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**Policy:** ADVANCE DECISIONS TO REFUSE TREATMENT

**Policy number:** 2.21

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## Rationale

**Hospice in the Weald** recognises that some people wish to make decisions about their future care should they lose capacity. 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 allow people to give instructions about any possible medical treatment should there ever come a time when they are unable to make decisions for themselves or to communicate them to others.

## Legal status

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

- 18 or over;
- Have the capacity to make an advance decision about treatment;
- Fully informed about the nature and consequences of an Advance Decision when they make it;
- Understanding that the Advance Decision should apply to specific treatment or circumstances that may arise;
- Not 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 or signed in their presence;
- This signature must be witnessed;
- This Decision must include the statement that the Decision is to apply even if life is at risk

The Advance Decision must be the most recent expression of the patient's wishes.

The Advance Decision then comes into force 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);
- The situation that arises or circumstance the patient is in are covered by the Advance Decision;
- The Advance Decision requires no unlawful intervention such as assisted suicide, euthanasia or omission of basic nursing care and symptom control.

## Actions for attending physician

- Before the Decision is photocopied be prepared to sign the Decision to confirm that the patient has fully discussed the Decision and its implications with you.
- Send a photocopy of the Decision to all relevant consultants and GP if and when the patient is discharged.
- Make an entry on the front page of PalCare alongside the DNAR status and in the Groups section to indicate that an Advance Decision is in place. The Decision should then be scanned into the Electronic Health Record (EHR) and saved with other correspondence.

## Witnessing of Advance Decision

Only one member of Hospice in the Weald staff should sign the Decision. They are signing to say they have witnessed the signature only and are not assessing the patient's capacity. There should also be one independent witness who is not a close relative or expected to gain from his/her Will.

If a doctor is asked to assess a patient's capacity then this needs to be recorded separately in the patient's notes.

## Advising the patient

- Should the patient express the desire to make an Advance Decision 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 Decision (Appendix 2-4) by their nurse or doctor.
  - 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 Advance Decision are only effective in the circumstances which are listed.
- Be ready to discuss the benefits and burdens of treatments that the patient is considering listing as those they would refuse.
- Advise the patient to reflect on their Decision at least every three months to ensure it continues to be valid. Decisions made a long time in advance are not automatically invalid or inapplicable but may raise doubts when deciding if they are valid and applicable.
- Ensure that the patient informs relatives and relevant doctors of the directions in the Advance Decision. 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.

## Overriding Advance Decision

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

1. If the patient is pregnant a doctor can override the Advance Decision 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 Advance Decision 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 Advance Decision applied to treatment of a cancer).
4. If emergency life saving treatment is required and there is no 'Do not resuscitate' order, a doctor is not bound to find an Advance Decision or check its contents if it is not readily available. The doctor is bound to give the necessary treatment to maintain or improve the patients' condition until the Advance Decision is found.
5. If the patient has done anything that clearly goes against their Advance Decision.
6. If the patient has subsequently made a Lasting Power of Attorney.
7. If the patient would have changed their mind if they had known more about current circumstances.

See Advance decision checklist Appendix 1

## Reference

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

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<b>Policy Originated:</b>	<b>June 2006</b>
<b>Date Reviewed:</b>	<b>December 2008</b>
<b>Review Due:</b>	<b>December 2010</b>

**Issuing Authority:**

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Appendix 1

<p><b>Always assume the person has capacity to consent to or refuse treatment. You are required to maximise the person's capacity and facilitate communication.</b></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><b>YES:</b> The person has capacity to make the decision him or herself. The advance decision is not applicable. Ask what s/he wants to do</p> <p><b>NO:</b> Continue with check list</p>
<b>IS THE ADVANCE DECISION VALID?</b>		
2	Has the person withdrawn the advance decision? (This can be done verbally or in writing)	<p><b>YES:</b> This is not a valid advance decision. Make sure that you have identified and recorded the evidence that the person withdrew the advance decision.</p> <p><b>NO:</b> Continue with check list</p>
3	Since making the advance decision, 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><b>YES:</b> This is not a valid advance decision. 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><b>NO:</b> Continue with check list</p>
4	Has the person done anything that is clearly inconsistent with the advance decision remaining his/her fixed decision?	<p><b>YES:</b> This is not a valid advance decision. 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 advance decision remaining his/her fixed decision, and record your reasons.</p> <p><b>NO:</b> The advance decision is valid. Continue with the checklist</p>
<b>IS THE ADVANCE DECISION APPLICABLE?</b>		
5	<p>(a) Does the advance decision <b>specify</b> which treatment the person wishes to refuse?*</p> <p>(b) Is the treatment in question that specified in the advance decision?</p>	<p><b>YES:</b> to both (a) and (b): Continue with the checklist</p> <p><b>NO:</b> This is not an applicable advance decision</p>
6	<p>If the advance decision has specified circumstances in which it is to apply (see question 3 above), do <b>all</b> of those circumstances exist at the time that the decision whether to refuse treatment needs to be made?</p> <p>(N.B. It is possible for a person to decide that the advance decision should apply in <b>all</b> circumstances)</p>	<p><b>YES:</b> Continue with the checklist</p> <p><b>NO:</b> This is not an applicable advance decision</p>

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

**Hospice in the Weald** recognises that some people wish to make decisions about their future care should they lack capacity. 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 any possible medical treatment 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 introduction of the Mental Capacity Act 2005, in April 2007, Advance Decisions 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 Advance Decision when you make it;
- You understand that the Advance Decision should apply to specific treatment or circumstances that may arise;
- You are not pressurised or influenced by anyone else;
- The Advance Decision is your most recent expression of your wishes.

The Advance Decision then 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 *must* be covered by the Advance Decision;
- The Decision is shown to the medical team attending you;
- The Advance Decision 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 Advance Decision.

### ***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, having an Advance Decision means that they know what the patient would have wanted. Having said that, not every situation can be planned for and any Advance Decision needs to be interpreted to ensure that it does still apply. When an Advance Decision does apply though, it gives the patient control over their future treatment. All through the process of planning one, 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 Advance Decision, nevertheless the doctors will follow your Advance Decision.

### ***Points to consider***

- The directions in your Advance Decision 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 Advance Decision 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.
- Your Advance Decision 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 affect 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 Advance Decision 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 Advance Decision in the following situations:
  1. If you are pregnant a doctor can override your Advance Decision if he/she believes the baby is capable of developing into a live birth. You can state that the Advance Decision is not to apply in this situation. If you state that you want the Advance Decision to apply regardless, it is important to know that its provisions cannot be guaranteed.
  2. The doctor treating you considers your Advance Decision 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 Advance Decision applied to treatment of a cancer). If life saving treatment is required a doctor is not bound to find your Advance Decision 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 Advance Decision is found. Therefore you should inform relatives and doctors of the directions in your Advance Decision in advance and ensure as far as you can that copies of your most recent Advance Decision are lodged with any notes relating to your care.



## HOW TO COMPLETE YOUR ADVANCE DECISION

1. You must tell your family doctor that you have made an Advance Decision. 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. You should make two photocopies of the original before you ask witnesses to sign them
4. 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 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.
5. 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.
6. Remember to review your Advance Decision 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 accordingly.



**MY ADVANCE DECISION TO REFUSE TREATMENT**

<b>My Name</b>	<b>Any distinguishing features in the event of unconsciousness</b>
<b>Address</b>	<b>Date of Birth</b>
	<b>Telephone Number</b>

**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. 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.

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 does not refuse the offer and or provision of basic care, support and comfort.**

**My Name**

**My advance decision to refuse treatment**

<b>I wish to refuse the following specific treatment:</b>	<b>In these circumstances:</b>

**(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).**

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

<b>I have discussed this with</b> (e.g. name of Health care Professional)	
<b>Profession / Job Title</b>	<b>Date</b>
Contact Details	
I give my permission for this document to be discussed with my relatives / carers	
<b>Yes</b>	<b>No</b> (please circle one)
<b>My General Practitioner is</b> (Name)	
Address	
Telephone	
<b>Optional Review</b>	<b>Date / Time</b>
Comment	
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)**

<b>Name</b>	<b>Relationships</b>	<b>Telephone Number</b>

**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.