

# Advance Decision to Refuse Treatment Information Pack

## Advance Decision to Refuse Treatment Explained

None of us know what the future holds. None of us know if or when we will need the support of others. What is certain is that if the need arises, we would like to be supported according to our wishes and preferences.

Therefore if carers and Healthcare Professionals know what our preferences are, then there is a greater likelihood that we will be supported at all times as we would like, even if we are unable to say. This requires us to think about, discuss and record our wishes and preferences in an Advanced Care Plan, so that the relevant carers know what they are. If this is what you would like to do, talk to your GP or Palliative Care Nurse.

A step further may mean that you also want to express a specific choice about future medical treatment that you do not want to receive. This may be because of religious beliefs, medical implications, or the way you choose to die. If you decide to refuse certain life sustaining treatments, you would need to fill out an ADRT document.

### An Advance Decision to Refuse Treatment (ADRT)

#### What is it?

An ADRT (previously known as a Living Will) is a decision you can make in advance to **refuse** specific treatments in certain circumstances in the future. This can include the right to refuse life sustaining treatment.

#### Why make an ADRT?

For people with progressive or life limiting illnesses, it is often especially important to plan ahead. Many people in this situation fear losing control and not being able to tell Healthcare Professionals their decisions themselves. An ADRT tells people about your decision and becomes active when you lose the ability to make decisions.

For many patients an ADRT can give them peace of mind and allows them to die with dignity on their own terms.

#### What are the advantages of an ADRT?

An advance decision to refuse treatment can be part of letting people know about your wishes and preferences. It can help discussions between Healthcare Professionals and your relatives or carers during a medical crisis if for any reason you can no longer communicate or express yourself.

#### What are the disadvantages of an ADRT?

It is important that before making an advance decision to refuse treatment you think about taking advice from your doctor. Your doctor will explain all of the facts involved in refusal of treatment including the possibility of any discomfort or putting life at risk.

### **What an ADRT treatment cannot do**

An advance decision to refuse treatment cannot be used to refuse the basic nursing care required to keep a person comfortable. Nor can an advance decision be used to request any form of treatment to accelerate death. It is not a will.

### **Where can I get hold of an ADRT form?**

Ask a Health or Social Care Professional. Often it is best to ask your GP or hospital team who may already be involved in your care.

### **Is an ADRT legally binding?**

Yes. This is a way of expressing a decision NOT to have a specific treatment in specific circumstances in the future and is legal providing the ADRT applies to the circumstances described in the document.

### **Who do I tell about my ADRT?**

If you have made an advance decision to refuse treatment you must be sure that the people involved in your care know this. Ask your nurse or doctor to help you do this. This will help to avoid difficult situations especially when an emergency happens.

## **YOU MAY DECIDE TO HAVE AN ALERT BRACELET OR CARRY A CARD**

### **Can I change my mind?**

Yes at any time. If you change your mind then simply inform all your Healthcare and Social Care Professionals straightaway. It is important that you inform all of the people who have a copy of the previous advance decision to refuse treatment because it is now cancelled. You will need to keep a list of those who hold a copy of the ADRT.

### **Important Safeguards**

- Discuss your decision with carers, family, health and social care professionals
- Distribute copies to people who need to know
- Review the decision as necessary, as circumstances can change
- If a decision is changed inform all people who need to know

### **What information to include in an ADRT**

**There is no set format but it is useful to include the following:**

- Your name
- Address
- Name/address/phone number of your GP
- Your signature
- Dated signature of at least one witness
- A clear statement of your wishes and the circumstances in which they apply
- A declaration that the decision is applicable even if it puts life at risk
- The name/address/phone number of any person you have nominated to be consulted about your wishes.
- Review dates/signature (views, circumstances, illness and treatment can change over time, so it is good to review periodically)
- Who has copies (eg Doctor, hospital, family, Ambulance Service)

## **Lasting Power of Attorney**

Lasting Power of Attorney allows a trusted family member or friend to make personal welfare decisions about treatments, on your behalf if you ever lose capacity to make those decisions yourself.

## **Where can I go for further help and support?**

The Public Guardianship Office offers information about Lasting Power of Attorney and the Mental Capacity Act. [www.publicguardian.gov.uk](http://www.publicguardian.gov.uk) booklets available online.  
Customer services: 0845 330 2900

Advance Directive to Refuse Treatment information website: [www.adrtnhs.co.uk](http://www.adrtnhs.co.uk)  
National Council for Palliative Care [www.ncpc.org.uk](http://www.ncpc.org.uk)  
End of Life Care Programme [www.endoflifecareforadults.nhs.uk](http://www.endoflifecareforadults.nhs.uk)

## **Acknowledgements:**

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Ann Main - MND Connect Adviser and MND Connect Team for user friendly advice, MND Association.

MND Connect - a confidential telephone advice line for Motor Neurone Disease

[mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org) MND Association website [www.mndassociation.org](http://www.mndassociation.org)

## **Glossary** *(terms of reference)*

### **Advance Decision to Refuse Treatment (ADRT)**

An ADRT is intended to be a binding refusal of certain kinds of treatment as specified by the person making the advance decision.

It will only come into effect if you are unable to convey your wishes because mental capacity is impaired. It allows you to specify precisely the kind of treatment and circumstances in which your wishes will take effect.

### **Lasting Power of Attorney (LPA)**

Creating an LPA means you can choose someone you trust to make health and social care decisions for you, if you are unable to do so. An LPA is a legal document registered with the Office of the Public Guardian.

### **Cardio-Pulmonary Arrest/Resuscitation**

Resuscitation is an emergency medical procedure given when the heart and/or breathing stops. It usually consists of chest compressions and artificial respiration given whilst efforts are made to re-establish heart and lung functions.

### **Artificial Hydration and Nutrition**

If a person is not able to swallow because of a medical problem, he/she can be given fluids and nutrition in ways other than by mouth. This is referred to as artificial hydration and nutrition. Artificial Feeding may be given intravenously (IV) via a drip into a vein or through a plastic tube called a nasogastric tube, (put through the nose, down the throat and into the stomach). If a PEG (percutaneous endoscopic gastrostomy) tube is in place, hydration and nutrition is given via this route.

### **Ventilation/non-invasive ventilation**

Non-invasive ventilation is given to relieve breathlessness, and improve sleep, via a machine that sucks air in, filters and pumps into the lungs via a face-mask or nasal tube (nippv)

Ventilation by means of tracheotomy is an incision into the trachea (windpipe) that forms an opening. A tube is inserted through the opening to allow breathing to take place.

SAMPLE COPY

**My Advance Decision  
to Refuse Treatment  
(ADRT)**

## Advance Decision to Refuse Treatment

<b>Name:</b> <i>(your name)</i>	<b>Any distinguishing features in the event of unconsciousness:</b> <i>(mole on face)</i>
<b>Address:</b> <i>(your address)</i>	<b>Date of Birth:</b> <i>(your date of birth)</i>
	<b>Telephone Number:</b> <i>(your telephone number)</i>

### What this document is for?

This Advance Decision to Refuse Treatment (also known as ADRT) has been written by me to state 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 cannot consent to or refuse treatment. This ADRT form replaces any previous ADRT I have made.

### Advice to the reader

I have written this document to identify my advance decision. I would always expect that Health and Social Care Professionals reading this document check that my ADRT is valid and applicable, setting out the specific treatments in certain circumstances.

### 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 ADRT.

If my ADRT is valid and applicable please ensure that you act on it as it is a legal document. Please help to share this information with relevant colleagues 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 wishes that might be relevant to my advance decision.

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

**Name:** *(maker of the ADRT)*

**These are my advance decisions, about my health care, in the event that I cannot consent to treatment and replace any previous decisions I have made.**

**In relation to my health problems, I have been diagnosed with:**

*Example (you may write something like this):*

*Motor Neurone Disease (MND) I am becoming progressively weaker. This condition causes great problems with daily activities including eating and drinking. I have talked about my feelings with my family. This is the right time for me to make this decision as I know MND is terminal and I wish to make choices about the way I die.*

**I would also wish to refuse life sustaining treatment, 'even if my life is at risk':**

I wish to refuse the following specific treatments:	In these circumstances:
<i>Cardio-pulmonary Resuscitation (re-starting my heart/breathing)</i>	<i>In the event that I have a cardiac or respiratory arrest.</i>
<i>Assisted Ventilation (breathing using a machine)</i>	<i>If I can no longer breathe by myself without the help of a machine or after simple attempts to help, have been tried to position me, clear my airway and remove secretions.</i>
<i>Artificial Feeding (via a tube in my stomach/drip)</i>	<i>When my Motor Neurone Disease has deteriorated to the point that I cannot swallow safely, even with the help of others.</i>
<i>Antibiotics</i>	<i>In the event that I have a severe chest infection that might threaten my life.</i>

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

<b>My signature:</b> <i>(your name)</i> (or nominated person)	<b>Date of signature:</b> <i>(same date as witness signing)</i>
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<b>Witness:</b> <i>(person who witnessed your signing)</i>	<b>Witness signature:</b>
Name:	Telephone:
Address:	Date:

<b>Person to be contacted to discuss my wishes:</b>	
Name: <i>(Mr P Smith)</i>	Relationship: <i>(son)</i>
Address: <i>(son's address)</i>	Telephone: <i>(son's telephone number)</i>

<b>I have discussed this with:</b> <i>(Dr Smith)</i>  <i>(e.g. name of Healthcare Professional)</i>  <b>Profession / Job Title:</b> <i>(Consultant Neurologist)</i> Contact Details: <i>(Department of Neurology, Good Hospital, Birmingham)</i>  Date: <i>(when you discussed)</i>  I give permission for this document to be discussed with my relatives/carers  <div style="display: flex; justify-content: space-around;"> <span>Yes</span> <span>No</span> <span>(please circle one)</span> </div>
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<b>My General Practitioner is:</b> <i>(name)</i>  Address: <i>(surgery address)</i>  Telephone Number:
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<b>Review 1:</b> Date/Time of review: _____ Valid until: _____ <i>(date you reviewed and decided this document is still valid)</i>
Maker's signature: _____ Witness signature: _____

**Review 2:** Date/Time of review:

Valid until:

Maker's signature:

Witness signature:

**The following list identifies which people have a copy of the ADRT and their contact details and have been told about this Advance Decision to Refuse Treatment.**

*Example*

Name:	Relationship:	Telephone Number:
	<i>GP</i>	
	<i>Brother</i>	
	<i>Friend</i>	
	<i>Birmingham Ambulance Service</i>	

**Further Information**

**I have written the following information that is important to me but does not directly relate to my Advance Decision to Refuse Treatment.**

*Example:*

*(you may decide to write things that are important to you such as staying at home rather than going into hospital, having your family around you, continuing to have medication for symptom control and comfort)*

**My Advance Decision to  
Refuse Treatment  
(ADRT)**

## Advance Decision to Refuse Treatment

<b>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 this document is for?

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If my ADRT is valid and applicable please ensure that you act on it as it is a legal document. Please help to share this information with relevant colleagues 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 wishes that might be relevant to my advance decision.

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

**Name:**

**These are my advance decisions, about my health care, in the event that I cannot consent to treatment and replace any previous decisions I have made.**

**In relation to my health problems, I have been diagnosed with:**

**I would also wish to refuse life sustaining treatment, 'even if my life is at risk':**

I wish to refuse the following specific treatments:

In these circumstances:




**Review 2:** Date of review:

Valid until:

Maker's signature:

Witness signature:

**The following list identifies which people have a copy of the ADRT and their contact details and have been told about this Advance Decision to Refuse Treatment:**

Name	Relationship	Telephone Number

**Further Information**

**I have written the following information that is important to me but does not directly relate to my Advance Decision to Refuse Treatment.**