



Advance Decisions to Refuse Treatment Policy

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Summary of document:

This policy sets out the operational requirements for responding lawfully and appropriately to advance decisions by patients and service users, regardless of disability, language, culture, gender or other factors

Scope:

This policy is relevant to all health care professionals (including General Practitioners) working in Hywel Dda University Health Board; any of whom may be asked to support a patient in making an advance decision, or respond to an advance decision made by a patient in their care (who has subsequently lost capacity to make the relevant decision for themselves). Social care professionals may also be involved.

To be read in conjunction with:

[Mental Capacity Act Code of Practice](#) (opens in a new tab)
[811 Mental Capacity Act Practice Guidance](#) (opens in a new tab)
[008 Policy for Consent to Examination or Treatment](#) (opens in a new tab)
[134 Do not attempt cardio pulmonary resuscitation for adults in Wales](#) Policy (opens in a new tab)

NG108 Decision-making and mental capacity

NG31 Care of dying adults in the last days of life

NG97 Dementia: assessment, management and support for people living with dementia and their carers

QS194 Decision making and mental capacity

QS184 Dementia

CG136 Service user experience in adult mental health

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[Include links to Patient Information Library](#)

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Advance decision to refuse treatment: An advance decision to refuse treatment enables someone aged 18 and over, while still capable, to refuse specified medical treatment for a time in the future when they may lack the capacity to accept or refuse treatment.

Keypoints:
Please summarise key points of the document

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INTRODUCTION

An advance decision to refuse treatment (referred to as an 'advance decision' throughout this policy) enables someone aged 18 and over, while still capable, to refuse specified medical treatment for a time in the future when they may lack the capacity to accept or refuse treatment (MCA Code of Practice).

An advance decision only comes into force when a person loses capacity to accept or refuse the specific treatment or procedure to which it refers.

There is no obligation on anybody to make an advance decision; it is an individual choice. Some people make them when they are healthy, as they want to keep control over what might happen in the future; some think of them in preparation for growing older (similar to making a will); and some might make an advance decision when they have been diagnosed with a particular condition. Some people prefer not to make an advance decision and would rather leave health care professionals to make decisions in their best interests should they lose capacity to make a decision that needs to be made.

POLICY STATEMENT

The Mental Capacity Act 2005 (MCA) sets out what an advance decision is; how one is made; and how and when it applies (see MCA Code of Practice).

This policy sets out the operational requirements for responding lawfully and appropriately to advance decisions by patients and service users, regardless of disability, language, culture, gender or other factors.

The Mental Capacity Act 2005 Code of Practice provides further guidance and practical examples around the making and use of advance decisions. A copy of the Code of Practice can be accessed through the Hywel Dda MCA web pages.

SCOPE

This policy is relevant to all health care professionals (including General Practitioners) working in Hywel Dda University Health Board; any of whom may be asked to support a patient in making an advance decision, or respond to an advance decision made by a patient in their care (who has subsequently lost capacity to make the relevant decision for themselves). Social care professionals may also be involved.

AIMS

The purpose of this policy is to provide health care professionals within Hywel Dda UHB with the information they need to support patients in making advance decisions, and to understand how to respond to an advance decision made by a patient in their care, who has subsequently lost capacity to make the relevant decision for themselves.

OBJECTIVES

The policy will ensure that health care professionals are informed of the legal requirements surrounding advance decisions so that they can fully support patients who want to make one, or who have already made one.

WHAT IS AN ADVANCE DECISION TO REFUSE TREATMENT?

It is a general principle of law and medical practice that adults with capacity have a right to consent to or refuse treatment. The courts have recognised that adults have a right to refuse treatment that they may require in the future, when they no longer have the capacity to make that refusal themselves (even if this refusal results in their death). An advance decision enables such a refusal to be made.

A valid and applicable advance decision to refuse treatment has the same force as a contemporaneous decision made by a patient with decision-making capacity. This is a fundamental principle of common law and is now set out in the Mental Capacity Act 2005. A person can make an advance decision to refuse treatment if:

- they are 18 or older, and
- they have the capacity to make an advance decision refusing treatment.

Health care professionals must follow an advance decision if it is valid and applies to the particular circumstances. If they do not, they could face criminal prosecution or civil liability.

Advance decisions can have serious consequences for the people who make them, particularly if they are refusing life sustaining treatment. Therefore, before health care professionals can apply an advance decision, there must be proof that the decision exists; is valid; and is applicable in the current circumstances. These tests are legal requirements.

DECIDING WHETHER AN ADVANCE DECISION IS VALID AND APPLICABLE

Validity of an advance decision

For an advance decision to be valid there has to be no doubt that:

- the person was 18 or over when they made their advance decision;
- they had capacity to make the decision when they made it (health care professionals should always start from the assumption that the person had the capacity to make the advance decision unless there are reasonable grounds for doubt).

An advance decision must be valid at the time it needs to be put into effect. The health care professional must try to find out if:

- the person has done anything that clearly goes against their advance decision which suggests they may have changed their mind;
- the person withdrew their decision while they still had capacity to do so;
- after making the advance decision, the person made a Health and Welfare Lasting Power of Attorney (LPA) giving the attorney authority to make treatment decisions that are the same as those covered by the advance decision (see section '[Relationship between advance decisions, lasting power of attorney and court appointed deputies](#)').

The advance decision is more likely to be considered valid if it has been regularly reviewed and updated by the patient. However, a decision that was made a long time ago should not automatically be seen as invalid, particularly if it includes a statement that its contents are intended to apply indefinitely. Careful consideration needs to be given to factors such as the impact of developments in medical treatment since the advance decision was made.

Applicability of an advance decision

To be applicable the advance decision must apply to the situation in question and in the current circumstances. The advance decision only applies when the person who made it is assessed as lacking the capacity to accept or refuse treatment at the relevant time.

The advance decision must also apply to the proposed treatment. It is not applicable to the treatment in question if:

- the proposed treatment is not the treatment specified in the advance decision;
- the circumstances are different from those that have been set out in the advance decision;
- there are reasonable grounds for believing that there have been changes in circumstance, which would have affected the decision if the person had known about them at the time they made the advance decision.

When deciding whether an advance decision applies to the proposed treatment, health care professionals must consider:

- how long ago the advance decision was made, and
- whether there have been changes in the patient's personal life that might affect the validity of the advance decision (e.g. the person is pregnant, and this was not anticipated when they made the advance decision), and
- whether there have been developments in medical treatment that the person did not foresee (e.g. new medications, treatment or therapies).

Disagreements about validity and applicability

If there is disagreement between health care professionals or between health care professionals and family members, it is the responsibility of the senior clinician making the decision about the provision of treatment to decide whether the advance decision is valid and applicable. They will need to consult with all relevant people and gather different views. The point of these discussions is not to overrule the advance decision but to make sure that it is valid. If there is reasonable belief that the advance decision made by the patient is valid and applicable it must be complied with. This process must be recorded in the clinical notes.

It is recommended that clinicians seek advice from the Health Board's Legal Services Department if there is any doubt about the validity and applicability of an advance decision (see [Appendix 1](#)).

It is not reasonable to refuse to follow an advance decision because the decision made by the person is considered to be wrong or irresponsible. If the person who made the advance decision had the capacity to make the decision at the time they made it, and the advance decision is valid and applicable, then it must be followed.

What if it is decided that the advance decision does not apply?

If the decision is made that an advance decision is not valid and applicable, it must still be considered as part of the assessment of what treatment to carry out in the person's best interests. This is because it is an expression of the person's wishes and feelings and as such needs to be taken into account. Justification for not following the advance decision must be clearly documented within the patient's health record.

WHAT IS INCLUDED IN AN ADVANCE DECISION?

There are no particular formalities about the format of an advance decision. It can be written or verbal, unless it deals with life-sustaining treatment, in which case it must be written and specific rules apply (see section '[Advance decisions that refuse life-sustaining treatment](#)').

An advance decision to refuse treatment:

- must state precisely what treatment is to be refused – a statement expressing a general desire not to be treated is not enough;
- should set out the circumstances when the refusal should apply – it is helpful to include as much detail as possible e.g. a person may state whether or not the decision would apply if they became pregnant.

A patient may place certain caveats on their advance decision, for example, they may have specified in their advance decision that they do not wish to be treated with present treatments, but may wish to allow for new treatments that may become available.

Written advance decisions

Some people chose to put their advance decision in writing (this is a requirement for refusal of life-sustaining treatment). They will usually have told others that the document exists.

There is no set format for written advance decisions, because the contents will vary depending on a person's wishes and situation. However, it is helpful to include the following information:

- full details of the person making the advance decision including name; date of birth; home address and any distinguishing features (in case health care professionals need to identify an unconscious person);
- the name and address of the person's GP and whether they have a copy of the document;
- a statement that the document should be used if the person ever lacks capacity to make treatment decisions;
- a clear statement of the decision, the treatment to be refused and the circumstances in which the decision will apply;
- the date the document was written (or reviewed);
- the person's signature (or, where the person is physically unable to sign for themselves, the signature of someone the person has asked to sign on their behalf and in their presence);
- the signature of the person witnessing the signature (essential where the person is refusing life-sustaining treatment; good practice in other situations).

The role of the witness is to witness the person's signature; it is not to certify that the person has the capacity to make the advance decision. The witness is usually a relative or friend of the patient but advance decisions can also be witnessed by a health or social care professional.

It is possible that a health or social care professional acting as a witness will also be the person who assesses the person's capacity. If so, the professional should make a separate record of the capacity assessment, because acting as a witness to the signature does not prove that there has been an assessment of capacity.

Hywel Dda University Health Board has produced a template for people to use when making an advance decision, if they so chose ([Appendix 2](#)). This is available in both Welsh and English.

Verbal advance decisions

There is no set format for verbal advance decisions; they will vary depending on a person's wishes and the situation. Health care professionals will need to consider whether a verbal advance decision exists and whether it is valid and applicable (see section '[Deciding on whether an advance decision is valid and applicable](#)').

Where possible, health care professionals should record a verbal advance decision to refuse treatment in a person's health record. This will provide a written record that could prevent confusion about the decision in the future. The record should include:

- 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 will apply;
- details of anyone who was present when the verbal advance decision was made and the role in which they were present (e.g. health care professional or family member); and
- whether they heard the decision, took part in it or are just aware that it exists.

If appropriate, patients should be offered the opportunity to use the health board advance decision template ([Appendix 2](#)) a copy of which can then be stored in the health record.

ADVANCE DECISIONS THAT REFUSE LIFE-SUSTAINING TREATMENT

Advance decisions can be used to refuse life-sustaining treatment, however the Mental Capacity Act imposes particular legal requirements and safeguards on the making of advance decisions to refuse life-sustaining treatment.

For an advance decision refusing life-sustaining treatment to be applicable it **must** meet the following requirements:

- it must be in writing;
- the person making the advance decision must sign it in the presence of a witness;
- the witness must sign the document in the presence of the person making the advance decision;
- it must include a clear, specific written statement from the person making the advance decision that it is to apply to the specific treatment even if their life is at risk.

Where a patient who lacks capacity has a valid and applicable advance decision to refuse cardio pulmonary resuscitation, a DNACPR form should be completed and filed in their health record.

WHAT CANNOT BE INCLUDED IN AN ADVANCE DECISION?

Requests for specific treatment

Nobody has the legal right to demand specific treatment, either at the time or in advance. This means that no-one can insist on being given treatments that health care professionals consider to be clinically unnecessary, futile or inappropriate. An advance decision can not, therefore, be used to request preferred treatment; it can only be used to refuse treatment.

Although requests for specific treatments do not have the same legal status as a *refusal* of treatment, any such requests or advance statements of wishes or preferences relating to treatment options should be considered by health care professionals when deciding what treatment is in the person's best interests (where the patient lacks capacity). The health board's template for an advance decision includes a section where the person can document any wishes and preferences ([Appendix 2](#)), so that these can be taken into account. Alternatively, the person may wish to consider the UHBs 'Planning Your Future Care Together' document which includes a detailed template for recording wishes and care preferences. This document can be accessed at [Microsoft Word - HD EOL Document 2d-Advance Care Planning - Patient Advice and Record_English.doc \(wales.nhs.uk\)](https://www.wales.nhs.uk) (opens in a new tab)

Unlawful requests

Nobody can ask for and receive procedures that are against the law, for example help with committing suicide.

Essential care

An advance decision cannot refuse actions that are needed to keep a person comfortable. Examples include warmth, shelter, actions to keep a person clean and the offer of food and water by mouth (an advance decision can refuse artificial nutrition and hydration). The MCA allows health care professionals to carry out these actions in the best interests of a person who lacks capacity to consent.

Non-health care issues

An advance decision does not cover financial situations, social care issues, care for pets or other social circumstances. Information regarding contingency arrangements for social issues such as these should be recorded elsewhere, for example in the care plan.

HELPING SOMEONE MAKE AN ADVANCE DECISION

Any health or social care professional, including those working in primary care, may be asked for advice or assistance by people considering making an advance decision to refuse treatment. The person wishing to make the advance decision must be over 18 and have capacity.

If a health care professional, working within Hywel Dda UHB, is asked for help or advice they should:

- provide the patient with a copy of the Hywel Dda Advance Decision Pack ([Appendix 2](#));
- explain the types of treatment that could be used and the consequences of a refusal;
- advise the patient that there is more information available from other sources including organisations linked to specific conditions;
- remind the patient that they may want to seek legal advice for assistance in expressing their decision clearly;
- advise the patient that it is important to regularly review and update their advance decision;
- advise the person to lodge a copy their advance decision with their GP, and provide a copy for their hospital health record (if they have one).

Any adult (18+) with capacity can make an advance decision refusing treatment. The person should be assumed to have capacity to make an advance decision unless there are reasonable grounds to doubt their capacity. Where there are reasons to doubt, an assessment of capacity should be undertaken (see the Health Board's Mental Capacity Act Practice Guidance for advice on assessing capacity).

HOW DO WE KNOW AN ADVANCE DECISION EXISTS?

Before health care professionals can apply a valid and applicable advance decision, there must be proof that it exists.

It is the responsibility of the person making the advance decision to make sure that their decision will be drawn to the attention of health care professionals when it is needed. The person making it may tell their family and friends, or they may tell their GP who may have a copy of the decision in the person's medical notes. If they have brought it to the attention of Health Board staff, a copy should be kept in the health record.

Some people will carry a card or wear a bracelet explaining where a copy of their decision is kept in case of an emergency.

If a health care professional is made aware of the existence of an advance decision, they should request a copy of it to be included in the health record or information about where a most recent

copy can be obtained. Any member of staff receiving a copy of an advance decision, either in the post or in person, should ensure that it is filed in the person's health record (Hospital health records contain a section for legal documents, where copies of advance decisions should be stored).

Where the existence of an advance decision is known, it is important that health care staff pass on this information to other relevant care providers, for example, if the patient is being discharged to a new place of residence, such as a nursing or care home.

EMERGENCY TREATMENT

Health care professionals should not delay emergency treatment to look for an advance decision if there is no clear indication that one exists. Treatment must be provided in the patient's best interests. If an advance decision is known and it is valid and applicable it must be followed. If it is refusing life sustaining treatment then it must be seen and must comply with the requirements outlined in [Section 'Advance decisions that refuse life-sustaining treatment'](#) of this policy.

WHAT IF I AS A HEALTH PROFESSIONAL DISAGREE IN PRINCIPLE WITH THE REQUEST IN THE ADVANCE DECISION?

No health professional is expected to act against their beliefs. Where this is the case, the care of the patient should be transferred to another health care professional in a timely manner. Where a transfer cannot be agreed, the Court of Protection can direct those responsible for the health care of the patient to make the necessary arrangements (contact the health board's Legal Services Department for advice – see [Appendix 1](#)). All health professionals have a duty of care not to abandon patients or act in a way that adversely affects their care.

CANCELLING ADVANCE DECISIONS

A person can cancel or withdraw their advance decision at any time whilst they still have capacity. This can be in writing or verbally, and they can destroy the original, and any copies of, the written document.

The cancellation of an advance decision can be done at any time, for example just before the person is given an anaesthetic in theatre. There are no formal processes to follow. If the advance decision is cancelled verbally, health care professionals must record the cancellation in the health record. If there is a written copy of the advance decision in the health record, they should draw a line through the advance decision and writing CANCELLED with a date. The patient should be advised that cancelled advance decisions are no longer valid. They will be retained as part of the health record.

If a patient does something that clearly goes against what they have said in their advance decision it may suggest that they have changed their mind. In this case, the doubt about the validity of the advance decision will need to be discussed and documented in the patient's health record.

MAKING CHANGES TO AN ADVANCE DECISION

People can make changes to an advance decision verbally or in writing, whether or not the original advance decision was in writing. It is good practice for health care professionals to record a change to the advance decision in the person's health record.

If a person wants to change an advance decision to include a refusal of life-sustaining treatment, they must follow the procedures described in [Section Advance decisions that refuse life-sustaining treatment](#).

ADVANCE DECISIONS ABOUT TREATMENT FOR MENTAL DISORDER

Advance decisions can refuse treatment for a physical or mental disorder. However, an advance decision regarding treatment for mental disorder can be overruled if a patient is detained under the Mental Health Act 1983, when treatment could be given compulsorily under Part 4 of the Act.

Valid and applicable advance decisions refusing any treatment that is *unrelated* to the reason for the detention can not be over-ruled.

RELATIONSHIP BETWEEN ADVANCE DECISIONS, LASTING POWER OF ATTORNEY AND COURT APPOINTED DEPUTIES

A valid and applicable advance decision to refuse treatment is as effective as a refusal made when a person has capacity. Therefore, an advance decision overrules:

- the decision of any Health and Welfare Lasting Power of Attorney (LPA) made *before* the advance decision was made i.e. an attorney cannot give consent to treatment that has been refused in an advance decision made *after* the LPA was signed;
- the decision of any court-appointed deputy i.e. a deputy cannot give consent to treatment that has been refused in an advance decision;
- the provisions of section 5 of the Act, which would otherwise allow health care professionals to give treatment that they believe is in a person's best interests.

A Health and Welfare LPA made *after* an advance decision will make the advance decision invalid *if* the LPA gives the attorney the authority to make decisions about the same treatment (health care professionals must see a copy of the LPA before enacting it). If the LPA specifically excludes the attorney from making the decision/s set out in the Advance Decision, then the Advance Decision

remains valid and should be followed. If there is no mention of the pre-existing Advance Decision in the LPA document, it may be advisable to take steps to check that the Advance Decision remains the persons fixed decision.

COURT OF PROTECTION

The Court of Protection does not have the power to overrule a valid and applicable advance decision to refuse treatment.

However, if there is genuine doubt or disagreement about the existence, validity or applicability of an advance decision, the Court of Protection can make a decision. While the court decides, health care professionals are able to provide life-sustaining treatment.

RESPONSIBILITIES

Chief Executive

Overarching responsibility for ensuring that Hywel Dda University Health Board is compliant with the law in relation to the Mental Capacity Act and Advance Decisions.

Chief Operating Officer

Holds delegated responsibility for the Mental Capacity Act.

Head of Consent and Mental Capacity

Responsible for ensuring this policy and associated documents are kept up to date, and for providing necessary training and awareness raising.

Mental Capacity Advanced Practitioners

Provide training in relation to advance decisions as part of existing MCA training programme across the UHB, ensuring awareness of the Advance Decision Pack.

Legal Services

Provide ad-hoc advice to staff (in conjunction with Mental Capacity Advanced Practitioners) when a patient has an advance decision but there is doubt about its validity or applicability.

Health care professionals

Health care professionals are responsible for ensuring that reasonable effort is made to ascertain whether or not a patient who lacks capacity has an advance decision to refuse

treatment. If one exists, they must check its validity and applicability. If it is valid and applicable they must follow it.

Health care professionals may be asked for advice or assistance by people considering making an advance decision to refuse treatment. In these circumstances, the health professional should offer the patient a copy of the Hywel Dda Advance Decision Pack ([Appendix 2](#)), and explain the basic principles of an advance decision to refuse treatment.

Heads of Service

Support health care professionals to obtain legal advice where they are unsure about the validity and applicability of an advance decision to refuse treatment. Ensure clinical staff are aware of the Advance Decision Pack, and that it is available for patients who wish to make an advance decision to refuse treatment.

TRAINING

Training for staff in relation to advance decisions to refuse treatment is included in all MCA training courses provided by the Mental Capacity Advanced Practitioners, and is also covered in the consent training provided by the Head of Consent and Mental Capacity. This training also incorporates awareness raising about the 'Advance Decision Pack'.

IMPLEMENTATION

Training in relation to advance decisions will continue as normal (see [training section](#)). Awareness raising in relation to the Advance Decision Pack will continue so that staff are aware of it and know where to access it for patients. English and Welsh language versions of the Advance Decisions Pack are accessible on the Intranet.

FURTHER INFORMATION

Further information can be obtained from the following sources:

- 1) Mental Capacity Act Code of Practice (can be accessed through Hywel Dda MCA web pages).
- 2) Hywel Dda University Health Board Mental Capacity Act web pages.

REVIEW

This policy will be reviewed after 3 years, or sooner, as required.

REFERENCES

1. Mental Capacity Act 2005 Code of Practice, London: TSO

APPENDIX 1: CONTACT DETAILS

Head of Consent and Mental Capacity: 01267 239772 (01825 4772)

Mental Capacity Advanced Practitioners: 01267 239668 (01825 4668)

Legal Services Department: 01437 834478

Appendix 2: Advance Decision Pack

This pack contains:

1) A blank Advance Decision to Refuse Treatment Form

When completed this is a legal document which sets out your advance decision to refuse treatment should you lose the capacity to make decisions about your treatment in the future. Advance decisions used to be called Living Wills, or Advance Directives.

2) An example of a completed Advance Decision to Refuse Treatment Form

This is intended to help you complete your own form.

3) Guidance notes

Step-by-step guidance and advice on filling out your Advance Decision to Refuse Treatment form.

A Welsh language version of this pack is also available.

This pack is produced by Hywel Dda University Health Board for guidance purposes.

The completed document belongs to the person making the advance decision.

Advance Decision to Refuse Treatment

A) My details:

My full name:

My date of birth:

My address:

Distinguishing features *[in the event of unconsciousness e.g. a distinctive mole]:*

This document sets out the decisions that I have made about my future care and treatment should I become unable to make those decisions for myself, because I have lost the mental capacity to do so.

I have the mental capacity to make the decisions set out in this document. I am not acting under any undue influence or duress.

I have carefully considered information about the treatment options available and how I wish to be treated if, in the future, I lose the capacity to refuse or consent to medical treatment, or the ability to effectively communicate my refusal or consent.

My decisions, as set out in this document, are intended to apply indefinitely unless specifically revoked.

I understand that this Advance Decision will only be followed if I lose the capacity to make or communicate the decisions set out in this document.

Note to Health care Professionals

- This document should be used in the event that I lose the mental capacity to make or communicate the decisions it contains.
- Please do not assume that I have lost capacity – I may need help and time to communicate.
- If I have lost capacity please check the validity and applicability of this Advance Decision to Refuse Treatment.
- If my Advance Decision is valid and applicable please ensure that you act on it as it is a legal document. Please help to share this Advance Decision with relevant colleagues who are involved in my treatment and care and need to know about it.
- Please also check with relatives and friends if I have made any other statements about my preferences or wishes that might be relevant to my advance decision.
- **This advance decision does not refuse the provision of basic care, support and comfort.**

B) My Advance Decision to Refuse Treatment

In the event that I lose capacity to make or communicate decisions for myself, this section lists the specific treatments or procedures that I **do not want** to receive, and the circumstances in which this refusal applies.

[Note to person making this advance decision: *If you wish to refuse treatment that is, or may be, life sustaining, you must state that you are refusing treatment ‘even if my life is at risk’ as a result. If you do refuse life-sustaining treatment then it is essential that this Advance Decision document is signed, dated and witnessed.]*

<p>State here if you wish to refuse life sustaining treatment, even if your life is at risk:</p> <p><i>[e.g. My decisions, as set out below, are to apply to life sustaining treatment even where these decisions place my life at risk]</i></p>	
<p>State here if there are circumstances under which your Advance Decision does not apply:</p> <p><i>[e.g. If I am pregnant, I wish to receive medical treatment leading to the safe delivery of my child, after which I wish to reinstate my advance decisions refusing treatment.]</i></p>	
<p>I wish to refuse the following specific treatments: <i>[e.g. Cardio-pulmonary resuscitation (re-starting my heart/breathing)]</i></p>	<p>In these circumstances:</p> <p><i>[e.g. In the event that I have a cardiac or respiratory arrest after being diagnosed with a life-limiting illness]</i></p>

If more space is required, continue on a separate sheet and ensure it is securely attached to this document.

C) My Wishes and Preferences

This space gives you the opportunity to express your wishes, preferences, values or beliefs. You cannot use an Advance Decision to request a specific treatment. However, noting down your treatment preferences or what you consider to be an acceptable quality of life, for example, will help the health care professionals looking after you to make decisions that are in your best interests.

D) Lasting Power of Attorney

***Only** complete this section if you have **already** appointed an attorney under a Lasting Power of Attorney through the Office of the Public Guardian.*

The contact details of the person/people to whom I have granted Lasting Power of Attorney:

1) Name:

Address:

Phone:

Type (please tick all that apply): Health and Welfare Property and Financial Affairs

2) Name:

Address:

Phone:

Type (please tick all that apply): Health and Welfare Property and Financial Affairs

E) GP details

GP name:

GP address:

GP phone:

F) Declaration of a health or social care professional (optional)

It is good practice to discuss your wishes with your GP, nurse, therapist, hospital doctor or social worker. You may also wish to ask them to witness your mental capacity by signing this declaration.

I have discussed the matters contained in this document with *(insert name of person making the Advance Decision)*

I am satisfied that this individual has the capacity to make the decision/s in this document and that they understand the consequences of these decisions.

Professional's name:

Job title:

Signature: Date:

G) Copies of this Advance Decision

I have deposited copies of this Advance Decision with: *[e.g. your GP, family members]*

1) Name:

Address:

Phone:

2) Name:

Address:

Phone:

H) Declaration and Signature

Person making the Advance Decision

This document sets out the decisions that I have made about my future care and treatment should I become unable to make those decisions for myself.

I confirm that I have the mental capacity to make the decisions set out in this document and that I am not acting under any undue influence or duress.

My decisions, as set out in this document are intended to apply indefinitely, unless specifically revoked.

I understand that this Advance Decision will only be followed if I lose the capacity to make or communicate the decisions set out in this document.

I understand that my comfort and personal hygiene will continue to be attended to.

Name:

Signature:

Date:

(If the maker of the Advance Decision is physically unable to sign, it may be signed on their behalf by another person, under the maker's direction and in the presence of the witness below. Tick here if someone other than the maker has signed above:)

Witness

I declare that the Advance Decision was signed or acknowledged in my presence.

Name :

Relationship:

Address:

Signature: Date:

I) Review

You should, if possible, review and reaffirm your Advance Decision on a regular basis.

I have reviewed my Advance Decision and reaffirm that the wishes stated in this document are my own and still apply. I confirm that this document is intended to apply indefinitely unless I specifically revoke it.

Signed: Dated:

Signed: Dated:

Signed: Dated:

EXAMPLE OF A COMPLETED FORM

Advance Decision to Refuse Treatment

A) My details

My full name:

My date of birth:

My address:

Distinguishing features *[in the event of unconsciousness e.g. a distinctive mole]:*

Large mole on left shoulder blade.

Scar on left hip from hip replacement.

This document sets out the decisions that I have made about my future care and treatment should I become unable to make those decisions for myself, because I have lost the mental capacity to do so.

I have the mental capacity to make the decisions set out in this document. I am not acting under any undue influence or duress.

I have carefully considered information about the treatment options available and how I wish to be treated if, in the future, I lose the capacity to refuse or consent to medical treatment, or the ability to effectively communicate my refusal or consent.

My decisions, as set out in this document, are intended to apply indefinitely unless specifically revoked.

I understand that this Advance Decision will only be followed if I lose the capacity to make or communicate the decisions set out in this document.

Note to Health Care Professionals

- This document should be used in the event that I lose the mental capacity to make or communicate the decisions it contains.
- Please do not assume that I have lost capacity – I may need help and time to communicate.
- If I have lost capacity please check the validity and applicability of this Advance Decision to Refuse Treatment.
- If my Advance Decision is valid and applicable please ensure that you act on it as it is a legal document. Please help to share this Advance Decision with relevant colleagues who are involved in my treatment and care and need to know about it.
- Please also check with relatives and friends if I have made any other statements about my preferences or wishes that might be relevant to my advance decision.

- **This advance decision does not refuse the provision of basic care, support and comfort.**

EXAMPLE

B) My Advance Decision to Refuse Treatment

In the event that I lose capacity to make or communicate decisions for myself, this section lists the specific treatments or procedures that I **do not want** to receive, and the circumstances in which this refusal applies.

[Note to person making this advance decision: If you wish to refuse treatment that is, or may be, life sustaining, you must state that you are refusing treatment ‘**even if my life is at risk**’ as a result. If you do refuse life-sustaining treatment then it is essential that this Advance Decision document is signed, dated and witnessed.]

<p>State here if you wish to refuse life sustaining treatment, even if your life is at risk:</p> <p><i>[e.g. My decisions, as set out below, are to apply to life sustaining treatment even where these decisions place my life at risk]</i></p> <p>My decisions, as set out below are to apply to life sustaining treatment even where these decisions place my life at risk.</p>	
<p>State here if there are circumstances under which your Advance Decision does not apply:</p> <p><i>[e.g. If I am pregnant, I wish to receive medical treatment leading to the safe delivery of my child, after which I wish to reinstate my advance decisions refusing treatment.]</i></p> <p>_____</p>	
<p>I wish to refuse the following specific treatments: <i>[e.g. Cardio-pulmonary resuscitation (re-starting my heart/breathing)]</i></p>	<p>In these circumstances:</p> <p><i>[e.g. In the event that I have a cardiac or respiratory arrest after being diagnosed with a life-limiting illness]</i></p>
<p>Artificial ventilation (breathing using a machine).</p>	<p>If I can no longer breath for myself without the help of a machine due to:</p> <ul style="list-style-type: none"> • Being in a coma, minimally conscious state or persistent vegetative state resulting in lack of awareness of myself and/or my environment; • paralysis; • brain damage; • a disease of the central nervous system; • or any other life-threatening or life-limiting physical illness or condition from which there is little or no prospect of recovery.

<p>Artificial feeding (via any means).</p>	<p>When my condition has deteriorated to the point that I cannot swallow safely, even with the help of others.</p> <p>If I am in a coma, minimally conscious state or persistent vegetative state resulting in lack of awareness of myself and/or my environment, and from which there is little or no prospect of recovery.</p>
<p>Cardio-respiratory resuscitation.</p>	<p>In the event that I have a cardiac or respiratory arrest after I have been diagnosed with any life-threatening or life-limiting physical illness or condition from which there is little or no prospect of recovery. (In these circumstances please ensure a DNACPR Form is completed and filed in my notes.)</p>

If more space is required, continue on a separate sheet and ensure it is securely attached to this document.

EXAMPLE

C) My Wishes and Preferences

This space gives you the opportunity to express your wishes, preferences, values or beliefs. You cannot use an Advance Decision to request a specific treatment. However, noting down your treatment preferences or what you consider to be an acceptable quality of life, for example, will help the health care professionals looking after you to make decisions that are in your best interests.

I would like to die at home with my family around me if at all possible.

I would like to continue to receive pain relief for symptom control and comfort even if it may shorten my life.

I do not have any religious beliefs that would affect my care and treatment.

I suffer from dry eyes and would be grateful if I could be given eye drops as required.

If I am taken into hospital, please contact my daughter. Her contact details are in Section D of this document.

D) Lasting Power of Attorney

Only complete this section if you have **already** appointed an attorney under a Lasting Power of Attorney through the Office of the Public Guardian.

The contact details of the person/people to whom I have granted Lasting Power of Attorney:

1) Name:

Address:

Phone:

Type (please tick all that apply): Health and Welfare Property and Financial Affairs

2) Name:

Address:

Phone:

Type (please tick all that apply): Health and Welfare Property and Financial Affairs

EXAMPLE

E) GP details

GP name:

GP address:

GPs phone:

F) Declaration of a health or social care professional (optional)

It is good practice to discuss your wishes with your GP, nurse, therapist, hospital doctor or social worker. You may also wish to ask them to witness your mental capacity by signing this declaration.

I have discussed the matters contained in this document with *(insert name of person making the Advance Decision)*

I am satisfied that this individual has the capacity to make the decision/s in this document and that they understand the consequences of these decisions.

Professional's name:

Job title:

Signature: Date:

G) Copies of this Advance Decision

I have deposited copies of this Advance Decision with: *[e.g. your GP, family members]*

1) Name:

Address:

Phone:

2) Name:

Address:

Phone:

EXAMPLE

H) Declaration and Signature

Person making the Advance Decision

This document sets out the decisions that I have made about my future care and treatment should I become unable to make those decisions for myself.

I confirm that I have the mental capacity to make the decisions set out in this document and that I am not acting under any undue influence or duress.

My decisions, as set out in this document are intended to apply indefinitely, unless specifically revoked.

I understand that this Advance Decision will only be followed if I lose the capacity to make or communicate the decisions set out in this document.

I understand that my comfort and personal hygiene will continue to be attended to.

Name:

Signature: Date:

(If the maker of the Advance Decision is physically unable to sign, it may be signed on their behalf by another person, under the maker's direction and in the presence of the witness below. Tick here if someone other than the maker has signed above:)

Witness

I declare that the Advance Decision was signed or acknowledged in my presence.

Name : Relationship:

Policy ref: 419

Address:

Signature: Date:

I) Review

You should, if possible, review and reaffirm your Advance Decision on a regular basis.

I have reviewed my Advance Decision and reaffirm that the wishes stated in this document are my own and still apply. I confirm that this document is intended to apply indefinitely unless I specifically revoke it.

Signed: Dated:

Signed: Dated:

Signed: Dated:

ADVANCE DECISION TO REFUSE TREATMENT

GUIDANCE NOTES

These guidance notes are to help you in filling in your Advance Decision form.

1) WHAT IS AN ADVANCE DECISION TO REFUSE TREATMENT?

An Advance Decision allows you to make a legally binding refusal of treatment if you lose capacity. Capacity is the ability to make decisions for yourself. This means that, if you lose capacity, health care professionals cannot lawfully give you treatment that you have refused in an Advance Decision.

An Advance Decision used to be called a living will or an advance directive. It is legally binding as long as it is valid and applicable (see sections 3 and 4 below).

2) WHAT AN ADVANCE DECISION CAN'T DO

You cannot use your Advance Decision to **request or demand** particular treatments. This is because, under the law in England and Wales, doctors do not have to give you a treatment just because you ask for it. Doctors decide whether a treatment is appropriate for your condition and then you decide whether or not you want the treatment.

You cannot use your Advance Decision to ask for your life to be ended (although you can refuse treatment that would sustain your life –see sections 3 and 6b. below).

You cannot use an Advance Decision to nominate someone else to decide about treatment on your behalf. Nominating another person to make decisions on your behalf is done by making a Lasting Power of Attorney (LPA) (see section 6d below).

3) HOW DO I MAKE MY ADVANCE DECISION VALID?

For your Advance Decision to be valid you must:

- be 18 or over, and have the mental capacity to make your Advance Decision;
- not have been forced by others to make your decision;
- say what treatment you refuse consent for (this can be in non-medical language);
- say the circumstances in which you want to refuse treatment;
- if you want to refuse life sustaining treatment, clearly state that your Advance Decision applies even if your life is a risk as a result of refusing the treatment, and have signed and dated your Advance Decision in the presence of a witness;

- sign and date next to any changes you make.

You **do not** need a solicitor to make a valid Advance Decision, although you can use one if you choose.

4) WHEN IS MY ADVANCE DECISION APPLICABLE?

Your Advance Decision is applicable if:

- you lose mental capacity to make decisions about your care and treatment;
- it covers the circumstances you are in and the treatments available to you;
- there are no reasonable grounds to believe that changes in circumstances since you made your Advance Decision would have changed the decisions you made in it.

5) WHAT IS MENTAL CAPACITY?

Mental capacity is the ability of a person to make decisions for themselves about a particular matter. If you are an adult with mental capacity you have the legal right to refuse any medical treatment. The law assumes that individuals have the capacity to make decisions unless it is proven otherwise.

Having mental capacity means being able to understand and retain information relating to the decision that needs to be made, being able to take that information into account when making your choice, and being able to communicate your decision in any way.

When decisions need to be made about your health care, a doctor or other health care professional needs to decide whether you have the capacity to make that decision. They do this on a decision-by-decision basis as you may have capacity to make straight forward decisions but not more complicated ones. Or you might lose capacity to make a decision for a short time (e.g. if you are knocked unconscious) or for the indefinite future (e.g. if you have advanced dementia).

6) COMPLETING THE ADVANCE DECISION FORM

Please make sure you print clearly when filling in the form – it is important that all the details can be read by the health professionals treating you.

A. Your details

It is important that this is completed in full so it is clear who has made the Advance Decision.

B. Your advance decision to refuse treatment

This section should give clear instructions to health care staff. It allows you to refuse specific treatments and list the particular situations you can think of in which you do not wish to receive that treatment. It is important to be as clear and specific as possible to help health care professionals work out if your Advance Decision applies in the situation that has arisen.

If you do not want to be treated with present treatments, but may wish to allow for new treatments that may become available, you need to specify this in your advance decision.

If you want to use your Advance Decision to refuse life sustaining treatment you **must** state this clearly within your Advance Decision. The template provides a space for you to record that your refusal applies even if your life is at risk. If you do not include this, then your request will not be valid and health care professionals will not be able to follow any part of your Advance Decision which refuses treatment which may save your life.

It is strongly recommended that you discuss your decisions with your GP, hospital doctor or nurse. They can provide advice about current available treatments; let you know if the details on your form are accurate; and discuss the implications of your refusal.

If you need more space, continue on a separate piece of paper and attach it securely to your Advance Decision.

C. Your wishes and preferences

This section allows you to set out your wishes, preferences, values and beliefs. This will help the health care professionals looking after you to make decisions that are in your best interests.

For example, if you have strong religious beliefs that mean you would never consider a blood transfusion, you will have used section A to refuse a blood transfusion but you can use section C to explain **why** you refuse it. This will help the doctors to understand your wishes.

If you have strong ideas about what you believe is an acceptable quality of life, you can include these here. For example you may want to state whether factors such as pain, loss of memory, or recognising and interacting with family and friends, are important to your idea of 'quality of life' and 'recovery'. You may also want to indicate the relative importance you attach to these different factors.

This section can also include instructions, such as who you want the doctors to contact if you are taken into hospital.

Remember that you cannot use an Advance Decision to demand a specific treatment, but health care professionals will take your wishes into account when making decisions about what treatment you should have.

D. Lasting Power of Attorney

A Lasting Power of Attorney (LPA) allows you to legally authorise someone to make decisions on your behalf if you lose capacity or the ability to communicate. There are two types of LPA: 'Property and Financial Affairs' and 'Health and Welfare'. **Only** attorneys under a Health and Welfare LPA

will be able to make decisions about your health care and medical treatment. If you chose to, you can give them the power to refuse life sustaining treatment on your behalf.

You can only appoint someone as an LPA through the Office of the Public Guardian (OPG). You cannot appoint an LPA through an Advance Decision. You should only complete section D if you have an LPA which is registered with the OPG. (Forms and information are available from the Office of the Public Guardian website: <http://www.justice.gov.uk/forms/opg>).

It is important to remember:

- If your Advance Decision is created after you have appointed a Health and Welfare LPA, then the Advance Decision takes precedence over any decisions made by the attorney.
- If the Health and Welfare LPA was created after the Advance Decision, then the LPA takes precedence. However, if you don't want your Attorney to make decisions about treatment that is included in your Advance Decision, you must say so on the LPA form.

Before 2007 you may have given someone **Enduring Power of Attorney (EPA)** for your financial affairs. EPAs do not grant power to make health care decisions on your behalf.

E. GP details

Please provide the contact details of your GP.

F. Health professional declaration

You do not need the permission of your GP, nurse or hospital doctor to make an Advance Decision. It is, however, a good idea to speak to a health professional about your decisions so that they can provide advice about current available treatments; let you know if the details on your form are accurate; and discuss the implications of your refusal.

You can also ask a health professional to witness your mental capacity by signing the declaration in section F. For an Advance Decision to be valid, you must have had capacity at the time that you made it. Having your GP or another health professional certify that you have mental capacity is a good way to confirm this. However, your Advance Decision is still legally valid even if it is not signed by a health professional.

G. Copies of this Advance Decision

It is important that you inform people that you have made an Advance Decision, because if your health care team does not know that you have one, they will not know how you wish to be treated.

It is a good idea to have at least three copies of your Advance Decision: one for yourself; one for your next of kin (a close relative or friend); and one for your GP to keep with your medical notes. If you have an existing health condition, it is also advisable to give one to your specialist hospital doctor.

It is advisable to make a note on the photocopies of where the original is kept.

H. Declaration and signature

This is the section where you sign and date your Advance Decision. If you are physically unable to sign the form, you can make a mark or ask someone else to sign it on your behalf. In this situation, a witness must be present and sign the form to confirm that it was signed by someone else at your request.

A witness **must** sign the form if your Advance Decision refuses life sustaining treatment, otherwise it will not be valid. Legally only one witness is required. This can be any competent adult (18 years old or over). To avoid your Advance Decision being questioned, it is good practice to make sure that your witness is not: your relative or partner; anyone who will inherit your money or property after your death; or anyone you have appointed as your Lasting Power of Attorney.

Your witness should watch you sign your Advance Decision and should then add their own signature and write the date, their name, address and relationship to you in the space provided. They are witnessing you signing your Advance Decision, **not** your ability or capacity to sign.

I. Review

Although the template provided contains the statement *'My decisions, as set out in this document are intended to apply indefinitely, unless specifically revoked'*, it is advisable to review and re-sign your Advance Decision regularly.

There is no clear guidance on how often you should do this, but the more recent the signature, the more certain the health care team will be that what you said in your Advance Decision is still what you want.

It is recommended that you review and re-sign your Advance Decision if:

- your health situation changes;
- you are going into hospital for serious treatment or surgery;

- you become aware of a new treatment or procedure that you need to include in your Advance Decision, or that will affect the decisions you have made;
- you are diagnosed with a condition that may affect your capacity in the future.

If you make changes to your Advance Decision you should also make the change on each of the copies of your Advance Decision that are held by other people (e.g. your GP, next of kin etc.), or send them new photocopies.

7) ADVANCE DECISION CHECKLIST

Check that you have completed all the necessary steps to make your Advance Decision legally valid and to maximise the chances of it being followed:

For your Advance Decision to be legally valid it should:

- State clearly what treatment/s you are refusing, if you lose capacity.
- State clearly the circumstances in which your refusal applies.
- Be signed and dated by you.
- Confirm that your refusal of treatment applies even if it will bring about your death (you only need to do this if you are using your Advance Decision to refuse life sustaining treatment).
- Be signed and dated by a witness (you only need to do this if you are using your Advance Decision to refuse life sustaining treatment).
- Sign and date any changes you have made to your Advance Decision.

To help ensure your Advance Decision is known about and followed it may be helpful to:

- Ask your GP/health professional to sign your Advance Decision to confirm that you had capacity when you made it.

- Inform those closest to you, your GP, and your health care team (if you have one) that you have made an Advance Decision, and give them copies.

- Discuss your health care and treatment wishes with your GP.