not wish to be informed.

It may be appropriate for patients considering making an ADRT to be given specific guidance (see appendix 2) as well as copies of the national information leaflets provided by the Department of Health. Support from a trained professional in conjunction with such leaflet may help to truly inform the patient of their choices.
B) Verbal Statements
(These are valid for refusal of non life-sustaining treatment ONLY)

There is no set format for how a verbal (non written) ADRT should be made. Remember that if the person retains capacity it is always necessary to obtain informed consent at the time of any proposed treatment (i.e. when an ADRT is not active). Health professionals will need to judge if this verbal ADRT is to be used following the patient’s loss of capacity to make decisions: he / she should be encouraged to translate their verbal request into a written ADRT but in any event, the verbal decision 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 refused and the circumstances in which the decision will apply. Record the substance of discussion with the patient relating to life-threatening situations when the verbal ADRT will not be applicable
- Detail who was present when the verbal ADRT was made (name and dated signatures of the professionals should be included in the medical records)
- Be highlighted to other members of the health care team involved in the patient’s care

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.

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, however if an ADRT refusing life-sustaining treatment is being added to an existing ADRT, then it must be done in writing. It is best practice to record dated changes in writing and to 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 recorded.

6.6 Storage and Distribution of Advance Decisions 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 copies of their ADRT to the relevant people including health and social care professionals / organisations. Some patients might have the support of a Key Worker (a named professional who is best placed to ensure the person receives coordinated, holistic care or timely end of life care). The Key Worker should be
trained to provide appropriate support and advocacy for the patient. It should be noted that the role of the Key Worker is to make known the patient’s wishes, not to make decisions on behalf of the patient or his / her family.

It is advised that:

- The maker should keep the original copy of the ADRT and ensure that its existence is readily identified e.g. by wearing a Medic Alert Bracelet, or placing the document in a prominent place in the home.
- The maker should be encouraged to give his or her own General Practitioner and other responsible health and social care providers a copy of the ADRT. The existence of this ADRT should be recorded in paper and electronic records and a copy will be included in the patient’s medical records. The records will also bear a yellow sticker to alert staff of the presence of an ADRT.

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 / Health Centre
- 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 an independent solicitor and ask them to store a copy of their ADRT, but this is not essential. 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. Each organisation is responsible for ensuring that they have appropriate systems in place to record and respect a valid and applicable ADRT.

It is expected that GP practices will have a supportive care register that identifies patients who have life-limiting diseases. This register might include details of advance care planning supported by other tools such as a Gold Standards Framework or Plan for the Last Few Days of Life. There should be appropriate recognition of such ADRTs or statements of preference in patients’ care plans and actions to ensure the patient achieves a dignified death. A copy of the ADRT should be included in the care plan / patient record.

### 6.7 Dealing 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 acknowledge its existence to the patient and alert the nurse in charge.

1. The nurse in charge should ensure that the patient or nominated individual provides a copy of the written document or that evidence of a verbal ADRT is
documented in the medical notes if there is no written document. N.B. If life-sustaining treatment is being refused, a written and witnessed document is mandatory

2. The nurse in charge should inform the senior medical practitioner responsible for the patient’s current medical care and offer the patient the opportunity to discuss his / her ADRT

3. The health care team should clarify the validity and applicability of the ADRT and a copy should be placed prominently in the patient’s medical records

4. The multidisciplinary team should be informed and the information reinforced at team handovers

5. The Head of Medical Records should be informed of the existence of an ADRT: a letter of acknowledgement will be issued to the patient by Medical Records and a yellow sticker added to the outside of the patient’s notes to alert staff to the ADRT

6. When possible, and with the patient’s consent if able, clarification should be sought with his relatives and carers as to whether they have been advised of the existence of the ADRT. The ADRT is, like any other health record, a confidential document and should not be discussed with anyone other than those providing direct care without the patient’s express consent. In the event that the patient is unable to give consent, the existence of the ADRT will only be shared with third parties if it is believed to be in the patient’s best interests

7. The patient should be encouraged, following a verbal ADRT, to complete a written ADRT if possible, offering a copy of the Trust policy containing guidelines, frequently asked questions and a proposed proforma (although the patient is not obliged to use this proforma). The patient may also be offered access to the Trust’s PALS Officers who can provide help and advice

8. Any team member must declare his / her conscientious objections to carrying out the instructions in the ADRT as soon as possible and they should be excused from caring for that patient without prejudice

Ensuring the Advance Decision to Refuse Treatment is Respected

This is especially important in emergency situations. Please see section above “Best Interest” for more detail. It is vital that by proper communication and documentation all relevant services including ambulance or other emergency services are informed of the ADRT. In rare circumstances where a valid and applicable ADRT has been made but its existence is not known or identified by such services, treatment must always be given until the existence, validity and applicability of an ADRT can be verified.
Documentation of Advance Decisions to Refuse Treatment

If the Advance Decision to Refuse Treatment was made verbally to a staff member and the Decision does not impact on life-preserving care, the following should be recorded in the patient’s notes:

- A note that the decision should apply if the person lacks capacity to make treatment decisions in the future
- A clear note of the decision, the treatment to be refused and the circumstances in which the decision would (or would not) apply. This is particularly important if the patient is a woman of child-bearing age as pregnancy may alter the original decision
- A comment on the person’s mental state and confirmation of their mental capacity to make the Advance Decision
- Details of anyone who was present when the verbal ADRT was made and the role in which they were present (e.g. family member, health care professional)
- Whether they heard the request or took part in discussion
- The content of any discussion, outcomes and conclusions and whether the patient’s prognosis as a result of with-holding treatment has been discussed and understood by the patient.

The opportunity to make Advance Decisions to Refuse Treatment must not be actively offered to patients in contact with the Trust

The patients may be offered the opportunity, though, to translate a verbal ADRT into a written document so that his information can be clearly recorded in their health records. It should be made clear to the patient that in life-sustaining situations, a written ADRT is mandatory.

Detailed, contemporaneous and accurate records should be kept in the patient’s medical records by all staff of all discussions concerning a patient’s wish to make an Advance Decision. If there is any doubt about the patient’s ability to understand and make an informed decision, the medical notes should include an assessment of the patient’s mental capacity using an assessment tool recommended in the Code of Practice. (Refer also to the five Principles at Appendix 1)

7 Training

The Trust is offering training related to the Mental Capacity Act to staff in a number of formats and exploration of e-learning modules and a competency framework will be used to support members of staff.

As part of this specialist guidance there is an accompanying Training Package for staff in health and social care. 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 include examples of:
• Breaking bad news linked to the patient’s concept of ADRT as part of collaborative Advance Care Planning
• Assessing mental capacity
• Making an ADRT
• Dealing with an ADRT when presented in a clinical environment

Clinical effectiveness / audit tools have been written by the Department of Health to support this guidance and will be forwarded to health and social care organisations at the time of full dissemination (October 2007). These tools are examples of how staff or organisations might evaluate the implementation of a local ADRT Policy.

Advanced levels of knowledge and skills will be required of certain members of staff especially if they are in a senior role and / or have responsibility for the care of the person.

8 Diversity and inclusion
The Trust is committed to ensuring that, as far as is reasonably practicable, the way we provide services to the public and the way we treat staff reflects their individual needs and does not unlawfully discriminate against individuals or groups on the grounds of any protected characteristic (Equality Act 2010). This policy aims to uphold the right of all staff to be treated fairly and consistently and adopts a human rights approach. This policy has been appropriately assessed.

9 Monitoring compliance with the policy

<table>
<thead>
<tr>
<th>Standard/process/issue</th>
<th>Monitoring and audit</th>
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<tr>
<td>Method</td>
<td>By</td>
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<tr>
<td>Discussion at the resuscitation council</td>
<td>2 years after implementation date</td>
</tr>
<tr>
<td>Review policy 2 years after implementation date</td>
<td></td>
</tr>
<tr>
<td>Compliance with Policy</td>
<td>6 Monthly audit to look ADRT</td>
</tr>
</tbody>
</table>

10 Consultation and review
This policy has been reviewed in consultation with the Reussitation council

11 Implementation of policy (including raising awareness)
This policy will be circulated by the Trust Secretary as detailed in OP 27 Policy for development, management and authorisation of policies.

12 References

Mental Capacity Act, Code of Practice 2005
Good Medical Practice. General Medical Council 2006
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

DCA - Department for Constitutional Affairs. For more information go to
www.dca.gov.uk

Department of Health. For more information go to 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/mentalcapacity/index.htm

PGO-Public Guardianship Office. For more information to
www.guardianship.gov.uk

13  Associated documentation
THE MENTAL CAPACITY ACT

The Mental Capacity Act (2005) provides a statutory framework for people who lack the capacity to make their own decisions or those who currently have capacity and wish to make preparation for a time in the future when they might lose that capacity. The Mental Capacity Act’s Code of Practice ‘has statutory force, which means that certain categories of people have a legal duty to have regard to it when working with or caring for adults who may lack capacity to make decisions for themselves’.

Notably this includes a variety of health and social care staff (medical and nursing staff, dentists, therapists, radiologists, paramedics for example) as well as those in more occasional contact (such as police and ambulance personnel, housing officers).

Family and paid carers, although not legally required to have regard to the Code of Practice, should use the guidance within the Code (as far as they are aware of it) to help with decision-making and implementing the wishes of the patient.

To aid understanding, a definition of someone who lacks capacity is given as: “a person who lacks capacity to make a particular decision or take a particular action for themselves at the time the decision or action needs to be taken”.

This does not necessarily pre-suppose that the person is incapable of making day-to-day decisions on their own behalf but that they may lack the capacity to make informed decisions about complex issues such as financial arrangements or health care. This may be the result of

1. a deterioration in mental capacity associated with conditions such as dementia, mental illness or mental frailness;

2. a transient condition - during unconsciousness, illness or anaesthetic for example, or if he / she is under the influence of drugs and / or alcohol;

3. a permanent or long-term lack of mental capacity to make some decisions. Those affected by learning disabilities, for example, may struggle to fully understand the impacts of the decisions they make.

The Code of Practice aims to clarify the processes associated with decision-making, confirming mental capacity and implementing decisions within a legal and ethical framework by making recommendations to underpin best practice. Any uncertainties or ambiguities associated with particular patients and / or circumstances should be brought to the attention of the Senior Manager with a view to discussion with the Trust’s Legal Services Department in the first instance.

There are no specific sanctions for non-compliance with the Code but a failure to comply can be brought before a court or tribunal in any civil or criminal proceedings. The court or tribunal can use evidence of non-compliance to affirm that actions have been taken / not taken or decisions made / not made in the person’s best interests. It is essential therefore, that all health and social care personnel are familiar with the Code as it applies to their practice.
THE FIVE STATUTORY PRINCIPLES OF THE MENTAL CAPACITY 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/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 under this Act for or on behalf of a person who lacks 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 least restrictive of the person's rights and freedom of action.
Appendix 2

Guidance for Staff in Responding to Patients requesting to make an Advanced Decision to Refuse Treatment (ADRT)

Example of Information Required from Patient:
Advance Decision to Refuse Treatment

It is always preferable for patients to have made an Advance Decision to Refuse Treatment prior to admission to hospital but there will inevitably be occasions when staff will be approached by (or on behalf of) a patient, with the request to make or amend an ADRT.

There will inevitably be occasions when patients express their wishes verbally or indicate that they have previously made a ‘Living Will’ or ‘Advanced Directive’. In these instances they should be given the opportunity to discuss and review their decisions with the health care team and should be encouraged to create a written document expressing their wishes. In the event of an existing document written prior to implementation of the Mental Capacity Act, advice should be sought from the patient’s solicitor, the Trust’s PALS Officers and its Legal Services Department about the validity of the document and how it might translate into an Advance Decision.

Recording Written Requests

Whereas written or verbal Advance Decisions to Refuse Treatment provide evidence of the treatments / procedures to be refused, in potential end-of-life situations the law demands a written and witnessed document that includes the following information:

- Name, address, date of birth of the person making the ADRT, along with a description of any distinguishing physical marks or features (in case the need for identification becomes an issue such as in unconsciousness or confusional states for example)
- Name and address of the GP and whether or not he / she holds a copy of the ADRT
- A statement that the document is to be implemented should the person lack the capacity to make an informed decision and that it is applicable ‘even if life is at risk’ if that is to be the case
- A clear statement of the ADRT, the treatment to be refused and the circumstances when the ADRT would apply and what circumstances would invalidate it, e.g. pregnancy, unexpected findings during a surgical procedure
- The date the document was written (or reviewed). It is good practice to include a version number, the numbers of copies distributed and who they were distributed to
- The person’s signature (or that of an individual asked by the person to sign on their behalf and in their presence)
- The signature of a witness to the patient’s signature and his / her relationship to the person

The patient should be provided with a copy of the Trust’s policy on Advance Decisions to Refuse Treatment with particular direction to the patient guidelines in the appendices.

The patient should be strongly advised to take independent medical advice and / or legal advice but they are not obliged to do so; he / she should be advised that there will be fees attached to legal advice.

Where assistance is required in contacting a solicitor, authorisation can be obtained from the Trust’s Legal Services Department or from the Senior Manager on call.

The Advance Decision should be written in clearly understandable language and witnessed by an independent person. Should it be necessary for a Trust employee to sign the ADRT as a witness to the patient’s signature, this should be undertaken by a consultant or senior professional who is not directly involved in the patient’s care.

If the patient is subsequently granted a Lasting Power of Attorney (Personal Welfare) that confers authority on his / her attorney to give or refuse consent to the treatment to which the ADRT relates, then the ADRT will no longer be effective.

Should an ADRT be drafted by the patient during an in-patient stay it should, with the patient’s consent, be included with the discharge letter sent to GP.
Guidelines for Patients making Advance Decisions to Refuse Treatment (ADRT)

Important: Before you complete your Advance Decision to Refuse Treatment please read all these notes carefully

Gateshead Health NHS Foundation Trust wishes to assure you and your carers that under all circumstances the health care team will strive to provide what they consider the best treatment for you. The ADRT is used to record particular aspects of treatment that you do not wish to have under specified circumstances.

This Advance Decision To Refuse Treatment is about medical treatment only. You cannot use it to say what is to happen after your death, or to make funeral arrangements, or to dispose of property after your death.

Is the Advance Decision legally binding?

It is clear that in England and Wales, an Advance Decision to Refuse Treatment is legally binding provided that:

- The document was signed by you at a time when you were mentally capable of making that kind of decision
- It really was your own decision and was not made under the influence of another person(s)
- Your refusal of future treatment(s) was intended to apply in the kind of (non-life-threatening) situation which later arose and you fully understood the consequences of your decision

AND/OR:
- You fully understood the consequences of your decision and you state in your ADRT that its instructions remain valid even if your life is at risk. You should indicate if there are specific conditions when the ADRT would become invalid, such as if you discovered that you were pregnant or if unexpected findings were made during a surgical procedure for instance.

The aim of Gateshead Health NHS Foundation Trust has been to clarify your rights relating to Advance Decisions and to provide information and a format that doctors are willing and able to use in the event that it becomes necessary. The following guidance is to help you to complete the form:

1. General Medical Treatment

There are three possible health situations described in the attached Advance Decisions document. You should read the questions carefully and make a choice by clearly deleting the option you do not want; each health care situation should be treated separately.

2. Particular Treatments and/or Investigations

If you have strong views about particular types of treatments and/or investigations, you can record them on the appropriate section of the form.

You are advised not to complete either section of the form before first discussing with your doctor (either your GP or your hospital consultant) even though you do not have to do so. It is essential that anything you write should be easily understood by the doctor who is treating you.

If you have views that you feel unable to express using this form, please make sure you discuss them with your doctor.

3. Presence of a Relative, Partner or Friend

If there is someone you would like to be with you before you die, you can nominate them on the form so that he/she can be contacted if your life is in danger.

You should make it clear in this section if you would like those caring for you to do their best to keep you alive for as long as is reasonable in order to give the person you have named a chance to be with you (although the best efforts to keep you alive may fail or the nominated person may be unable to get here in time to be with you). You should be aware that this instruction might mean that the doctors would temporarily disregard your choices as set out in section 2 of the form and also any refusal of particular treatments and/or tests.

4. Health Care Proxy

There may be someone whom you would like to take a lead in making your wishes known to the health care team on your behalf if you become unable to do so. This person is known as a ‘Health Care Proxy’. The legal status of a Health Care Proxy remains uncertain but doctors will, in practice, pay attention to what your Proxy says and consider their comments before making a decision about your care. Your Health Care Proxy may be your husband/wife or partner, a relative or any other person. If you would like an independent Health Care Proxy, the PALS Officer can help you arrange for an independent advocate to act on your behalf.

5. Signatures – Yourself and Witness

When you have completed the form you must sign and date it in the presence of an independent witness. The witness does not need to read your Advance Decision but should watch you sign before adding his/her signature and other details as requested on the form.

The witness must be 18 or over and must not be any of the following:

- Your husband/wife or partner
- A relative
• Anyone who stands to gain anything by your death, for example by inheriting anything from you
• Anyone you have appointed as Health Care Proxy or his / her husband / wife / partner
• A member of the health care team who is directly involved with your care

6. Discussion with a doctor

Although we recommend that you discuss your wishes with a doctor before you make your Advance Decision, you do not have to do so. However, you may decide later to do so, even after you have signed the document. If you decide to discuss the document with a doctor at any stage, please write the doctor’s name, address and contact telephone number in the space provided. A different doctor caring for you may want to confirm your wishes by contacting the doctor with whom you discussed your ADRT.

7. What to do with your Completed Advance Decision to Refuse Treatment

Make sure that those close to you (including and especially your Health Care Proxy if you have appointed one) know that you have made an Advance Decision to Refuse Treatment and where to find it. You may want to send a copy to your GP and / or your solicitor if you have one.

Once you have made an Advance Decision to refuse Treatment:

• You should make sure that the doctor who is treating you (your GP and / or your hospital doctor) knows about your ADRT and what it says
• Hand in a copy of your ADRT (you should retain the original copy yourself) and ask for it to be added to your hospital records and to the notes of any doctor who is looking after you. The Trust’s Legal Services Department can arrange for you to have a copy of your Advance Decision made and authorised if only the original is available; you should ask that the original copy be returned to you. Ideally the version number should be included and a record kept of the numbers of copies and their distribution
• Hospital staff will notify the Head of Health Records on receipt of an Advance Decision and a letter of acknowledgement will be sent to you to say that the ADRT has been received
• It is important to know that you have the right to alter or cancel your Advance Decision at any time. If you do cancel the ADRT, remember to tell everyone who has a copy, for example your GP or your hospital doctor
• You must also bear in mind that the clinician or clinical team looking after you can only act in accordance with the law prevailing at the time and that this may change between the date you make your ADRT and the time when you undergo your treatment. This is particularly relevant if you have already made a ‘Living Will’ or ‘Advanced Directive’ and you should discuss the document with your health care team, your solicitor or a PALS Officer
• If you subsequently grant a Lasting Power of Attorney (Personal Welfare) that confers authority on your attorney to give or refuse consent to the treatment to which the ADRT relates, then the ADRT will no longer be effective.

Checklist for writing an Advance Decision to Refuse Treatment

In drawing up an ADRT, the BMA advises that, as a minimum, the following information is included:

• Full name and date of birth
• Any distinguishing features e.g. scars, tattoos
• Address
• Name and address of the General Practitioner and whether he / she holds a copy of the ADRT
• A clear statement of the ADRT, the treatment to be refused and the circumstances when the ADRT would apply
• A clear statement that the ADRT is to be implemented even when life is at risk if this is applicable
• Any conditions or situations that would exempt the ADRT (e.g. pregnancy)
• The name, address and contact details of a nominated person if applicable
• Whether advice was sought from health and / or legal professionals (inclusion of their names and contact details if consulted)
• Signature
• Witness signature and relationship to patient
• Date drafted and reviewed, version number
Proforma for an Advance Decision to Refuse Treatment

(To be completed by the patient)

Introduction

Gateshead Health NHS Foundation Trust wishes to assure you and the people who care for you that under all circumstances the health care team will strive to provide what they consider to be the best treatment for you.

You are strongly advised to discuss your thoughts with a doctor before completing this document so that you are fully aware of all of the implications of refusing treatment. A member of the nursing staff can arrange for you to speak to a senior member of the medical team responsible for your care or you can contact your own GP if you prefer.

If you choose not to discuss your Decision with a doctor the Trust will still implement your wishes as long as you have been able to demonstrate that you are aware of the implications of refusing specific treatments in certain conditions.

Section 1 of this document is to record particular aspects of treatment that you do not wish to have under specified circumstances. Refusal of these treatments is not considered to put your life at risk.

Section 2 of the form relates to with-holding treatments that might save your life. This means that in the opinion of a health care professional, if you do not receive these treatments you may die.

If you have completed section 1 but not completed section 2, your doctor will continue to provide you with any and all active treatment he / she feels reasonable and appropriate if your life is at risk. With your consent (wherever possible), this will include consultation with your next of kin and / or your nominated Health Care Proxy as appropriate.

This Advance Decision to Refuse Treatment is about medical treatment only. You cannot use it to say what is to happen after your death, or to make funeral arrangements, or to dispose of property after your death.
ADVANCE DECISION TO REFUSE TREATMENT DECLARATION

This is an important document and Gateshead Health NHS Foundation Trust recommends that you discuss your Advance Decision with a doctor, but you do not have to. You are strongly recommended to seek the help and / or advice of an independent solicitor, although this will incur legal costs.

Please add your name and birth date at the foot of pages 2 – 10 inclusive

I Print name)........................................................................................................OF
(Address)..................................................................................................................make this Advance
Decision on .........................................................(DATE) to state my wishes in case I become unable to communicate and cannot take part in discussions about my medical care and/or treatment

My date of birth is ..........................................
Please describe any distinguishing features (e.g. birthmarks, scars, tattoos) and their location(s).........................................................
..............................................................................................................................Medical Records number..............................................................(if applicable)
Version number.........Copy No........... of.....................(TOTAL COPIES)
Section 1: Particular Treatments or Investigations

If you have any wishes about particular medical treatments or tests, you can record them here. If you wish to refuse a particular treatment or investigation, you should say so clearly (please specify the circumstances when these wishes would be implemented).

I have the following wishes about a particular medical treatment, test or investigation that does not affect my life expectancy:

Name ........................................Date of Birth..............................................
(please print)
Section 2: General Medical Treatment When Life is at Risk

There are three possible health conditions described below. These relate to situations where your life might be at risk. Within each of the three situations you should clearly delete one of the choices to indicate your advance refusal of treatment in these circumstances.

You should treat each case separately and it is important to note that you do not have to make the same choice for each condition.

I……………………………………………………………………………………………………………declare that my wishes regarding my medical treatment are as follows:

<table>
<thead>
<tr>
<th>1</th>
<th>Life-threatening condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>If I have a physical condition from which there is no likelihood of recovery <strong>AND</strong> it is so serious that my life is nearing its end:</td>
<td></td>
</tr>
<tr>
<td><strong>I DO WISH TO BE KEPT ALIVE BY MEDICAL TREATMENT</strong></td>
<td></td>
</tr>
<tr>
<td><strong>I DO NOT WISH TO BE KEPT ALIVE BY MEDICAL TREATMENT.</strong> I wish any interventions to be limited to keeping me comfortable and free from pain and I refuse any and all other treatment <strong>even if my life is at risk</strong></td>
<td></td>
</tr>
</tbody>
</table>

(please delete CLEARLY as appropriate)

Name .................................Date of Birth.................................

(please print)
(2) Permanent Mental Impairment
If my mental functions become permanently impaired with no likelihood of improvement AND the impairment is so severe that I do not understand what is happening to me AND my physical condition means that medical treatment would be needed to keep me alive:
I DO NOT WISH TO BE KEPT ALIVE BY MEDICAL TREATMENT. I wish any interventions to be limited to keeping me comfortable and free from pain and I refuse any and all other treatment even if my life is at risk.

(please delete CLEARLY as appropriate)

(3) Persistent Unconsciousness
If I become persistently unconscious with no likelihood of regaining consciousness:
I DO NOT WISH TO BE KEPT ALIVE BY MEDICAL TREATMENT. I wish any interventions to be limited to keeping me comfortable and free from pain and I refuse any and all other treatment even if my life is at risk.

(please delete CLEARLY as appropriate)

Name ........................................Date of Birth............................................
(please print)
If you consult(ed) a doctor about the Advance Decision please complete this section

I have discussed this Advance Decision with the following doctor:

Doctor’s (Print name)...........................................................................................................
OF (Name of Practice)........................................................................................................
........................................................................... Tel. No .............................................

If you consult(ed) a solicitor about your Advance Decision please complete this section

I have recorded my intentions as set out in these instructions with the following person or firm of solicitors to whom you may wish to apply for further information with regards to any amendments or revocation that might apply to this Advance Decision from time to time. Please insert contact details here:

Name .......................................................... Date of Birth ................................................
(please print)
SIGNATURES

The witness must sign after witnessing your signature and should then print his/her name in the space provided

My Signature ................................................................. Date ..............
Print name .............................................................................
in the presence of my witness .......................................................
(print name)

Signature of witness ............................................................ Date ..............
Printed name of witness ............................................................
Address of witness .................................................................
..........................................................................................
..........................................................................................
.................................................................Tel.
No ..............................................................
Relationship to you (e.g. friend, relative, doctor etc) .......................
..........................................................................................
..........................................................................................

THIS DOCUMENT REMAINS EFFECTIVE UNTIL I MAKE IT CLEAR THAT MY WISHES HAVE CHANGED

Name .................................................. Date of Birth ...................................
(please print)
Contact Details

I wish the following person to be contacted in the event that my Advance Decision to Refuse Treatment has to be implemented

<table>
<thead>
<tr>
<th>Name</th>
<th>Relationship</th>
<th>Address</th>
<th>Day Tel No. (home/mobile)</th>
<th>Evening Tel No. (home/mobile)</th>
<th>Is this person aware of your Advance Decision?</th>
<th>May we discuss your ADRT with him / her?</th>
</tr>
</thead>
</table>

I appoint the following person as my Health Care Proxy

<table>
<thead>
<tr>
<th>Name</th>
<th>Relationship</th>
<th>Address</th>
<th>Day Tel No. (home/mobile)</th>
<th>Evening Tel No. (home/mobile)</th>
</tr>
</thead>
</table>

The following person is my Solicitor.

I have made a Lasting Power of Attorney (Personal Welfare)
I have not made a Lasting Power (Personal Welfare)

(please delete as appropriate)

<table>
<thead>
<tr>
<th>Name</th>
<th>Address</th>
<th>Day Tel No. (home/mobile)</th>
<th>Evening Tel No. (home/mobile)</th>
</tr>
</thead>
</table>

Name ..................................Date of Birth..................................
(please print)
Presence of a Relative, Partner or Friend

You can complete this section if you would like a particular person to be with you if your life is in danger. Please note, however, that it may not be possible to contact your named person or for him/her to arrive in time.

If my life is in danger, I wish the following person(s) to be contacted to give him/her the chance to be with me before I die:

Name (1)........................................................................................................................................
Relationship..................................................................................................................................
Address...........................................................................................................................................
Day Tel No. (home/mobile)...........................................................................................................
Evening Tel No. (home/mobile).....................................................................................................
Is this person aware of your Advance Decision?.........Yes .../...No.....
Name (2)........................................................................................................................................
Relationship..................................................................................................................................
Address...........................................................................................................................................
Day Tel No. (home/mobile)...........................................................................................................
Evening Tel No. (home/mobile).....................................................................................................
Is this person aware of your Advance Decision?... ....Yes.../...No......

[DO] / [DO NOT] (please clearly delete as appropriate) wish those caring for me to do their best to keep me alive for as long as is reasonable in order to give the person I have named above a chance to be with me.

(This instruction might mean that the doctors would temporarily disregard your choices as set out in section 2 of the form and also of any refusal of particular treatments and/or tests)

Name ......................................................... Date of Birth ..................................................
(please print)
Statement by Health Care Proxy

I (print name)...............................................................agree to act as Health Care Proxy for ....................................................... if he/she becomes unable to make his/her wishes known.

- I understand that I will be consulted, as far as possible, when decisions about tests or treatments need to be made

- I understand that my role as Health Care Proxy is to inform the health care team of what I know of ..................................................’s beliefs or wishes about his/her future care, so that these beliefs and wishes can be taken into account when the health care team make decisions about his/her care

- I understand that I cannot insist on any treatment which the health care team does not feel would be in ..................................................’s best interests

Signed..............................................................Date...........................................

Name (please print)........................................Date of Birth.........................
Dear Mr. / Mrs/ Ms..........................................................

We have recently received notification from you that you wish to have an Advance Decision to Refuse Treatment (ADRT) registered with Gateshead Health NHS Foundation Trust.

This letter has been sent for your records as written confirmation and to inform you that we will record the details of your wishes and make the necessary amendments to your medical records held within the Trust to reflect the ADRT policy (a copy is enclosed).

The policy includes our standard guidelines concerning ADRTs and a checklist to help you if you have not yet drafted your document.

We strongly recommend that you contact your GP, if you have not yet done so, to discuss your decision (although you do not have to do so).

Finally, if you wish to discuss your decision, request advice or receive more comprehensive information about ADRTs, please contact the Trust’s Patient Advice and Liaison (PALS ) service on 0191 445 6129.

PALS is an independent service and its role is to help and advise patients regarding health care issues.

Yours sincerely

Health Records Manager
Encl: ADRT Policy
Advance Decisions to Refuse Treatment
Frequently Asked Questions

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 (ADRTs).....What are they?

There may be times in the future when you 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 do not wish to have in particular circumstances in the future. An Advance Decision to Refuse Treatment is how you record such decisions.

What goes in an Advance Decision to Refuse Treatment?

Any specific treatment that you DO NOT wish to have in the future. There is no set format in writing an ADRT. Making an ADRT is entirely voluntary and can be verbal unless your decision includes refusing treatment that sustains life when it must be written and witnessed to meet certain criteria.

Are Advance Decisions to Refuse Treatment legally binding?

Yes they are. 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 and not influenced by health care professionals, friends, family or people who provide care for you though, of course, their views may be sought.

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 (meeting certain criteria if you are refusing life sustaining treatment).

Where can I get advice about Advance Decision to Refuse Treatment?

By asking a health or social care professional or the hospital's PALS Officers. Often it is best to ask your GP or the hospital team who may already be involved in your care as they can tell you the likely implications of refusing certain treatments in specific conditions.
**Special Circumstances**

There are a number of circumstances that might make an ADRT more complicated to write and for professionals to follow, for example should a woman become pregnant in the future or if she is found to be pregnant at a time when the ADRT is to be implemented. You should always seek legal 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 if there is an emergency.

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

Yes. An Attorney can be appointed by you under a Lasting Power of Attorney (Personal Welfare (LPAPW) 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?**

An 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. Ask someone to witness who is independent and has nothing to gain as a consequence of the ADRT.

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

Although you are not obliged to, we strongly advise you to talk your advance decisions through with your close family, the doctor, nurse or GP who are involved in your care. If you have a family solicitor, it may be useful to talk your wishes through with them and you can discuss clinical choices with your GP or your health care team.

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

You do. Once you have discussed and decided on what treatment you don’t want, you can complete the Advance Decision to Refuse Treatment using the attached form or in any other style you prefer as long as it meets the criteria required.

**Does a doctor or nurse have to sign my Advance Decision to Refuse Treatment?**

No. We advise you, however, 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. This can be particularly helpful in emergency situations.

**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 or social worker involved in your care and possibly to your family solicitor. Don't forget to keep your original 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, you can change your mind 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 (PALS) (Telephone 0191 4456128) 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

*(courtesy of The Mental Capacity Act Code of Practice 2005)*

**Attorney**
Someone appointed under a Lasting Power of Attorney who has the legal right to make decisions within the scope of their authority on behalf of the person who made the Power of Attorney

**Lasting Power of Attorney (LPA)**
A Power of Attorney created under the Act to make decisions on behalf of another. There are two types, one for Personal Welfare (LPAPW) and one for Property & Financial Affairs (LPAPA). They are usually appointed in situations where the patient has a long-standing problem related to mental capacity and decision-making

**Basic Care**
Basic care is defined as the administration of pain/anxiety relieving medication or the performance of any procedure, which is solely or primarily designed to provide comfort to the patient or alleviate that person’s pain, symptoms or distress. This includes hygiene, offering oral diet and / or fluids and medications to relieve distressing symptoms; it does not include administration of hydration or nutritional supplements via intravenous lines or feeding tubes

**Independent Mental Capacity Advocate (IMCA)**
Someone who provides support and representation for a person who lacks capacity to make specific decisions, where the person has no-one else to support them. The IMCA service is established under section 35 of the Act and the functions of IMCAs are set out in section 36. It is not the same as an ordinary advocacy service

**Life-Sustaining Treatment**
Treatment that, in the view of the person providing health care, is necessary to keep a person alive; it includes administration of parenteral (intravenous or via feeding tubes for example) fluids and nutritional supplements

**Patient Advice & Liaison Service (PALS)**
A service providing information, advice and support to help NHS patients, their families and carers. PALS act on behalf of service users when handling patients and family concerns and can liaise with staff, managers and, where appropriate, other relevant organisations to find solutions

**Statutory Principles**
The five key principles are set out in appendix 3. They are designed to emphasise the fundamental concepts and core values of the Act and to provide a benchmark to guide decision-makers, professionals and carers acting under the act’s provisions. The principles generally apply to all actions and decisions taken under the Act

**Key Worker**
This is a named professional who is best placed to ensure the person receives coordinated, 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.

Health Care Proxy
An individual who has been nominated, with their consent, to interpret the wishes of the patient to his/her health care team. The Health Care Proxy does not have the legal right to make health care decisions on behalf of the patient but may advocate for the patient’s wishes.

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
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.

**Plan for the Last Few Days of Life**
The plan empowers health and social care professionals to deliver high quality proactive care to dying patients and their relatives regardless of diagnosis. The plan 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.