mnd
New South Wales

Preparing for the FUTURE

Your support
to the motor
neurone disease
association of
NSW will have
an impact

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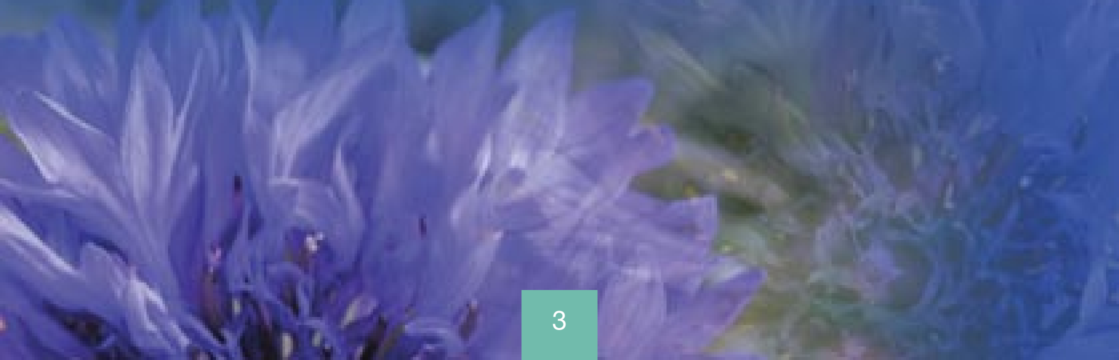

The Impact of Your Will

Making a Will is an important way to secure the future of your loved ones and to make known your wishes to those you leave behind.

By leaving us a gift in your Will (a bequest), it is also a tremendous and thoughtful way of supporting the work of the Motor Neurone Disease Association of NSW Inc. (MND NSW). It ensures that we can continue to support all those affected by Motor Neurone Disease (MND), be they the people living with MND or their loved ones, for it is estimated that for every person diagnosed with the disease another fourteen people will live with the consequences of MND forever.

Keeping Your Will Up To Date

When you originally wrote your Will, whether five or twenty five years ago, your life would have been different from what it is today. Perhaps others depended on you then more than they do now. Perhaps previously named beneficiaries have passed away or you have new additions to your family and new causes that you care about.

Keeping your Will up to date is essential. It is important that you review your Will every few years and if you have added a number of codicils (a codicil is a change or addition that you can make to your Will), it is advisable that you see your solicitor and rewrite your Will so there is no chance of confusion or misunderstanding. If you have yet to write your Will for the first time, you should attend to this as soon as possible as approximately 40% of people who die each year die without a Will – that is they die Intestate. The State Government then determines who will benefit from the estate according to strictly defined rules and in many instances it is not how the deceased had intended. For instance, in situations where you have no living relatives closer than cousins, your estate will go to the State Government.

Remember, your Will is probably the most important document you will ever sign. Only you know what you would like to happen to your estate and there must be no opportunity for misinterpretation in the wording and no omission of instructions for important funds such as your superannuation or business interests.

What Is Motor Neurone Disease?

Motor Neurone Disease is a neurological condition which robs people of the ability to walk, speak, move their limbs, and eventually their breath.

The vast majority of cases of MND (95%) are ‘sporadic’, which means the disease appears out of the blue, typically affecting adults between the ages of 55 and 65. However, some people as young as 18 have contracted the disease. In a small proportion of cases (about 5%) there is a family history of the disease, and it is passed on genetically. Where MND is familial it is normally autosomal dominant; this means the child of a familial MND person has a 50/50 chance of developing the disease in the future.

It is estimated that MND develops in about 2.44/100,000 people each year. In Australia there are about 1,300 to 1,400 people with MND. Of these about 400 (at any one time) patients live in NSW. The incidence rate (number of new cases each year) is approximately 140 in NSW which is similar to that of multiple sclerosis (MS). However the high mortality rate associated with MND means that there are few people living with the disease at any one time. Sadly, approximately half of all patients die within two to four years. One in five people will survive to five years, and about one in ten will survive to ten years. At present there is no effective treatment for stopping the progress of the disease so research is vital for future sufferers.

Why support the Motor Neurone Disease Association of NSW?

MND NSW supports people with MND and their loved ones during the most difficult of times. We offer family support which includes regional advisors, access to important information, a telephone information and support service, loan of equipment, volunteer visitors and support groups. In addition we provide grants such as the Bill Gole Research Fellowship for research into various aspects of the disease.

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"Living with MND offers me no hope," said Lorrie, "but Noel and I have two choices. We can laugh at the small things or we can feel sorry for ourselves. We chose to laugh."

Lorrie's Story

Lorrie and Noel built their house in 1975 – a home that has been filled with laughter and tears. Perched high on a ridge north of Sydney, they look out over the beautiful Ku-ring-gai Chase National Park. Not in their wildest dreams did they ever imagine that this home would become Lorrie's prison. In fact Lorrie has two prisons. Her healthy and alert mind is trapped inside a body that is rapidly loosing its ability to move and the house with its thirty odd steps from street level to the front door keeps her house-bound now that she is no longer able to walk.

Lorrie loved to dance. In fact, she taught drama and dance sport to thousands of students over the years. But that all stopped when she started getting muscle cramps and losing movement in arms and legs.

"Living with MND offers me no hope," said Lorrie, "but Noel and I have two choices. We can laugh at the small things or we can feel sorry for ourselves. We chose to laugh.

MND NSW has been wonderful; lending me an electric bed and other equipment which otherwise we would have had to purchase. And there is also the help at the end of the phone on the days when I just cannot find something to laugh about.

Knowing there is no cure for MND means there is no sense of hope; that is the hardest feeling. If only there was more money available for research. I pray that one day there will be a cure – not for me, for I know it is too late, but for all those who come after me."

To honour Lorrie and the hundreds of people living with MND in NSW each and every day we ask you to make a difference.

All it takes is money and each of us can make that possible, by making a donation now and or leaving a bequest in our Wills to the **Motor Neurone Disease Association NSW**.

You Are Key To Our Continuing Work

Your valuable gifts will form a key part of the Association's long-term income and help us to continue to provide essential information, support and advice for people, like Lorrie, living with MND, their families and carers. It will also help us to continue the search for better treatments, and ultimately a cure, for MND.

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How To Leave A Gift In Your Will

To make a Will, we strongly advise that you make an appointment with a solicitor or trustee company. However, there are five steps in preparing your Will. They are:

➊ Valuing your assets

The best way to start is by roughly valuing everything you own. This is known as your 'estate'. Most people say they have nothing to leave and they are usually surprised after listing all their assets (what you own) and then deducting all their liabilities (what you owe).

When compiling a list of assets you should think of the following items:

- your share of any assets owned as a tenant in common
- all assets that you own personally
- any superannuation death benefit paid to your estate (as determined by the Superannuation Trustees)
- interest in a partnership (less otherwise agreed)
- shares that you hold in a private company
- rights held under any contracts

However, it is not unusual for people to forget to list and state what they intend to do with the following assets which in today's world often constitute the bulk of an individual's estate:

- assets held as joint tenant with one or more people
- assets owned by a company (you may be a shareholder in that company)
- superannuation (depending on the beneficiary nomination)
- assets held in a Trust

- life assurance policy proceeds paid directly to a beneficiary

These assets are not automatically covered by the terms of your Will. They must be listed and allocated specifically.

All your assets must be accounted for under the terms of your Will otherwise you will die partially intestate and an application for Administration will need to be made to the courts.

❷ Deciding who will benefit from your Will

These are the people and charities who will be, in legal terms, your beneficiaries. Simply note down their names and addresses and what you would like to leave them. It is not recommended to omit a member of your family or household as they could challenge your Will. This will delay finalising your affairs and also cost the estate money to fight any subsequent court case.

Your solicitor or trustee company can give you more information, but in general there are six major types of bequests:

- **Specific Bequests** are gifts of particular articles of property, houses or land, shares, cars, furniture, jewellery, artworks etc. given to a particular person or organisation
- **General Bequests** are usually gifts, sums of money or percentages of the value of your estate given to people or organisations
- **Residual Bequests** are made up of the remainder of your estate after the Specific and General Bequests have been distributed. You may wish to leave residual bequests to your family or friends or a charity such as the Motor Neurone Disease Association of NSW.

- **Proportional Bequests** are when you decide to leave a specific proportion of your residual estate e.g. 70% of my residuary estate to Motor Neurone Disease Association of NSW
- **Alternative Bequests** are when you make provision in your Will that if any named beneficiary cannot accept your bequest, then the Motor Neurone Disease Association of NSW, for example, will benefit
- **Trusts and Testament Trusts** are increasingly popular forms of bequests. Whilst created for different purposes they have potential tax advantages and your name can be remembered forever. It is imperative that you seek legal advice before you establish any sort of trust.

❸ Choosing your Executors

There are numerous steps in the administration of an estate, from assisting in the arrangement of the funeral, identifying and collecting assets, paying all debts, identifying all beneficiaries, applying for a Grant of Probate from the Court, completing taxation matters to the distribution of assets to beneficiaries.

Consequently the people you choose as your Executors (preferably have more than one) must have the time and ability to administer your estate. Always ask them first and if one Executor dies or lacks capacity (the ability to carry out his or her affairs without assistance) then a new Executor should be nominated.

❹ Choosing a Solicitor or Trustee Company

Making a Will is not as expensive as most people think – but because it is a legal document, we strongly advise you to use a solicitor or trustee company.

If you do not have a solicitor, contact our Bequest Officer and you will be put in touch with a MND NSW honorary solicitor who will write a simple Will for a discounted fee, provided you leave the MND NSW a bequest in your Will.

❺ Keeping your Will Safe

Once your Will has been signed and witnessed (do not ask a beneficiary to witness your Will for they will be immediately disqualified from receiving a bequest from you), you should keep it in a safe place, such as with your solicitor or trustee company.

We also recommend that you keep a copy of your Will for your reference and let your Executor know where the original is kept.

Wording To Use

If you wish to make a gift to **MND NSW,** we suggest you insert the following clause in your Will or add a codicil to your Will:

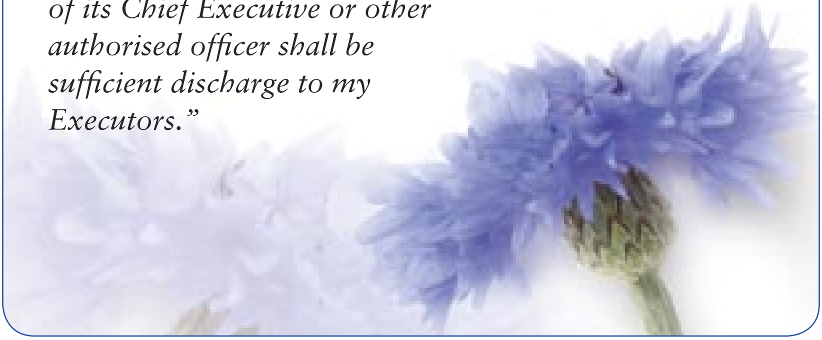
Specific Legacies

"I give to the Motor Neurone Disease Association of NSW Inc. the sum of $______________ for its general purposes, free of all duties and taxes payable upon or in consequence of my death and I declare that the receipt of its Chief Executive or other authorised officer shall be sufficient discharge to my Executors."

OR

Residual Bequests

"I give, devise and bequeath the rest and residue of my estate to the Motor Neurone Disease Association of NSW Inc. and I declare that the receipt of its Chief Executive or other authorised officer shall be sufficient discharge to my Executors."



What Else Should I Consider?

There are two other issues that need to be addressed. They are the appointing of an Enduring Guardian and giving someone your Power of Attorney.

A Power of Attorney is as important for life planning as making a Will. It enables you to appoint someone whom you would prefer to manage your financial and business interests. The Power can be activated immediately or at a time when you can no longer do this for yourself. It is easy to think that this may only become necessary when you are elderly, but unfortunately a car accident or illness could render you unable to manage your affairs, for either a short time or permanently. Having no Power of Attorney could leave you and your family in an uncertain and untenable position.

An Enduring Guardian is someone you choose to make personal, medical or lifestyle decisions on your behalf when you are not capable of doing this for yourself.

Choosing an Attorney or a Guardian is not an easy decision because, similarly to choosing an Executor of your Will, you need to appoint people who have the time and ability to manage your affairs.

What Is A Power Of Attorney?

A Power of Attorney is a legal document that authorises one person to act in the place of another with regard to business and financial affairs. There are two types of Power of Attorney:

Enduring Power of Attorney

An Enduring Power of Attorney is a Power of Attorney that continues to operate notwithstanding the subsequent loss of mental capacity by the person giving the authority to act.

General Power of Attorney

A General Power of Attorney ceases to operate if the person loses mental capacity.

What Is An Enduring Guardian?

An Enduring Guardian does not have responsibility for your finacial affairs. They are concerned only with life style issues. You choose which decisions you want your Enduring Guardian to make. These are called functions. You can direct your Enduring Guardian on how to carry out the functions. For example, you can give them the power to decide on your health care but not where you live. If your Enduring Guardian has a health care function, they will be able to see your medical records to help make decisions for you.

We recommend that you discuss this with your family and solicitor or the Guardianship Tribunal before signing the relevant forms that appoints your Attorney or Guardian.

I often wondered why John, the girls and I, never asked the questions: 'Why John?' 'Why us?' 'Why our family?' It was only looking back that I understood that with MND the question is 'Why anyone?'

“Why Anyone?” asks Pamela Hennessy

I often wondered why John, the girls and I, never asked the questions: ‘Why John?’ ‘Why us?’ ‘Why our family?’ It was only looking back that I understood that with MND the question is ‘Why anyone?’

Sadly I know from our journey with MND (October 1996 to February 1999) that the courageous, inspirational spirits living with MND, and their families, need special care. They also need hope for the future through research that will develop treatments and find a triumphant cure. I also know we would all do anything to prevent precious people dear to us from finding themselves locked into the relentless journey dictated by the progress of MND.

There are important ways we can all help turn the tide on Motor Neurone Disease.

We can keep in touch with our unique MND Family by getting together and supporting one another. We can also consider giving now or making a future bequest in our Will to benefit MND care, support and research. Like each drop of rain in our water catchments, each contribution to the MND Association makes an impact.

WE can indeed MAKE A DIFFERENCE!
Please join me and our growing group of benefactors.
Take care, we care!

Recognising Your Generosity

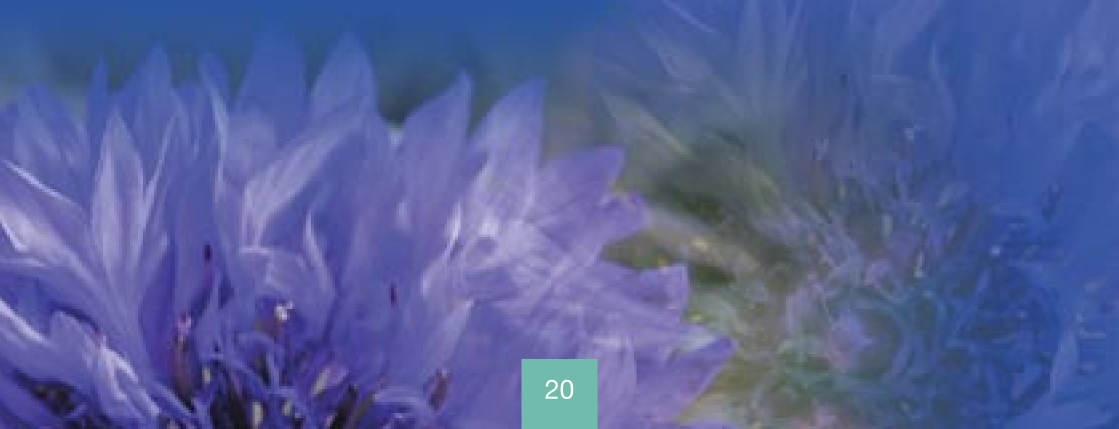
The Blue Cornflower Society

The Blue Cornflower Society, named after the symbol of hope for people living with MND, has been formed to recognise benefactors, like Pamela, supporting the vital work of the MND NSW.

All too often we hear about a bequest only after the benefactor has passed away. The Blue Cornflower Society provides us the opportunity to celebrate our benefactors' support with them, and at the same time encourage others to consider this form of assistance.

Membership to the Blue Cornflower Society is open to anyone who confirms in writing that they have left a bequest of any nature to MND NSW. Blue Cornflower Society members are valued supporters of the Association. They will be invited to lunch regularily to hear interesting speakers, meet like-minded friends, and learn what their support can make possible. They will also have their name listed, with their approval, on the Association's Honour Roll.

We invite you to pledge a bequest and join
The Blue Cornflower Society.



If you would like additional information about leaving a bequest to Motor Neurone Disease Association of NSW or about our work please contact:

The Bequest Officer
Motor Neurone Disease Association of NSW
Locked Bag 5005, Gladesville NSW 1675
FREECALL: 1800 777 175 PHONE: 02 9877 0999 FAX: 02 9816 2077

Please act on my instructions as indicated below.

TITLE: Dr, Mr, Mrs, Miss, Ms (Others please specify):

NAME:

ADDRESS:

POSTCODE:

PHONE: MOBILE:

EMAIL:

☐ I have already made a bequest to Motor Neurone Disease Association of NSW in my Will and would like to become a member of the Blue Cornflower Society.

☐ I plan to write or change my Will to leave a bequest to Motor Neurone Disease Association of NSW.

☐ I would like to speak to the Bequest Officer in strictest confidence.

Members of the Blue Cornflower Society will, with their permission, have their names listed in the Honour Roll

☐ As a benefactor please list my name on the Honour Roll as;

Additional Information (Optional)

NAME OF SPOUSE/PARTNER:

YOUR DATE OF BIRTH: SPOUSE'S DATE OF BIRTH:

SOLICITOR'S NAME:

SOLICITOR'S ADDRESS:

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Our Mission

To provide and promote the best support for people living with motor neurone disease, their families and carers, to advance research and to raise awareness.

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**MOTOR NEURONE DISEASE
ASSOCIATION OF NSW INC.**

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This information booklet has been complied by MNDA NSW and is general in nature. It should not replace formal legal advice such as that provided by a lawyer or trustee company.