



14A

Advance Decision to Refuse Treatment (ADRT) and advance care planning

Information for people with or affected by motor neurone disease


Please note this sheet includes sensitive information about end of life decisions. Read when you feel ready to do so.

With motor neurone disease (MND), you may wish to discuss and write down how you would like your future care or treatment to be delivered. If you become unable to make or communicate your own decisions, leaving instructions can help guide those involved in your care.

This information sheet looks at how advance care planning can support you with this. In particular it explains how to use an Advance Decision to Refuse Treatment (ADRT) form. An ADRT explains which treatments you wish to refuse or have withdrawn in specific circumstances in the future.

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: What do I need to think about when refusing or withdrawing treatments?**
- 5: How do I find out more?**
- 6: 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.

This information has been evidenced, user tested and reviewed by experts.

Please note: 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 on a computer, tablet or mobile device and print out. Find this information sheet and an interactive ADRT form on our website by selecting *Information sheets* at: **www.mndassociation.org/careinfo**

We offer support to people living with and 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 area.

If you live in Scotland, see *Useful organisations* in section 5: *How do I find out more?* for details about MND Scotland.

This information sheet focuses on Advance Decision to Refuse Treatment. This is a legal document governed by the Mental Capacity Act 2005. Some of the words in this sheet are terms used in the Act, which you may not be familiar with. We have provided a glossary of what some of these words mean.

What do the words mean?

Mental capacity:	the ability to make or communicate a particular decision, usually about treatment or care.
Mental Capacity Act 2005:	an Act designed to protect and empower people in England and Wales who cannot make or communicate decisions about their care and treatment, or need support to do so.
Having mental capacity:	when a person is able to make or communicate a particular decision, even if they need support to do this.
Lacking mental capacity:	when a person is not able to make or communicate a particular decision, even with all possible support from the people supporting them.
Life-sustaining treatment:	a treatment that may be keeping you alive.

You can find out more about mental capacity and the Act in section 9 of *End of life: a guide for people with motor neurone disease* (see *Further information* at the end of this sheet).

1: How can I plan ahead?

Discuss advance care planning with your GP, neurologist, specialist MND nurse or specialist palliative care team before making any decisions. They can advise you 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 if needed in the future.

Why do I need to think about planning ahead?



"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."

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. Your guidance can assist others if you become unable to make or communicate particular decisions (even with support). This is known as 'lacking mental capacity'.

People with MND have told us that leaving clear instructions about future care can ease anxiety.



"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:

- **Energy levels:** MND can cause extreme tiredness (known as fatigue), which may make complex conversations more difficult.
- **Speech and communication:** if both speech and the ability to gesture are affected, conversations will become more difficult and tiring. These symptoms are likely to get worse over time.
- **Thinking and reasoning:** up to half of people with MND experience some changes to thinking and reasoning as part of the disease. Although this is usually mild, it can be severe in some cases, and make it more difficult to process information. A small number of people may develop a type of dementia, which requires additional support.



For more information, see information sheets:
11D – *Managing fatigue*
7C – *Speech and communication support*



and our guides:
Emotional and psychological support
Changes to thinking and behaviour with MND



“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 lose capacity to make particular complex or difficult decisions, you still have the right to make other choices, such as what you want to do during the day. Other people will only make a decision on your behalf if you have lost mental capacity, even after having all possible support to make or communicate the particular decision.

If you feel concerned about a possible lack of personal control over your future care, ask your health and social care team for guidance. They can help you record your decisions in an appropriate way. Don’t be afraid to raise the subject yourself. Many professionals find it difficult to know if you are ready for these types of conversation, and may be wary of raising them.

If you want to open this type of conversation but are unsure how, you could begin with something like: ‘I’m worried about the future and wondered if you could help me plan ahead for my care?’



“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. Discussing this with your health and social care team can help.

You can also contact our MND Connect helpline for practical guidance and emotional support. The team can introduce you to our services and other helpful organisations:

Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org

What are the different ways I can plan ahead?

There are a number of different ways you can plan ahead for your future care, including:

Advance care planning: You can discuss your preferences for your future care with your health and social care team and those important to you. From these discussions you can create a written Advance Care Plan (ACP), which enables you to set out your preferences for your future care.

An Advance Care Plan is not legally binding. However, it helps guide people who have to make particular decisions on your behalf if you become unable to make or communicate them 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 this should be delivered
- your preferred location for care
- your preferred place of death
- arrangements for dependants, 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: You can write down your wishes, feelings, values and preferences about what you would like or not like to happen with your future care and treatment in advance. This statement can be written separately or included with advance care planning documents. It can then be used to guide people who may need to make particular decisions on your behalf if you lose capacity, but advance statements will not be legally binding.

Advance Decision to Refuse Treatment (ADRT): You can write down instructions in an ADRT to refuse or withdraw specific treatments in the future if you become unable to make or communicate decisions about these treatments (lacking mental capacity). An ADRT will be legally binding in England and Wales if:

- it is completed correctly
- all the conditions stated in the ADRT are met
- you can no longer make or communicate decisions about the treatments covered in your ADRT.

See sections 2 and 3 of this information sheet for details about creating and using an ADRT.

Lasting Power of Attorney (LPA): You can legally give one or more people (known as attorneys) authority to make decisions on your behalf. This could be a family member, friend, partner or civil partner, or professional (eg a solicitor). Your LPA needs to be completed while you have mental capacity.

There are two types of LPA:

- one that covers your health and personal welfare
- one that covers your property and financial affairs.

These are legal documents governed by the Mental Capacity Act 2005 (for England and Wales). They need to be registered with the Office of the Public Guardian before they can be applied, which will cost money.

The Office of the Public Guardian can tell you how much the fees are (see *Useful organisations* in section 5: *How do I find out more?* for contact details).

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

You can make, register, change and end your Lasting Power of Attorney online, if wished, at: **www.gov.uk/power-of-attorney**

If you have made a Lasting or Enduring Power of Attorney in England or Wales between 1 April 2013 and 31 March 2017 (or have been power of attorney for someone else), you may be entitled to a part refund of the application fees.

Go to: **www.gov.uk/power-of-attorney-refund** for more information.

If you lack mental capacity, the LPA for health and welfare enables the person appointed as your attorney to make decisions about your care and treatment for you in your best interests. You will need to choose whether you want them to be able to make decisions about life-sustaining treatment on your behalf, as well as other decisions about your care.

A health and welfare LPA will only be used if the person who made it does not have mental capacity to make a particular decision.

If you include decision-making about life-sustaining treatments in your health and welfare LPA, this part of the LPA will invalidate your ADRT if you made one previously. Your ADRT would still act as a guide, but the person appointed as your attorney in the LPA will have the higher authority. This means they can make decisions for you, if you become unable to do so, even if different to those in your ADRT.

However, if you make a new ADRT or revise your existing one after the LPA is made, it will not be invalidated. This means that your attorney must follow what your new ADRT directs.

If your LPA only covers property and finance, your ADRT will remain valid. For more information on the property and finance LPA, see:

www.gov.uk/lasting-power-attorney-duties/property-financial-affairs

Enduring Power of Attorney (Northern Ireland only): In Northern Ireland, Power of Attorney is known as an Enduring Power of Attorney (EPA) and needs to be registered through the Office of Care and Protection (see *Useful organisations* in section 5: *How do I find out more?* 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 in Northern Ireland.

Do Not Attempt Cardiopulmonary Resuscitation (DNACPR): When your heart and breathing stop (known as 'cardiopulmonary arrest'), healthcare professionals may try to restart them (known as 'cardiopulmonary resuscitation', or CPR).

A DNACPR is a decision not to try to restart the heart and breathing. This decision can be made and recorded in advance to guide the healthcare professionals present if a person's heart and breathing stop. This decision should be made in discussion with you, or someone close to you if you lose capacity to make this decision. This conversation may be raised if a healthcare team think it's likely a person's heart and breathing could stop at some point. For more information on resuscitation see section 4: *What do I need to think about when refusing or withdrawing treatments?*

Other ways to plan: You can plan ahead in other ways, such as making a will. Making a will enables you to decide what happens with your money and belongings (known as estate) after your death.



"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."

When ready, you can read more about planning ahead in our guide: *End of Life: a guide for people with motor neurone disease*. 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 (see *Further information* in section 5: *How do I find out more?*).

Planning for urgent situations


Regardless of any decision-making about your future care, it is important to think about 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 can we access emergency treatment out of hours (beyond GP surgery and clinic opening hours)?


Keep any contact details of emergency care teams or care notes where they can be easily found if needed.

Ask the following teams for guidance:

- your GP and wider health and social care team, who can advise on local support systems and refer you to specialist help
- specialist palliative care professionals (eg at your local hospice), who have in depth knowledge of end of life care (your GP or another healthcare professional can refer you to this kind of support)
- adult social care services for an assessment of your care needs. Contact them through your local authority (or through your local health and social care trust in Northern Ireland).

 For more information on palliative care professionals, see:
Information sheet 3D – *Hospice and palliative care*

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 your main carer's needs too. It is yours and your carer's right to have an assessment of both your needs.

 For more information on social care, see:
Information sheet 10F – *Your rights to social care*

You may find the following useful:

Message in a bottle: a sticker on your fridge and the inside of your front door that tells paramedics or other healthcare professionals that a special 'bottle' (a white plastic container with a green lid) can be found inside the fridge. The bottle is designed to contain essential personal and medical details. If you cannot fit all of your forms into the bottle, you could add a note that you have other forms, such as an Advance Care Plan or ADRT, and where to find them. These bottles are free of charge and you can usually get them from your local chemist.

You can also find details through the Lions Clubs website at: www.lionsclubs.co

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 people with medical conditions and allergies. This is usually provided in the form of a bracelet or necklet, which you pay for. This can include an engraving of the words 'advance decision' which alerts healthcare professionals that you have an ADRT. They also create an electronic medical record for you and can include a copy of your ADRT if you wish. The system is supported by a 24-hour emergency telephone service.

You can find details at: www.medicalert.org.uk

The MND Association provides the following tools, which may also be useful (see *Further information* in section 5: *How do I find out more?*):

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, and includes space for you to record key contacts. The card also gives a warning that you may be at risk with oxygen.

MND Alert Wristband: a wristband that can be worn at all times if wished. It alerts medical teams that you have MND if you are admitted to hospital. The band also gives a warning that you may be at risk with oxygen.

A web address is printed to help professionals find information about urgent and emergency support for MND.

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 if you are admitted to hospital or a hospice, or if you have care workers at home. If you have completed an Advance Care Plan, you may not require *Understanding my needs* as well, but it can be a useful document to explain your needs to care services.

If you create any advance care planning documents or an ADRT, keep them secure, but ensure they can be easily found in an emergency. For example, locking them away in a cupboard could make them difficult to access when needed. Paramedics and medical teams need to see these to be able to carry out your wishes. It is important to ensure your carers know where these documents are kept, too.

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

Sharing your records: There are increasing ways that local healthcare systems can share your medical records with each other, including advance care planning documents and ADRTs. This enables different healthcare professionals to access your health records and know what your wishes are.

Ask your healthcare team about the following:

- **Summary Care Record:** an electronic record of your basic health information, which can be seen by healthcare professionals involved in your care. You can choose to add more information to your Summary Care Record, such as your preferences for future care and advance care planning documents. Anyone registered with a GP in England has a basic Summary Care Record, unless they specifically choose not to have one.
- **Electronic Palliative Care Co-ordination Systems (EPaCCS):** these systems exist in some areas to enable your end of life and palliative care records to be shared with different professionals.
- **Recommended Summary Plan for Emergency Care and Treatment (ReSPECT):** ReSPECT helps you and your healthcare professionals agree recommendations for your care in emergency situations. If you cannot make or communicate decisions, the resulting ReSPECT form is easy for healthcare teams to use and access. It combines wishes for your future care with your preferences about Cardiopulmonary Resuscitation (CPR). This is currently available in some parts of the UK, and is likely to roll out across more areas by 2020.

2: How does an ADRT work?

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

While you have capacity to make decisions, you can refuse or ask for treatments to be withdrawn. However, if you want to refuse a treatment at some point in the future, you are recommended to do this in writing, using an ADRT form. This is necessary if your future instructions include refusal or withdrawal of life-sustaining treatment.



“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’.”

ADRTs are governed by the Mental Capacity Act 2005 in England and Wales. An ADRT will be a legally binding document if it is valid and applicable for the specific circumstances stated in the ADRT, and can only be used if you lack capacity to make the treatment decisions it covers.

You must have mental capacity to make and communicate your own decisions when you make the ADRT.

An ADRT is also sometimes known as an ‘Advance directive’ or ‘Living will’, but the Mental Capacity Act 2005 does not use these terms and they have no legal meaning.

Will an ADRT apply in Northern Ireland?

The Mental Capacity Act 2005 does not apply in Northern Ireland, which means an ADRT is not legally binding there. However, it can still be used by health and social care professionals to help guide their decisions based on your preferences.

Do I have to have an ADRT?

No. Whether or not to make an ADRT is your choice. This might depend on your outlook, faith or how discussions with family and professionals inform your views.

If you do decide to make an ADRT, and if this includes decisions about life-sustaining treatments, it must be completed correctly, signed and witnessed to be legally binding. For more information on completing an ADRT, see section 3: *How do I make and record decisions in an ADRT?*

Making an ADRT can bring a sense of personal control, but you need to be very precise about what you want to happen and under what circumstances. Everyone involved in your care then needs to be aware of the ADRT.

If you decide not to make an ADRT, you can still discuss your preferences for your future care with your healthcare team. If you wish, you can write these down in another advance care planning document (see *What are the different ways I can plan ahead?* in section 1: *How can I plan ahead?*).

Health and social care professionals and others involved in your care can still use this to inform any decisions they may have to make on your behalf.

Your ADRT will not apply unless you have lost the capacity to make or communicate a decision about the treatment in question. If you have mental capacity to make the decision yourself, you can make whatever choices you want, even if different to those in your ADRT.

However, if these decisions are very different to those stated in your ADRT, it might be worth updating your ADRT to reflect this. For example, if your ADRT states that you do not want non-invasive ventilation (NIV) to be introduced under any circumstances in the future, and then you start using NIV while you have capacity to make that decision yourself, you may wish to update your ADRT to reflect this.

Who needs to know about my ADRT?

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

- your carer, partner, and close relatives or 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 easy to access. If the ADRT is needed, healthcare professionals may need to see the original for them to act upon your wishes. It is helpful to keep a list of everyone who has a copy.

Some people buy and wear jewellery, such as a necklet or bracelet, which informs healthcare professionals they have an ADRT (for more information, see details about MedicAlert in *Planning for urgent situations* in section 1: *How can I plan ahead?*). Some people prefer to carry a card informing people that they have an ADRT and listing who has a copy.



"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 or need to amend my ADRT?

You can change your mind about anything in your ADRT at any time. As your views, circumstances, illness and treatment may change, it is useful to review your ADRT on a regular basis.

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

It is important to notify your attorney for your Lasting Power of Attorney (LPA) if you have one. An ADRT dated more recently than an LPA cannot be overruled by the LPA for decision-making on life-sustaining treatment (see *What are the different ways I can plan ahead?* in section 1: *How can I plan ahead?* for more information on LPA).

Even if you do not make any changes during a review, add a date and signature to your ADRT to show that it is up to date. This will tell the reader when you last revised the details, so they know it represents your most recent decisions. Again, this will affect your Lasting Power of Attorney if you have made one.

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

Before making an ADRT, discuss the contents with your health and social care team to ensure:

- you are clear about which treatments you wish to refuse or have withdrawn
- you understand what might happen if you refuse a particular treatment. In some cases, this may mean putting your life at risk
- you complete the ADRT form correctly.

An ADRT is a legal document governed by the Mental Capacity Act 2005 and will not be legally binding unless it is completed correctly. Using the blank ADRT form at the end of this sheet, or a blank form provided by another reputable organisation, can help you ensure your ADRT meets the requirements of the Mental Capacity Act 2005.

If you wish to view the Mental Capacity Act 2005, we provide a link in *Further information* at the end of this sheet.

You have to be 18 years old or over to create an ADRT.

An ADRT can be made in verbal or written format. If it includes decisions about life-sustaining treatment, it must be made in written format, which can be handwritten or typed. It can also be completed by someone else if you are unable to do this yourself.

What details *must* be included in an ADRT?

As well as your personal details, you must include the following in your ADRT for it to be legally binding:

- the specific treatments you want to refuse or have withdrawn
- the circumstances in which you want this to happen (you can refuse a treatment in all circumstances if you wish).

If you include decisions about life-sustaining treatment, it must also be written, witnessed, and include the following:

- your signature or the signature of another person on your behalf, carried out in your presence and under your direction
- a declaration that your decisions apply, '**even if my life is at risk as a result**' (the phrase in bold must be used).

What details are useful to include in an ADRT form?

It is also useful to include the following in a written ADRT:

- the name and address of your GP
- the dated signature of at least one witness over the age of 18 (ideally not a partner, spouse, relative, your attorney for a Lasting Power of Attorney or anyone who may benefit under your will)
- 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).

We have provided space for all these details in the blank ADRT form at the end of this sheet. You may wish to see how these details are filled in on the example completed ADRT form for reference at the end of this sheet too.

What decisions can be included in an ADRT?

You can refuse or ask for withdrawal of treatment that may be life-sustaining if, for example:

- you do not want it to be introduced
- it is no longer helping or has become a burden.

For example, your ADRT may include decisions about refusal or withdrawal of:

- mechanical breathing support (non-invasive or invasive ventilation)
- tube feeding
- antibiotics
- or about not wishing to be resuscitated in an emergency.

Have a discussion with your healthcare team about:

- possible treatment decisions you may need to make in the future
- when each treatment may be offered
- the benefits and burdens of these treatments

- how the treatment may be stopped and symptoms managed in another way
- what will happen if the treatment is refused or is withdrawn.



“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 needed to keep you comfortable
- ask for anything, such as medication, to deliberately cause or speed up death
- ask for treatments
- determine what should happen following your death (an ADRT is not a will)
- donate your body to medical research.

You can include some further information about your general preferences for care, but this will only advise the professionals involved in your care. While these additional comments should be considered, they will not be legally binding in the same way as an instruction to refuse or withdraw treatment in your ADRT.

It is probably more effective to record your general preferences about care in an Advance Care Plan.

The following section contains sensitive information about refusing or withdrawing specific treatments. Read when you feel ready to do so.

4: What do I need to think about when refusing or withdrawing treatments?

You may receive the following treatments with MND, which can be refused or withdrawn, if wished. This section explores some of the things you may need to consider if you make decisions about these treatments in your ADRT. If you have other health conditions, as well as MND, there may be other things you need to think about. Seek advice from your healthcare team if you need further information on refusing or withdrawing treatments in your ADRT.

Assisted ventilation

What is it?

Assisted ventilation is where a machine helps support your breathing (we have shortened 'assisted ventilation' to 'ventilation' for the rest of this document).

There are two types:

- **Non-invasive ventilation (NIV):** where the machine provides extra air flow through a mask or mouth piece to assist your breathing. If you begin to rely on NIV all the time (known as being dependent) it becomes a life-sustaining treatment.
- **Invasive ventilation (tracheostomy):** where the machine takes over your breathing, through a tube inserted into the windpipe, through the neck. With MND, you are likely to become dependent on this type of ventilation, which means it becomes a life-sustaining treatment.



For more information on breathing and ventilation, see: our range of information sheets 8A-E


What do I need to think about when refusing ventilation?

Refusing either type of ventilation in your ADRT means that you do not want it introduced in the future. If your breathing muscles begin to weaken with MND, this will get worse as the disease progresses, and your life will be at risk. If you do not want to be ventilated, your respiratory team will advise on positioning, medication and other support to help ease any anxiety and breathlessness.

What do I need to think about when having ventilation withdrawn?

If you do use ventilation to support your breathing, there may come a time when you feel it no longer helps or may become a burden. It is your right to ask for it to be withdrawn in the future, even though your life will be at risk. You need to provide clear details in your ADRT about the circumstances in which you would want this to happen.

If you are dependent on either type of ventilation when it is withdrawn, death is likely to follow in a relatively short period of time. This is usually peaceful, and medication can be provided before the ventilation is withdrawn to relieve feelings of breathlessness and anxiety.

 For more details about withdrawal of ventilation, see:
Information sheet 8C – *Withdrawal of ventilation with MND*


It is important to know that invasive ventilation (also known as ‘tracheostomy’) is sometimes introduced during emergency treatment or resuscitation. With MND, it can be difficult to then stop using this support. While it may prolong your life, other symptoms caused by the muscle weakness of MND will continue to progress. This has implications for your future care, as you will require increasing levels of care.

While it is possible to use invasive ventilation at home, there is a risk that you may need 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.

Tube feeding


What is it?

With a feeding tube, you can receive food, drink and medicine through a tube inserted into your stomach through the abdominal wall. This is fitted in hospital either as a day patient or during a short stay. You can still eat and drink by mouth after the tube is fitted, for as long as you feel safe or wish to do so. However, if you reach a point where this is the only way that you can receive food and drink, it will be a life-sustaining treatment.

 For more information on tube feeding, see:
Information sheet 7B – *Tube feeding*

What do I need to think about when refusing a feeding tube?

If you do not want to have a tube fitted in the future, you need to be exact about the circumstances you want to refuse this in your ADRT. If your swallowing ability begins to weaken with MND, this will get worse as the disease progresses. You are likely to lose weight and, over time, your life will be at risk. Your dietitian and your speech and language therapist can continue to advise on your nutrition, fluids and swallow, with or without a tube fitted.

 For more information on how your swallow may be affected with MND, see:
Information sheet 7A – *Swallowing difficulties*

If swallowing is increasingly affected, eating and drinking by mouth may cause bits of food and drink to get into the lungs. This can cause repeated chest infections, which may develop into a condition known as aspiration pneumonia.

What do I need to think about when having a feeding tube withdrawn?

If you use a feeding tube, there may come a time when you feel it will no longer help or may become a burden. It is your right to ask for it to be withdrawn in the future, even though your life will be at risk. This most often means that the tube is not used, rather than having it taken out. You need to provide clear details in your ADRT about the circumstances in which you would want this to happen.

When eating and drinking by mouth are no longer possible, or you have the feeding tube withdrawn, you may not feel as hungry as you might fear. This is because your appetite is likely to decrease throughout the course of the disease. You can decide to stop receiving food, drink, medicine or all of these through your tube. However, without another way of receiving nutrition or fluids, your life will be at risk and a natural death will follow over a period of time. The speed at which this happens can vary from person to person, but the professionals supporting you can help you feel more comfortable.

You can continue to receive medicine through your tube even if you decide to stop having food or fluids in this way, if you wish.

Antibiotics

What are they?

Antibiotics are a type of medicine used to treat infections.

What do I need to think about when refusing antibiotics?

If you choose to refuse antibiotics, you need to be aware that the infection they are prescribed to treat may not get better. There may be a risk to your life if the infection is life-threatening.

Be specific about the circumstances in which you want to refuse antibiotics in your ADRT. For example, you may wish to refuse antibiotics that treat an infection that could be linked to the progress of MND, like aspiration pneumonia. However, you may still want antibiotics to be used to treat an infection not directly linked to MND, such as a water infection (also known as a urine infection). You can also decide whether to refuse antibiotics given to you in a certain way but not others. For example, you may wish to continue receiving antibiotics through a feeding tube, but not into your veins (known as 'intravenously').

If you do choose to refuse antibiotics in your ADRT, you can still expect your health and social care team to provide the best possible support, manage any distressing symptoms and help keep you comfortable.

Resuscitation

What is resuscitation?

Resuscitation is the process of restarting a person's heart and breathing if they have stopped (called 'cardiopulmonary arrest'). The procedure used to try to restart your heart and breathing is called cardiopulmonary resuscitation (CPR).

You can choose whether you want to refuse resuscitation completely or under certain circumstances in the future. A recorded decision to refuse resuscitation is often called a DNACPR (which means 'Do not attempt cardiopulmonary resuscitation').

A DNACPR should be made and signed by your healthcare team, in discussion with you, or someone close to you if you don't have mental capacity to make this decision. It can

guide healthcare professionals who are present if your heart and breathing stop. You can choose to refuse resuscitation in advance in an ADRT, which means will be legally binding in England and Wales.

Without a DNACPR, healthcare professionals will attempt CPR in most cases. However, there may be a reason why CPR is unlikely to work depending on your condition and circumstances. In this case, CPR may not be attempted.

What do I need to think about when refusing resuscitation?

If you choose to refuse resuscitation in the future, and your heart and breathing stop at any point, you need to be aware that death will follow.

You must be clear and specific in your ADRT about the circumstances in which your refusal of resuscitation will apply, as your healthcare team may need to make quick decisions in unexpected situations. For example, you may not wish to be resuscitated if something related to MND causes your heart or breathing to stop working. However, you may feel differently about resuscitation at an earlier stage of the disease (eg in the event of an accident).

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

It may be helpful to be aware of the following:

- a DNACPR is also sometimes known as a DNAR or DNR (meaning 'do not attempt resuscitation' or 'do not resuscitate')
- the decision to attempt CPR is made by the clinical team in charge of your care
- neither you nor your family can insist that CPR be tried
- 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.

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 on a computer, tablet or mobile device and print off. Find this information sheet and the form on our website by selecting *Information sheets* at:

www.mndassociation.org/careinfo

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

Healthcare providers in some areas may use standard forms for advance care planning. Recording your plans on the preferred document for the area you live in may help professionals feel confident about its use.

This is especially important if paramedics or emergency care teams are called out. Ask your GP, neurologist or a specialist palliative care professional in your area for guidance.

5: How do I find out more?

Useful organisations

Please note, we do not necessarily endorse any of the following organisations, but have included them to help you begin your search for more information. The contact details are correct at time of print, but may change between revisions. 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).

The Cinnamon Trust

An organisation dedicated to helping people in later years, or with life-shortening conditions, to find foster care or alternative homes for their pets.

Address: 10 Market Square, Hayle, Cornwall TR27 4HE

Telephone: 01736 77 900

Email: through the website contact page

Website: www.cinnamon.org.uk

Citizens Advice

Free and confidential advice to help resolve legal, money and other issues.

Telephone: 03444 111 444 (England, or contact your local Citizens Advice Bureau)
03444 77 2020 (Wales)

Website: www.citizensadvice.org.uk (England)

www.citizensadvice.org.uk/wales (Wales)

www.citizensadvice.org.uk/nireland (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.

Telephone: 08000 21 44 66

Email: through the website contact page

Website: www.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 for people living in England or Wales.

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

Website: **www.gov.uk**

Health in Wales

Online information about NHS services in Wales, including a directory of the Welsh health boards.

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

Hospice UK

For information about hospice care and help finding your nearest hospice.

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

Telephone: 020 7520 8200

Email: info@hospiceuk.org

Website: **www.hospiceuk.org**

Lions Clubs International (British Isles and Ireland)

A community service organisation, helping to promote the Message in a Bottle scheme to assist paramedics in case of emergencies.

Address: Lions Clubs International, 257 Alcester Road South,
Kings Heath, Birmingham B14 6DT

Telephone: 0845 833 9502

Email: enquiries@lionsclubs.co

Website: **<http://lionsclubs.co>**

MedicAlert

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

Address: The MedicAlert Foundation, 327 Upper Fourth Street,
Milton Keynes MK9 1EH

Telephone: 01908 951 045

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**

NHS Choices

Online information to help you make informed choices about health.

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

Health advice and information in Wales.

Telephone: 0845 46 47 or 111 if available in your area

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

NHS Northern Ireland

Online information on NHS and social care services in Northern Ireland.

Website: **<http://online.hscni.net/>**

NI Direct

Online government advice, for guidance on benefits and other entitlements for people living in Northern Ireland.

Website: **www.nidirect.gov.uk**

The Office of Care and Protection

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

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

Telephone: 028 9072 5953

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

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.nhs.uk/Service-Search/Patient-advice-and-liaison-services-\(PALS\)/LocationSearch/363](http://www.nhs.uk/Service-Search/Patient-advice-and-liaison-services-(PALS)/LocationSearch/363)**

Northern Ireland: Patient and Client Council

Freephone: 0800 917 0222

Email: info.pcc@hscni.net

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

Wales: Refer to your local Community Health Council (CHC)

Website: **www.wales.nhs.uk/sitesplus/899/home**

ReSPECT

A process and form that enables your healthcare team to easily access a record of your preferences and decisions for emergency care, if you become unable to make them.

Email: through the website contact page

Website: **www.respect.org.uk**

Samaritans

Confidential emotional support, 24 hours a day.

Address: Freepost RSRB-KKBY-CYJK, PO Box 9090, Stirling FK8 2SA

Telephone: 116 123

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, Francis Crick House, 6 Summerhouse Rd, Moulton Park Industrial Estate, Moulton Park, Northampton NN3 6BJ

Acknowledgements

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

Simon Chapman, Formerly Director of Policy and External Affairs at NCPC and Dying Matters, now consulting via @SimonSimply

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Christina Faull, Palliative Medicine Consultant, LOROS, Leicester

Heidi Jew, Care Centre Coordinator, Birmingham MND Care Centre

Ben Lobo, National Lead for ADRT Project Team, Mid Trent Cancer Network

David Oliver, Consultant in Palliative Medicine, Wisdom Hospice, Rochester and Honorary Reader, Centre for Professional Practice, University of Kent

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*

3D – *Hospice and palliative care*

7A – *Swallowing difficulties*

7B – *Tube feeding*

7C – *Speech and communication support*

8A – *Support for breathing problems*

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

8C – *Withdrawal of ventilation for motor neurone disease*

8D – *Troubleshooting for non-invasive ventilation (NIV)*

8E – *Air travel and ventilation for motor neurone disease*

10D – *NHS Continuing Healthcare*

10F – *Your rights to social care*

We also provide the following guides and tools:

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. Comes supplied with our *Living with MND* and *End of life* guides, but are also available to order from MND Connect

MND Alert Wristband – a wristband to alert medical teams that you have MND if you are admitted to hospital. It also gives a warning that you may be at risk with oxygen. A web address is also printed to help professionals find a page about urgent and emergency support for MND. Comes supplied with our *Living with MND* and *End of life* guides, but are also available to order from MND Connect

What you should expect from your care – our pocket sized booklet to help you open conversations about your care with health and social care professionals. It features the main points from the NICE guideline on 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, Francis Crick House, 6 Summerhouse Rd,
Moulton Park Industrial Estate, Moulton Park,
Northampton NN3 6BJ

MND Association website and online forum

Website: **www.mndassociation.org**

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

We welcome your views

We'd love to know what you think we're doing well and where we can improve our information for people with or affected by MND, or Kennedy's disease. Your anonymous comments may also be used to help raise awareness and influence within our resources, campaigns and applications for funding.

To feedback on any of our information sheets, access our 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, Francis Crick House, 6 Summerhouse Rd,
Moulton Park Industrial Estate, Moulton Park, Northampton NN3 6BJ



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Version: 2

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Example copy for reference only

My Advance Decision to Refuse Treatment (ADRT)

1. My details

My personal information	
Name: <i>Sample text:</i> Mr A Smith	Any distinguishing features in the event of unconsciousness: <i>Sample text:</i> Mole on chin
Address: <i>Sample text:</i> 1 The Avenue Anytown AA1 1ZZ	Date of birth: <i>Sample text:</i> 01 January 1958
	National Health Service (NHS) number: <i>Sample text:</i> xxx xxx xxxx
	Telephone number: <i>Sample text:</i> 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 about my medical treatment or to communicate them. I may need help and time to make and communicate decisions. I may have to use an alternative method of communication, which may include a communication aid.

If I have lost capacity to make decisions about my medical treatment, 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:

Sample text:

Motor neurone disease (MND), a life-shortening condition that progressively affects my muscles and has no cure.

This affects me in the following ways:

Sample text:

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 as a result'**

(please tick this box if you agree with this statement):

I wish to refuse the following specific treatments:

In these circumstances:

<p><i>Sample text:</i> Cardiopulmonary resuscitation (re-starting your heart and breathing)</p>	<p><i>Sample text:</i> I wish to refuse cardiopulmonary 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.</p>
<p><i>Sample text:</i> Non-invasive ventilation (where a machine helps to support your own breathing through a mask)</p>	<p><i>Sample text:</i> 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 <input checked="" type="checkbox"/> machine.</p>
<p><i>Sample text:</i> Invasive ventilation (where a machine breathes for you following a tracheostomy)</p>	<p><i>Sample text:</i> I wish to refuse invasive ventilation if I cannot be consulted about its use, ie during emergency treatment or resuscitation.</p>
<p><i>Sample text:</i> Alternative feeding methods (through a tube into your stomach or by drip)</p>	<p><i>Sample text:</i> I wish to stop receiving food and fluids through my feeding tube when I can no longer swallow safely, even with the help of others.</p>
<p><i>Sample text:</i> Antibiotics</p>	<p><i>Sample text:</i> I wish to refuse antibiotics in the event that I have a severe chest infection that may threaten my life.</p>

Example copy for reference only

4. My signature

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

5. Witness signatures

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: <i>Sample text:</i> Mrs A Smith	Relationship: <i>Sample text:</i> Wife

Address: <i>Sample text:</i> 1 The Avenue Anytown AA1 1ZZ	Telephone: <i>Sample text:</i> XXXXXX 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: <i>Sample text:</i> Dr Jones	Profession/Job title: <i>Sample text:</i> Neurologist
Contact details: <i>Sample text:</i> Neurology Ward Anytown Hospital Anytown AA1 1DE	Date document was discussed: <i>Sample text:</i> 1 February 2017
My General Practitioner (GP) is:	
Name: <i>Sample text:</i> Dr Blake	Telephone number: <i>Sample text:</i> xxxxx xxx xxx
Address: <i>Sample text:</i> 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:
<i>Sample text:</i> Mrs A Smith	<i>Sample text:</i> My wife and main carer	<i>Sample text:</i> xxxxx xxx xxx

<i>Sample text: Dr Jones</i>	<i>Sample text: My neurologist</i>	<i>Sample text: xxxxx xxx xxx</i>
<i>Sample text: Dr Blake</i>	<i>Sample text: My GP</i>	<i>Sample text: xxxxx xxx xxx</i>
<i>Sample text: Mr T Jagot</i>	<i>Sample text: My friend and carer</i>	<i>Sample text: xxxxx xxx xxx</i>
<i>Sample text: Mrs Andrews</i>	<i>Sample text: My solicitor</i>	<i>Sample text: xxxxx xxx xxx</i>

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: <i>Sample text:</i> 23 September 2017
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:

Sample text:

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 *Information sheets* at:

www.mndassociation.org/careinfo

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 about my medical treatment or to communicate them. I may need help and time to make and communicate decisions. I may have to use an alternative method of communication, which may include a communication aid.

If I have lost capacity to make decisions about my medical treatment, 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: