



LINDSEY LODGE HOSPICE AND HEALTHCARE

ADVANCE DECISIONS TO REFUSE TREATMENT (ADRT)

CONTENTS

SECTION NUMBER	SECTION TITLE	PAGE NO
	Introduction	3
Section 1	Summary	3/4
Section 2	What is an ADRT?	4
Section 3	What are the Benefits?	4
Section 4	What are the Risks?	5
Section 5	Who can make an ADRT?	5
Section 6	What should people include in an ADRT?	6
Section 7	Process	6/7
APPENDIX 1	NHS App Instructions	7
	References	8

INTRODUCTION

This policy deals with advance decisions to refuse treatment at a future date. The Mental Capacity Act refers to these as ‘advance decisions’. Advance decisions to refuse treatment that are both valid and applicable under the requirements of the Mental Capacity Act will be legally binding for everyone involved in the care of the individual. This makes advance decisions to refuse treatment quite distinct from other aspects of advance care planning.

The Act and Code of Practice clearly define that the responsibility for making an advance decision lies with the patient making it. It is recommended for the patient to discuss their advance decision with a senior healthcare professional. If necessary this professional may give advice or support during this process about how to make the advance decision and ensure that health and social care professionals are aware of it. This may also be an opportunity to discuss the person’s future care and treatment.

1. Summary

- ❖ An advance decision 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 consent to or refuse that treatment.
- ❖ An advance decision to refuse treatment must be valid and applicable to current circumstances. If it is, it has the same effect as a decision that is made by a person with capacity: healthcare professionals must follow the decision.
- ❖ Healthcare professionals will be protected from liability if they:
 - stop or withhold treatment because they reasonably believe that an advance decision exists, and that it is valid and applicable
 - treat a person because, having taken all practical and appropriate steps to find out if the person has made an advance decision to refuse treatment, they do not know or are not satisfied that a valid and applicable advance decision exists.
- ❖ People can only make an advance decision under the Act if they are 18 or over and have the capacity to make the decision. They must say what treatment they want to refuse, and they can cancel their decision – or part of it – at any time.
- ❖ If the advance decision refuses life-sustaining treatment, it must:
 - be in writing (it can be written by someone else or recorded in healthcare notes)
 - be signed and witnessed, and
 - state clearly that the decision applies even if life is at risk.
- ❖ To establish whether an advance decision is valid and applicable, healthcare professionals must try to find out if the person:
 - has done anything that clearly goes against their advance decision
 - has withdrawn their decision
 - has subsequently conferred the power to make that decision on an attorney, or would have changed their decision if they had known more about the current circumstances
- ❖ Sometimes healthcare professionals will conclude that an advance decision does not exist, is not valid and/or applicable – but that it is an expression of the person’s wishes. The healthcare professional must then consider what is set out in the advance decision as an expression of previous wishes when working out the person’s best interests.

- ❖ Some healthcare professionals may disagree in principle with patients' decisions to refuse life-sustaining treatment. They do not have to act against their beliefs. But they must not simply abandon patients or act in a way that affects their care.
- ❖ Advance decisions to refuse treatment for mental disorder may not apply if the person who made the advance decision is or is liable to be detained under the Mental Health Act 1983.

2. What is an ADRT?

It is a general principle of law and medical practice that people have a right to consent to or refuse treatment. The courts have recognised that adults have the right to say in advance that they want to refuse treatment if they lose capacity in the future – even if this results in their death. A valid and applicable advance decision to refuse treatment has the same force as a contemporaneous decision. This has been a fundamental principle of the common law for many years and it is now set out in the MCA Code of Practice.

This applies if:

- ✓ the person is 18 or older, and
- ✓ they have the capacity to make an advance decision about treatment.

Healthcare 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 (they could be charged for committing a crime) or civil liability (somebody could sue them). If there are any grounds for reasonable doubt about any issues relating to the validity of the advance decision, the professional may provide treatment to sustain life or prevent serious deterioration to the person's condition while the issue is resolved, if it is considered to be in the person's best interests.

Advance decisions can have serious consequences for the people who make them. They can also have an important impact on family and friends, and professionals involved in their care. Before healthcare professionals can apply an advance decision, there must be proof that the decision: - exists, is valid and is applicable to the current circumstances. These tests are legal requirements under section 25(1).

3. What are the benefits?

Some people may fear future illness and sometimes want to set out some principles to guide their future care. Benefits may be as follows:

- ✓ Providing the person with better control over their circumstances and so reducing the chance of potentially distressing situations
- ✓ Advance decisions may be useful in some circumstances, for example when a person states that specified treatments should be withheld or withdrawn when a particular stage has been reached in the trajectory of a life-threatening condition
- ✓ By enabling the person to refuse burdensome treatments and express a wish for a natural death.
- ✓ An advance decision can be made as part of an advance care planning process

The MCA requires people to specify the treatment they wish to refuse and they may specify the circumstances, if any, in which that treatment is to be refused. It may be difficult to create a sufficiently specific advance decision to refuse treatment unless somebody already has a particular condition diagnosed. Once there is a diagnosis, it will be easier to anticipate specific events on the disease pathway which may give rise to a specific treatment decision.

4. What are the risks?

Advance decisions that refuse treatment in a blanket approach applicable in all circumstances may inadvertently disadvantage a person. For example:

- ✘ An advance decision refusing treatment other than comfort measures after a stroke might prevent good treatment and rehabilitation opportunities, with the result that, rather than dying, the person is left with worsened long term disability
- ✘ A person with dementia (lacking capacity to make decisions about medical treatment) can be physically reasonably well. This person could have a urinary tract infection which could be treated easily with a short course of antibiotics. If a refusal of antibiotics has been made this might prevent appropriate treatment and lead to distress.

This illustrates the need for great care to be taken in drafting an advance decision to avoid unintended adverse consequences.

It is worth noting that an advanced decision to refuse treatment cannot be used to refuse basic comfort and care.

5. Who can make an ADRT?

It is up to individuals to decide whether they want to refuse treatment in advance. They are entitled to do so if they want, but there is no obligation to do so. At the time of writing an advanced decision to refuse treatment, the individual must have capacity to make the decisions being made.

Many people prefer not to make an advance decision, and instead leave healthcare professionals to make decisions in their best interests at the time a decision needs to be made. Another option is to make a Lasting Power of Attorney. This allows a trusted family member or friend to make personal welfare decisions, such as those around treatment, on someone's behalf, and in their best interests if they ever lose capacity to make those decisions themselves.

People can only make advance decisions to *refuse* treatment. Nobody has the legal right to *demand* specific treatment, either at the time or in advance. So no-one can insist (either at the time or in advance) on being given treatments that healthcare professionals consider to be clinically unnecessary, futile or inappropriate. But people can make a request or state their wishes and preferences in advance. Healthcare professionals should then consider the request when deciding what is in a patient's best interests if the patient lacks capacity.

Nobody can ask for and receive procedures that are against the law (for example, help with committing suicide). As section 62 sets out, the Act does not change any of the laws relating to murder, manslaughter or helping someone to commit suicide.

6. What should people include in an ADRT?

An advanced decision to refuse treatment:

- ✓ Must state precisely what treatment is to be refused – a statement giving a general/vague desire to not be treated is not enough
- ✓ May set out circumstances when the refusal should apply – it is helpful to include as much detail as possible
- ✓ Will only apply at the time when the person lacks capacity to consent to or refuse the specific treatment.

There is no set form for written advance decisions, but is helpful to include the following:

- ✓ Full details of the person including date of birth, home address and any distinguishing features
- ✓ The name and address of the person's GP and whether they have a copy of the document
- ✓ 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 (it is advisable to review ADRTs regularly)
- ✓ The person's signature (or representative)
- ✓ The signature of the witness

A suggested template for documenting an ADRT can be seen in appendix A.

Advanced decision to refuse life-sustaining treatment

- ✓ Must be in writing
- ✓ Signed by the individual/representative
- ✓ Witnessed
- ✓ Clear, specific and include "...even if my life is at risk"
- ✓ Cannot override comfort measures – warmth, shelter and basic care

Lasting Power of Attorney (LPA) and ADRT

- An attorney (LPA) cannot give consent to treatment that has been refused in an advance decision made after the LPA was signed
- An 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

7. Process

At Lindsey Lodge Hospice we respect and promote patient's involvement in their care and the opportunity to express and document their wishes.

Part of the initial assessment is to enquire about any ADRTs the patient may already have. Copies will be obtained to hold in the hospice record if the patient wishes. This would be a good opportunity to review the content of the ADRT to ensure it is still relevant and applicable. The appropriate part of the Palliative care template will be updated on SystmOne.

If a patient decides they wish to complete an ADRT and they have the mental capacity to do so, it is recommended that they start the process with a conversation with a doctor. This conversation will cover the likely scenarios that may occur in the future and to understand what kind of treatments the patient may wish to refuse. The process of writing an ADRT may be straight forward and require a single meeting, or may involve a series of discussions to ensure the patient is fully aware of their choices.

If the patient completes an ADRT whilst at the hospice, copies will be made and distributed amongst the relevant others that have been identified.

A copy will also be saved within the SystemOne record and uploaded into the patient's EPaCCS record.

The appropriate part of the palliative care template will be updated on SystemOne.

It is good practice to review ADRTs on a regular basis. Annually would be an acceptable timeframe for most individuals.

Appendix A



ADRT-NHS-Print-Form-v8-April-2013.pdf

REFERENCES:

The National Council for Palliative Care and NHS National End of Life Care Programme: Advanced decisions to refuse treatment- A guide for health and social care professionals 2013.

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