



14A

Advance Decision to Refuse Treatment (ADRT)

Information for people with or affected by motor neurone disease

Please note this sheet includes sensitive information about end of life decisions.

With motor neurone disease (MND), you may be concerned about your future care if you become unable to make or communicate decisions for yourself. By writing down your wishes in advance, you can explain how you would like things to happen.

This information sheet provides an overview of the ways you can plan ahead and describes how to use an Advance Decision to Refuse Treatment (ADRT). An ADRT tells people involved in your care about treatments you wish to refuse or withdraw in the future, in specific circumstances. The content includes the following sections:

- 1: How can I plan ahead?**
- 2: How does an ADRT work?**
- 3: How do I make and record decisions in an ADRT?**
- 4: How do I find out more?**
- 5: Completed sample form and blank form to use if you wish**

 This symbol is used to highlight **our other publications**. To find out how to access these, see *Further information* at the end of this sheet.

 This symbol is used to highlight **quotes** from other people with or affected by MND.



The MND Association has been certified as a producer of reliable health and social care information.

www.england.nhs.uk/tis

Please note: at the end of this information sheet you will find the example of a completed ADRT form to help guide you and a blank form to use if you wish. You can also download this form to complete onscreen. Find this information sheet and the form on our website by selecting *Our care information sheets* at: www.mndassociation.org/publications

Please note: we offer support to people living with or affected by MND in England, Wales and Northern Ireland. We try to ensure that our information is accurate for all three countries, but always ask your GP or local health and social care providers how systems work in your region.

See *Useful organisations* towards the end of this sheet for details about MND Scotland.

1: How can I plan ahead?

We recommend discussing advance planning with your GP or specialist palliative care professionals before making any decisions. They can advise on:

- the options available to you
- the advantages and disadvantages of each option
- how to write your wishes correctly, so your guidance can be used.

Why should I plan ahead?

Thinking about the future with MND can feel distressing, both for yourself and those close to you. Planning ahead often leads to sensitive discussions about end of life decisions and you may not feel ready.

However, it can be helpful to write down clear instructions about your wishes, in case those involved in your care need to act on your behalf. This may help them feel more confident about supporting you.

People with MND have told us that it can also bring peace of mind:



"I had put it off for so long that it was a weight off my shoulders. It helped me address a number of issues which were on my mind...and to set them aside."

Have these conversations as early as you can, as MND can affect:

- **Speech and communication:** if both speech and the ability to gesture are affected, conversations will become more difficult and more tiring. These symptoms are likely to get worse over time.
- **Thinking and reasoning:** about 1 in 2 people with MND experience changes to thinking and reasoning as part of the disease. Although this is usually mild, it can be severe in some cases.



"I felt it was important to plan ahead now, as I can always change any wording if I want to...because I have speech problems, I didn't want any misunderstanding."

If you feel anxious about a possible lack of personal control over your future care, ask your health and social care team for help with your decision making. Don't be afraid to raise the subject, as they may find it difficult to know if you are ready for this.

For example, you could begin with, 'I'm worried about the future and wondered if you could help me plan ahead?'



"Having someone to guide you through, at the right time for you, is so important."

If you feel overwhelmed by grief and sadness as you think about these decisions, you may need support. Your health and social care team can help or you can contact our helpline, MND Connect:

Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org

How do I plan ahead?

You can plan ahead in the following ways:

Advance Care Plan: This is a written plan that helps you set out preferences for your future care. This is not legally binding, but helps guide choices on your behalf if you became unable to make decisions or communicate for yourself. You can include a wide range of instructions, such as:

- special requirements for food and drink
- how any spiritual and religious beliefs should be reflected in your care
- who you prefer to provide personal care and how personal care should be delivered
- your preferred location for care
- your preferred place of death
- arrangements for dependents, particularly if they need care arranged
- how to manage practical issues, such as emergency care for your pet.



"I am personal and my care should be personal...one size does not fit all."

Advance statement: This is not legally binding, but can be used to let people know whether you would like certain treatments introduced, refused or withdrawn in the future. This can be written separately, but is often included with your Advance Care Plan to guide professionals if decisions need to be made on your behalf.

Advance Decision to Refuse Treatment (ADRT): You can write down decisions on an ADRT to refuse or withdraw specific treatments in advance. When completed correctly, this is legally binding. See later sections for details about creating and using an ADRT.



“It would have been helpful if someone had sat down with both of us and said, ‘these are the things you need to be thinking about’. It’s not pleasant having to think about and face these things, but it’s necessary.”

Lasting Power of Attorney (LPA): You can legally appoint one or more representatives (whether a family member, friend or professional) to act on your behalf in case you become unable to make choices yourself. This needs to be completed while you are still able to make and communicate decisions.

An LPA can cover financial decisions, or health and welfare decisions, or both. It is a legal document governed by the Mental Capacity Act 2005. It needs to be registered with the Office of the Public Guardian (OPG), who can tell you how much this will cost (see later heading *Useful organisations* for contact details). For many, this is an expensive option.

The process may take several weeks, but you can ask a legal professional to help. This will add costs to the LPA fee, but may save you time and energy.

If you become unable to make decisions or communicate, the LPA for health and welfare allows someone to act on your behalf for your care and treatment. This part of the LPA will invalidate your ADRT, if you have made one. However, it is still worth maintaining your ADRT, as the person who has power of attorney can refer to this for guidance. If your LPA only covers property and finance, your ADRT remains valid.

In Northern Ireland, Power of Attorney is known as an Enduring Power of Attorney (EPA) and is registered through the Office of Care and Protection (see *Other organisations* towards the end of this sheet for contact details). The Mental Capacity Act 2005 does not apply in Northern Ireland and an EPA can only enable decisions on your behalf concerning property and finance, not personal welfare or care related matters. As a result, your ADRT cannot be overruled by an EPA.

Making a will: If you die without a will, it is known as dying intestate. If you had any debts, these will be paid first. Your money and possessions will then be given to family members, as defined by law.



“It’s positive to do the practical things, eg making a will. That’s something you can do and tick off the list...it makes me feel in control.”

Making a will allows you to decide who benefits from your estate after any debts are cleared. It also makes the process of administering your estate much easier for your family and friends. This is particularly true if your loved ones are not legally related to you.

You do not have to seek help from a legal professional to make a will, but it is advised.

Other ways to plan: When ready, you can read more about planning ahead in *End of Life: a guide for people with motor neurone disease* (see later heading *Further information* for details about our publications).

The guide covers all aspects of end of life decision making, getting your affairs in order and how to manage difficult conversations about this subject with family, friends and professionals.

Planning for urgent situations

Regardless of any decision making about your future care, it is important to consider the following questions:

- What will happen if my main carer is unable to support me for any reason?
- Where can I find appropriate care and support if my main carer needs a break (usually called respite care)?
- How do we access emergency treatment out of hours?

Keep any contact details for out-of-hours or emergency help where they can be easily found if needed.

Ask the following teams for guidance:

- your GP and health and social care team, who can advise on local support systems and refer you to specialist help
- specialist palliative care professionals and your local hospice, who have in depth knowledge of end of life care (you may need to be referred by your GP)
- adult social care services for an assessment of your care needs. Contact them through your local authority (or in Northern Ireland through a local health and social care trust).

An assessment of your care needs by a social worker or key worker gives you the opportunity to find out what support is available in urgent situations or emergencies. They can also advise and arrange care services to help you with daily activities and assess the needs of your main family carer.

You may find the following useful:

Message in a bottle: a sticker on your fridge and the inside of your front door tells paramedics or other health and social care professionals that a special bottle can be found inside the fridge. This contains essential personal and medical details. If you cannot fit all of your forms into the bottle, you could add a note that you have an advance care plan and an ADRT, and where to find them. These bottles are free of charge and can usually be obtained from your local chemist. You can also find details through the Lions Club website: www.lionsmd105.org/Community/MIAB

Carer's Emergency Card: this can be carried by a carer to alert someone to your care, in case they are involved in an accident and unable to support you. The cards are usually available from your local authority, who may also provide a registration service to help direct services to you, should an emergency arise.

MedicAlert: a registered charity that provides an identification system for individuals with medical conditions and allergies. This is usually provided in the form of a bracelet or necklet, which you pay for, and the scheme is supported by a 24-hour emergency telephone service. This can include an engraving of the words 'advance decision' which alerts health and social care professionals that you have an ADRT. They also create a medical record for you and can include a copy of your ADRT if you wish. You can find details at: www.medicalert.org.uk

MND Alert Card: a small card to keep in your purse, wallet or pocket, to alert hospital staff that you have MND if you are admitted to a ward. It states that you need specialist help with space to record key contacts. (see later heading *Further information* for details about our publications).

Understanding My Needs: this write-on leaflet lets you record basic notes about your needs. These notes say how you would like to be cared for should you be admitted to hospital or a hospice (see later heading *Further information* for details about our publications). If you have completed an advance care plan, you may not need Understanding My Needs, but it can also be useful to explain your needs to care services.

Make important documents easy to find: If you make advance care plans or an ADRT, keep them secure, but ensure they can be easily found in an emergency. For example, it is not advisable to lock them away in a safe, as this could make them difficult to access when needed. Paramedics and medical teams need to see these to be able to carry out your wishes.

Ask your GP for advice about local systems as some ambulance services will hold copies of ADRTs for people with limited life expectancy.

2: How does an ADRT work?

If you are 18 years or over, an Advance Decision to Refuse Treatment (ADRT) is a written instruction to refuse or withdraw specific treatments, under precise circumstances in the future.

In England and Wales, this is a legally binding document, as long as it has been completed correctly. In Northern Ireland it is not legally binding, but can still be used to guide health and social care professionals and everyone involved in your care.

When can an ADRT be used?

In England and Wales an ADRT is legally binding, but can only be actioned if you lose the ability to make or communicate decisions for yourself.

You must be able to make and communicate reasoned decisions when you sign the ADRT for it to be valid (known as having mental capacity, as governed by the Mental Capacity Act 2005).

The Mental Capacity Act is not applicable in Northern Ireland which means an ADRT is not legally binding there, but it would still be used by health and social care professionals to help guide their decisions.

Do I have to have an ADRT?

Whether or not to have an ADRT is your choice. This will depend on your outlook and how discussions with your family and professionals inform your views.

If you do decide to create an ADRT it must be written correctly and signed to be legally binding. This can bring a sense of personal control, but it needs to be very precise about what you want to happen and when. Everyone involved in your care then needs to be aware of the ADRT.

If this feels too difficult, you can still write down your general preferences in an Advanced Care Plan (see earlier heading, *How do I plan ahead?*). Health and social care professionals and others involved in your care can still use this to guide any decisions made on your behalf.

As your ADRT only becomes valid if you become unable to make or communicate decisions, you can make whatever choices feel right for you in the meantime, even if different to those in the ADRT.



“By making an ADRT I’m hoping it will psychologically help my partner to make these difficult decisions by saying, this is ok, this is what I want.”

Who needs to know about my ADRT?

It is extremely important to ensure everyone involved in your care is aware of your ADRT, including:

- your carer, partner, and close relatives and friends
- your GP and key members of your health and social care team
- local paramedics and emergency teams
- the person you have appointed as attorney, if you have Lasting Power of Attorney or Enduring Power of Attorney in place.

Your original signed ADRT should be easily accessible. If the ADRT is needed, the original may be required by health and social care professionals for them to act upon your wishes.

It is helpful to keep a list of everyone that has a copy. Sometimes people wear a bracelet or carry a card informing people that they have an ADRT and listing who has a copy (see earlier heading, *How can I plan ahead?*).



"I have discussed ADRT with my partner and relatives, but I'm about to discuss it with a few close friends who will be able to support my partner when the time comes, as my relatives live abroad."

What happens if I change my mind?

As your views, circumstances, illness and treatment may change, it is useful to review the ADRT on a regular basis.

If you make any changes to your ADRT, you need to inform everyone that has a copy and ask them to destroy the previous version.

Even if you have not made any changes, add a date and signature to record when it was last reviewed or revised. Copies of the updated version can then be distributed to the people that hold the ADRT.

3: How do I make and record decisions in an ADRT?

If the ADRT is not completed correctly, it will not be valid. This means it will not be legally binding and your wishes may not be carried out. Before creating an ADRT, discuss the contents with your health and social care team to ensure:

- you are clear about which treatments you wish to decline
- you understand the possibility of discomfort and putting your life at risk
- you complete the ADRT form correctly.

What details have to be included in an ADRT?

The document can be handwritten or typed in any format. It can also be completed by someone else if you are unable to do this yourself.

However, for your ADRT to be valid, it must include the following:

- your name and address
- the name and address of your GP
- a clear statement about which future treatments you want to refuse or have withdrawn and the precise circumstances in which this would apply
- a declaration that your decisions apply, '**even if my life is at risk**' by refusing a treatment that may be life sustaining (the phrase in bold must be used)
- your signature or the signature of another person on your behalf, carried out in your presence and under your direction
- the dated signature of at least one witness over the age of 18 – ideally not a partner, spouse, relative, anyone who stands to benefit under your will or your appointed representative for a Lasting Power of Attorney
- the name, address and telephone number of any person you have nominated to be consulted about your wishes
- names of those who have copies (eg doctor, hospital, family, ambulance service).

If you change your ADRT, the new version should also show the review dates with a signature.

What decisions can be included in an ADRT?

You can refuse or request withdrawal of life-sustaining treatment if it is no longer helping or has become a burden. For example, this may include instructions about:

- refusal or withdrawal of mechanical breathing support
- refusal or withdrawal of tube feeding
- refusal of antibiotics
- not wishing to be resuscitated in an emergency.

Talk to your health and social care team to find out about the timing for both introduction and withdrawal of treatments, and what is likely to happen.



"From our experience, it is better to be in a position where you feel as prepared as you can be."

What decisions cannot be included in an ADRT?

An ADRT cannot be used to:

- decline basic nursing care required to keep you comfortable
- request anything, such as medication, to deliberately cause or accelerate death
- ask for new treatments to begin
- determine what should happen following your death (an ADRT is not a will).

You can include some further information about your general preferences for care, but this will be advisory only. While these additional comments should be considered, they will not be legally binding in the same way as advance decisions to refuse treatment. It is probably more effective to record general preferences about care in your Advance Care Plan.

What do I need to think about when making these decisions?

If you use non-invasive ventilation (NIV) to mechanically support your breathing, there may come a time when it is no longer helping or feels like a burden. Your respiratory team can advise about ventilation and what to expect (see *Further information* at the end of this sheet about our publications, which include a range of sheets about breathing and ventilation.)

If you are dependent on ventilation and ask for it to be withdrawn, you need to be aware of the risk to your life. A natural death is likely to follow in a relatively short period of time. This is usually peaceful and medication can be provided to relieve distress and anxiety.

You must be clear about the circumstances in which your decisions will apply. For example, you may not wish to be resuscitated if something related to MND causes your heart or breathing to stop working (see later heading *What else do I need to know about resuscitation?*). However, you may feel differently about resuscitation at an earlier stage of the disease, eg in the event of an accident.

It is possible for invasive ventilation (tracheostomy) to be introduced during emergency treatment or resuscitation. Unlike NIV, which supports your own breathing, invasive ventilation means the machine is breathing for you. With MND, it can be difficult to then stop using this support. While it may prolong your life, other symptoms continue to progress. This has implications for your future care, as you will become more dependent on others. Although you can be fully ventilated in this way at home, there is a risk that you may require 24-hour care in a hospital or nursing home.

If you decide you do not want invasive ventilation, even in an emergency, you need to be specific about this in your ADRT.

What else do I need to know about resuscitation?

A recorded decision to refuse resuscitation is called a DNACPR (which means 'Do not attempt cardiopulmonary resuscitation').

If you have a DNACPR, you can still ask for and expect to receive the best possible medical and nursing care to ensure your comfort.

A DNACPR will be respected in most instances, but it is not legally binding on its own. For example, a doctor may still attempt resuscitation if the reason your breathing or heart stops is not linked to MND.

Providing an instruction about DNACPR in your ADRT makes it legally binding in England and Wales. Be clear about the circumstances in which you want this to happen, as your health and social care team may need to make decisions in unexpected circumstances.

The following may be helpful:

- if your heart stops beating and your breathing stops, it is called cardiopulmonary arrest
- the procedure used to attempt to restart your heart and breathing is called cardiopulmonary resuscitation (CPR)
- the decision to attempt CPR is made by the clinical team in charge of your care
- there may be a reason why CPR is unlikely to work depending on your condition and circumstances, in which case it may not be attempted
- neither you nor your family can insist that CPR be tried
- you can refuse CPR, which may result in a recorded decision not to attempt resuscitation called a DNACPR
- your health and social care team can advise how to arrange a DNACPR
- a DNACPR can be suspended or cancelled as circumstances change. For example, it could be suspended if you need surgery, as CPR may be appropriate in the unlikely event that your heart or breathing stop during that short time (see earlier heading *What do these decisions mean?*).

Where can I get an ADRT form?

At the end of this information sheet you will find an example of a completed ADRT form to help guide you and a blank form to use if you wish. You can also download this form to complete onscreen. Find this information sheet and the form on our website by selecting *Our care information* sheets at: **www.mndassociation.org/publications**

You can also ask a health or social care professional, such as your GP or a member of your hospital team, for a form and for guidance when writing your advance decisions.

4: How do I find out more?

Useful organisations

Please note, we do not necessarily endorse the organisations listed here and cannot be held responsible for anything stated on their website or supplied as a service or product. These are supplied to help you search for further information.

We keep this information updated, but the contact details may be subject to change before the next revision. If you need help locating an organisation, please contact our helpline MND Connect (see *Further information* at the end of this sheet for contact details).

Be ready for it

A website to help you discuss end of life with useful checklists of things to consider.

Address: c/o Norfolk & Suffolk Palliative Care Academy, NHS Great Yarmouth and Waveney CCG, 1 Common Lane North, Beccles, Suffolk NR34 9BN
Email: GYWCCG.nspca@nhs.net
Website: <http://bereadyforit.org.uk>

Citizens Advice Bureau

Free guidance to resolve legal, money and other problems from over 3,200 locations. Search for your local branch on the Get Advice page of the website.

Telephone: 08444 111 444 (England)
0844 477 2020 (Wales)
Website: www.citizensadvice.org.uk (main site)
www.adviceguide.org.uk/ (online help site)
www.citizensadvice.co.uk/en/Where-We-Are (Northern Ireland)

Dying Matters

A membership organisation offering a wide range of resources to help people start conversations more easily about dying, death and bereavement.

Address: c/o The National Council of Palliative Care, The Fitzpatrick Building, 188-194 York Way, London N7 9AS
Telephone: 08000 21 44 66
Email: info@dyingmatters.org
Website: <http://dyingmatters.org>

Find Me Help

Online service to help you find local services that can assist with end of life needs. This is hosted on the Dying Matters website.

Email: through the website contact page
Website: <http://help.dyingmatters.org>

GOV.UK

Online government advice, for guidance on benefits and other entitlements.

Email: see website for email addresses, for each type of enquiry

Website: **www.gov.uk**
www.nidirect.gov.uk (Northern Ireland)

Help the Hospices

An organisation offering information about hospice care, what services are available, who provides them, who can receive hospice care and how to get referred.

Address: Hospice House, 34-44 Britannia Street, London WC1X 9JG

Telephone: 020 7520 8200

Email: info@helpthehospices.org.uk

Website: **www.helpthehospices.org.uk**

MedicAlert

A registered charity providing an identification system for individuals with medical conditions and allergies, usually in the form of bracelets or necklets, and supported by a 24 hour emergency telephone service.

Address: MedicAlert House, 327-329 Witan Court, Upper Fourth Street,
Milton Keynes MK9 1EH

Telephone: 0800 581420 (freephone)

Email: info@medicalert.org.uk

Website: **www.medicalert.org.uk**

MND Scotland

Care, information and research funding for people affected by MND in Scotland.

Address: 2nd Floor, City View, 6 Eagle Street, Glasgow G4 9XA

Telephone: 0141 332 3903

Email: info@mndscotland.org.uk

Website: **www.mndscotland.org.uk**

The National Council for Palliative Care (NCPC)

An umbrella charity for all those involved in palliative, end of life and hospice care in England, Wales and Northern Ireland.

Address: The Fitzpatrick Building, 188-194 York Way, London N7 9AS

Telephone: 020 7697 1520

Email: enquiries@ncpc.org.uk

Website: **www.ncpc.org.uk**

NHS Choices

Online information to help you make informed choices about health.

Telephone: see NHS Direct for helpline

Email: through the website contact page

Website: **www.nhs.uk**

NHS 111

24-hour NHS helpline for non-emergency medical advice.

Telephone: 111

Email: through the website contact page

Website: search for NHS 111 at: **www.nhs.uk**

NHS Direct Wales

Similar to NHS 111, but for medical advice in Wales.

Telephone: 0845 46 47

Website: **www.nhsdirect.wales.nhs.uk**

NHS Northern Ireland

Information on NHS services in Northern Ireland. This is an online service.

Email: through the website contact page

Website: **www.hscni.net**

NI Direct

Like GOV.UK for Northern Ireland, with online help about benefits and health services.

Email: through the website contact page

Website: **www.hscni.net**

The Office of Care and Protection

Handles applications for Enduring Power of Attorney (EPA) in Northern Ireland.

Address: Office of Care and Protection, Room 2.2A, Second Floor,
Royal Courts of Justice, Chichester Street, Belfast BT1 3JF

Telephone: 028 9072 4733

Website: search for enduring power of attorney at: **www.nidirect.gov.uk**

Office of the Public Guardian

Handles applications for Lasting Power of Attorney (LPA) in England and Wales.

Address: PO Box 16185, Birmingham B2 2WH

Telephone: 0300 456 0300

Textphone: 0115 934 2778

Email: customerservices@publicguardian.gsi.gov.uk

Website: search for office of the public guardian at: **www.gov.uk**

The Patient Advice and Liaison Service (PALS)

Confidential advice and help about NHS services and health matters.

Website: **www.pals.nhs.uk**

Northern Ireland: Patient and Client Council

Freephone: 0800 917 0222

Email: info.pcc@hscni.net

Website: **www.patientclientcouncil.hscni.net**

Wales: Please refer to your local Community Health Council (CHC)

Samaritans

Confidential emotional support, 24 hours a day, for people experiencing feelings of distress or despair.

Address: Freepost RSRB-KKBY-CYJK
Or: Chris, PO Box 90 90, Stirling, FK8 2SA
Telephone: 08457 90 90 90
Email: jo@samaritans.org
Website: **www.samaritans.org**

References

An extensive list of references have been used to support our information resources about end of life decisions. These are available on request from:

Email: infofeedback@mndassociation.org

Or write to:

Information feedback, MND Association, PO Box 246, Northampton NN1 2PR

Acknowledgements

Thanks to the following for their kind assistance with the original development or revision of this sheet:

Idris Baker, Consultant in Palliative Medicine, ABM University Health Board, South Wales

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Further information

The Mental Capacity Act 2005 can be viewed using the following link:
www.legislation.gov.uk/ukpga/2005/9/contents

We have related information sheets you may find helpful:

1A - *NICE guideline on motor neurone disease*

7A - *Swallowing difficulties*

7B - *Tube feeding*

8A - *Support for breathing problems*

8B - *Ventilation in motor neurone disease (MND)*

10D - NHS Continuing Healthcare

We also provide:

End of life: a guide for people with motor neurone disease – our comprehensive and candid publication to help you manage difficult conversations and find out more about your options for end of life decisions

Understanding My Needs – a write-on form to help you explain your needs and wishes in case you are admitted to hospital or require any care services

MND Alert Card – a write-on card to provide your key contacts in case you are admitted to hospital and let staff know you have MND

You can download most of our publications from our website at: **www.mndassociation.org/publications** or order in print from the MND Connect team, who can provide additional information and support:



MND Connect

Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org

MND Association, PO Box 246, Northampton NN1 2PR

MND Association website and online forum

Website: **www.mndassociation.org**

Online forum: **<http://forum.mndassociation.org>** or through the website

We welcome your views

Your feedback is really important to us, as it helps improve our information for the benefit of people living with MND and those who care for them.

If you would like to provide feedback on any of our information sheets, you can access an online form at: **www.surveymonkey.com/s/infosheets_1-25**

You can request a paper version of the form or provide direct feedback by email: infofeedback@mndassociation.org

Or write to:

Information feedback, MND Association, PO Box 246, Northampton NN1 2PR

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Version: 4

Example copy for reference only

My Advance Decision to Refuse Treatment (ADRT)

1. My details

My personal information	
Name: Mr A Smith	Any distinguishing features in the event of unconsciousness: Mole on chin
Address: 1 The Avenue Anytown AA1 1ZZ	Date of birth: 01 January 1958
	National Health Service (NHS) number: XXX XXX XXXX
	Telephone number: XXXXX XXX XXX

What is this document for?

This document has been completed by me or with my authorisation. It states in advance any treatments I do not want in the future, under specific circumstances. This form replaces any previous ADRT that I have made.

It should only be used if I can no longer refuse or consent to treatment because I have become unable to make or communicate (by any means of communication) decisions about my healthcare.

By completing this document, I understand it is still my right to receive basic care, support and comfort.

Advice to anyone reading my ADRT:

Before any actions are taken, please do not assume I have lost capacity to make decisions or to communicate. I may need help and time to communicate.

If I have lost capacity, please check the validity and applicability of this ADRT. If it 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 involved in my treatment and care, who 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 decisions.

Example copy for reference only

2. My condition

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

Motor neurone disease (MND), a life-shortening condition that has no cure.

This affects me in the following ways:

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 my advance decisions about my future care and treatment, as I am having increasing difficulties with speech and communication.

I know MND will shorten my life and I wish to make choices about what will happen with my future care and treatment at end of life.

My advance decisions in this ADRT state any treatments I wish to refuse or withdraw if they are no longer working and have become a burden, even if this means my life is at risk.

Example copy for reference only

3. My advance decisions

The following instructions state which treatments I wish to refuse and the precise circumstances in which each action will apply.

Please note, these are examples only and your advance decisions or the circumstances in which you want these to apply may be different. Discuss your wishes and needs with your health and social care team before making these decisions.

Unless stated otherwise below, I confirm that the following decisions to refuse treatment are to apply 'even if my life is at risk' <input checked="" type="checkbox"/>	
(please tick this box if you agree with this statement):	
I wish to refuse the following specific treatments:	In these circumstances:
Cardio-pulmonary resuscitation (re-starting my heart and breathing)	I wish to refuse cardio-pulmonary resuscitation in the event that I have a cardiac or respiratory arrest due to the impact of motor neurone disease or any related condition, such as a severe chest infection.
Non-invasive ventilation (where a machine helps to support your own breathing through a mask)	I wish to have non-invasive ventilation withdrawn if despite simple attempts to position me, clear my airway and remove secretions, I can no longer breathe by myself without the help of the machine.
Invasive ventilation (where a machine breathes for you following a tracheostomy)	I wish to refuse invasive ventilation if I cannot be consulted about its use, ie during emergency treatment or resuscitation.
Alternative feeding methods (through a tube into my stomach or by drip)	I wish to have any form of alternative or tube feeding withdrawn when I can no longer swallow safely, even with the help of others.
Antibiotics	I wish to refuse antibiotics in the event that I have a severe chest infection that may threaten my life.

Example copy for reference only

4. My signature *(Please print form to sign)*

My signature (or nominated person):	Date of signature: <i>This should be the same date as the witness signatures as they are witnessing your signing of the form.</i>
--	---

5. Witness signatures *(Please print form to sign)*

Witness statement: I testify that the maker of this Advance Decision to Refuse Treatment signed it in my presence and made it clear that he/she understood what it meant. I do not know of any pressure being brought on him/her to make such an advance decision and I believe it was made by his/her own wish. As far as I am aware, I do not stand to gain from his/her death.	
First witness	
Name:	Address:
Signature:	
Date signed: <i>They are witnessing your signature, so this should be the date when you sign the document.</i>	Telephone number:
Second witness <i>(only one witness is required, but it is preferable to have two)</i>	
Name:	Address:
Signature:	
Date signed:	Telephone number:

Example copy for reference only

6. Important contacts

If you need to discuss my wishes, the person I would like you to contact first is:	
Name: Mrs A Smith	Relationship: Wife
Address: 1 The Avenue Anytown AA1 1ZZ	Telephone: XXXXX XXX XXX
I give permission for this document to be discussed with my relatives/carers: (please tick this box if you agree with this statement: <input checked="" type="checkbox"/>	
I have discussed this document with the following health and social care professional:	
Name: Dr Jones	Profession/Job title: Neurologist
Contact details: Neurology Ward Anytown Hospital Anytown AA1 1DE	Date document was discussed: 1 February 2014
My General Practitioner (GP) is:	
Name: Dr Blake	Telephone number: XXXXX XXX XXX
Address: Local Surgery Anytown AA1 1DE	

Example copy for reference only

These people have a copy of this ADRT or have been told about my advance decisions:		
Name:	Relationship:	Telephone number:
Mrs A Smith	My wife and main carer	xxxxxx xxx xxx
Dr Jones	My neurologist	xxxxxx xxx xxx
Dr Blake	My GP	xxxxxx xxx xxx
Mr T Jagot	My friend and carer	xxxxxx xxx xxx
Mrs Andrews	My solicitor	xxxxxx xxx xxx

7. Review dates

I confirm that the decisions in this document are current and apply unless I specifically state otherwise.

I have reviewed this ADRT on the following dates:

Review 1	
My signature: My name	Date of review: 23 July 2014
Review 2	
My signature:	Date of review:
Review 3	
My signature:	Date of review:
Review 4	
My signature:	Date of review:

Example copy for reference only

8. Further information

The following information is important to me, but does not directly relate to my Advance Decision to Refuse Treatment:

You may wish to write things such as:

If this ADRT becomes valid because I can no longer make decisions or communicate, I would prefer to:

- stay at home if possible
- have my family around me
- continue to have medication for symptom control and comfort

This is the end of the example form. The following pages provide a blank form to create your own ADRT, if you wish.

You can also download this form to complete on screen. Find this on our website by selecting *Our care information sheets* at:

www.mndassociation.org/publications

My Advance Decision to Refuse Treatment (ADRT)

1. My details

My personal information	
Name:	Any distinguishing features in the event of unconsciousness:
Address:	Date of birth:
	National Health Service (NHS) number:
	Telephone number:

What is this document for?

This document has been completed by me or with my authorisation. It states in advance any treatments I do not want in the future, under specific circumstances. This form replaces any previous ADRT that I have made.

It should only be used if I can no longer refuse or consent to treatment because I have become unable to make or communicate (by any means of communication) decisions about my healthcare.

By completing this document, I understand it is still my right to receive basic care, support and comfort.

Advice to anyone reading my ADRT:

Before any actions are taken, please do not assume I have lost capacity to make decisions or to communicate. I may need help and time to communicate.

If I have lost capacity, please check the validity and applicability of this ADRT. If it 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 involved in my treatment and care, who 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 decisions.

2. My condition

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

This affects me in the following ways:

4. My signature *(Please print form to sign)*

My signature (or nominated person):	Date of signature:
--	---------------------------

5. Witness signatures *(Please print form to sign)*

Witness statement: I testify that the maker of this Advance Decision to Refuse Treatment signed it in my presence and made it clear that he/she understood what it meant. I do not know of any pressure being brought on him/her to make such an advance decision and I believe it was made by his/her own wish. As far as I am aware, I do not stand to gain from his/her death.	
First witness	
Name:	Address:
Signature:	
Date signed:	Telephone number:
Second witness <i>(only one witness is required, but it is preferable to have two)</i>	
Name:	Address:
Signature:	
Date signed:	Telephone number:

6. Important contacts

If you need to discuss my wishes, the person I would like you to contact first is:	
Name:	Relationship:
Address:	Telephone:
I give permission for this document to be discussed with my relatives/carers: (please tick this box if you agree with this statement: <input type="checkbox"/>)	
I have discussed this document with the following health and social care professional:	
Name:	Profession/Job title:
Contact details:	Date document was discussed:
My General Practitioner (GP) is:	
Name:	Telephone number:
Address:	

These people have a copy of this ADRT or have been told about my advance decisions:

Name:	Relationship:	Telephone number:

7. Review dates

I confirm that the decisions in this document are current and apply unless I specifically state otherwise.

I have reviewed this ADRT on the following dates:

Review 1	
My signature:	Date of review:
Review 2	
My signature:	Date of review:
Review 3	
My signature:	Date of review:
Review 4	
My signature:	Date of review:

8. Further information

The following information is important to me, but does not directly relate to my Advance Decision to Refuse Treatment: