

8: Putting affairs in order

This section provides guidance about financial and legal matters to ensure your affairs are in order.

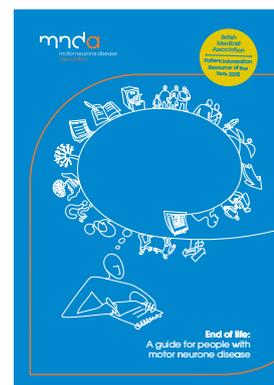
The following information is an extracted section from our full guide *End of life: A guide for people with motor neurone disease*.

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**

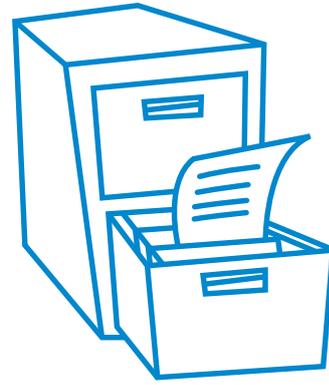
Email: mndconnect@mndassociation.org



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

8: Putting affairs in order

This section provides guidance about financial and legal matters to ensure your affairs are in order.



Please note that the information in this section does not represent legal advice. All efforts are made to ensure accuracy at time of going to print, but details can change between revision dates. It is provided as an overview of what to consider and we recommend that you seek qualified legal and financial guidance in all matters.

“ Discussing and facing the financial and practical arrangements including the house, wills and funeral is important for my wife’s peace of mind.”

As you approach end of life, it is important to consider your financial, legal and practical arrangements. This can feel emotionally challenging as it underlines the finality of what lies ahead. However, planning ahead can help ensure that:

- you receive appropriate care as your needs increase
- your estate is handled in the way you would wish when you die
- those close to you have access to any advance care plans and advance decisions, so they can support you if you become unable to communicate your choices
- those close to you have access to important documents, records and accounts, so they can administer your affairs in the simplest way following your death
- your dependants are supported in the way you would prefer.

A summary table towards the end of the section provides a simple checklist of what to consider.

Planning is equally important if you do not have an immediate family circle, to ensure that health and social care professionals are aware of your wishes.

“ Being single and living with MND creates unique issues about accommodation, finance, transport, coping with life as you lose the ability to speak, walk, etc.”

Providing access to records

Ensure other people can find essential details when needed.

Gather all important documents and records: keep these in one secure place for ease of access during your care and in the event of your death. You may decide to give access to your main carer, partner, relatives or close friends, depending on your personal circumstances, care needs and who you name as executor(s) in your will.

List all main contacts and passwords: important contact details will be needed after your death, eg for your bank, insurance companies, etc. Add passwords and filenames for computer access if relevant, but make sure these notes are kept secure.

Provide written permission: your main carer will find it easier to talk to health and social care professionals on your behalf if they have your written consent to discuss your medical records.

Making a will

A will lets you leave instructions about what will happen to your money, property and possessions (known as your estate), in the event of your death. A simple will is not usually expensive and could save your family costs in legal fees.

“ I don't want to mope about thinking about things that I can't do. It's nice to do the practical things, eg making a will. That's something you can do and tick off the list, if you like...It makes me feel in control.”

Dying without a will

If you die without a will (called 'dying intestate'), the law decides what happens to your estate and those close to you may not receive the share you would have wished.

For example:

- you may want your estate to pass to close friends or charities, but without a will it could pass to distant relatives instead
- you may have children from a previous relationship who you would like to inherit something, but if you remarried and do not have a will, everything may go to your current spouse
- if you are neither married or in a civil partnership, and your bank accounts and home are in your sole name, your partner

will have no entitlement without a will, even if you live with them. In this instance, they may no longer have the right to live in your property after you die, or it may cost a great deal in legal fees to challenge how the estate is distributed.

Can I write my own will?

You can write your own will, but this is a legal document and needs to be worded correctly to be valid. Assistance from a qualified solicitor or reputable will-writing company is generally recommended, particularly if you:

- have complex finances
- need to provide for someone who is unable to make decisions (known as lacking mental capacity)
- need to provide for someone under 18 years of age
- have your own business
- have overseas finance or property
- share a property with someone who is not your husband, wife or civil partner
- have family members who may challenge your will, eg children from another marriage.

Search for *making a will* on the government online service www.gov.uk to find out more.

What needs to be included in a will?

Your will needs to include:

- who you want to benefit (known as beneficiaries) and the specific items or amounts you want them to receive
- who gets anything else that is left (known as the residue)
- who should benefit if the people you have named to receive items or amounts die before you do
- who you wish to appoint as guardians for any children under 18
- who is going to sort out your estate and carry out your wishes after your death, known as your executor (you can have more than one executor if required).

Your will must be signed and dated by two witnesses to your own signature. These witnesses cannot benefit from the will and must not be related to you or anyone else who benefits.

Your executor can be a relative or friend. They will have a legal responsibility to ensure your estate is distributed as instructed in your will. This can take a long time, particularly if a property needs to be sold, so you must ask first if they are prepared to accept this task. If your estate is likely to be complex, your executor may wish to appoint a legal professional to assist them after your death.

Unless you appoint a professional executor (which could be expensive), your executor will only be able to claim direct expenses from your estate. However, you can leave your executor items or amounts in the will if you wish.

When you have completed your will, keep it safe and secure, but ensure your executor can access it easily after your death, including passwords for any related computer records.

Can I change my will?

You can update your existing will, with an official alteration (called a codicil), or you can change your will at any time by making a new one. The new will should state that it revokes (officially cancels) all previous wills and codicils, and you should destroy your old will.

If you marry or enter a civil partnership, this makes any existing will invalid unless the will has been written to take the new relationship into account. A divorce does not invalidate a will, but following the decree absolute, a divorced partner cannot act as executor or benefit in any way. Should you wish to leave them something, you need to write a new will.

Can my will be challenged?

Your will can be challenged after you die, usually because:

- someone feels they have the right to make a claim, or a larger claim, against your estate
- someone thinks you lacked the ability to make decisions when it was written (known as mental capacity). For example, they believe that you had dementia or that medication was affecting your ability to make reasoned choices.

[See Section 9: Advance care planning and advance decisions for details about mental capacity and Power of Attorney.](#)

Can I make gifts to people before I die?

Some gifts made to others during your lifetime could be subject to inheritance tax after your death.

Inheritance tax is a tax charged to your estate when it passes a certain value. You can find out more from the Probate and Inheritance Tax Helpline: 0300 123 1072.

Your finances at end of life

As you approach end of life with MND, you are likely to need increasing care and support. This means you will need assistance to manage your finances. You may also wish to ensure that all your financial affairs can be easily dealt with following your death.

“ He wanted to make sure that everything was set up and that things were in order. That is one advantage of MND, that it gives you time to sort stuff out. He used to sit me down and we would look at spreadsheets together. I found this really hard because I knew what it represented, but that was his way of facing it.”

Access to bank accounts

If you have someone you trust to help you manage your finances, they will need to access your bank account. Ask your bank for advice, as there are various ways this can be done. The following options provide an overview.

Create a joint account: this may be helpful if your partner needs access to joint funds. A joint account will transfer to the other person's name after you die. Bear in mind that if the joint account is overdrawn when you die, the other person will be responsible for this debt. There is also a chance that if one of you is unable to make or communicate decisions (known as lacking mental capacity), the bank may freeze the account which means the other person cannot access the funds.

Third party mandate: you can write to your bank to allow someone to temporarily operate a bank account for you. This usually requires filling in a form, often called a third party mandate. You must be able to make this decision yourself and authorise the form. This is better than providing them with your account details and passwords, to prevent any risk of them being accused of fraud.

Transfer benefits to another account: you can arrange for benefits to be paid into someone else's account, so they can access the money for you. You must be able to make this decision yourself and authorise the form.

If you have a sole account, no-one will be able to access this after you die as the account will be frozen by the bank until your estate has been administered. And remaining funds or debt linked to the account will be counted as part of your estate.

*See the heading **Administering your estate and probate** in Section 10: **What happens after I die?***

You can also arrange for someone to have Lasting Power of Attorney to manage your finances in case you either become unable to do this or unable to make decisions on your own behalf. In Northern Ireland this is called Enduring Power of Attorney.

*See the heading **Do I need someone to act on my behalf?** in Section 9: **Advance care planning and advance decisions.***

What happens to any debts?

Your debts have to be paid from the proceeds of your estate, as administered by the executor of the will. You should investigate all debts, including any outstanding mortgage on your home, to find out what will happen after you die and whether your spouse or partner will still be responsible for payment.

If there is not enough money in the estate to pay all the debts, and you owned property (eg your own home), this may be at risk. People who are owed money from the estate (known as creditors) may agree to place a charge against a property, which means they will be repaid when the property is sold at a future time. However, some may try to force the sale. If you are worried this might occur, seek advice from a debt counselling agency.

What else will my executor or family need to know?

In addition to bank account access, you may wish to list details for the following. These will help your executor when sorting out the estate. They will also help your partner, spouse or close family to continue budgeting and managing the household:

- income and tax records
- any benefits or pensions that you claim, including private pensions
- household, vehicle or expensive item insurances
- health and general life insurances
- mortgage details and any life insurance policy to cover the mortgage
- investments, stocks and shares
- regular bills, such as water, gas, electricity and telephone
- annual bills, such as TV licences

- details for service companies, such as window cleaning or boiler servicing
- car records, such as the previous MOT certificate and registration
- paperwork if you have a vehicle through the Motability scheme
- hire purchase or credit agreements
- paperwork for any loans
- trust funds, grants or charitable funding
- membership fees and subscriptions.

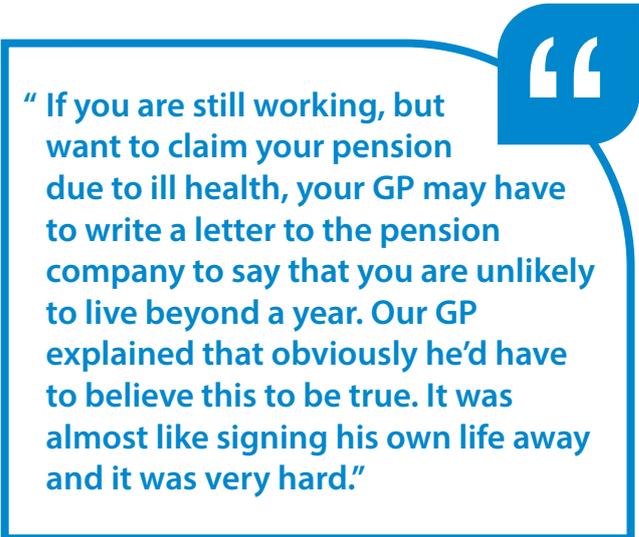
See also Section 10: *What happens after I die?*

You may wish to sell certain investments or cancel agreements that no longer feel appropriate (where feasible). Try to get qualified independent financial advice before making any major financial decisions, as there can be unexpected consequences.

For example, taking a lump sum from your pension may affect your eligibility for certain benefits where income and savings are taken into consideration. If you have a private pension, it may provide benefits for your partner should you die before retirement age.

See Further information at the end of Part 3: *What do those close to me need to know? for a list of information sheets on financial support and employment.*

If you are employed, it may be worth considering early retirement, but it can impact on the benefits you will be allowed to claim. You may also want to check if your employer runs a death in service scheme, as this may benefit your family after your death. Explore all of these options carefully before making decisions.



“ If you are still working, but want to claim your pension due to ill health, your GP may have to write a letter to the pension company to say that you are unlikely to live beyond a year. Our GP explained that obviously he’d have to believe this to be true. It was almost like signing his own life away and it was very hard.”

It can be very difficult to get health and insurance cover following diagnosis. Try not to depend on existing insurances for financial back-up until you know exactly what cover will or will not be provided. Ask the insurance companies to explain this to you.

If you have any questions about how to manage your finances towards end of life, you may wish to contact our helpline, MND Connect. They can provide information or direct you to specialist help.

See Further information at the end of Part 3: *What do those close to me need to know? for contact details.*

Support for dependents

As you approach end of life, thinking about how your dependents will manage in the future can cause great anxiety. It is important to discuss the options with your family and, if necessary, with social care professionals and legal representatives.

If you have adult dependents who require your financial or personal support, talk to your local adult social care service through your local authority (or in Northern Ireland, through your local health and social care trust).

If the dependent person lives in a different area, you may also need to approach their own adult social care service. Social workers or care managers will be able to provide guidance on available care options and provide an assessment if required.

“ My mother’s got dementia. We’ve just helped her to move into a care home. I have MND, but I’ve been more concerned about her than anyone else.”

If you have children, and you know who you would like as guardians, ask them if they would be prepared to accept this responsibility. If they agree, you can name them as guardians in your will.

You should consider this even if the other parent is going to continue looking after your children in the event of your death, in case they also die before the children reach 18. Should this happen, and guardians have not been appointed, the courts will decide who looks after your children.

See earlier heading in this section, *Making a will.*

Who will look after my pets?

If you have pets, you may need to plan for them too. A family member or friend may be willing to take over their care, but this needs to be discussed in advance.

It is worth contacting organisations such as The Cinnamon Trust: www.cinnamon.org.uk. They may be able to arrange alternative care for a temporary period, should you need to go into hospital, or find a new home for your pet at a time that feels right for you (or following your death). If an adoptive owner cannot be found, local rescue centres can usually help.

See Section 16 *Useful organisations for full contact details.*

Personal needs

Discussion with health and social care professionals, particularly those involved in specialist palliative care services, will help you to make informed choices about how you would like to be supported as the disease progresses.

This guide focuses on end of life decisions to help you ask searching questions and access the best possible care that feels right for you.

These discussions may help you plan ahead with more confidence. You can make people aware of your wishes by using:

- a document called an Advance Care Plan, which lets you record preferences about your ongoing care (this helps guide the professionals who support you)
- an Advance Decision to Refuse Treatment (ADRT), which informs professionals of the specific circumstances in which you would want life-sustaining treatments to be refused or withdrawn
- a Lasting Power of Attorney (LPA) in England and Wales, or Enduring Power of Attorney (EPA) in Northern Ireland, which allows a trusted relative or friend to make decisions on your behalf

See Section 9: *Advance care planning and advance decisions for more detail on how to make these arrangements.*

It is important to tell everyone involved, including close family and friends, health and social care professionals and emergency medical teams about these records. Also ensure these documents are accessible, or your wishes may not be carried out.

You may also want to consider the following:

- whether you would like to donate your organs or tissue for transplant or research purposes

See Section 12: *Organ and tissue donation.*

- a funeral savings plan or pre-paid funeral, but seek advice from the Funeral Planning Authority:
<http://funeralplanningauthority.co.uk>

See Section 16: *Useful organisations for full contact details.*

- what you would like to happen at your funeral.

See Section 10: *What happens after I die? for more details about funerals.*

“ We’ve met with a funeral director and discussed how we’d like my funeral. I wanted to get all this sorted so my wife didn’t have to deal with it...we’ve ‘parked’ this so that we don’t have to worry about it. Once you’ve thought about these things you can get on with living.”

Roles and relationships

Roles change when dealing with a progressive illness like MND and your partner may have to take on tasks that are unfamiliar. It may be useful to tell your partner about everyday activities you have always taken responsibility for, such as cooking, how appliances and the heating system work, dates for family birthdays or seasonal gardening tasks.

This can also be a time for resolving any difficulties in family relationships and thinking about how you would like to be remembered. You can do this face to face, but also through letters that you can leave for others, audio and video recordings, scrapbooks, memory boxes and sentimental items.

See Section 7: Discussions with family and children.

Memories are not just about recording the past, but about the time you have now. Your life will continue to change as you adjust to the progression of the disease, but many people find that approaching end of life enables more focus on their immediate circle of family and friends.

“ He wanted to concentrate on living, making plans for each day and living each day as well as the limitations allowed. This involved spending as much time as possible with family and friends.”

Digital legacy

Your digital legacy refers to any online records you leave in your name. You may wish to think about:

- if online access to banking or financial accounts will need cancelling or administration and how to inform the executors of your will about this
- whether any digital items with financial value need to be included in your will, such as ebooks you have authored
- whether your right to pass on anything you ‘own’ online depends on the terms and conditions of the organisation where it was sourced or is now stored
- what happens to any digital records that have emotional value rather than financial worth, such as photographs
- what happens to any social media accounts you run (you may wish to provide passwords to someone you trust for guardianship, as the content may be comforting for family and friends).

For more detail about digital legacies and what to consider, see the Digital Legacy Association at:

<https://digitallegacyassociation.org/for-the-public>

Summary of things to consider

The following table provides a checklist of things to consider when putting your affairs in order, with references to other useful sections in this guide.

See Further information at the end of Part 3: What do those close to me need to know? for a list of publications relevant to the subjects covered in this section for a list of relevant publications.

	Things to consider	Useful sections
Legal	<ul style="list-style-type: none"> • Select a legal professional for assistance with legal documents, such as your will. • Make a will. • Keep all important documents, certificates and records in one safe place. • Note where to find important documents, with a list of key contacts. Give these instructions to your main carer, partner, relative or friend. • If required, arrange for Power of Attorney for your chosen representative. 	<p>9: <i>Advance care planning and advance decisions</i></p>
Care	<ul style="list-style-type: none"> • Provide written consent for health and social care professionals to discuss your medical history with your main carer, partner, relative or friend. • Ensure you have your wishes, needs and preferences for future care recorded on an Advance Care Plan (ACP). • Record any advance decisions about refusal or withdrawal of treatments on an Advance Decision to Refuse Treatment (ADRT) form. • Talk through end of life planning with your health and social care team. • Make any arrangements for organ or tissue donation, if wished. 	<p>3: <i>Difficult conversations with professionals</i></p> <p>4: <i>What to expect as the disease progresses</i></p> <p>6: <i>What care is available?</i></p> <p>9: <i>Advance care planning and advance decisions</i></p> <p>12: <i>Organ and tissue donation</i></p>
Dependants	<ul style="list-style-type: none"> • Arrange care services for adult dependants, if they need support during your end of life care or after your death. • Make arrangements for guardianship for children under 16 (even if you have a partner, in case both of you die before the child/children become adult). 	<p>7: <i>Discussions with family and children</i></p> <p>11: <i>Inherited MND and genetic counselling</i></p>

	Things to consider	Useful sections
Financial	<ul style="list-style-type: none"> • Consider who will help manage your bank account, credit cards or safety deposit box, if needed, and how this will be done. • Find out what will happen to any outstanding mortgage on your home or to any debts that you owe when you die. • Keep all financial and tax records in one safe place, including sources of income such as pensions, shares, insurance and benefits. • Note where to find important documents, with a list of key contacts. Give these instructions to your main carer, partner, relative or friend. 	<p>10: <i>What happens after I die?</i></p> <p>15: <i>Help from the MND Association</i></p> <p>16: <i>Useful organisations</i></p>
Personal	<ul style="list-style-type: none"> • If you wish, decide how you would like to be remembered, through letters, recordings, video or keepsakes. • Discuss any wishes you may have about your funeral with family and friends. • Gather contact details for wider family and friends that you would like to be informed about your death. • Let people know about any arrangements for organ or tissue donation, if planned. 	<p>7: <i>Discussions with family and children</i></p> <p>9: <i>Advance care planning and advance decisions</i></p> <p>10: <i>What happens after I die?</i></p> <p>12: <i>Organ and tissue donation</i></p>
General	<ul style="list-style-type: none"> • Leave instructions about how and when to do tasks that have always been your responsibility, eg car services and MOTs, insurance renewals or how to operate household appliances. • Inform anyone who needs to help manage your digital legacy - in other words, any records, documents, resources, media or presence you have online (see earlier text in this section for details). 	<p>15: <i>Help from the MND Association</i></p> <p>16: <i>Useful organisations</i></p>

Key points

- Without a will, your estate may not be administered in the way you would prefer. Those you wish to benefit may not be entitled to receive gifts or funds.
- Once you have made your plans, try to keep all important records together in a secure place where they can be easily found by those supporting you.
- Provide a trusted person with passwords to computer records you may have, so they can access these to assist you or manage your estate after your death.

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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*.

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

Telephone: **0808 802 6262**

Email: mndconnect@mndassociation.org



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

www.england.nhs.uk/tis