

Advance Decision Pack

This pack contains:

1) An 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 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 Healthcare 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.*]

State here if you wish to refuse life sustaining treatment, even if your life is at risk:
[e.g. My decisions, as set out below, are to apply to life sustaining treatment even where these decisions place my life at risk]

State here if there are circumstances under which your Advance Decision **does not** apply:
[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 wish to refuse the following specific treatments: <i>[e.g. Cardio-pulmonary resuscitation (re-starting my heart/breathing)]</i>	In these circumstances: <i>[e.g. In the event that I have a cardiac or respiratory arrest after being diagnosed with a life-limiting illness]</i>

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 healthcare 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) Health professional declaration (optional)

It is good practice to discuss your wishes with your GP, nurse or hospital doctor. 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.

Health professionals 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]*:

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 Healthcare 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.]

State here if you wish to refuse life sustaining treatment, even if your life is at risk:
[e.g. My decisions, as set out below, are to apply to life sustaining treatment even where these decisions place my life at risk]

My decisions, as set out below are to apply to life sustaining treatment even where these decisions place my life at risk.

State here if there are circumstances under which your Advance Decision **does not** apply:
[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 wish to refuse the following specific treatments: <i>[e.g. Cardio-pulmonary resuscitation (re-starting my heart/breathing)]</i>	In these circumstances: <i>[e.g. In the event that I have a cardiac or respiratory arrest after being diagnosed with a life-limiting illness]</i>
Artificial ventilation (breathing using a machine).	If I can no longer breath for myself without the help of a machine due to: <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.
Artificial feeding (via any means).	When my condition has deteriorated to the point that I cannot swallow safely, even with the help of others. If I am in a coma, minimally conscious state or persistent vegetative state resulting in lack of awareness of myself and/or my environment.
Cardio-respiratory resuscitation.	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.

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 healthcare 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 Enfys Jones. 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) Health professional declaration (optional)

It is good practice to discuss your wishes with your GP, nurse or hospital doctor. 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.

Health professionals 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:

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, healthcare 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.

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 healthcare 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 senile 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 healthcare 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 healthcare professionals work out if your Advance Decision applies in the situation that has arisen.

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 healthcare 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 healthcare 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 healthcare 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 healthcare 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.

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 you 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 healthcare 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.

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 healthcare team (if you have one) that you have made an Advance Decision, and give them copies.
- Discuss your healthcare and treatment wishes with your GP.