



Policy: **Advance Decisions to Refuse Treatment**

Policy number: **2.21**

1. Policy Statement

Hospice in the Weald recognises that some people wish to make decisions now about their future care in order that those involved in their care (including any informal care givers) are aware of their preferences and wishes – especially in the event that they lose capacity (the ability to make decisions for themselves) at some point in the future. Planning for future care can involve many different types of discussions and decisions. Three main outcomes of Advance Care Planning (as detailed in the Mental Capacity Act 2005) are:

A verbal or written advance statement of wishes and feelings, beliefs and values

An advance decision to refuse treatment

A lasting power of attorney

Other discussions and decisions that can be made in advance might include emergency health care plans and decisions to not attempt cardiopulmonary resuscitation (if not included as part of an Advance Decision to Refuse Treatment).

Advance Decisions to Refuse Treatment (ADRT) allow people to give instructions about refusing specific medical treatments should there ever come a time when they are unable to make decisions for themselves or to communicate them to others. They are enacted when a patient loses capacity and, provided they are deemed to be valid and applicable at that time, they are legally binding.

2. Related policies, guidelines and procedures

Policies: Consent 3.01

3. Responsibility and Accountability

Policy formulation and review: Julie Tribe, Head of Ward
Clinical Approval: Dr Helen McGee, Medical Director
Compliance: All clinical staff

4. Relevant Dates

Policy originated: June 2006
Last Review Date: August 2014
This Review Date: September 2018

5. *Legal Status*

Since the introduction of the Mental Capacity Act 2005 in April 2007, Advance Decisions to Refuse Treatment (ADRT) have been recognised in Statute Law. An ADRT enables someone to refuse specific medical treatment, for a time in the future when they may lack the capacity to consent to or refuse this treatment. However, for this to be valid, at the time of making the ADRT, the person must:

- be 18 or over;
- have the capacity to make an advance decision about treatment;
- be fully informed about the nature and consequences of an ADRT when they make it;
- understand that the ADRT should apply to a specific treatment or circumstances that may arise;
- not be pressurised or influenced by anyone else.

If the decision is to refuse **life sustaining** treatment it must be:

- In writing or written down for them;
- Signed by or signed in the presence of the person making the ADRT;
- This signature must be witnessed (see point 7);
- This ADRT must include the statement that “the Decision is to apply even if life is at risk”

The ADRT must be the most recent expression of the patient’s wishes.

The ADRT then comes into force (i.e. is applicable) if:

- The patient becomes incapable of making any decision because they are either unconscious or lack mental capacity. (Mental capacity should be reassessed on a number of occasions if appropriate, as it may fluctuate – see Consent Policy 3.1 for guidance about how to assess capacity);
- The situation that arises or circumstance the patient is in *is* covered by the ADRT;
- The ADRT requires no unlawful intervention such as assisted suicide, euthanasia or omission of basic nursing care and symptom control.

6. *Advising the patient*

- Should the patient express the desire to make an ADRT or to exercise control to ensure life-prolonging measures are not activated against their wishes:
 - They should be given the Hospice in the Weald information sheets on Advance Decisions to Refuse Treatment (Appendix 2-4) by their nurse or doctor to take away and read and discuss with their family / carers as appropriate.
 - When they have read the information sheets they should be encouraged to ask questions to clarify details as necessary.
 - It is important to emphasise that directions in their ADRT will only be effective in the circumstances which are listed and to discuss the option of a Lasting Power of Attorney for Health and Welfare
- Be ready to discuss the benefits and burdens of treatments that the patient is considering listing as those they would like to refuse.
- Advise the patient to reflect on their ADRT at least every three months to ensure it continues to be valid. An ADRT made a long time in advance is not automatically invalid or inapplicable but is more likely to be questioned by healthcare professionals involved in deciding whether it is valid and applicable.

- Ensure that the patient informs relatives and relevant doctors of the directions in the ADRT. It is the responsibility of the person making the advance decision to make sure this will be drawn to the attention of the healthcare professionals when needed.

7. Actions for attending healthcare professional

- Before the ADRT is photocopied, be prepared to sign the ADRT in order to confirm that the patient has fully discussed the ADRT and its implications with you. You are not confirming that the patient has capacity to sign the document. If any capacity assessment is needed this should be done prior to completion of the form and the full capacity assessment should be documented in the patient's electronic care record (ECR).
- The patient should keep the original document.
- Send a photocopy of the ADRT to all relevant consultants and the patient's GP. Make an entry on the Advance Care Planning Details page in the patient's electronic care record (ECR). The ADRT should then be scanned into the ECR

8. Witnessing of Advance Decisions to Refuse Treatment

- Ideally the patient's signature should be witnessed by someone who is not a close relative or expected to gain from the patient's Will.
- In a situation where an independent witness cannot be found (e.g. if the patient is on the In-Patient Ward, IPW) then a member of hospice staff can witness the patient's signature. They are signing to say they have witnessed the signature only and are not making a statement about the patient's capacity. They should use the hospice address as their contact details rather than their personal address.
- If a doctor is asked to assess a patient's capacity, then this needs to be fully recorded separately in the patient's electronic care record detailing the capacity assessment process.

9. Overriding Advance Decisions to Refuse Treatment

Although a clear decision to refuse treatment is legally binding, a doctor can override the directions in an Advance Decision to Refuse Treatment in the following situations:

1. If the patient is pregnant a doctor can override the ADRT if he/she believes the baby is capable of developing into a live birth.
2. The patient had withdrawn the advance decision
3. If the doctor considers the ADRT is either not valid or not applicable in the circumstances (for example if the patient had a road accident and needed acute care or resuscitation but their ADRT applied to treatment of a cancer). See appendix 1 for algorithm for deciding whether an ADRT is valid and applicable.
4. If emergency life saving treatment is required and there is no 'Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)' order, a doctor is not legally bound to find an ADRT or check its contents if it is not readily available. The doctor is bound to give the necessary treatment to maintain or improve the patient's condition until the ADRT is found.
5. If the patient has done anything that clearly goes against their ADRT (e.g. the patient's ADRT states that they would not want intravenous antibiotics in the event of a chest infection that hasn't responded to oral antibiotics but they have agreed to hospital admission and intravenous antibiotics whilst they have had capacity – under these circumstances it would be important to discuss the situation with the patient and, if they are still keen that their ADRT should hold, a statement to this effect should be added to the ADRT).

6. If the patient has subsequently made a Lasting Power of Attorney for Health and Welfare (see Consent policy 3.1)
7. If the patient would have changed their mind if they had known more about current circumstances.

10. References

1. <http://www.justice.gov.uk/protecting-the-vulnerable/mental-capacity-act> (accessed 1/10/14) (no current changes, accessed 05/09/2018)
2. Advance Decisions to Refuse Treatment: A guide for health and social care professionals. NHS End of Life Care programme and the National Council of Palliative Care. September 2008 (no current changes, accessed 05/09/2018)
3. http://www.adrt.nhs.uk/pdf/Advance_Decisions_Checklist.pdf (accessed 5/8/14) Decision making checklist (appendix 1) no current changes, accessed 05/09/2018
4. NHS choices website. Advance Decisions to Refuse Treatment: (accessed 5/8/14) No current changes, accessed 05/09/2018
5. <http://www.nhs.uk/CarersDirect/moneyandlegal/legal/Pages/Advancedecisions.aspx>

Decision Making Checklist

<p>Always assume the person has capacity to consent to or refuse treatment. You are required to maximise the person's capacity and facilitate communication.</p>		
Question		Answer YES/NO
1	Does the person have capacity to give consent to or refuse treatment him or herself, with appropriate support where necessary	<p>YES: The person has capacity to make the decision him or herself. The Advance Decision to refuse Treatment (ADRT) is not applicable. Ask what s/he wants to do</p> <p>NO: Continue with check list</p>
IS THE ADVANCE DECISION VALID?		
2	Has the person withdrawn the ADRT? (This can be done verbally or in writing)	<p>YES: This is not a valid ADRT. Make sure that you have identified and recorded the evidence that the person withdrew the ADRT.</p> <p>NO: Continue with check list</p>
3	Since making the ADRT, has the person created a lasting power or attorney (LPA) giving anybody else the authority to refuse or consent to the treatment in question?	<p>YES: This is not a valid ADRT. The donee(s) of the LPA must give consent to or refuse the treatment. The LPA decision must be in the person's best interests.</p> <p>NO: Continue with check list</p>
4	Has the person done anything that is clearly inconsistent with the ADRT remaining his/her fixed decision?	<p>YES: This is not a valid ADRT. It is important to identify what the person has done, discuss this with anybody close to the person, explain why this is inconsistent with the ADRT remaining his/her fixed decision, and record your reasons.</p> <p>NO: The ADRT is valid. Continue with the checklist</p>
IS THE ADVANCE DECISION APPLICABLE?		
5	<p>(a) Does the ADRT specify which treatment the person wishes to refuse?*</p> <p>(b) Is the treatment in question that specified in the ADRT?</p>	<p>YES: to both (a) and (b): Continue with the checklist.</p> <p>NO: This is not an applicable ADRT.</p>
6	If the ADRT has specified circumstances in which it is to apply *(see question 3 above), do all of those circumstances exist at the time that the decision whether to refuse treatment needs to be made? (N.B. It is possible for a person to decide that the ADRT should apply in all circumstances)	<p>YES: Continue with the checklist</p> <p>NO: This is not an applicable ADRT.</p>

7	Are there reasonable grounds for believing that circumstances exist which the person did not anticipate at the time of making the ADRT and which would have affected his/her decision had s/he anticipated them?		YES: If such reasonable grounds exist, this will not be an applicable ADRT. It is important to identify the grounds, discuss this with anybody close to the person, and identify why they would have affected his/her decision had s/he anticipated them, and record your reasoning. NO: Continue with the checklist
LIFE SUSTAINING TREATMENT			
8	Is the ADRT both valid and applicable according to the criteria set out above?		YES: Continue with the check list NO: This is not a binding ADRT to refuse the specified life sustaining treatment
9	In your opinion is the treatment in question necessary to sustain the person's life?		YES: Continue with the checklist NO: This is a binding ADRT to refuse the specified non-life-sustaining treatment. It must be respected and followed
10	Does the ADRT contain a statement that it is to apply even if the person's life is at risk?		YES: Continue with the checklist NO: This is not a binding ADRT to refuse the specified life-sustaining treatment
11	Is the ADRT: <ul style="list-style-type: none"> • In writing and • Signed by the person making it or by somebody else on his/her behalf and at his/her direction and • Signed by a witness? 		YES TO ALL: This is a binding advance decision to refuse the specified life-sustaining treatment. It must be respected and followed NO TO ANY: This is not a binding advance decision to refuse the specified life-sustaining treatment

* N.B. It is possible to use layman's language to specify both treatment and circumstances

ADVANCE DECISIONS TO REFUSE TREATMENT PATIENT INFORMATION

Hospice in the Weald recognises that some people wish to make decisions now about their future care in case they should lose capacity (the ability to make decisions for themselves) at some point in the future. Specifically, they may not wish for intense efforts to be made to keep them alive if they feel that their quality of life would not give them the dignity that they currently enjoy. Advance Decisions to Refuse Treatment (sometimes known as Living Wills), allow people to give instructions about refusing possible medical treatments should there ever come a time when they are unable to make decisions for themselves or to communicate them to others. Hospice in the Weald has therefore produced this document to help those people who may be thinking about these issues.

Since the Mental Capacity Act of 2005 came into force in 2007, Advance Decisions to Refuse Treatment (referred to as ADRT) have become recognised in statute law.

A clear written or recorded verbal decision to refuse treatment in advance is generally considered to be legally binding if:

- You are over 18 when you make the decision;
- You have mental capacity;
- You are fully informed about the nature and consequences of your ADRT when you make it;
- You understand that the ADRT should apply to specific treatments or circumstances that may arise;
- You are not pressurised or influenced by anyone else;
- The ADRT is your most recent expression of your wishes.

The ADRT comes into force if:

- You then become incapable of making any decision because you are either unconscious or you lack mental capacity;
- The situation that arises or circumstances you are in is covered by the ADRT;
- The ADRT is shown to the medical team attending you;
- The ADRT cannot require any unlawful omission or intervention such as assisted suicide or euthanasia;
- The provision of basic nursing care and symptom control cannot be prevented through an ADRT.

Advantages and disadvantages

When a medical team is faced with a difficult decision about what treatment or care to provide for a patient who is not in a position to make a decision themselves at the time, having an ADRT means that they know what the patient would not have wanted. Having said that, not every situation can be planned for and any ADRT needs to be interpreted to ensure that it does still apply. When an ADRT does apply, it gives the patient some control over their future treatment. Throughout the process of planning an ADRT, the opportunity to discuss difficult issues with close family and friends is most helpful.

Remember, of course, that even when you lack capacity you may have wishes, but you may be unable to express them. Should these be different from those in your ADRT, nevertheless the doctors will follow your ADRT.

Points to consider

- The directions in your ADRT are only effective if you specify the circumstances in which they would be necessary and you may well need help in discussing this. If your wishes are not clear, doctors are obliged to act in your best interests and they will begin by prioritising measures in favour of preserving your life.
- If you are aware of any specific treatment which has unwanted side-effects or consequences then it is a good idea to state that you refuse that treatment. This is best decided upon in consultation with your doctor who can inform you of likely treatments and their benefits and burdens. It is also important to realise that treatments may change and you should update your ADRT accordingly. It is wise to reflect on your document and sign and date it, at least 3 monthly to ensure your decision is valid.
- You can only make an advance decision to REFUSE a specific treatment; you cannot say you would like to have a treatment in the future.
- An ADRT is a written document and although it can be changed or re-written if your wishes change, it is fairly static. An alternative to writing an ADRT is to appoint someone close to you as your Lasting Power of Attorney (LPA) for Health and Welfare. If you have an LPA for Health and Welfare, then if you lose capacity to make decisions in the future, that person will have to be consulted about any medical decisions about you. They can then take into account the situation you are in and make decisions in your best interests, based on their knowledge of what you would have wanted for yourself. Some people feel this is more flexible and appropriate for them. Ask your healthcare professionals about this option if you are interested but please note an LPA must be registered with the Office of the Public Guardian and there is a charge for this.
- Your ADRT provides for the refusal of treatment and here are a few examples of the scope this could take:
 1. If you want to remain as clear-minded as possible you could request that you would only accept medicine that had no or minimal effects on your mental awareness. However, if this compromises your symptom control or causes distress, the doctors may, in extreme circumstances overrule this in your best interests.
 2. You could instruct as to when you would like the ADRT to commence, for example, by requesting that doctors make every effort to maintain you until a specified person arrives, or has reasonable time to arrive, before withdrawing treatment.
- Although a clear decision to refuse treatment is legally binding, a doctor can override the directions in your ADRT in the following situations:
 1. If you are pregnant, a doctor can override your ADRT if he/she believes the baby is capable of developing into a live birth. You can state that the ADRT is not to apply in this situation. If you state that you want the ADRT to apply regardless, it is important to know that its provisions cannot be guaranteed.
 2. The doctor treating you considers your ADRT is either not valid or not applicable in the circumstances (for example if you had a road accident and needed acute care or resuscitation but your ADRT applied to treatment of a cancer). If life saving treatment is required a doctor is not bound to find your ADRT or check its contents if it is not readily available. S/he is bound to give you the necessary treatment to maintain or improve your condition until the ADRT is found. Therefore you should inform relatives and doctors of the directions in your ADRT in advance and ensure as far as you can that copies of your most recent ADRT are lodged with any notes relating to your care.

HOW TO COMPLETE YOUR ADVANCE DECISION TO REFUSE TREATMENT

1. You must tell your family doctor that you have made an Advance Decision to Refuse Treatment (ADRT). Ideally your wishes should be discussed with him/her before completing the directive.
2. If you have any specific wishes relating to your treatment, you should write these down in the spaces provided.
3. The healthcare professional who has discussed the ADRT with you should complete the relevant box on the form.
4. You should make two photocopies of the original before you ask witnesses to sign them.
5. All three forms should then be signed by someone who is not a close relative or expecting to benefit from your Will. You should then sign and date all copies of the forms in front of this witness. If you are unable to sign, you can direct someone to sign on your behalf and the witness must then sign to indicate that they witnessed the nominated person signing the document in front of you.
6. Give one completed form to your GP, to be put in your medical records. Give the second copy to the consultant (if any) overseeing your care, and keep the last form for yourself. Inform close relatives and/or friends of the existence of the Advance Decision to Refuse Treatment.
7. Remember to review your Advance Decision to Refuse Treatment at regular intervals to ensure that it still represents your wishes. Signing and dating at the bottom when you do this will indicate how recently you have thought about it. If you change your mind about anything you have written, tell your GP, your named person and anyone else close to you and amend your Advance Decision to Refuse Treatment accordingly.

MY ADVANCE DECISION TO REFUSE TREATMENT

My Name	Any distinguishing features in the event of unconsciousness
Address	Date of Birth
	Telephone Number

What is this document for?

This advance decision to refuse treatment has been written by me to specify in advance which treatments I do not want in the future. These are my decisions about my healthcare, in the event that I have lost mental capacity and can not consent to or refuse treatment. This advance decision replaces any previous advance decision I have made.

Advice to the reader

I have written this document to identify my advance decision to refuse treatment. I would expect any health care professionals reading this document in the event I have lost capacity, to check that my advance decision is valid and applicable, in the circumstances that exist at the time.

Please Check

Please do not assume I have lost capacity before any actions are taken. I might need help and time to communicate.

If I have lost capacity please check the validity and applicability of this advance decision to refuse treatment.

This advance decision becomes legally binding and must be followed if professionals are satisfied it is valid and applicable. Please help to share this information with people who are involved in my treatment and care and need to know about this.

Please also check if I have made any other statements about my preferences or decisions that might be relevant to my advance decision.

This advance decision to refuse treatment does not refuse the offer and or provision of basic care, support and comfort.

My Name

My advance decision to refuse treatment

I wish to refuse the following specific treatment:	In these circumstances:

(Note to the person making this statement: If you wish to refuse a treatment that is or may be life-sustaining, you must state in the box above that you are refusing that treatment even if your life is at risk as a result. An advance decision refusing life-sustaining treatment must be signed and witnessed).

My Name	
My Signature (or nominated person)	Date of Signature
Witness	Witness Signature
Name of witness	Telephone
Address	Date
Person to be contacted to discuss my wishes	
Name	Relationship
Address	Telephone

I have discussed this with (e.g. name of Health care Professional)	
Profession / Job Title	
Contact Details	Date
Signature of Professional	Date

I give my permission for this document to be discussed with my relatives / carers	
Yes	No (please circle one)
My General Practitioner is (Name)	
Address	
Telephone	
Optional Review	
Comment	Date / Time
Maker's Signature	Witness Signature

My Name

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

Name	Relationships	Telephone Number

Further Information (optional)
I have written the following information that is important to me. It describes my hopes, fears and expectations of life and any potential health and social care problems. It does not directly affect my advance decision to refuse treatment but the reader might find it useful.