



10: What happens after I die?

This section looks at how you can influence what happens after you die and provides guidance for those close to you.

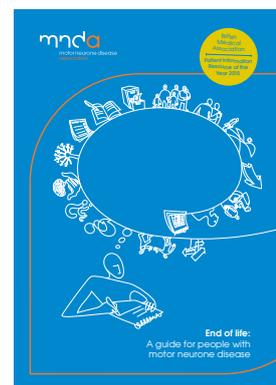
The following information is an extracted section from our full guide *End of life: A guide for people with motor neurone disease*.

All of the extracted sections, and the full guide, can be found online at: www.mndassociation.org/eolguide

The full guide can be ordered in hardcopy from our helpline, MND Connect:

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org



End of life:
A guide for people with
motor neurone disease

10: What happens after I die?



This section looks at how you can influence what happens after you die and provides guidance for those close to you.

Please be aware that the following pages contain sensitive information. You may want to shape the way things happen after your death, but if not, your family, carer, close friends or executors of your will may find this section helpful.

“ You worry about what will happen to your family after you've gone. It is therefore reassuring for everyone concerned to plan ahead and feel prepared for what is to come.”

See end of this section for a *Summary of tasks* that need to happen following a death.

Informing other people

There are three main groups of people that should be informed when you die:

- family and friends
- work colleagues (if you were still employed or had been recently employed)
- relevant organisations.

You can help make this easier for those close to you by listing who should be informed, with contact details from your address book, computer or telephone.

Those close to you may find it emotionally difficult to tell wider family and friends that you have died. It may help to ask trusted people to assist, as and when the time comes, and later to help send funeral details. They can also help inform relevant organisations.

It is also useful to group together details for organisations that need to be contacted. These generally include:

Health and social care contacts:

such as your GP, your dentist and any specialists that you may have seen on a regular basis for MND. If you die in hospital or a hospice, they may be informed through their systems.

Government and local authority contacts:

to stop any benefits, pension payments or social care services you may have received. In England and Wales, use the Tell Us Once service to avoid repetition:

www.gov.uk/tell-us-once

or in Northern Ireland search for *bereavement service* at:

www.nidirect.gov.uk

Financial contacts:

such as your bank, insurance or investment companies. It is important for your executor or family to inform these contacts as soon as possible. Once these organisations know that you have died, they will usually give your executors or relatives time to sort out your affairs, even if debts are involved. Telling them also helps prevent possible fraud, such as someone using your stolen identity.

Legal contacts:

such as your solicitor, who may be familiar with your estate. However, unless you have stated that you want your executor or family to use a preferred legal professional (perhaps where your estate is complex), they may find it worthwhile to compare costs, as legal fees can vary widely.

Service contacts:

where personal and household payments may need to be cancelled or amended. For example, house insurance may need to be transferred to another name or it may no longer be valid.

See Section 8: *Putting affairs in order.*

Funeral arrangements

Attending a funeral enables those close to you to acknowledge what has happened. This can help them say goodbye and begin to adjust.

You may wish to leave instructions about the way you want your funeral to be arranged. You may have preferences due to:

- cultural requirements, where religious rites or other rituals need to be observed
- strong beliefs or views about what you would or would not want to happen at your funeral
- a wish for particular songs, memories and messages to be shared.

However you may prefer not to be involved in these arrangements.

“ Regarding funeral arrangements, I couldn’t care less! I’ve made provision to pay for the funeral and buy a few beers, but the details are for someone else to think about.”

The choice is yours and this should be respected, but it can help to let those close to you know your main preferences, which may be influenced by your religion, culture or beliefs.

For example:

- if you wish to be cremated or buried (and if so, where?)
- if you want a religious ceremony or not.

“ I’ve thought about where I’ll be. It makes me think about the spiritual aspect.”

See Section 2: *Emotional and psychological support*, which includes content about spiritual and religious support.

If you do want to provide specific instructions, you may find that your family and friends find this difficult to discuss.

“ I heard a piece of music years ago and decided that it was what I wanted to be playing when my coffin was carried in. Planning a funeral is really important to me but it’s amazing how many people won’t talk about it.”

Having open discussions with your family about your funeral can be very positive, so they know your wishes.

See Section 7: *Discussions with family and children.*

However, if this proves to be difficult, you can instruct a funeral director in advance who will help guide your family and friends when the time comes.

“ I’ve chosen everything for my funeral, the music and where my ashes will be scattered. It’s all with the undertakers. I did all this myself because I knew what I wanted, and to take it out of the hands of my daughter.”

You can also add funeral instructions in your will. There is no legal obligation for relatives to follow these instructions, but your executors are responsible for seeing that the instructions in your will are carried out, as far as is reasonably possible. There may be a financial limitation or another reason why something cannot be carried out, but leaving clear details about your wishes may help relieve other people of some of the decision-making.

“ My husband loved music and chose some for his funeral. It was hard to have these discussions, but allowed us to reflect and cry together. So much of his funeral was his choice and I found this very comforting.”

What type of funeral can I have?

Funerals can be arranged in many ways. The main types are:

- a traditional religious ceremony according to your faith, usually conducted by a local faith leader
- a civil funeral (which may include some religious content, such as hymns and prayers), usually conducted by a civil celebrant
- a funeral with no religious content, usually conducted by a humanist celebrant.

“ I’m not religious, so don’t see any point in going through an elaborate church ceremony.”

The funeral service can be formal or informal, as directed by the person who is making the arrangements and your instructions if you have left written details about your preferences. For example, would your option be a cremation or a burial? If a burial, you may prefer a formal setting or more natural, as within reserved woodland (known as a green burial site).

You may wish to choose a funeral director to help with arrangements, or a funeral specialist if particular cultural or religious rites need to be observed. If you don’t already know who will conduct your funeral, your funeral director can advise about local faith leaders and civil or humanist celebrants.

Try to select a funeral director who belongs to a professional association, such as the National Association of Funeral Directors (NAFD): <https://nafd.org.uk> or the Society of Allied and Independent Funeral Directors (SAIF): <https://saif.org.uk>, who use codes of practice and complaints procedures.

See Section 16: Useful organisations for full contact details.

The funeral director or specialist organisation will guide the entire process and will usually book any additional professional services that are required. Your wishes and those of your family will be incorporated into the planning wherever feasible and your family will be asked to provide details about you and your history should the service include a memorial speech.

It is usually left to the family to arrange any reception and catering following the funeral, although some funeral directors may be happy to help organise this.

Paying for the funeral

Essential funeral costs can be charged to your estate, but if the proceeds from your estate do not meet the costs, whoever arranges the funeral is still expected to pay the final bill.

Although your bank account is likely to be frozen after your death (until your estate has been sorted), most banks will release money to cover funeral costs, as long as there is enough in the account. The bank will require a formal invoice and will make the payment directly to the funeral director. If the bank is willing to do this, your family or partner does not have to pay up front and then wait until the estate is administered to be repaid.

If your family are likely to need financial help with the funeral, there are benefit payments available, as long as they qualify.

A one-off funeral payment may be provided, although this is unlikely to cover the full cost of the funeral. Your partner or spouse may also be eligible for other bereavement benefits.

Search for funeral payment or bereavement benefits at www.gov.uk for latest online government information.

It is important to note that any reception arrangements and refreshments provided after the funeral are not considered to be essential funeral expenses and therefore cannot be charged to the estate.

Funerals can be very expensive and sometimes in unexpected ways. For example, you may wish to have a cardboard coffin thinking it will be less expensive, but it can cost more than a wooden coffin.

You may wish to ask a funeral director about expected costs. They will also be able to tell you about saving plans and pre-paid funeral plans, which may be a way to offset the cost for your relatives. Seek advice from the Funeral Planning Authority: www.funeralplanningauthority.com

See Section 16: Useful organisations for full contact details.

It is important that your family or executors do not sign any paperwork with a funeral director until they are sure they want to employ their services. If they do sign before this, they may have signed a legal contract and be liable for payment.

Administering your estate and probate

If you have any bank accounts, savings, property or other assets when you die, this is known as your estate. This needs to be administered, which means giving items or amounts from your estate to those who are entitled (your beneficiaries). This is decided in your will or, in the absence of a will, by law (under the rules of intestacy).

If you live in Northern Ireland, the process used to administer someone's estate is very similar to that in England and Wales, but there will be some differences. You can find out more from the NI Direct website: www.nidirect.gov.uk/what-is-probate

See Section 16: Useful organisations for contact details.

What is probate?

Probate is a court order that proves the validity of your will and allows your executor or executors to administer your estate according to your will.

You may find the following definitions useful:

Grant of probate: this is the document provided by the courts to your executor. It proves they have the right to deal with your estate through probate, when approaching organisations about your funds or property.

Letters of administration: if you have not written a will, you will not have a named executor. In this instance, a personal representative will be appointed by the courts to administer your estate according to the law. This person is usually your spouse or civil partner (or children if you are single), who will be provided with letters of administration as proof of their authority.

Grant of representation: this is a general term used to refer to either a grant of probate or letters of administration, whichever might apply.

A grant of representation may not be required if your estate is simple and low in value. In these cases financial organisations, such as banks and insurance companies, will help guide your executor or family to release any funds.

A grant of representation for probate is likely if:

- the value of your estate or an account reaches a certain limit (financial organisations may set different limits at which they would request probate for release of funds)
- you own a property in your sole name

- you own a joint property but wish for part or all of your share to pass to someone else, eg a child.

There may be other circumstances that mean probate is necessary and depending on the complexity of your estate, your executor or family may need professional legal help.

How is an estate administered?

The following provides a brief and simple overview. The full process depends on your estate and the instructions you leave in your will. Your executor or personal representative should seek legal advice if in any doubt.

Whoever administers your estate will need to:

- inform people about your death who hold any of your assets, such as banks where you have an account
- inform people about your death if you owe them money (known as creditors)
- work out how much your estate is worth at the date of your death
- pay inheritance tax if appropriate
- apply for the grant of representation
- place statutory notices (usually small newspaper adverts) to inform any unknown creditors, should they need to make a claim against your estate. If in doubt, ask a legal professional for advice (this is not mandatory, but will protect your executor or personal representative against late claims, for which they could become liable themselves if they do not place these notices)
- gather all funds and items to be distributed, including the sale of property if required (known as collecting assets)
- pay any debts
- prepare a set of accounts for the estate
- distribute the estate to beneficiaries (those named in your will or, if there is no will, as decided by law).

Where it is recognised that your estate will not be able to pay its debts, even with the sale of any property, personal representatives should seek legal advice before taking any action. Making a mistake could result in them being liable for your outstanding debts.

Your executor or representative may also want to contact the Probate and Inheritance Tax helpline with any queries: **0300 123 1072**. Or they can search for probate and inheritance on the GOV.UK government information website at: www.gov.uk for details about the grant of representation, probate and administering your estate.

[See Section 16: Useful organisations for details of other organisations that may be able to provide guidance.](#)

Bereavement support for family and friends

Everyone will have an individual response to their unique loss, depending on circumstances, background and emotional state. It is important to realise that grief can encompass many feelings and may feel irrational, but grief is personal and there is no right or wrong way to experience it.

You may be concerned about how your family and friends will cope with their grief when you die. It is normal for bereavement to feel very distressing and isolating, but with an incurable and life-shortening illness like MND, the grieving process usually begins in advance of the bereavement. This is known as anticipatory grief and may impact on the wellbeing of your family before and after your death.

Anticipatory grief can take its toll on health and wellbeing. Having to then deal with bereavement and the aftermath can be very tough. The progressive nature of the condition means that your main carer and family probably had to provide increasing support during the course of the disease and may have experienced multiple and difficult emotions through this period.

Pre-bereavement counselling may be available to help with the impact of anticipatory grief. If you feel this would help you or your family, ask your GP for advice on services. Sometimes a local hospice can also provide this type of support.

“ If you're a carer, be aware of the effect the death might have on your health. The shock of suddenly not being a carer and having to deal with certificates, registration, stopping pensions before more payments are credited, notifying family and friends, fielding the inevitable telephone calls and arranging a funeral can be very stressful.”

It may be worth encouraging your main carer (often your partner) to think about booking health check-ups, both now and in the future. These appointments can be useful during the challenges of the caring role, but are recommended following bereavement, as your carer may feel exhausted physically and emotionally.

“ The carer is the one left with all the memories and can shoulder a lot of guilt.”

Sometimes, a life-shortening condition can bring people closer together, providing time for reflection. It can help families to make up for past quarrels and opens up opportunities for everyone to share their feelings.

Carers and those close to you may also find it helpful to talk to someone else in confidence. Our helpline MND Connect can provide a listening ear and guidance, including details about organisations who provide bereavement support. They can also offer information about bereavement and funeral benefits, and returning to work if wished.

See *Further information* at the end of Part 3: *What do those close to me need to know?* for useful resources, including our guide *Finding your way with bereavement* and publications to support carer wellbeing.

You may also find it helpful to contact your local branch or group of the MND Association. Where an Association visitor is available, they will usually continue to provide support during bereavement.

See *Further information* at the end of Part 3: *What do those close to me need to know?* for our helpline contact details and Section 16: *Useful organisations* for support, such as *Cruse Bereavement Care*.

Summary of tasks

The following checklist explains what needs to happen following your death.

Task	When	Who
Death is confirmed or 'verified'	<p>As soon as practical after death. In hospital, staff may give your family time alone with you first.</p> <p>Should you die at home, your family or main carer should contact your GP as soon as they feel ready to do so. They do not have to call 999 as well if the death was expected.</p>	<p>A doctor can verify a death. A registered nurse with relevant training can also verify a death, where this was expected. Keeping in touch with your GP towards the end of life is important for your care and to ensure everyone is kept informed about what is happening. Verifying a death is a simpler process if the doctor has seen you within 14 days of death.</p> <p>The person who verifies death will usually disconnect any medical equipment.</p>
Organ and tissue donation	<p>As soon as possible after death. This may only be possible if you die in hospital.</p>	<p>Tell all those involved in your care about any arrangements for organ or tissue donation.</p> <p>See Section 12: Organ and tissue donation for details.</p>
Your body is moved to a mortuary or funeral director's premises. There may be cultural or religious requirements. For example, if your body needs to remain at home for a period of time before the funeral.	<p>After death is confirmed and as soon as arrangements can be made.</p> <p>If your death happens at the time expected, a GP can authorise a funeral director to move your body and confirm the death at their premises.</p>	<p>By mortuary or funeral director staff. If at home, a member of your family will usually need to inform the funeral director. If your body is held in a hospital mortuary first, your family will be asked to appoint a funeral director and make arrangements for them to transfer your body to their chapel of rest.</p>

Task	When	Who
<p>The Medical Certificate of Cause of Death is provided or the coroner investigates the death.</p>	<p>After death has been confirmed.</p>	<p>A doctor gives the completed certificate to your family or representative, or arrangements are made for investigation by the coroner.</p> <p><i>See Key points at the end of this section.</i></p>
<p>Registration of death</p>	<p>In England, Wales and Northern Ireland this must be done within five days of the death (it is a criminal offence not to register a death).</p> <p>The person registering your death has to make an appointment with a Registrar in England and Wales, or a District Registrar in Northern Ireland. If possible, they should take your NHS medical card, National Insurance Number, birth and any marriage certificates, driving licence, passport, a Council Tax Bill and a utility bill as proof of address. If your spouse or civil partner has survived you, their National Insurance Number may also be required.</p>	<p>The Medical Certificate of Cause of Death must be taken to the Registrar by a close relative, someone present at the death, the person taking responsibility for the funeral or an administrator from the hospital.</p> <p>The registrar will provide the necessary documents to enable your funeral to proceed and your estate to be administered. The registrar will explain what each document is for to your relative or the person registering your death.</p> <p>Extra certified copies of the death certificate can be purchased by the person registering the death, as this document is likely to be needed several times during the administration of your estate. Photocopies may not be acceptable.</p> <p><i>Search for 'register a death' at www.gov.uk for more details in England and Wales, or www.nidirect.gov.uk in Northern Ireland.</i></p>
<p>Arranging and holding the funeral</p>	<p>Usually within two weeks of death, depending on cultural requirements or investigation by the coroner.</p> <p><i>See Key points at the end of this section.</i></p>	<p>Family and friends may wish to make their own arrangements, but this is usually done with the assistance of a funeral director.</p> <p><i>See earlier heading in this section, What type of funeral can I have?</i></p>

Task	When	Who
<p>Informing health, government, financial, legal and service organisations</p> <p>See earlier heading in this section, <i>Informing other people.</i></p>	<p>As soon as possible to avoid problems with overpayments, receiving income or benefits that may need to be repaid, or having to return a Motability vehicle.</p>	<p>This can be done by family or friends, or executors of your will. Some of these contacts may need to be made during the administration of your estate.</p> <p>See Section 8: <i>Putting affairs in order for more detail about making a will.</i></p>
<p>Claiming funeral and bereavement benefits</p>	<p>Within three months of your death.</p>	<p>If eligible, bereavement benefits only apply to your spouse or civil partner. Funeral payments can be claimed by close family or close friends if they are taking responsibility for the funeral, but may have to be repaid from your estate.</p>
<p>Administering the estate</p>	<p>This usually begins after the funeral, but can take time depending on the complexity of your affairs.</p> <p>See earlier heading in this section, <i>Administering your estate and probate.</i></p>	<p>Where you have a will, this will be done by your executors. Where there is no will, the law decides what happens to your estate.</p> <p>See Section 8: <i>Putting affairs in order for more detail about making a will</i></p>

Key points

- In most cases of MND, your death will not be referred to the Coroner or for post mortem. However, this may be necessary if the doctor is unable to issue the Medical Certificate of Cause of Death, when he has not seen you for more than 14 days before your death or believes that someone else may have been involved in your death. It may also be necessary if you appear to have died from something unrelated to MND, which needs to be determined.
- If your doctor is able to provide a Medical Certificate of Cause of Death immediately after your death, it can be a shock for your family or friends. It will be the first time they see your death confirmed in writing and it may help if they know to expect this.
- Try to get your affairs in order before you die, such as making a will. This will make the practical tasks after your death much simpler for those close to you, during a difficult and emotional time.

See also Section 12: *Organ and tissue donation* and Section 13: *Suicide and assisted suicide.*

See Section 8: *Putting affairs in order.*

Impact from the coronavirus pandemic

Communicating with organisations after a death

- You can notify most banks or building societies of a death by telephone or online. This can be done at a branch, but book an appointment for this and take all the documents they request. This does not have to be the branch of the person who died.
- Many financial organisations offer a notification form to download, complete and return by post, as with National Savings and investments.
- Some solicitors and trust companies offer remote services. Others will see you in person, but by appointment only.

Registration and Death Certificates

- Doctors and registrars now communicate online, so you may not be handed the Medical Certificate of Cause of Death. However, once cause of death has been confirmed, you still need to register the death. This may be possible by telephone or online. Check your council website or ask your funeral director about death registration in your area. Let the registrar know if you cannot access the internet to order or pay for the death certificate online, or ask a trusted person to do this for you.
- The registrar will issue the certificate for burial or cremation directly to the funeral director and give you a unique code. Use this code with the Tell Us Once service online. Ask the registrar for a paper certificate, as you may need this to inform the Department for Work and Pensions of the death.

- If the coroner is involved, they will post you a coroner's certificate and tell you when you can register the death (unless an inquest needs to be held).

Funerals and bereavement support

- Most funeral directors still meet people at their premises, but by appointment only. This enables social distancing guidelines, gives the newly bereaved time as needed and enables hygiene measures between meetings.
- Most funeral directors do not permit open coffin visits if the person died from coronavirus. This may be possible for other causes of death, with a limited number of people and visits.
- The number of people who can attend a funeral may be limited. This can vary depending on the size of the church, cemetery or crematorium chapel, with seating individually spaced. People from the same household may be able to sit together, but this must be arranged through your funeral director and with the chapel's permission.
- When leaving a funeral service, social distancing must be maintained and mourners may not be allowed to touch the coffin.
- If bereavement support cannot be offered in person, it may be available by telephone, webchat or video contact. There may be a waiting list.

Find our coronavirus information at:
www.mndassociation.org/coronavirus

Further information

We produce a wide range of publications to help you gather information about MND and its management. The following may be useful in relation to the subjects covered in Part 3: *What do those close to me need to know?*

From our numbered information sheet range:

- 1A: NICE guideline on motor neurone disease
- 1B: Information about MND or Kennedy's Disease in other languages or Braille
- 8C: Withdrawal of ventilation
- 10A: Benefits and entitlements
- 10E: Work and MND
- 10G: Support for families with children
- 14A: Advance Decisions to Refuse Treatment (ADRT)

From our research information sheet range:

- I: Tissue donation for motor neurone disease research

From our other publications:

Advance Decisions to Refuse Treatment (ADRT) pack which includes our ADRT information sheet, a sample completed ADRT form and a blank form to fill in, if you wish.

Understanding My Needs a write-on tool to enable you to record basic notes about your needs and how you would like to be cared for, if admitted to hospital or a hospice.

MND Alert Card a small card to keep in your purse, wallet or pocket, to alert hospital staff that you have MND and need specialist help, with space to record key contacts.

MND Alert Wristband a silicon alert band you can wear at all times, so that hospital and emergency staff are made aware you have MND and may be at risk with oxygen.

What you should expect from your care a pocket sized booklet to help you use the NICE guideline on MND at appointments.

Living with motor neurone disease a guide about MND to help you manage the impact from diagnosis onwards and maintain the best possible quality of life.

Caring and MND - support for you a comprehensive pack focused on the wellbeing of family and unpaid carers.

Caring and MND quick guide a small A5 booklet to help someone new to the caring role.

Telling people about MND ways to open difficult conversations with family, children, friends and professionals.

Emotional and psychological support for suggestions and details about therapies.

Changes to thinking and behaviour with MND for ways to help manage these changes.

Finding your way with bereavement for information about bereavement support. See also: www.mndassociation.org/bereavement

When someone close has MND - a workbook for children aged four to ten an activity book designed to help a trusted adult communicate with a child about MND and to help the child develop ways to cope with the impact.

So what is MND anyway? a resource for young people who are close to someone with MND, written with the help of young carers who have supported someone with the disease.

Supporting children and young people close to someone with MND a guide for teachers, social workers and other supporting professionals to help them better understand how MND can affect the whole family, and provide suitable assistance for younger members.

How to access publications and further information:

Most of our publications can be downloaded from our website: www.mndassociation.org or you can order them from **MND Connect**, our support and information helpline:

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org

MND Connect can also help you locate external services and providers, and introduce you to our services as available, including your local branch, group, Association visitor or regional staff.

See Section 15: *Help from the MND Association*, for details about our services.

Online forum:

Hosted by the MND Association at:

<https://forum.mndassociation.org> for you to share information and experiences with other people affected by MND. Our forum includes an area for those bereaved by MND.

Free will writing service:

See www.mndassociation.org/freewills about The National Free Wills Network - our membership enables free will writing support for people affected by MND.

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MND Association

Francis Crick House (2nd Floor)

6 Summerhouse Road, Moulton Park

Northampton NN3 6BJ

Tel: 01604 250505

Website: www.mndassociation.org

Registered Charity No. 294354

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For references and acknowledgements please refer to the full guide, *End of life: A guide for people with motor neurone disease*.

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