# Living with
# motor neurone disease

## Day-to-day

### for people with MND, their family and friends

mnd Aware

**Living with motor neurone disease: day-to-day for people with MND, their family and friends**

MND NSW
Locked Bag 5005. Gladesville NSW 1675
MND Info Line Freecall 1800 777 175
Ph. 02 8877 0999   Fax. 02 9816 2077
admin@mndnsw.asn.au
mndnsw.asn.au
ABN 52 650 269 176

**Publication feedback**
We welcome suggestions from people using this document so that it can be improved over time.

**Publication disclaimer**
The content of this booklet is provided for information purposes only. The content has been reviewed to support its accuracy by appropriately qualified and experienced people. MND NSW does not accept any liability to any person for the information or advice (or the use of such information or advice) which is provided in this booklet or incorporated into it by reference.

The information in this booklet is provided on the basis that all people accessing this resource undertake responsibility for assessing the relevance and accuracy of its content for their own purposes. In regard to symptom control: this publication is not an exhaustive source of information on symptom control. The medication suggested is not guaranteed to be effective or appropriate in all cases. Naturally, the decision rests with the prescribing doctor and/or nurse, taking into consideration the needs, wishes, and susceptibility of the patient.

If you have health concerns that may need immediate attention, you should seek medical advice.

201.201806

# Introduction

***Living with motor neurone disease: day-to-day for people with MND, their family and friends*** has been developed by the Motor Neurone Disease Association to provide you with information about living with MND at home.

MND is a very individual disease and not everyone gets the same symptoms. The patterns of weakness in MND vary from person to person. Therefore not all the information in this publication may be relevant to your particular situation. Just read those parts that you think will help you now. You can come back to the other parts if or when you need to.

## Publications in the Living with Motor Neurone Disease series

### Living with motor neurone disease: aspects of care

- provides an overview of MND and strategies for symptom management

### **Living with motor neurone disease: day-to-day**

- **provides strategies for living at home with MND, more in-depth information and day-to-day tips**

### Living with motor neurone disease: services and resources

- provides contact details for organisations that provide services and information that may be of interest to people living with MND
- searchable online directory at mnd.mndnsw.asn.au

### Living with motor neurone disease: for carers

- for family and friends caring for a person with MND - provides information about the importance of looking after yourself

## For more information

Contact your MND Association. See back cover for full contact details.

# About MND New Zealand

The New Zealand Motor Neurone Disease Association (MND New Zealand) is a non-profit, registered charity established over 30 years ago for the purpose of supporting those living with MND.

We offer information and support to people living with a diagnosis of MND along with their whanau/carers and the health professionals and service providers involved.

We work to increase awareness and understanding of MND in New Zealand and to be a reliable link to information related to MND, its management, and ongoing research.

## Information

- MND New Zealand provides reliable information for people with MND and their whanau, through our support service and at www.mnd.org.nz
- We provide education about the needs of people with MND to the broad range of health professionals and service providers involved in their care.
- We share research news and stories about living with MND from around the world on our Facebook page at www.facebook.com/mndanz

## Support

- Our MND support advisors are qualified health sector professionals with knowledge and experience related to MND. They are a key point of contact for people with MND and their whanau and carers.
- Our support advisors offer free, personalised support and advocacy for those living with MND through home visits, phone, text and email.
- Our support advisors are well connected with local service providers and can liaise on behalf of those living with MND to facilitate access to services and equipment as appropriate to individual needs.

## Research

- MND New Zealand works to advance opportunities for New Zealanders with MND to participate in research if they wish, and grow the field of MND research in New Zealand.
- We fund the NZ MND Registry (www.mnd.org.nz/registry) and the NZ MND Research Network (www.mndresearch.auckland.ac.nz).

## Advocacy

- MND New Zealand advocates for change through raising community awareness about the needs of people living with MND.
- Our MND support service assists people with MND, their whanau and carers to self-advocate to service providers and funders.
- We advocate for the needs of people with MND at a political level and encourage statutory agencies to fulfill their obligations.

Donations, fundraising and bequests fund 90% of MND New Zealand services. Just 10% of our income is received from the Ministry of Health under a Disability Information & Advisory Services (DIAS) contract.

Membership of MND New Zealand is free for people with MND who live in New Zealand. Contact National Office on (09) 624 2148 or visit mnd.org.nz for more information.

# Contents

# Getting information about MND

The MND Association keeps a close watch on motor neurone disease research progress and findings, including stem cell research findings, and always has the latest information available. We support and promote any new treatments that have been proven through research and scientific peer review to improve survival or symptom management for people with MND.

You can get more information about MND from:

- your neurologist
- your general practitioner
- other health professionals involved in your care
- your MND Association advisor
- the MND Association.

Additionally many people use the Internet to find information about MND.

## Using the Internet as a health information source

The Internet can be a valuable health information source. However, costly and unproven therapies for MND are often advertised on the internet or may be recommended by well-meaning people. It can be difficult for people living with MND and their families to distinguish fact from fiction, or paid advertising from good quality health information.

### Deciding about the quality of information you have found

From Health Insite, the Australian Government gateway to reliable health information at healthinsite.gov.au

The following questions may help you to decide if information you have found on the Internet is of good quality.

1. Why was it created (purpose)?

- Does the site state why it was developed?
- Who developed the site? Can you find any apparent bias or conflict?
- Who is it aimed at and pitched for - health professionals, general public, young people, children?

2. Who is responsible for the information (authority)?

- Is it clearly stated who is responsible for the information content?
- What are the author's qualifications and can they be verified?
- Are there contact details such as email, postal details, phone numbers, including toll free? Is feedback and interaction encouraged?
- Is the publisher a reputable one?
- Does the site provide details of the quality assurance process used to ensure that information on the site meets a high standard?
- What are the qualifications of the authors and people who approve information for the site?
- Do the producers of the site have a commercial interest? For example, companies often have good information but only about their products.
- Is information provided on the site's privacy policies and are there appropriate disclaimers?

### 3. Is the information up-to-date?

- How often is the site updated?
- Is the date clearly visible?
- Are there other features to indicate that information is kept up-to-date?
- Is all of this information clear and easy to understand?

### 4. Is the subject coverage complete and indepth?

- Does it include links to other reputable sites?
- For diseases or conditions, does it indicate:
  - the causes
  - how to prevent it
  - how to recognise it
  - how it is diagnosed
  - treatments/procedures (and alternatives)
  - care and quality of life issues associated with the disease or condition?
- Does it provide balanced and unbiased information without being opinionated?
- Does it have good coverage of topics?
- Is it clear what sources of information were used to develop the page, study or publication?
- How extensive is the coverage?
- For information on treatments, does it cover:
  - how treatments work
  - what are their benefits and risks
  - what are the effects on quality of life
  - what is the likely effect of non-treatment
  - are there alternatives for obtaining the information, such as phoning or having reports posted to you?
- Is there help available, either by instructions on the site or via email?

### 5. How easy is the site to use?

- Is it easy to navigate the site and find information?
- Is it carefully laid out and are there any additional features such as images to enhance the information?
- Is it easy to know where you are in the site and to find additional information on the topic?

Health information on websites should not take the place of your health provider/patient relationship and should not be used for self-diagnosis. There are many factors that need to be considered in relation to your health and the diagnosis of any condition. Use the Internet as an information resource and ask a health professional about any issues raised by the information or anything that you don't understand, such as medical terms. Avoid any online health practitioner who proposes to diagnose or treat you without a proper physical examination and a full consultation regarding your medical history.

# Feelings and attitudes, and those of family and friends

## Feelings and attitudes

Each person is unique and reacts in their own way. You, your partner, your children, other people in your family and your friends may experience very similar feelings and attitudes. More commonly, however, you will all react differently at different times.

During the early stages of the disease a wide and confusing array of emotions may be experienced. You and your family are adjusting to a new way of life that includes having a life-limiting disease. You may experience:

- *Not wanting to talk about it.* For some people, acting as though everything was as it was before the diagnosis, is a coping mechanism that provides relief when new stresses or losses occur. Even though there is an awareness of the condition and its prognosis, the person (with MND, partner, family member or friend) may be acting as though nothing has changed.
- *Beating it.* Some people with MND, their family and friends, might adopt a 'fighting' attitude - where they fight the disease to try to overcome it. They may spend time searching for a cure and investigating alternative medicines and vitamin supplements.
- *One team.* Some people think of themselves and their body, or themselves and their partner/family/friends as one, a team that will work together to deal with life's needs, day by day.
- *Feeling overwhelmed.* Some people may feel totally unable to cope with facing the future with MND.
- *Heightened appreciation.* Some people reach a stage of heightened appreciation of treasured relationships, the joy of a new day - in fact, a more positive approach to living.
- *Just getting on with it.* Many people with MND actively address symptoms as they arise and just get along with life. Some people may feel a conflict with this, feeling that doing so is not accepting the impact of the disease on their future.
- *Other feelings, emotions and attitudes.* The list is endless and there are no right or wrong feelings, emotions and attitudes.

If the disease is progressing quite rapidly you may feel you don’t have enough time to learn how to cope with one situation before another change occurs. This can be emotionally difficult and has been described as having to cope with a 'spiralling series of losses'.

The emotions accompanying loss, particularly anger, fear and anxiety, can be strong emotions. It can be frustrating and distressing if you can no longer do things you have been used to doing. It can be helpful to share these feelings with others and to focus on what can be done. Keep planning pleasurable activities, hobbies and challenges.

Having open discussions with your family and friends about your arrangements for financial, health and lifestyle decision-making may be helpful. Encourage those around you to set in place their own arrangements at the same time you are setting yours in place. These arrangements can be formal or informal, although some arrangements require specific documentation to be legally enforceable. See *Planning ahead*, page. 9.

Understanding about the later stage of MND and talking to your family, friends, MND Association advisor and the health and community care team may help allay fears and distress.

## Communicating about emotional issues

It can be hard to communicate about emotional issues.

### Tips for communicating about emotional issues

- Be honest and truthful in your discussion of issues
- Understand your own feelings and avoid confusing them with those of the other person
- Avoid diminishing the importance of painful feelings and thoughts
- Maintain a sense of humour, it can help defuse misunderstandings

At times, you may just share sadness, tears and laughter.

Sometimes, you may feel that sharing your emotions and feelings with those closest to you may burden or worry them. You may find it helpful to talk to people who are not involved directly such as your doctor, MND Association advisor, counsellor, social worker, clergy or others living with MND.

## Talking with young people about MND

### Children may react in a variety of ways often depending on their age and personality

- Young children may cry and be upset when they are first told but have short memories and may soon be playing and laughing as their focus is distracted
- Older children may become distant and withdrawn and refuse to talk about what is happening
- Some older children may also withdraw geographically by spending more time at friends' houses
- Others may act out in an effort to deal with their anger and fears regarding the future loss of a parent

A child's reaction is not a personal attack on you.

It may be helpful for your children to talk to a counsellor. Alternatively, it may be helpful for you to talk to a counsellor to discuss how best to support your children and how to better understand their individual reactions and behaviours.

There is the potential for children to lose the attention of both parents. This can happen if one parent has MND and the other parent is busy caring for the person with MND and/or being the breadwinner. Extended family such as aunts, uncles and grandparents, and close family friends, can be extremely important in filling in the parenting or caring gaps.

Children may need or have a particular desire to help care for their parent with MND. This can offer an opportunity for a unique closeness and interaction with their parent. It is important, however, that they are still able to be children and have time for their friends, sports, interests and studies.

Creating opportunities for children to share their day with their parent with MND is important for the children and keeps the parent in touch with their world.

An information pack of six booklets, *Talking with Young People about MND*, is available from the MND Association.

## Friends

Relationships may change following an MND diagnosis. Some friends may seem to not understand and some newer acquaintances may rise to the occasion and become involved.

### Friends

- May not know what to say or do - try to understand why they react as they do
- Might really want to help but not be sure about what they can do
- Can help with practical matters, such as gardening and shopping, allowing you more quality time with your family
- Might appreciate you reaching out to them for assistance as it provides a way for them to be with you or to show their concern and support for you
- Can add interest to your life at home if you are finding it difficult to get out and about

It may also be helpful to:

- ask one friend to communicate information and updates on your behalf to others
- use apps or a social networking site to set up a group so that an update only needs to be sent to one 'place'. This group can also be useful for the coordination of offers of assistance from extended family, friends and neighbours (see *Getting organised,* page 52).

## Linking up with others

Most people with MND and their family and friends do not know much, if anything, about the disease before their diagnosis. Many people find it helpful to link up with others who know what it is like to live with MND, even though they might initially think they would never find this helpful or enjoyable.

Linking up with others who are living with MND can provide you with the opportunity to chat about MND with others who know what it is like to be diagnosed with MND and share ideas and tips for living with MND.

### You and your family and friends can link up with others living with MND through:

- Attending MND Association events for people living with MND which may include:
  - information evenings for people recently diagnosed with MND
  - information days for people living with MND
  - local support groups and coffee mornings
  - carers workshops
  - research updates and forums
  - past carer get-togethers and workshops
  - telephone link-up sessions
- Online forums and groups

For more information about events in your locality contact your MND Association.

## Linking up online

From Cybersmart, the Australian Government national cybersafety and cybersecurity education program at cybersmart.gov.au

### Choose how you embrace the online world

- Every time you go online, you can choose who you provide information to, which doors you open and how you engage with others
- Choosing consciously means being aware that you are in control of the decisions you make online
- It means thinking before sharing your personal information and understanding that your choices can last forever
- When you choose consciously you make well informed decisions about who you share information with, and are able to take charge of how you interact online

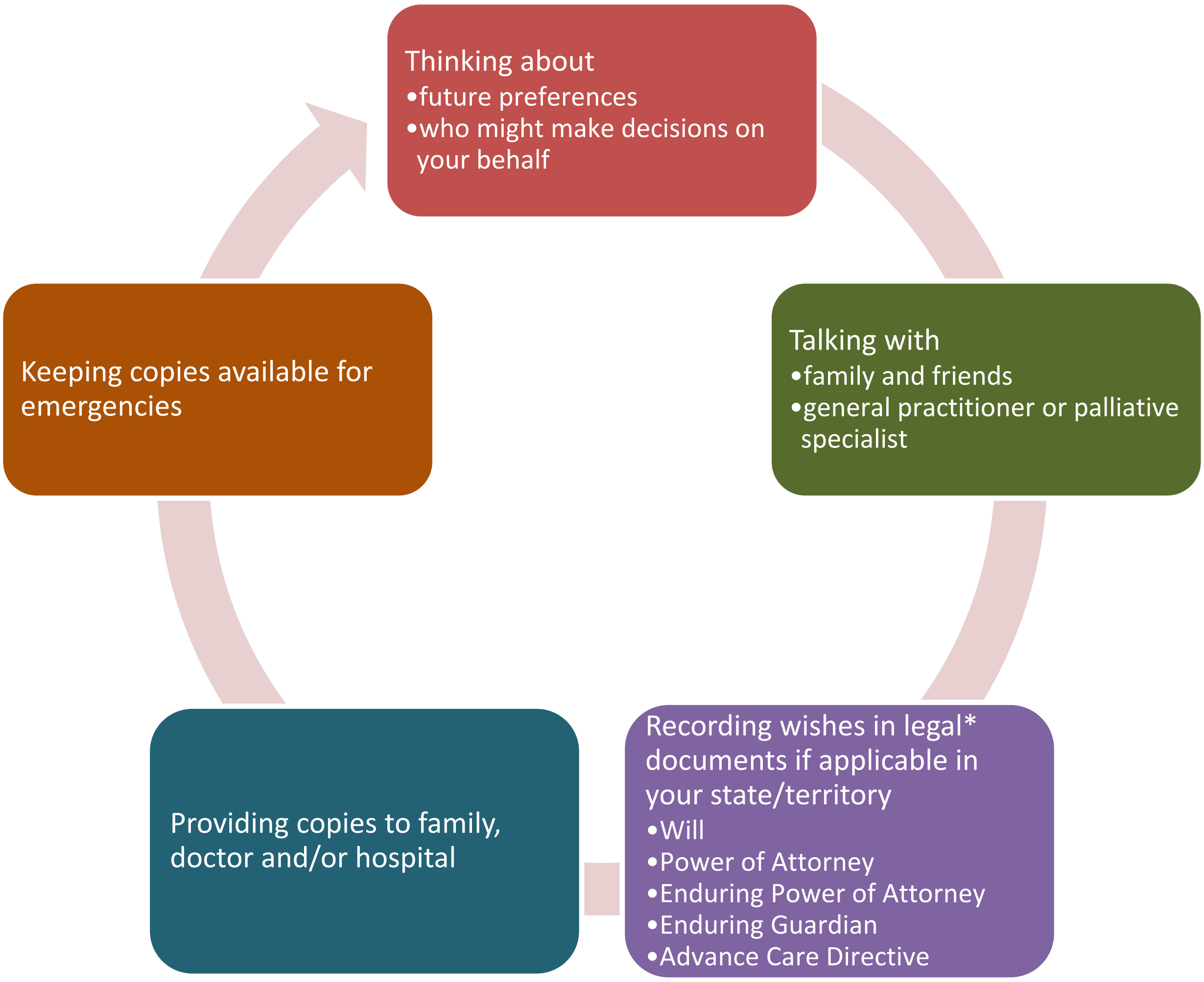
### Use your digital literacy and know-how to protect yourself

- Set your privacy and security settings and check them regularly
- Choose your friends wisely. Not everybody online is who they claim to be
- Think before you post - what you do online can affect your whole world (images, statuses, comments etc)
- Consider others and your actions - ask for permission if it's not your content/image
- Be careful opening a message if you don't know the sender
- Decide if you really want your location displayed by your devices or app

# Planning ahead

Open discussions with your family and friends about your arrangements for financial, health and lifestyle decision-making may be helpful. Encourage those around you to set in place their own arrangements at the same time you are setting yours in place.

## Possible planning steps



Thinking about
- future preferences
- who might make decisions on your behalf

Talking with
- family and friends
- general practitioner or palliative specialist

Recording wishes in legal* documents if applicable in your state/territory
- Will
- Power of Attorney
- Enduring Power of Attorney
- Enduring Guardian
- Advance Care Directive

Providing copies to family, doctor and/or hospital

Keeping copies available for emergencies

***Australian states and territories and New Zealand** have separate legislation covering Wills, Powers of Attorney, Guardianship and Advance Care Directives.

Legal documents should be prepared in **your state/territory/country of residence** because of differences in laws.

For more information speak with your solicitor, general practitioner and/or organisations that may be able to assist. For more information see the MND Association resource *Living with motor neurone disease: services and resources*.

# Preparing a Will

## What is a Will and who should have one?

A Will is a legal document that clearly sets out how you want your estate (property, finances and belongings) to be distributed when you die. It is recommended that everyone 18 years and over should make a Will.

## Can I change my Will?

You should review and update your Will when there are major changes in your life – such as getting married or divorced, having children, buying a house or business.

## What is an executor?

An executor is the person who administers your estate after you die. They carry out your wishes outlined in your Will. They should be someone you consider as capable, trustworthy and reliable, as well having the ability to remain independent in the event of a dispute.

## Can I write my own Will?

Yes, but there are certain legal requirements to make it valid. You should seek the assistance of a professional such as your local solicitor or a trustee company to help prepare your Will and make sure your intentions are clearly documented.

## What happens to my estate if I die without a Will?

If you die without a Will (called intestate), your assets will be divided up by a pre-determined legislated formula, with certain family members receiving a defined percentage of your assets. If you die intestate and have no surviving relatives, as defined by the legislated formula, the government will receive your estate.

## What happens if I don't clearly outline in my Will what my wishes are for my children?

Not providing adequately for children could result in your Will being contested. Not nominating guardian/s for any children aged under 18 could also mean that it becomes more difficult for the Court to decide who should have day-to-day care of the children.

## If I have moved from overseas and made a Will where I previously lived, should I make a new Will?

Due to differences in laws overseas, you should have a Will made in your country of permanent residence to include all your assets.

# Appointing an Attorney under an Enduring Power of Attorney (EPA) in Relation to Property

© This information has been adapted and reproduced for New Zealand law with permission from NSW Trustee & Guardian (www.planningaheadtools.com)

## What is an Enduring Power of Attorney (EPA) in relation to property?

An EPA in relation to property is a legal document where you appoint an Attorney to manage your finances and property on your behalf. An Attorney cannot make decisions about your lifestyle, medical treatment or welfare. An EPA in relation to property ceases when you die.

## What is the difference between an ordinary Power of Attorney and EPA in relation to property?

An ordinary Power of Attorney ceases to have effect if a person loses mental capacity.

An EPA in relation to property continues to be in force after you lose the capacity to manage your own affairs.

You can make either, but you should consider an EPA in case of future incapacity or as you age. It is too late to appoint someone you choose once you lose mental capacity.

If you’re no longer able to manage your financial affairs and you don’t have an EPA in relation to property then an application to the Family Court may be required to appoint a Property Manager to deal with your affairs.

## When can an Attorney manage my financial affairs?

Your Attorney for property can be activated either while you still retain mental capacity, or when you lose mental capacity to the extent that you are no longer able to make decisions.

## Who can I appoint as my Attorney?

It is important to choose someone you trust and who understands your wishes. An attorney should have the skills and ability to manage your finances and act in your best interests. You can appoint your solicitor, a trustee organisation or someone in your life you trust.

## How can I appoint an Attorney in relation to property?

To appoint an Attorney for property you need to complete an Enduring Power of Attorney for property which is available on the Ministry of Social Development’s ‘Super Seniors’ website. Alternatively, a lawyer or trustee company can help you prepare the documents.

You and your Attorney/s have to sign the form. You also need to have your signature witnessed and certified by a legal person. This will be either a lawyer, a qualified legal executive or a representative of a trustee company. You can appoint more than one person to be your Attorney for property.

## Once I have an EPA in relation to property, will I lose control of my finances?

No. The appointment of an Attorney gives formal authority for the chosen individual to manage your financial affairs, according to your instructions. You can define these powers to be very broad, or confine them only to specific property. You can also appoint someone to monitor how the Attorney is carrying out their role.

## How and when can I cancel an EPA in relation to property?

You can cancel (revoke) it at any time if you have the capacity to do so. To revoke an Attorney’s power to act you must write a letter to your Attorney to inform them that their appointment is revoked. Keep a copy of the letter yourself and notify your bank or other financial institutions of any changes.

## Appointing an Attorney under an Enduring Power of Attorney (EPA) for Personal Care and Welfare

### What is an Enduring Power of Attorney (EPA) for personal care and welfare and why should I use one to appoint an Attorney?

An Attorney appointed under an EPA for personal care and welfare is a person you choose to make decisions on your behalf in areas of lifestyle and health such as medical decisions, accommodation and services. An EPA for personal care and welfare only comes into effect if you can no longer make decisions for yourself due to incapacity. Appointing an Attorney for personal care and welfare can avoid conflict and distress for you and your family and ensures you are in control of who makes decisions on your behalf. An Attorney cannot make or alter a Will for you unless directed by the Family Court, and they cannot make decisions about your money or assets. They cannot consent to a range of significant medical procedures, or deny lifesaving treatment.

### How can I appoint an Attorney for personal care and welfare?

To appoint an Attorney for personal care and welfare, you need to complete an Enduring Power of Attorney for personal care and welfare which is available on the Ministry of Social Development's 'Super Seniors' website. You and your Attorney have to sign the form. You also need to have your signature witnessed and certified by a legal person. This will be either a lawyer, a qualified legal executive or a representative of a trustee company. You can only appoint one person to be your Attorney for personal care and welfare.

### Who can be an Attorney for personal care and welfare?

Given the important nature of this decision-making role, the person you appoint should understand their responsibilities and should support you to make your own decisions where possible. Your Attorney should be someone you trust to be able to take into account your views and previous lifestyle choices and to make decisions in your best interests. Also, they must be over 20, not bankrupt, and have mental capacity.

### Can my nominated Attorney be changed or cancelled?

You can cancel (revoke) your EPA while you still have capacity by giving your proposed Attorney notice in writing. If you don't have capacity, only the Family Court can revoke the EPA.

## What is legal capacity?

The law around capacity and decision making for adults is the Protection of Personal and Property Rights Act 1988. This law assumes that every adult has the mental capacity to make decisions: they can make and understand the consequences of their decisions, and they can then communicate those decisions. Capacity can be affected temporarily because of illness or the effects of medication, or permanently affected due to conditions such as intellectual disability, dementia, mental illness or brain injury. It is important not to assume that just because someone has memory problems or a disability, they can't make their own decisions.

If you have concerns about a person's capacity, you should request an assessment by a health professional. You should ask the person's doctor to undertake the assessment or for an appropriate specialist referral. To plan ahead, you must be deemed to have capacity.

If someone has lost the capacity to make decisions about their welfare or finances an application will need to be made to the Family Court for an Attorney to be appointed.

# What is Advance Care Planning and an Advance Directive?

## What is Advance Care Planning?

Advance Care Planning is a process that helps you to plan for future health care. This process involves thinking about your values and beliefs and your wishes about what health care you would like to have if you cannot make your own decisions.

An important part of the planning process is to discuss your wishes with your family and other people who are close to you, as well as talking to your General Practitioner or other health professionals about any medical conditions you have.

You may also choose to write down your wishes in an Advance Directive.

## Importance of Advance Care Planning

Advance Care Planning is a way to make sure that people who are involved in your life understand your wishes about medical treatment and health care. This will help to guide them if you become seriously ill or injured and cannot make your own decisions about health care. Like making a Will or appointing an Enduring Power of Attorney (EPA), Advance Care Planning is an important part of planning ahead.

You can start to talk about Advance Care Planning any time, as part of general discussions about your health or medical care. Many people start to think about Advance Care Planning because they have health problems or a serious illness that will get worse over time. However, Advance Care Planning can also guide families and health professionals if you have an unexpected accident or illness.

Advance Care Planning is a process that occurs over time, and may be reviewed when your situation changes. You must have capacity to make an Advance Directive.

## The Advance Care Planning Process

Advance Care Planning is not a single process. Advance Care Planning should include:

- talking to your family and other people close to you about your wishes, values and beliefs about medical care and treatment towards the end of your life
- talking to your doctor and other health professionals about any medical or health issues you have, what treatments are available and what choices you would like to make about your medical care
- thinking about what 'Living Well' means to you and what treatments you would want to have that may prolong your life, and what treatments you would refuse
- appointing an EPA for personal care and welfare (an Attorney)[1] who would make medical decisions for you if you were unable to make your own decisions
- writing down your wishes, perhaps as an Advance Directive.

## Writing an Advance Directive

As part of the Advance Care Planning process, you may decide to write an Advance Directive. An Advance Directive records your choices about possible future health care procedures including specific wishes about treatments that you would like to have in the event of a medical crisis, life-threatening illness or injury, and any treatments you would refuse.

There is no specific form to use for an Advance Directive. It can be written or oral but it is wise to put it in writing. It is a good idea to discuss your wishes and treatment options with

---

[1] See for more information Appointing an Attorney under an Enduring Power of Attorney (EPA) for Personal Care and Welfare resource

your treating doctor. You can request that your Attorney for personal care and welfare refers to your Advance Care Plan or Directive before making any medical or health decisions.

**Your treating doctor is more likely to consider your Advance Directive to be valid if:**

- You were competent to make it
- You intended your directive to apply to the present circumstances, which may be different from those anticipated
- You were sufficiently informed to make the decision
- You made the decision of your own free will
- It is current (it wasn't written a long time ago and you have not changed your mind since writing it)

Doctors and health care professionals will only consider your Advance Directive if you have lost mental capacity, are unconscious or otherwise unable to communicate.

Your Advance Directive should be taken into account in deciding what is in your best interests. Be aware that your doctors and health care professionals are under no absolute legal obligation to follow an Advanced Directive that is not consistent with good medical practice. Your doctor, for example, would be under no legal obligation to follow your request in your Advanced Directive for a particular course of palliative care or for assisted dying.

You should keep your Advance Directive in a place that is easily accessible for you or for others to obtain if needed. Keeping a copy close to you (such as in your wallet) is sometimes suggested. You should also give a copy of your Advance Directive to your Attorney for care and welfare, doctor, health care facility, family members or other important people in your life. Remember to give updated copies to these people whenever you change your Advance Directive.

## Changing your Advance Directive

You can update or re-write your Advance Directive whenever you like as long as you have capacity. It is a good idea to read over anything you have written once a year to make sure it is still current. You may also change your Advance Directive if your health needs or life circumstances change. Make sure you sign and date your Advanced Directive when you have reviewed it so health professionals know that it is current.

Remember to give updated copies to your Attorney for care and welfare, doctor, health care facility, family members or other important people in your life whenever you review your Advance Directive.

## For more information

Speak with your solicitor or general practitioner for more advice. Templates for Advance Directives are available on the New Zealand Medical Association and Health and Disability Commissioner websites.

# Around the home

This section includes practical ideas to help you live at home with MND. Some of the ideas are simple changes and other ideas may involve major changes that require planning and expense. Not all of the ideas in this section are relevant to all people with MND because patterns of muscle weakness in MND vary from person to person.

## How can an occupational therapist help?

An occupational therapist (OT)

- Can advise you about what changes in your home environment could make it easier for you and your family
- Will visit your home and discuss with you the changes you could make for your specific situation including home modifications, specialised equipment and suggestions that will help make daily living easier
- Is usually the first health professional, apart from your doctor, you will have contact with and who will visit you in your home
- Will be able to answer any questions you have about the changes you can make to your home to make life easier

Your MND Association advisor can assist you to contact an OT in your area.

## Getting in and out of your home

How easy it is to get into and out of your home?

- Are the pathways wide enough for a walking aid or wheelchair?
- Are the pathways level?
- Do you have any steps? Do you need grab rails to help you get up the stairs or would you need larger stairs (increased depth) to accommodate a frame?
- If steps cannot be managed, can they be replaced with a ramp? Would a portable ramp work or would you need a more permanent ramp?

## Inside your home

The layout of your home may make it easier or harder to get around

- Is your home single level or a multi-level?
- Do you use stairs to get to the bedroom or bathroom?
- Is there a room downstairs you can use as your bedroom?
- Are the doorways and hallways wide enough for walking aids or wheelchairs?
- Is there a bathroom on the same level as the living room and bedroom?
- Is the furniture arranged to make it easy to move about?
- Do you have any loose rugs and mats that you might trip over?
- Are there extension leads or power cords lying across the floor?
- Do you have lever taps and lever door handles throughout the house? These are the easiest ones to use.

## In the lounge/TV room

- Is the furniture arranged so there is enough room to move about without bumping into furniture, especially if a wheelchair or walking aids are used?
- Are the television, telephone and chairs positioned so that if a person has weak neck muscles they can avoid unnecessary neck rotation to view the television or chat with people in the room?
- Can the seat height of a chair be increased because it is easier it get out of a raised chair than a lower one? You can do this by putting the chair on a specially constructed platform, by using a firm cushion or by using a chair raiser.
- Would you be more comfortable in a power raiser recliner chair that you move from a sitting to standing position? With this type of chair, you can rest in the chair in a reclined position. Your OT can assess the suitability of a raiser/recliner for your individual needs.

## In the kitchen

- Can the table height be adjusted so that it can still be used while sitting down, and have enough room underneath the bench/table for a wheelchair, if necessary?
- Consider the range of modified equipment available which may help in meal preparation or simply for moving items around, for example:
  - Easireacher (similar to long handled tongs)
  - ergonomic knife/utensils that have modified handles and design to help with holding, manipulating the utensil or exerting pressure
  - lightweight containers with large handles
  - tray mobile; a tray on wheels which can be pushed along.
- Other options to consider:
  - use of microwave
  - lower the temperature of hot water from taps to avoid scalds.

## In the bedroom

- You may need extra space for:
  - you and others helping you to be able to move around
  - equipment that may be needed in the bedroom, for example a hoist or wheelchair. If a hoist is used, it usually requires extra circulation space and under-bed clearance.
- Beds of a standard bed-height can be difficult to get on and off. You may be able to raise the height of the bed by using bed blocks.
  - Is the bed at the right height for a person who might be assisting you to get in and out of bed?
  - Consider using an adjustable bed, either mechanical or electrical, as you can raise and lower the height of the bed as needed. Also you can adjust this type of bed to raise your head and knees for comfort if required.
- Items you can use that can make it easier to turn in bed including satin nightwear, satin or silk draw sheets or a turning slide or sheet.

### In the bathroom

- Is it large enough for a wheelchair and any other equipment that might be needed?
- Is the layout easily accessible?
- Watch out for slippery floors - keep floors dry and be very careful when the floor becomes wet.
- The following items can make showering easier:
  - hobless shower area - to avoid having to step into the shower
  - hand shower
  - grab rails
  - shower stool or chair
  - bath board / bath seat - fitted across the bath to avoid the need to climb into the bath.
- The following can make toileting easier:
  - increase the height of the toilet and/or provide arms to push up, for example, using a toilet surround, raised toilet seat or over-toilet aid
  - ensure the toilet paper is within easy reach
  - bidets are an option to consider for people with poor upper limb function
  - grab rails near the toilet
  - mobile commode.

## Slips, trips and falls

### Reduce your risk of falls

- If you are tripping over your own feet because of drop foot or weak ankles, talking to your physiotherapist about splints may be helpful. Splints are fairly unobtrusive and can make a lot of difference to stability.
- Use walking aids if the occupational therapist or physiotherapist has prescribed these.
- Always have a walking stick measured to correct height, or walking frame correctly adjusted.
- Wear shoes that support your feet well. High heels, thongs, scuffs and slippers can make it much harder to walk.
- Remove loose floor rugs and other trip hazards.
- De-clutter your house so you don’t have to walk around chairs and coffee tables when moving from one room to another.
- If you are having difficulty holding your head up because of weak neck muscles, wearing a neck and head support collar when you are walking will help you see potential hazards ahead.

### What to do if you have a fall?

If you are walking with someone and feel that you are about to fall, get them to try to control the fall by lowering you gently to the floor, being careful that the person helping you does not endanger or hurt themselves.

*If you have a fall*

- Keep calm
- Check if you are injured
- Take time to collect yourself before you get up or before anyone helps you up

If you are alone, take time to collect yourself, before deciding what to do. Is the phone in reach? Do you have a personal alarm necklace or bracelet? Can you get into a comfortable position while waiting for help?

It is important that people don't try to help you up after a fall unless they know how to give assistance. They could severely damage their back or drop you while trying to assist.

**If you are not injured and can help yourself up:**

- Ask someone to place a solid chair near you
- Get onto your hands and knees and then place your hands up onto the chair
- Push down on the chair and lift one leg through, then the other, so your feet are on the floor (and your hands are still on the chair supporting you)
- Push yourself up to sit on the chair

**If you are not injured and can't help yourself up:**

- If you have a hoist and the person with you has been trained how to use it, the hoist can be used to assist you back up
- If you don't have a hoist or other means of assistance to get up, call an ambulance*

**If you are injured or unable to get up:**

- Call an ambulance*, or if available, seek other medical advice. While waiting for assistance, get comfortable by:
  - asking someone to place a pillow under your head
  - covering yourself with a blanket to keep warm
  - if you feel able, moving into a supported sitting position

*Ambulance services usually charge an attendance fee even if you are not transported to hospital. In Australia, Medicare does not cover ambulance service fees.

## Safe use of a wheelchair

Your occupational therapist can advise you on the right wheelchair for your needs. When getting around in a wheelchair:

- put the brakes on when you are moving to or from the wheelchair
- travel slowly down slopes
- use the foot plate as a foot rest, but do not stand on the foot plate
- if the wheelchair tyres have an inner tube
  - keep the tyres inflated - this can be done at a petrol station or by using a home compressor; correct tyre pressure is usually noted on the outside rim of the tyre
  - have a spare inner tube on hand
- if the wheelchair is battery powered, charge the battery overnight and follow the manufacturer instructions for use.

# Getting comfortable

Although the first symptom of MND for some people is leg muscle weakness, the first symptoms for others may be hand or arm muscle weakness, or a weakness of the neck muscles. These symptoms may be experienced individually or in combination.

As MND progresses, the movement and postural support provided by the muscles can be greatly reduced. Joints and ligaments can be left unsupported and unprotected.

## How can a physiotherapist help?

A physiotherapist:

- Can advise you about physical activity, mobility, movement and postural support
- Can show the people helping you to move, such as your family or carer, how they can safely assist you to move from one position to another, for example, moving from a chair to a bed

Your MND Association advisor can assist you to contact a physiotherapist in your area.

## Temperature control

People with MND may feel the cold and heat more than other people and a number of strategies may be used to help overcome this problem.

- layers of clothing
- loose fitting clothing
- thermal underwear
- mittens
- shawls
- microfibre blankets
- gloves with fingers cut out
- hand or foot massage
- place hands in a bowl of warm water
- electric blanket
- foot warmers
- fans or air conditioning

It is important that if you are unable to reposition your body yourself or if you are unable to call for a person to assist you, you choose the safest strategy for your needs. For example, there is a risk of burning your skin in a foot warmer if you cannot reposition your feet; you could get over-heated with an electric blanket if you cannot adjust the temperature; or get overly hot or cold in an air-conditioned room if you cannot adjust the temperature.

## Managing swollen ankles, feet and hands

Tips for swollen ankles, feet and hands

- Seek the advice of your doctor or physiotherapist - there may be other causes
- Raise your legs or place your hands so that they are level with your body
- Use leg support socks, stockings or gloves
- Wear shoes with adjustable Velcro fastening

## Preventing pressure sores

Pressure sores are also known as pressure injuries and bed sores. They start as inflamed red areas on the skin. They are caused by constant pressure or friction on the skin and underlying tissue.

Pressure sores can develop when you have reduced mobility because you may be sitting or lying in the same position for too long. The pressure areas are the parts of your body that make contact with a seat while you are sitting or a bed while you are lying down.

To prevent pressure sores:

- Change your position regularly - approximately every two hours or more, depending on you individual needs
- Avoid friction of the skin particularly over the pressure areas
- Check your pressure areas, looking particularly for signs of redness or skin breakdown
- Keep all areas of your skin clean and dry
- Use pressure relieving items such as sheepskins, pressure relieving cushions, mattresses and overlays

## Moving yourself from one position or place to another

Aids and equipment that can assist you or someone helping you to change your position include a monkey bar, sliding transfer bench, turntable, turning sheet, bed pole, hoist, electric recliner chair, electric bed and a reclining or tilting wheelchair.

Because patterns of muscle weakness vary from person to person, your occupational therapist can make an assessment of your situation and recommend the most suitable method of transfer, aids and items of equipment for you.

Generally, to transfer yourself from a bed or chair to standing:

- Use a chair with arms, not a deep lounge chair, and check the height of chair/bed is appropriate
- Slide to the front of chair/edge of bed and tuck your feet in under yourself. Your feet should be flat on the floor
- Place your hands on the arms of chair/bed
- Bring your head and shoulders forward in line with your knees, keeping your back straight and looking forward
- To stand, push hands downwards onto arms of the chair or bed while raising your bottom off the chair/bed. If moving to a walking frame, place one hand on the frame, then the other. Do not pull on the walking frame to get up into standing position

To transfer yourself from standing to a chair or bed:

- Place the back of your legs against the chair or bed
- Place both hands on the arms of the chair or on the bed
- Lower your bottom into chair or onto bed, using your arms for balance and to support your weight while lowering down into the chair/bed

## How someone can help you move from one position or place to another

You may need assistance to move weakened arms and legs into comfortable positions during the day, to turn in bed at night and to move (transfer) from or to a chair or bed.

There are many different techniques for safe transfers. Your neck, shoulders, arms, hands, legs and feet may all need support for repositioning or transfers. Don’t let anyone pull your arms, legs or neck to help you into a new position, it can cause shoulder, leg or neck injury.

There are also many aids and items of equipment that can be used to make transfers safer for a person with MND and the person assisting them. Because you may not be able to support your own weight, the person assisting you to reposition may need to use a transfer belt or hoist to support your weight while they are assisting you. Your physiotherapist or occupational therapist can make an assessment of your situation and recommend the best techniques for you and the person assisting you.

### General tips for transfers or moving when someone is assisting you to move

- Have an action plan:
  - make sure you both know what is going to happen before the person assisting you starts helping
  - remind the person helping you to have everything in place before they begin
- Use aids and equipment that are of the right height and design (chair, bed and toilet) to make it easier and safer for both of you
- Don’t let anyone:
  - pull on your neck, arms or legs to help you into a new position
  - use your neck as a lever to move you
- Don’t use the neck of the person assisting you as a lever to get in to the sitting position. Instead, they can place their arms around your upper back to help you into a sitting position
- Make sure the person assisting you is transferring you to a stable area - not steep or so you are unbalanced

### A person lifting you needs to:

- Use the right techniques so that you don’t get injured and they don’t get injured
- Have correct foot placement to avoid twisting their spine unnecessarily
- Stand with their feet apart in line with their hips to give them more stability when lifting you
- Keep very close to you while they are lifting you - this reduces the chances of them twisting or bending their back forward or sideways when lifting
- Bend their knees so their legs take the strain rather than their back
- Transfer weight through their legs rather than twisting and bending the spine
- Use transfer and lifting aids

## General tips for transferring or changing position with assistance

If you are unable to move very much you may become uncomfortable very quickly. You may find that you might need frequent assistance to transfer to a new position, turn or reposition.

It may take you a minute or two to receive feedback from your body about the comfort of a new position. Very subtle adjustments of your arms and legs may be necessary and the support of cushions and pillows often helps.

If someone is helping you transfer to or from a chair or bed, or into a new position, remind them to keep their back straight and bend their knees.

To transfer to a bed, with assistance:

- Sit on the bed in a spot that will allow your head to be on the pillow once you are lying down
- With assistance as needed, move into a side lying position, then lift your legs onto the bed
- With assistance as needed, roll from a side lying position onto your back

To transfer out of a bed, with assistance:

- With assistance as needed, roll to a side lying position
- With assistance as needed, move your legs over the edge of the bed until they are at a right angle to the bed
- Have the person assisting you place one hand under your shoulder that is on the bed, and their other hand on either your other shoulder or hips
- Have the person assisting you ease you up into a sitting position

To reposition yourself in bed with assistance:

- Plan what is going to happen - think ahead to avoid unnecessary movements
- Get as high up in the bed as you can manage

If the person assisting you cannot manage on their own, you may need a hoist. Make sure the person using the hoist is confident before they attempt to help you transfer. Your occupational therapist or community nurse can demonstrate safe operation of a hoist.

## Tips for a comfortable hospital, respite or residential care stay

If you need to stay in hospital or in short-term respite or residential care consider what works best at home and make that the basis for making your stay away from home more comfortable.

If you have some special care needs that must be met, ask the doctor who arranged your admission to explain these to the relevant hospital personnel. These needs could include for example, a special mattress, a special nurse call button or regular range of motion exercises and stretches.

If you are referred by your own general practitioner to the emergency department, your general practitioner is the doctor who can best advise the hospital of your particular needs. Sometimes it is also possible to ring the occupational therapist for the ward prior to admission if there is something special to be arranged.

In the event of an unplanned admission, your care needs will only be recognised slowly unless you are prepared beforehand. Have a summary of your care needs in writing in a handy place at home, ready to take with you just in case you do need an unplanned admission.

### Checklist of what to take when staying away from home

☐ Pyjamas, gown, slippers, comfortable day clothes

☐ Medicare and private health insurance fund cards

☐ Copies of care plans used at home

☐ Any aids and items of equipment that assist you with communication, eating, drinking, breathing and mobility (including if used: enteral feed pump and non-invasive ventilation unit, glasses and hearing aids). Label these with your name and phone number

☐ Medicines

☐ Power board if you have multiple items requiring power

☐ Written summary of your care needs including:

- communication needs and information about any communication devices or other strategies you use
- vision needs including whether you usually use glasses or if your vision is poor
- hearing needs and any need for a hearing aid
- memory and understanding, and whether your memory or understanding has been affected my MND
- toileting, skin care and mouth care needs
- diet and any food or fluid consistency needs
- aids needed for eating or drinking
- method for attracting the attention of nursing staff
- method of getting in and out of bed or chair
- preferences for lying in bed and usual sleep times, any special sleep or bedding needs
- medicines, dose and time of day, and how medicines are taken
- allergy information
- medical history
- personal preferences about interventions and any advance care directives

# Everyday personal care

Weakened arm, hand, leg and foot muscles can make it harder for you to undertake your day to day personal care including showering, shaving and dressing. Your occupational therapist can advise on strategies, aids and items of equipment that you may find helpful.

## If someone is helping you with your personal care

If someone is helping you with your personal care remind them to wash their hands before and after helping you.

This will reduce the risk of them passing an infection onto you.

## Showering

### Tips for showering

- Use grab rails to steady yourself
- Sit on a shower chair or shower commode for your shower
- Use soap on a rope, place soap in a stocking or use liquid soap
- Shower every other day and have a wash on the days you do not shower

### Tips for getting dry after a shower

- Make sure any areas that have skin folds or creases are dry, particularly in the groin area, under the breasts, behind the back of the knees, between toes and under the arm
- Sit on a bed to dry yourself or while someone is helping you get dry
- Have loops attached to towels so that the towel can be looped over your hand so you don't need to hold the towel to move it around your body
- Use a towelling bathrobe
- Use a smaller towel, hand towel or face washer for drying
- Use hairdryer on a cool or warm setting for drying your feet

## Eye, nose and ear care

### Tips for eye, nose and ear care

- Clean the eyes with clean damp cotton wool and gently pat dry
- Have someone help you with nose care
- Speak to your GP or community nurse about any signs of infection or redness

## Hair care

### Tips for hair care

- Use a long, angled comb or brush
- Get your hair trimmed into an easily managed style

## Mouth and teeth care

### Tips for mouth and teeth care

- Use a low foaming toothpaste
- Use an electric toothbrush
- Swab the mouth with non-alcohol water-based solutions of bicarb soda (1/2 tsp to 1 cup of water), salt (1 tsp to 1 cup of water), peppermint oil (1tsp to 1 cup water) or grapeseed oil (100%) can be an alternative to brushing the teeth. There are also commercially available mouth swabs such as Toothettes from Orthocare
- Avoid alcohol based mouthwashes and lemon and glycerine swabs as these can make the mouth dry
- Check the mouth daily for signs of caught food, oral thrush and ulcers

## Skin care

Watch out for any changes in skin condition, see *Preventing pressure sores*, page 20.

Use a moisturiser if your skin is getting dry.

### How to look after your skin when using non-invasive ventilation

- Skin breakdown may occur on the nose due to the pressure of the mask
- To minimise the risk of skin breakdown:
  - use a properly fitted mask
  - wash face with soap and water and dry well prior to putting on the mask
  - get a commercially available dressing from your local pharmacy, and place it on the bridge of your nose to protect your skin
  - use a different shaped mask for day use if using the machine during the night and day
- Contact your respiratory specialist early if skin breakdown occurs

## Nails

### Tips for nail care

- A local podiatrist may be able to do home visits to cut your toenails and fingernails
- Family and friends might like to assist with your nail care, and perhaps give you a light hand or foot massage at the same time
- Some areas have local volunteers who can assist with nail care and hand and foot massages

## Shaving

### Tips for shaving

- Sit down with equipment within reach
- Lower and angle mirrors to suit your chair height
- Use an electric razor
- Elevate and support your arm on a cushion or similar
- Secure the razor and carefully move your face against it

## Toileting

### Tips for toileting

- Wear easy to remove, loose fitting or modified clothes that make it easier for you to adjust your clothing for toileting
- Use facial tissues or flushable towelettes as toilet paper so you won’t need to separate toilet paper sheets for use
- Use a padded and/or raised toilet seat
- Use a stand alone bidet, or one attached to an existing toilet seat for washing and drying after toileting, to remove the need for toilet paper
- Use continence pads or pants
- Use a portable urinal, available for males and females. It can be helpful to practice with the portable urinal before you need to rely on it

## Menstruation

If you have arm weakness, managing menstruation may be a problem. It is possible to prevent periods or stop them altogether using specific medications. Your GP can advise you on the most suitable treatment.

## Clothing and dressing

### Tips for clothing and dressing

- Use elastic or Velcro to replace buttons, snap fasteners, zippers and side seams
- Use elastic to replace shoe laces, or wear slip on shoes
- Wear loose or easy to put on clothing including wrap-around clothing, elastic waist bands, front opening dresses and cardigans
- Use other dressing techniques such as putting trousers on while lying down
- Put clothes on the weaker side first; when undressing, take clothes off the weaker side last
- If wearing a bra, try front fastening bras, or do bra up at the front, then rotate bra around your chest
- Use a long handled shoe horn
- Use a sock/stocking gutter which is a device to assist with putting on socks/stockings

# Eating well

Commonly, people with MND do not eat enough. Symptoms such as spasticity, cramps, fasciculation and emotional lability can cause increased energy expenditure. Muscle weakness can make it harder to drink, prepare meals and eat. Not eating enough can lead to muscle loss.

Eating well, even when you may not feel like it, is important because people with MND who are dehydrated and malnourished have poorer outcomes than people with MND who are well-nourished.

Take the time to identify any difficulties you are having and to get advice about your particular needs.

## Getting advice from a dietitian, speech pathologist/therapist and occupational therapist

| A dietitian can advise about: | A speech pathologist/therapist can advise about: | An occupational therapist can advise about: |
|---|---|---|
| • How much food you need to eat to maintain your body weight<br>• How to modify food and fluids so they are easier to eat and drink. If you have weakened lip, mouth and throat muscles you may find it easier to swallow food and fluids of a particular consistency | • Swallowing difficulties including the management of saliva, coughing and sensations of choking | • Helpful utensils and aids for eating and drinking |

Your MND Association advisor can provide you with information to assist you to contact your local dietitian, speech pathologist/therapist and occupational therapist.

## Timing of meals and drinks

Tips for timing of meals and drinks

- Time meals so that eating and drinking are not hurried or pressured - if swallowing takes twice the usual time, so will a meal or a drink
- Offer the most nutritious meal when the person is not tired - it may be better to eat the main meal at lunch time rather than in the evening
- Frequent small snacks may be less tiring to swallow than larger serves at regular meal times
- Always have drinks available - small sips regularly help reduce dehydration
- Have a drink after every meal and between meals, for example, mid-morning and mid-afternoon

# Liquids

## Getting enough liquids

It is very important that you drink enough liquid every day for rehydration. Recommended fluid intake[2] is at least 2100-2600ml per day (8-10 cups) for men and women. Liquids include water, milk, other drinks, soups, yoghurt and custard. A variety of fluids help tempt the taste buds.

If you have swallowing difficulties your speech pathologist/therapist or dietitian may recommend fluids of a particular consistency. Liquid consistency[3] is usually described as Mildly, Moderately and Extremely Thick.

| Mildly Thick or Level 150 | Moderately Thick or Level 400 | Extremely Thick or Level 900 |
|---|---|---|
| • Fluid runs freely off the spoon but leaves a mild coating on the spoon. *Mildly Thick* fluids are thicker than fluids such as fruit nectars but not as thick as a thickshake | • Fluid slowly drips in dollops off the end of the spoon. *Moderately Thick* fluids are similar to the thickness of room temperature honey or a thickshake | • Fluid sits on the spoon and does not flow off it. *Extremely Thick* fluids are similar to the thickness of pudding or mousse |

## Fluids that are naturally thick

Some moderately and mildly thick fluids are available in the supermarket. These include fruit nectars, such as apricot, pear and mango nectar, and tomato juice. Various fruits and vegetables can be blended and strained. For those who can tolerate milk products, milk shakes made with ice cream provide high nutritional content as well as natural thickness.

## Fluids that can be thickened by pureed (vitamised) fruit or vegetables

Liquids can also be thickened in other ways. For example, pureed fruit can be added to fruit juice and pureed vegetables can be added to clear soups.

## Commercially available thickened fluids and thickeners

You can buy commercially available pre-thickened drinks and liquid thickeners. Liquid thickeners can be used to thicken the consistency of water and other liquids. For details of suppliers see the MND Association resource *Living with motor neurone disease: services and resources*.

### Tips for using commercial thickeners

- Follow the manufacturer's instructions for use
- When measuring ingredients remember to level off the contents of the cup or spoon
- Mix using a blender or whisk to eliminate lumps
- Allow fluid to stand for at least 10 minutes to thicken
- Store thickened fluids in the refrigerator for up to 24 hours - they will thicken more on standing

---

[2] Nutrient Reference Values, NHMRC, nrv.gov.au/nutrients/water.htm accessed 19 Dec 2011

[3] The Australian Standardized Terminology and Definitions for Texture Modified Foods and Fluids. Nutrition & Dietetics 2007; 64 (Suppl. 2): S53–S76

## To help prevent weight loss or to regain weight

To help prevent weight loss or to regain weight, follow these ideas[4]:

### Tips for preventing weight loss or to regain weight

- Eat small frequent meals and snacks
- Eat whether you feel like it or not
- Eat ‘high energy’ snacks such as fruit buns, yoghurt, custard, milky puddings, scones or pikelets (with jam and cream), crumpets, muffins
- Drink nourishing fluids, like milk, smoothies, coffee made on milk, hot chocolate, fruit juice and creamy soups; rather than water, tea or coffee
- Do not skip meals - your appetite is not usually a good guide for how much you need to eat
- Use full fat milk, yoghurt, custard and cheese; not low fat
- Use creamy sauces and dressings
- Add margarine, butter, cheese or sour cream to vegetables
- Add cream, ice cream, custard or yoghurt to fruit
- Add milk powder to milk, yoghurt, custard, desserts, soups, casseroles
- Make porridge by cooking oats with milk, not water
- Choose creamy soups, and add milk, milk powder and cream, rather than having clear soups or broth
- Spread bread, toast and savoury biscuits thickly with butter or margarine
- Cook foods in oil
- If you don't want to cook, try convenience foods, frozen meals and restaurant take-away, or arrange a home-delivered meal service or attend a day centre or luncheon group

## Preparation and presentation

### Tips for preparing and pesenting meals

- Prepare enough for three or four meals and freeze in serving sizes
- Make sure food is stored and served at the right temperature
- 'Mix and match' different combinations of meats and vegetables
- When pureeing or mincing meats, vary flavours with sauces, fruit juice, chutneys and relishes
- Maintain the presentation and appeal of food. If food is pureed, keep individual components separate

## Commercially available products for boosting energy intake

There are many commercial products designed to boost your energy intake. These include high protein drinks, glucose polymers, high energy desserts, dessert mixes. Also, special nutritional supplements are available through pharmacies. Assessment by a dietitian will provide valuable information on individual nutritional requirements. The dietitian will recommend the most suitable products for your specific needs. For more details of suppliers and brands see the MND Association resource *Living with motor neurone disease: services and resources.*

---

[4] Simple Hints for Undernutrition, Caryn Kneale, Dietitian, Ryde Aged Care and Rehabilitation Service, 2009

## When someone is assisting you to eat or drink

### Tips for when someone is assisting you to eat or drink

- Sit in an upright position
- Try to breathe comfortably through your nose and settle your breathing
- Let them know you may need several swallows to clear each mouthful
- Have a signal to let them know that your mouth is clear, so they know when to offer you more food
- Ask them to place food towards the back of the tongue
- Avoid distractions and talking - focus on chewing and swallowing
- When someone is assisting you to eat or drink for the first time provide them with written information about:
  - how you communicate
  - how you prefer to sit for eating and drinking
  - how you take medication
  - what the right consistency of food and drinks is for you
  - what foods and drinks you need to avoid
  - what special utensils are needed
  - what is involved in your mouth care
  - what to do if you have coughing
  - who to contact for more information - partner, carer, speech pathologist/therapist and general practitioner

## Recommendations from health professionals for food consistency

Your speech pathologist/therapist or dietitian may recommend foods of a particular consistency to replace your regular food consistency if you have swallowing difficulties. Recommendations[5] for food consistency in a modified diet are generally described as:

| Texture A or Soft | Texture B or Minced and Moist | Texture C or Smooth Pureed |
|---|---|---|
| • Foods may be naturally soft, such as a ripe banana, or may be cooked or cut to alter texture<br>• Foods are diced or sliced and require little, if any, cutting<br>• This includes casseroles, pasta, fish and finely chopped meat moistened with gravy or a sauce | • Foods that are naturally very soft or have been minced or mashed so that they are free from big lumps, skin, stalks or pips<br>• The food keeps its shape when put on the plate<br>• Additional sauce and gravy help in moisturising and mobilising the food | • Foods which have been pureed (vitamised or blended) so that they are smooth, moist and lump-free, but may have a grainy quality<br>• They are not runny and do not need to be chewed |

---

[5] Extract from The Australian Standardized Terminology and Definitions for Texture Modified Foods and Fluids. Nutrition & Dietetics 2007; 64 (Suppl. 2): S53–S76

### *Texture A - Soft diet recommended foods*

Texture A - Soft diet foods may be naturally soft, such as a ripe banana, or may be cooked or cut to alter texture. Foods are diced or sliced and require little, if any, cutting. This includes casseroles, pasta, fish and finely chopped meat moistened with gravy or a sauce. A soft diet is easy to chew but has more texture than a minced and moist diet.

| Texture A - Soft diet - Recommended foods[6] | | Avoid |
|---|---|---|
| Bread, cereals, rice, pasta, noodles | Soft sandwiches with very moist fillings, for example egg and mayonnaise, hummus (remove crusts and avoid breads with seeds and grains) | *Dry or crusty breads, breads with hard seeds or grains, hard pasty, pizza*<br>*Sandwiches that are not thoroughly moist*<br>*Course or hard breakfast cereals that do not moisten easily, for example toasted muesli, bran cereals*<br>*Cereals with nuts, seeds and dried fruit* |
| | Breakfast cereals well moistened with milk | |
| | Soft pasta and noodles | |
| | Rice (well cooked) | |
| | Soft pastry, for example quiche with a pastry base | |
| | Other soft, cooked grains | |
| Vegetables, legumes | Well cooked vegetables served in small pieces or soft enough to be mashed or broken up with a fork | *All raw vegetables (including chopped and shredded)*<br>*Hard, fibrous or stringy vegetables and legumes, for example sweet corn, broccoli stalks* |
| | Soft canned vegetables, for example peas | |
| | Well cooked legumes (the outer skin must be soft), for example baked beans | |
| Fruit | Fresh fruit pieces that are naturally soft, for example banana, well-ripened pawpaw | *Large/round fruit pieces that pose a choking risk, for example whole grapes, cherries*<br>*Dried fruit, seeds and fruit peel*<br>*Fibrous fruits, for example pineapple* |
| | Stewed and canned fruits in small pieces | |
| | Pureed fruit | |
| | Fruit juice | |
| Milk, yoghurt, cheese | Milk, milkshakes, smoothies | *Yoghurt with seeds, nuts, muesli or hard pieces of fruit*<br>*Hard cheeses, cheddar and hardened/crispy cooked cheese* |
| | Yoghurt (may contain soft fruit) | |
| | Soft cheeses, for example Camembert, ricotta | |
| Meat, fish, poultry, eggs, nuts, legumes | Casseroles with small pieces of tender meat | *Dry, tough, chewy, or crispy meats*<br>*Meat with gristle*<br>*Fried eggs*<br>*Hard or fibrous legumes*<br>*Pizza* |
| | Moist fish (easily broken up with the edge of a fork) | |
| | Eggs (all types except fried) | |
| | Well cooked legumes (the outer skin must be soft), for example baked beans | |
| | Soft tofu, for example small pieces, crumbled | |
| Desserts | Puddings, dairy desserts, custards, yoghurt and ice-cream (may have pieces of soft fruit) | *Dry cakes, pastry, nuts, seeds, coconut, dried fruit, pineapple* |
| | Moist cakes (extra moisture, e.g. custard may be required) | |
| | Soft fruit-based desserts without hard bases, crumbly or flaky pastry or coconut, for example apple crumble | |
| | Creamed rice, moist bread and butter pudding | |
| Other | Soup - (may contain small soft lumps, e.g. pasta) | *Soups with large pieces of meats or vegetables, corn or rice. Sticky or chewy foods, for example toffee. Popcorn, chips, biscuits, crackers, nuts, edible seeds* |
| | Soft fruit jellies or non-chewy lollies | |
| | Soft smooth chocolate | |
| | Jams and condiments without seeds or dried fruit | |

---

[6] Extract from The Australian Standardized Terminology and Definitions for Texture Modified Foods and Fluids. Nutrition & Dietetics 2007; 64 (Suppl. 2): S53–S76

### *Texture B - Minced and Moist diet recommended foods*

Texture B - Minced and Moist includes foods that are naturally very soft or have been minced or mashed so that they are free from big lumps, skin, stalks or pips. The food keeps its shape when put on the plate. Additional sauce and gravy help in moisturising and mobilising the food.

| Texture B - Minced and Moist diet - Recommended foods[7] | | Avoid (in addition to the foods to avoid listed for Texture A - Soft) |
|---|---|---|
| Bread, cereals, rice, pasta, noodles | Breakfast cereal with small moist lumps, for example porridge or wheat flake biscuits soaked in milk | *All breads, sandwiches, pastries, crackers and dry biscuits*<br>*Gelled breads that are not soaked through the entire food portion*<br>*Rice that does not hold together, for example parboiled, long-grain, basmati*<br>*Crispy or dry pasta, for example edges of a pasta bake or lasagne* |
| | Gelled bread (bread soaked in water, juice, broth or syrup with gelatine for setting) | |
| | Small, moist pieces of soft pasta, for example moist macaroni cheese (some pasta dishes may require blending or mashing) | |
| Vegetables, legumes | Tender cooked vegetables that are easily mashed with a fork | *Vegetable pieces larger than 0.5 cm or too hard to be mashed with a fork*<br>*Fibrous vegetables that require chewing, for example peas* |
| | Well cooked legumes (partially mashed or blended) | |
| Fruit | Mashed soft fresh fruits, for example banana, mango | *Fruit pieces larger than 0.5 cm*<br>*Fruit that is too hard to be mashed with a fork* |
| | Finely diced soft pieces of canned or stewed fruit | |
| | Pureed fruit | |
| | Fruit juice | |
| Milk, yoghurt, cheese | Milk, milkshakes, smoothies | *Soft cheese that is sticky or chewy, for example Camembert* |
| | Yoghurt (may have small soft fruit pieces) | |
| | Very soft cheeses with small lumps, for example cottage cheese | |
| Meat, fish, poultry, eggs, nuts, legumes | Coarsely minced, tender, meats with a sauce | *Casserole or mince dishes with hard or fibrous particles, for example peas, onion*<br>*Dry, tough, chewy, or crispy egg dishes or those that cannot be easily mashed* |
| | Casseroles dishes may be blended to reduce the particle size | |
| | Coarsely blended or mashed fish with a sauce | |
| | Very soft and moist egg dishes, for example scrambled eggs, soft quiches | |
| | Well cooked legumes (partially mashed or blended) | |
| | Soft tofu, for example small soft pieces or crumbled | |
| Desserts | Smooth puddings, dairy desserts, custards, yoghurt and ice-cream (may have small pieces of soft fruit), creamed rice | *Desserts with large, hard or fibrous fruit particles (e.g. sultanas), seeds or coconut*<br>*Bread-based puddings*<br>*Pastry and hard crumble* |
| | Soft moist sponge cake desserts with custard, cream or ice-cream, for example trifle, tiramisu | |
| | Soft fruit-based desserts without hard bases, crumbly or flaky pastry or coconut, for example apple crumble with custard | |
| Other | Soup - (may contain small soft lumps, e.g. pasta) | *Soups with large pieces of meats or vegetables, corn or rice*<br>*Lollies including fruit jellies and marshmallow* |
| | Plain biscuits dunked in hot tea or coffee and completely saturated | |
| | Salsa, sauces and dips with small soft lumps | |
| | Very soft smooth chocolate | |
| | Jams and condiments without seeds or dried fruit | |

---

[7] Extract from The Australian Standardized Terminology and Definitions for Texture Modified Foods and Fluids. Nutrition & Dietetics 2007; 64 (Suppl. 2): S53–S76

### *Texture C - Smooth Pureed diet*

Texture C - Smooth Pureed are foods which have been pureed or vitamised using a blender, hand held food processor, sieve or hand mincer. Care needs to be taken to ensure a single, smooth, non-lumpy consistency) so that the food is smooth, moist and lump-free, but may have a grainy quality. They are not runny and do not need to be chewed.

| Texture C - Smooth Pureed diet - Recommended foods[8] | | Avoid (in addition to the foods to avoid listed for Texture A and B) |
|---|---|---|
| Bread, cereals, rice, pasta, noodles | Smooth lump-free breakfast cereals, for example semolina, pureed porridge | *Cereals with course lumps or fibrous particles, for example all dry cereals, porridge*<br>*Gelled breads that are not soaked through the entire food portion* |
| | Gelled bread (bread soaked in water, juice, broth or syrup with gelatine for setting) | |
| | Pureed pasta or noodles | |
| | Pureed rice | |
| Vegetables, legumes | Pureed vegetables | *Coarsely mashed vegetables*<br>*Particles of vegetable fibre or hard skin* |
| | Mashed potato | |
| | Pureed legumes, for example baked beans (ensuring no husks in final puree) | |
| | Vegetable soups that have been blended or strained to remove lumps | |
| Fruit | Pureed fruits, for example commercial pureed fruits, vitamised fresh fruits | *Pureed fruit with visible lumps* |
| | Well mashed banana | |
| | Fruit juice without pulp | |
| Milk, yoghurt, cheese | Milk, milkshakes, smoothies | *All solid and semi-solid cheese including cottage cheese* |
| | Yoghurt (lump-free), for example plain or vanilla | |
| | Smooth cheese pastes, for example smooth ricotta | |
| | Cheese and milk-based sauces | |
| Meat, fish, poultry, eggs, nuts, legumes | Pureed meat/fish (pureed with sauce/gravy to achieve a thick moist texture) | *Minced or partially pureed meats*<br>*Sticky or very cohesive foods, for example peanut butter*<br>*Scrambled eggs that have not been pureed* |
| | Souffles and mousses, for example salmon mousse | |
| | Pureed legumes, hummus | |
| | Soft silken tofu | |
| | Pureed scrambled eggs | |
| Desserts | Smooth puddings, dairy desserts, custards, yoghurt and ice-cream | *Desserts with fruit pieces, seeds, nuts, crumble, pastry or non-pureed garnishes*<br>*Gelled cakes or cake slurries that are not soaked through the entire food portion* |
| | Gelled cakes or cake slurry, for example fine sponge cake saturated with jelly | |
| | Soft meringue | |
| | Cream, syrup dessert toppings | |
| Other | Soup - vitamised or strained to remove lumps | *Soup with lumps*<br>*Jams and condiments with seeds, pulps or lumps* |
| | Smooth jams, condiments and sauces | |

---

[8] Extract from The Australian Standardized Terminology and Definitions for Texture Modified Foods and Fluids. Nutrition & Dietetics 2007; 64 (Suppl. 2): S53–S76

## Example meal plans

### *Texture A - Soft diet example*

- **Breakfast**
  - Weetbix with stewed apple
  - fortified milk*
  - soft boiled egg
  - bread with butter and honey
- **Midmorning**
  - fruit yoghurt
- **Lunch**
  - salmon and avocado sandwich
  - yoghurt
- **Afternoon**
  - fruit smoothie
- **Dinner**
  - beef and vegetable casserole
  - mashed potato and steamed pumpkin
  - zucchini
  - ice cream
- **Supper**
  - hot chocolate
  - sponge cake

### *Texture B - Minced and moist diet example*

Note: Some of the foods and fluids mentioned may need thickening to the appropriate liquid consistency

- **Breakfast**
  - Weetbix with stewed apple
  - fortified milk*
  - soft boiled egg
- **Midmorning**
  - canned peaches with yoghurt
- **Lunch**
  - minestrone soup (well cooked)
  - ripe banana and cream
- **Afternoon**
  - fruit smoothie
- **Dinner**
  - savoury beef mince
  - mashed potato
  - mashed pumpkin
  - boiled diced zucchini
  - ice cream
- **Supper**
  - hot Milo made with fortified milk*

### *Texture C - Smooth pureed diet example*

- **Breakfast**
  - fruit juice
  - pureed rolled oats and unprocessed bran
  - fortified milk*
  - pureed scrambled egg
- **Midmorning**
  - pureed apple with yoghurt
- **Lunch**
  - pureed minestrone soup
  - pureed banana with cream
- **Afternoon**
  - fruit smoothie
- **Dinner**
  - pureed beef casserole
  - mashed potato
  - mashed pumpkin
  - Ice cream
- **Supper**
  - hot Milo made with fortified milk*

### *Texture C - Smooth pureed diet with thickened fluids example*

- **Breakfast**
  - thickened fruit juice
  - pureed rolled oats with skim milk powder and unprocessed bran
  - thickened milk
  - scrambled egg
- **Midmorning**
  - pureed apple with yoghurt
- **Lunch**
  - thick pureed minestrone soup
  - pureed banana with cream
- **Afternoon**
  - thickened fruit smoothie
- **Dinner**
  - pureed beef casserole
  - mashed potato
  - mashed pumpkin
  - baked custard
- **Supper**
  - thickened hot Milo made with fortified milk*

*To make fortified milk, add 1 tablespoon skim milk powder to 200 ml milk

## Foods available in supermarkets that may be suitable for a texture-modified diet

**Supermarket foods that may be suitable for a texture-modified diet**

- Dips and spreads
- Soft cheese
- Soups
  - creamed soups can be thickened using mashed potato, corn flour or thickening agent
- Sauces, condiments and dressings
  - pre-prepared sauces and dressings can add moisture and often energy to foods
- Cream, thickened cream, coconut cream, evaporated milk and full cream milk powder can provide extra moisture and energy to dishes
- Savoury foods
- Canned vegetables, tuna, skinless and boneless salmon, tomato puree, instant mashed potato
- Desserts
- Mousse, creme caramel and yoghurt
- Fruit
- Pureed fruit snacks
- Cereals
- Rice and other smooth high protein cereals
- Milk powder, cream and sugar can be added to cereal for extra energy

## Foods and fluids requiring special consideration for people with swallowing difficulties

The following foods and fluids require special consideration[9]

- Bread requires an ability to both bite and chew. Chewing stress required for bread is similar to that of raw apple. The muscle activity required for each chew of bread is similar to that required to chew peanuts. For this reason, individuals who fatigue easily may find bread difficult to chew. Bread requires moistening with saliva for effective mastication. Bread does not dissolve when wet; it clumps. It poses a choking risk if it adheres to the roof of the mouth, pockets in the cheeks or if swallowed in a large clump. This is similar to the noted choking effect of 'chunks' of peanut butter.
- Ice-cream is often excluded on diets for individuals who require thickened fluids. This is because ice-cream melts and becomes like a thin liquid at room temperature or within the oral cavity.
- Jelly may be excluded from diets for individuals who require thickened fluids. This is because jelly separates into particles in the mouth if not swallowed promptly.
- 'Mixed' or 'dual' consistencies are difficult for people with poor oral control to safely contain and manipulate within the mouth. These are consistencies where there is a solid as well as a liquid present in the same mouthful. Examples include individual cereal pieces in milk (e.g. cornflakes in milk), fruit punch, minestrone soup, commercial diced fruit in juice, watermelon.

---

[9] The Australian Standardized Terminology and Definitions for Texture Modified Foods and Fluids. Nutrition & Dietetics 2007; 64 (Suppl. 2): S53–S76

- Individuals who require thickened fluids will require their soups thickened to the same consistency as their fluids unless otherwise advised by a speech pathologist/therapist.
- Special occasion foods or fluids (e.g. chocolates, birthday cake) should be well planned to ensure that they are appropriate for individuals requiring texture-modified foods and/or thickened fluids.
- Nutritional supplements may require thickening for individuals who require thickened fluids.
- Medication - Individuals on Texture C - Smooth Pureed diet are unsuitable for oral administration of whole tablets or capsules. Consult with medical and pharmaceutical staff. Individuals requiring any form of texture-modified food or fluids may have difficulty swallowing medications. Seek advice if in doubt.

## Recipes

For recipes see the MND Association booklet *Recipes for people with swallowing difficulties.*

# Communication

## Communication and MND

A person with MND who has weak speech and breathing muscles may have a soft or weak voice, or a complete loss of speech.

A person with MND who has reduced movement in the body, arms or hands may find it difficult to operate a phone, tablet or computer.

Augmentative and alternative communication (AAC) systems are solutions that can be put in place to assist your communication. AAC solutions are often very simple and can be used by you to:

- support or replace your speech
- assist you to use a phone, tablet or computer.

## Regular review of communication needs

All people with MND need regular review of their communication needs.

In addition, get immediate advice about your communication needs if:

- your speech slows or slurs and is reduced to 125 words per minute
- weak body, arm or hand muscles are changing the way you would usually use a phone, tablet or computer
- speech difficulties or weak body, arm or hand muscles are causing you to reduce the time you usually would spend on a phone, tablet or computer.

### Who provides a communication needs review and advice?

**Speech pathologist/therapist**

- early assessment

**Occupational therapist**

- seating and positioning
- wrist supports
- switches, pointers
- mobile arm supports and tables

**Speech pathologist/therapist, occupational therapist**

- communication aids
- using a phone, tablet or computer
- environmental control units

If you don’t have a local speech pathologist/therapist or occupational therapist, talk to your general practitioner, neurologist or MND Association advisor about how you can access speech pathology and occupational therapy services.

## Communication tips

If MND is affecting your speech it is easier for you to communicate with someone if they are willing to learn about the strategies, aids and equipment you use for communication.

### Others can communicate with you more effectively by:

- Being at eye level and making eye contact
- Avoiding distractions from others, a television set or radio
- Being a good listener
- Asking closed questions – those that can have a yes or no answer
- Asking just one question at a time
- Waiting for you to finish what you are saying, and not jumping in to finish your words and sentences
- Watching facial expressions for cues
- Speaking in their usual voice

### You can help the situation by:

- Sitting up straight to help with your breathing, which is the 'fuel' for voice and speech
- Timing your breathing with speech, for example:
  - taking a deep breath before speaking
  - taking frequent 'top-up' breaths while speaking
  - limiting the number of words or syllables spoken per breath
- Planning conversations for when you are less tired
- Trying to be patient if people don’t understand and then:
  - speaking more slowly
  - saying fewer or just one word at a time
  - saying the most important word in the message to give the listener the context of the statement
  - saying the first letter of the most important word
- Using a communication aid, if you have one, to get your message across

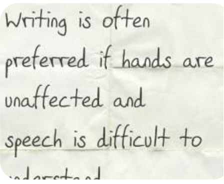
### Barriers to effective communication for a person with MND and those they are trying to communicate with include:

- Feeling rushed or preoccupied
- Tiredness
- Embarrassment, or fear of being unable to understand or be understood
- Not letting someone know if you have not understood what they are communicating

## Strategies often suggested

### Explore low technology communication aids

Low technology communication aids include writing, flip-books, charts, boards and eye movements.



Writing is often
preferred if hands are
unaffected and
speech is difficult to

Writing is often preferred if hands are unaffected and speech is difficult to understand. Magna Doodle, white boards and note books can be used.

I have lost my
voice, but I can
hear and
understand you.

Several cards in a small flip wallet can be used for name, contact details, a short explanation of the communication difficulty and other frequently used phrases.

Communication charts and books can be made up according to each person's need. These may include phrase, letter and picture charts. They can also be created in dual languages. Sample communication charts are usually available from a speech pathologist/therapist, the MND Association and online.

See-through boards, such as the ETRAN board, can be used with eye movements to point to letters or words. The board is positioned between the user and the person they are communicating with.

An agreed set of eye movements can also be used for simple communication. For example one blink or raising the eyebrows for 'yes' and two quick blinks or closing the eyes for 'no'.

Signing with the hands to replace speech is not usually an effective communication strategy for most people with MND. This is because shoulder, arm and hand muscles may also be deteriorating, or may start deteriorating once the technique is established, resulting in additional communication issues as the disease progresses.

## Find out about battery operated communication aids

Small portable battery operated communication aids are commonly used by people living with MND.

A voice amplifier includes a small microphone and speaker with adjustable volume. Is it useful if speech is very soft or if speaking loudly causes breathlessness.

The MessageMate stores and plays pre-recorded messages. It can be activated by touch or switch scanning*. Recordings can be made by the individual or a family member. It can be used as a language interpreting tool if set up with specific words/icons in one language and pre-recorded messages in a different language.

The Lightwriter outputs typed words and sentences as spoken words and/or text on two small screens positioned on the front and back of the device. It is not a computer. It is a text to speech device.

Portable devices such as the iPad and Android tablet computers can be used with specific apps that display or output spoken words from digital keyboards or communication charts. Commonly used communication apps include Verbally, SpeakIt, Proloquo2go (pictured) and Predictable. Some of these apps can be used with switch scanning* if the person's hand function also deteriorates.

A laser head pointer, which is a laser light that can be fixed to a headband or cap, can be used with communication charts when mobilty and hand functions are very weak, but head support and head movement is good. The laser light beam is directed by head movement to letters, words or phrases on a chart. It is used with a switch* for the user to turn the light on or off.

*See *Use switches that only need very small movements*, page 42.

## Use accessibility settings on devices you may already have

Mobile phones, tablet computers, laptops and desktop computers often have standard features that include accessibility settings and ease of access settings. Many have features so that the device can be used without touch, a mouse or keyboard.

## Try out modified mouses

Use of a standard computer mouse requires shoulder, arm, hand and finger dexterity and smooth movement. A modified mouse can be used to replace a standard computer mouse. Mouses described below use a USB connection, but may also be available in wireless styles.

Point-it! is a joystick USB mouse for a Windows computer. Knobs for the joystick aid comfort during use and include carrot, sponge ball and T bar styles. It can also be used with a switch* to select the left or right mouse click.

The switch adapted mouse is useful for people who can move a mouse but are not able to click the left or right mouse buttons. It is a standard USB mouse for a Windows computer with a socket that can be used to connect a switch* to select the left or right mouse click with one or more switches.

The SmartCat/EasyCat touch pad USB mouse for a Windows computer is much the same as a laptop mouse pad, minimising movement of the arm and hand for access to the computer. It has built-in left and right click buttons. The user taps, scrolls or moves across the touch pad with their fingers to move the cursor.

The Track Ball USB mouse for a Windows computer is available in various styles and designed for the user to move the ball with any part of the body, including the foot and toes. It has built-in left and right click buttons and can also be used with a switch* to select the left or right mouse click.

The Mini Track Ball USB mouse for a Windows computer is designed to be held in one hand while the user moves the ball with their thumb. It has built-in left and right click buttons.

The SmartNav USB mouse replacement for Windows or Mac computer includes an infrared camera and specialised reflective adhesive dots. One of the dots is placed on the user (usually on a cap worn by the user or the bridge of a pair of glasses). The infrared camera tracks the movement of the dot for computer cursor movement and operation of the onscreen keyboard.

*See *Use switches that only need very small movements*, page 42.

## Use switches that only need very small movements

Switches are often used by people who have reduced movement and/or communication difficulties. This is because they only require very small movements of the hand, finger, foot, elbow or chin to be activated. A person uses the switch to turn a device on or off, or to send a command such as a mouse click. Switches connect to switch compatible devices either directly through a 3.5mm switch input jack or indirectly through a switch interface. For more information on switch interfaces see *Try out some switch interfaces*, page 43.

The following switches all connect through a 3.5mm switch input jack or a switch interface.

The Click switch is designed to be used with light finger control. The finger can be resting on top of the switch, until the user pushes it down to activate the switch. The force of the push needed can be adjusted.

The Cushion/Pillow switch is a soft switch particularly suitable for head or cheek activation. The switch is activated by pressing the top foam surface. The soft material allows it to be attached to a wheelchair or pillow and is removable and machine washable.

The Jelly Bean switch is the most commonly used switch and it is activated by pressing the surface. It has mounting sockets which allow for easy attachment to mounting systems for positioning the switch near where the person can activate it.

The Magic Wand switch is activated by the very smallest body movement and contact with bare skin. It is usually positioned near the head or hand, with the face or finger used to activate it with the slightest touch.

The Micro Light switch requires very little pressure, as little as 10g, to activate the switch. It is usually positioned near the user's finger.

The Papoo switch is a hands-free movement activated switch. This device detects movement, such as a wave of a hand or finger over the sensor, up to 1cm away and registers this as activation.

The Self Calibrating Auditory Tone Infrared (SCATIR) switch is activated by the smallest of movements of the face or hand. The infrared light detects movement to activate the switch.

The Spec switch is similar to the Jelly Bean switch except much smaller, approximately the size of an Australian 10 cent piece. It is a pressure activated switch which can be easily mounted on a variety of systems.

The String switch is activated by a slight pull on a length of string attached to the switch. The string does not need to be grasped. It can be attached, with care, to the wrist, finger or any other site.

## Try out some switch interfaces

Not all communication devices, including some tablet computers, have an input socket suitable for 3.5mm switch jack.

A Bluetooth switch interface can be used to connect a switch to a device that has Bluetooth capability but does not have an input socket suitable for 3.5mm switch jack. The 3.5mm switch jack can be plugged into the switch interface, which uses a wireless Bluetooth connection to the communication device, enabling the switch and the communication device to work together.

The APPlicator (previously known as Switch4Apps) Bluetooth switch interface.

The Therapy box (T Box) Bluetooth switch interface.

## Explore mounting systems for communication devices

Mounting systems are used to temporarily or permanently position a communication device for use. Features include:

- how the mounting system is attached to a table, chair, wheelchair or bed
- how the device is attached to the mounting system and the length, breadth and weight of devices that can be attached
- how easy it is to position the device for user comfort and reach once the device is mounted
- how easy it is to move or remove the mounting system when the device is not in use.

The Latitude switch mount can be used to mount a switch to various surfaces including a wheelchair, table, bench and bed.

The RAM Ez Roll'r mounting system provides suction mounting for an iPad on suitable surfaces including a table, bench and bed.

The Universal switch mount is an adjustable mounting system for a switch. The base of the mount can either be free standing or attached by clamp.

## Think about being comfortable while using your devices

The Ergo Rest is a movable forearm support designed to provide support for the arm. The user can rest their arm in the support while using a device or switch.

## Call devices

A person can use a call device to let someone, who is within hearing distance of the activated device, know they need an item or assistance. Call devices range from a hand bell through to switches connected to switch adapted door chimes, intercom systems or pressure buzzers. An occupational therapist can help you find the best means of operating a call device.

The switch adapted door chime is in two parts: the switch part and the chime part. The switch part remains with the person needing assistance and they press the switch when they need assistance. The chime part is positioned near the person responding to the chime. When the switch is pressed by the person needing assistance, the other person will hear the chime and know that assistance is needed.

## Care alerters

Care alert systems differ from call devices. A care alert system is used to notify a person who is not within hearing distance or in the immediate area. The person needing assistance usually wears a special pendant or bracelet that has a button that can be pushed to activate the call for assistance.  Care alert systems are provided by commercial providers. For more information on providers see the MND Association resource *Living with motor neurone disease: services and resources*.

## Environmental control units

Environmental control units (ECUs) are common in everyday life. Most people are familiar with ECUs that operate a specific device, for example a 'TV remote', used to adjust TV volume, change the channel and turn a TV on and off. Other types of common ECUs include remote controllers used with a DVD player, air-conditioner, electric fan, lights and roller blinds.

Programmable ECUs allow a user to operate multiple appliances or systems from the one device.

A GEWA Prog is hand-held environmental control unit which can be used to control a variety of devices including TV, DVD, stereo or other infrared controlled device. It is designed to assist people restricted to a wheelchair or a bed, or who have difficulties operating switches or buttons.

The HouseMate Lite is an environmental control unit designed to aid people with limited mobility and speech. The user can record up to 20 infrared commands from other remote controls. Long sentences for playback command for voice activated systems can also be recorded.

# Living independently at home

Maintaining your independence at home is possible with the assistance of family, friends and your local health and community care services.

> *"You need to be prepared to consider any help that is offered. This doesn't mean accepting all offers, just being open to what is available. Many people and services would ask 'What do you need?'.*
>
> *When you have never been in a situation you don't always know the possible solutions. You also need to be open as a family to each other's needs, opinions and strengths.*
>
> *Our two most important contacts were our MND advisor from the Motor Neurone Disease Association and our Case Manager. Mum and Dad qualified for government assistance with home help. Our initial contact was through the hospital social worker but the alternate route would have been through the local community centre."*
>
> Julie, adult daughter of Bill

## MND and health and community care services

Services commonly needed by people living with MND

- Medical review and symptom management
- Information about MND and available support options
- Individualised advice about mobility, communication and eating well
- Assistance with personal care, cleaning, meal preparation, gardening and transport
- Timely access to aids and equipment
- Emotional support, counselling
- Respite care
- Palliative care

Your MND Association advisor can assist you, your family and friends by:

- Providing information about MND
- Supporting and maintaining contact through home visits, telephone and email
- Assisting you to identify what services you need now or may need in the future
- Providing referral and assistance for timely access to health and community services
- Assisting with access to other MND Association Support Service programs - equipment, support groups, carer education, information sessions and volunteer assistance where available
- Providing information about, and liaising with, MND multidisciplinary clinics and services
- Advocating on your behalf

## Getting your needs and issues dealt with

Not all people with MND will have the same needs. When your extended family, friends and service providers offer assistance, think about the tasks that you and your family spend a lot of time or energy on that you would choose not to do, freeing up your time and energy for enjoyable time and activities with each other.

The *MND Association Support and needs checklist* is a tool you can use to think about the support you currently have, your needs, and the actions that would support you to continue to remain as independent as possible.

### Support and needs checklist

What support do I currently have?

☐ Family
☐ Friends
☐ GP
☐ Neurologist
☐ MND Association information, MND Association advisor, coordination of support, equipment, education and support programs (support group, workshops etc)
☐ Help at home (domestic, home maintenance)
☐ Personal care
☐ Other ________________________________________

What is it that is important for me to maintain?

☐ Living arrangements
☐ Family relationships and activities
☐ Friends and activities
☐ Independence - mobility
☐ Communication - speech, email, phone, text
☐ Interests and hobbies, access to the community
☐ Other________________________________________

What are the symptoms of MND that impact on my daily life?

☐ Muscle weakness causing changes to mobility and independence
☐ Difficulty with speech, swallowing, saliva
☐ Difficulty using a phone, email, tablet, computer
☐ Fatigue, changes to sleeping patterns
☐ Shortness of breath
☐ Difficulty in controlling emotions such as crying and laughing
☐ Other ________________________________________

What tasks do I have difficulty with because of the symptoms of MND?

☐ Walking, climbing stairs
☐ Talking
☐ Showering, dressing, other personal care activities and toileting
☐ Sleeping
☐ Cleaning and laundry – hanging clothes on the clothes line

***(cont'd over)***

## Support and needs checklist

☐ Shopping, food preparation and eating
☐ Writing, using a keyboard, mouse or tablet
☐ Using the telephone or mobile phone
☐ Accessing outdoors
☐ Driving
☐ Gardening
☐ Participating in social activities with family and friends
☐ Other ______________________________________

### What actions would support me to continue to remain as independent as possible?

☐ Someone to assist me to plan for my future who knows about MND
☐ Information about MND and support options that is individualised for me and my family
☐ Someone to talk to about MND and adjusting to possible changes in my lifestyle
☐ Assessment by an occupational therapist to recommend equipment and modifications to my home that will help me remain as independent as possible and ensure safety of myself and my carers
☐ Assessment by a physiotherapist to ensure safety in my mobility
☐ Speech therapy assessment to recommend communication aids and assistance with swallowing and saliva management
☐ Assessment and advice about staying connected by email, phone, text, tablet and computer
☐ Training and support for my service providers so they understand MND and help me better
☐ Support for my partner and children
☐ Access to training and support activities for me and my family to help us live better with MND
☐ Social support to give me, my partner and family a rest
☐ Assistance with tasks around the home such as cooking, cleaning, washing
☐ Assistance with personal care
☐ Assistance to access the community – transport, support person
☐ Modifications to home – ramp access or bathroom modified etc
☐ Equipment – bathroom aids, manual wheelchair, power wheelchair, walking frame, hoist, bed, seating
☐ Other ______________________________________

When service providers agree to take some action for you, or on your behalf, keep an action list so you can refer back to it if you need to follow anyone up.

Figure 1 Sample action list

| Issue | Who | By when | Notes |
|---|---|---|---|
| | | | |
| | | | |

## Getting through the 'paperwork' and understanding services

> *"Every service requires you to complete forms. It would be wonderful if they could all link up but it doesn't happen. Be patient, have your basic information ready when you make phone calls."*
>
> Julie, adult daughter of Bill

All health and community care services have differences ranging from the type of service provided and where the service is provided through to whether you are eligible for the service, how you apply for the service, how long from when you apply to when the service can start and whether you need to pay for the service.

The *Checklist for people living with MND accessing health and community care services* (below) describes many features of health and community care services. You can use the topics covered in the Checklist as a guide for your questions when someone mentions a service to you or when you are speaking with a new service.

### Checklist for people accessing health and community care services

What is the type of service?

☐ Medical review and symptom management
☐ MND progression review
☐ Individualised information about MND and available support options
☐ Advice about mobility, communication, eating well
☐ Assistance with personal care, cleaning, meals, washing, gardening, transport
☐ Timely access to aids and equipment
☐ Care coordination
☐ Emotional support, counselling
☐ Respite care
☐ Palliative care

Who provides the service?

☐ Private, commercial
☐ Non-government, not for profit
☐ Public

Where is the service provided?

☐ Home
☐ Local community health centre
☐ Public clinic
☐ Acute care hospital
☐ Private clinic

Are you eligible to get the service?

☐ Age criteria, for example, under 65
☐ Locality criteria, for example, local council or health area
☐ Income and assets criteria
☐ Urgent need criteria
☐ Because you do or don't get access to a different health and community care service, funding package or scheme

***(cont'd over)***

## Checklist for people accessing health and community care services

### How do you get access to the service?

☐ Referral from doctor
☐ Referral from other health professional
☐ Referral from an organization, for example, MND NSW
☐ Self refer

### Who do you contact to get access to the service?

☐ Register online or by phone
☐ Register in person
☐ Register in writing by completing a form
☐ Registered by a third party, for example, a family member or a service provider
☐ No registration needed, just turn up

### How long does it take to get access to the service?

☐ Time from your first call or referral to the service accepting or declining you
☐ Wait list time once the service accepts your referral
☐ Partial acceptance, for example, 4 hours home care approved, but 8 hours needed

### How long do you get the service?

☐ Permanently or until you no longer need it
☐ Until a particular date, when your access is reviewed
☐ Until a particular date, when you need to reapply

### Do you pay for the service, and if you do, how and when you pay for it?

☐ Free
☐ Medicare full bulk bill or partial
☐ Private health insurance
☐ National Disability Insurance Scheme
☐ My Aged Care Home Support Programme or Home Care Package
☐ Co payment or full payment
☐ Flat rate or as a percentage of a pension or other income

### Does accessing a particular service affect your eligibility to access a different service?

### Who do you contact once you are using the service to talk about service-related day-to-day matters?

☐ Central website or phone number
☐ Local contact
☐ Contact number for after hours if necessary

### Who can talk to the service about you?

☐ Just you
☐ People you have provided the service with consent to speak with, for example, your partner, family member, other services

> *“Many services can only be accessed by the Responsible Person, usually the Carer which was Mum. It is often possible to have the Responsible Person nominate one or more others to talk with the service on their behalf once the initial contact or registration has been made. This meant my brothers or I could make phone calls on Mum’s behalf but you do need to ask about this and do so at the initial contact.”*
>
> Julie, adult daughter of Bill

## Making appointments and amalgamating service visits

Make appointments for the time of the day you usually have the most energy. If you are travelling to your appointment, plan your trip and allow enough time so you do not arrive rushed.

> *“If you are using a wheelchair, when you make appointments make sure you state clearly that you are in a manual or electric wheelchair. Access for both need ramps but the electric wheelchair also needs wider doors.*
>
> *If you are non-ambulatory you need to highlight that a hoist may be needed to move you from the wheelchair. Some medical tests require you to lie down which is a problem if you can’t transfer out of the wheelchair without a hoist.*
>
> *Also be aware of the difficulty of eye tests at the optometrist if you can’t reach the testing equipment (those that require you to put your chin on the machine). Dad didn’t need a dentist after he was in the wheelchair but I imagine that would be another difficulty. You do need to highlight the situation every time you make an appointment as it isn’t always remembered.*
>
> *Some services were very willing to come to the house but some others needed to have the situation explained (our case manager was very skilled at this) or we needed to find an alternate provider. Make the appointment for the home visit at a time that suits you, for example, after your shower or not during a meal time. If your service provider is coming to your home, encourage them to contact your other service providers beforehand so that visits can be conducted jointly. For example, your speech pathologist and your occupational therapist; or your home cleaning service and your physiotherapist.”*
>
> Julie, adult daughter of Bill

## Getting your issues dealt with

### Tips for getting your issues dealt with

- Ask questions if you are unsure
  - about the service the person is from
  - what the service provides
- Keep asking questions until you understand what is being said
- Bring your list of issues
- Make a list of questions for this visit and bring the list with you
- Take notes, have someone with you or ask the service provider to make notes and send them to you
- If the service provider is visiting you at home you do not need to ‘entertain’ them

## When your extended family, friends or neighbours want to help

It is not uncommon for people with MND to get offers of help from extended family, friends and neighbours; or for school communities, sporting clubs or other community groups that know the person with MND to contact them or their family wondering what they can do to 'help'.

It can be hard accepting offers of help. Sometimes people hesitate accepting an offer of help because they feel like they are asking too much, or that what they might need will be an imposition on the person making the offer. Others may feel they want to keep their MND 'private' and not have others in their house, or that they don't want to feel like they might 'owe' a person.

However, when you accept an offer of help from your extended family, friends or neighbours, you are providing them with the opportunity to 'do something' to show their care and concern for you and your family. You are also providing them with a familiar way to stay in touch with you and your family because you are probably not getting out and about as much as you might have previously.

Saying 'yes' to offers of help from extended family, friends or neighbours can free up your close family from tiring daily tasks. This can allow your family to get some time and rest for themselves, and/or spend more time doing enjoyable things with you.

### Getting organised

Think about "What are the things that would really help us at the moment?"

Some people make a list and keep it on the fridge. Others might have a list they keep online and update regularly.

**People might prefer to assist with jobs outside the house such as:**

- Gardening
- Taking the rubbish out
- Walking the dog
- Shopping
- Getting your children to events, or taking them out for recreational activities
- Pre-preparing meals

**Or inside jobs such as:**

- Folding the washing
- Reading aloud
- Watching a television show with you while your other family members go out
- Just 'being around' in a non-intrusive way

In fact one of the tasks you might be able to delegate to a person offering to help is for that person to help make a specific list with you and to coordinate the offers against what needs to be done. Then, when people offer to help they have a person to speak with and a list to choose from.

By providing the means by which people can 'choose' what they might do, you are enabling the person making the offer to stay within what is comfortable for them to do. For example, some people might prefer a very physical task, like mowing the grass once a fortnight, whereas others might prefer something inside, such as folding the washing, or providing a meal once a week.

### When you might need help but your extended family and friends live far away and you don't know your neighbours

Local community groups, service clubs and church communities are often very welcoming to newcomers. Contact them to find out what programs they have that may be of assistance to you. Your MND Association advisor may also be able to put you in touch with others who can offer practical help.

> *"With assistance, Dad participated with his target shooting club and took trips out and about. Friends and family visited for teas and lunches, and grandchildren now treasure the time and conversations they had with him. We all spent more time with our parents than we would have in other circumstances and learnt much about our parents' great strengths, love and sense of humour. Dad delighted in taking silly photos with my youngest brother to post on Facebook. It took a lot of teamwork from many people to grant Dad his wish to stay at home. We learnt so much along this journey we hope that by sharing our experiences we can assist other families in achieving their desired outcome too."*
>
> Julie, adult daughter of Bill

## Keeping track of services, contacts and day-to-day care

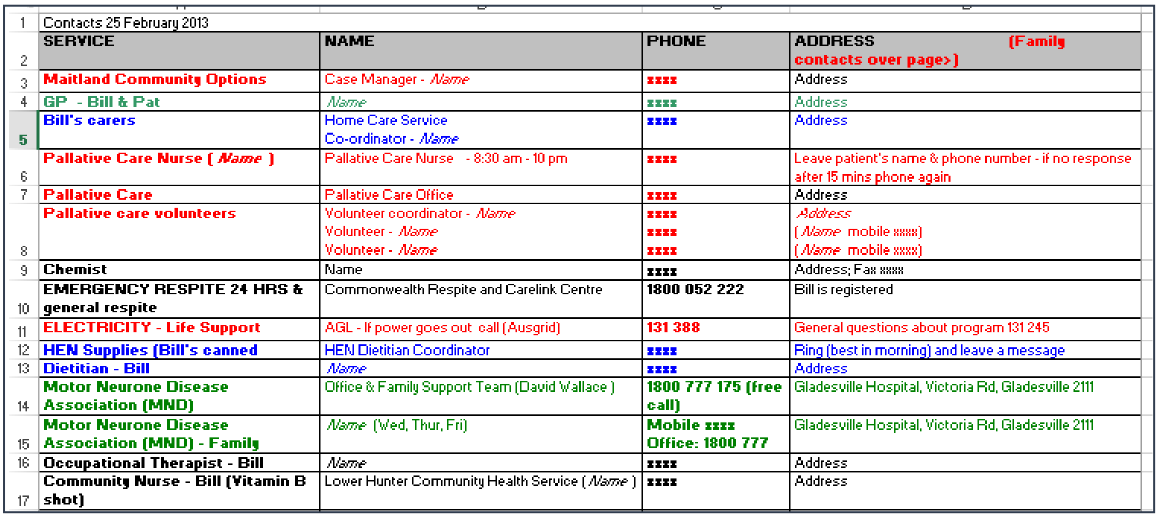
It can be helpful for you to develop your own way of keeping track of services, contacts and day-to-day care because of the range of services you may be in touch with.

> *"Dad and Mum have been amazing through all this; adapting to the constant flow of people through the house, the many names and titles, the multitude of new concepts and equipment that they acquired. I made a table of all of Mum and Dad's contacts and services (name, organisation, phone number and address) including family members. I updated these regularly and made multiple copies to provide to medical specialists and services which saved a great deal of time at appointments. We also taped a copy to the kitchen bench near the phone for our easy reference and each of the siblings carried a copy."*
>
> Julie, adult daughter of Bill

### Using word processing programs

Word processing programs can be used to create simple lists of contacts and appointments.

Figure 2 Sample contacts list used by Julie and her family



| | | | | |
|---|---|---|---|---|
| 1 | Contacts 25 February 2013 | | | |
| 2 | **SERVICE** | **NAME** | **PHONE** | **ADDRESS** **(Family contacts over page>)** |
| 3 | **Maitland Community Options** | Case Manager - *Name* | xxxx | Address |
| 4 | **GP - Bill & Pat** | *Name* | xxxx | Address |
| 5 | **Bill's carers** | Home Care Service<br>Co-ordinator - *Name* | xxxx | Address |
| 6 | **Pallative Care Nurse ( *Name* )** | Pallative Care Nurse - 8:30 am - 10 pm | xxxx | Leave patient's name & phone number - if no response after 15 mins phone again |
| 7 | **Pallative Care** | Pallative Care Office | xxxx | Address |
| 8 | **Pallative care volunteers** | Volunteer coordinator - *Name*<br>Volunteer - *Name*<br>Volunteer - *Name* | xxxx<br>xxxx<br>xxxx | *Address*<br>( *Name* mobile xxxx)<br>( *Name* mobile xxxx) |
| 9 | **Chemist** | Name | xxxx | Address; Fax xxxx |
| 10 | **EMERGENCY RESPITE 24 HRS & general respite** | Commonwealth Respite and Carelink Centre | **1800 052 222** | Bill is registered |
| 11 | **ELECTRICITY - Life Support** | AGL - If power goes out call (Ausgrid) | **131 388** | General questions about program 131 245 |
| 12 | **HEN Supplies (Bill's canned** | HEN Dietitian Coordinator | xxxx | Ring (best in morning) and leave a message |
| 13 | **Dietitian - Bill** | *Name* | xxxx | Address |
| 14 | **Motor Neurone Disease Association (MND)** | Office & Family Support Team (David Wallace ) | **1800 777 175 (free call)** | Gladesville Hospital, Victoria Rd, Gladesville 2111 |
| 15 | **Motor Neurone Disease Association (MND) - Family** | *Name* (Wed, Thur, Fri) | **Mobile xxxx**<br>**Office: 1800 777** | Gladesville Hospital, Victoria Rd, Gladesville 2111 |
| 16 | **Occupational Therapist - Bill** | *Name* | xxxx | Address |
| 17 | **Community Nurse - Bill (Vitamin B shot)** | Lower Hunter Community Health Service ( *Name* ) | xxxx | Address |

You can also use word processing programs to develop your own specific care plans and guides.

## Using photos and video

Take photos or make your own videos from your phone, tablet or video camera, showing particular ways of, for example, comfortable positioning.

Figure 3 Sample laser pointer instructions written by Michael and his family

LASER POINTER INSTRUCTIONS DON'T GET LASER IN EYES

Plug wires in

Place purple cushion between ........ legs. This is the on/off switch.

Use headband or glasses, point 40 degrees down.

Set up Communication Board

Switch unit to LATCH to start

Use bag to hold latch assembly

←←← Switch unit to TIMER at finish & pack unit away in pieces so battery does not go flat.

## Using apps and web-based tools

There are many thousands of free and paid tools you can use for keeping track of services, contacts and day-to-day care. Types of tools include:

- apps for phone, tablet or other devices. App is short for application, and an application is the word used to describe a software program
- websites and other web-based tools.

**When you choose an app to install, think about:**

- The reputation of the developer
- Comments and reviews others have made about it
- Permissions you are granting during the install procedure

For example you may feel ok about installing an app developed by the Australian or New Zealand government, but not a medication management app from an individual developer in another country, or vice-versa.

**When you find a 'handy' website or other web-based tool consider:**

- The reputation of the person or orgnisation running the site and controlling the information you contribute
- Any ongoing costs
- Any 'add-on' costs
- The level of information you need to provide about yourself to participate
- The site's privacy policy and how it might use your information

### *Privacy, confidentiality, use of your information, permissions and cost*

Before you install an app or register to use a website or web-based tool think about the benefits you expect against any potential privacy risks and costs. Depending on the app you install, it may be able to:

- ask you to make purchases inside the app
- read your web bookmarks and history
- use your device's contacts and/or calendar information
- use your device's location
- use your device's text messaging and/or multimedia media messaging service
- use your phone and/or its call history
- use files or data stored on your device
- use your device's camera and/or microphone
- access your device's Wi-Fi and Bluetooth connection information, like if Wi-Fi is turned on and the name(s) of connected devices
- access your device ID(s), phone number, whether you're on the phone, and the number connected by a call including:
  - read phone status and identity
  - read and write your social stream eg FaceBook (on some social networks)
- specifically target you with advertising.

### *Apps and MND*

Apps for keeping track of services, contacts and day-to-day care that you might consider include apps that may assist with:

- Liaising with services - for example, government agencies and taxi services
- Managing contacts and appointments
- Tracking and managing medication
- Tracking symptoms and function
- Care planning
- Care coordination
- Communciating with your friends as a 'group'
- Health information and health service directories
- Access apps such as wheelchair accessible rail stations and local public toilets
- Contact apps for staying in touch with family and friends

### *Getting apps*

You can download and install apps for your device from the internet:

- the Apple App Store for Apple devices (for example iPhone, iPad)
- Google Play for android products (for example, Samsung phone, android tablets)
- Windows Store for Windows products (for example, Windows phone, Windows tablets).

# Leisure

## Getting around

Most facilities in the community are now accessible for people with mobility needs. The trick is to plan ahead. For local events, contact the venue directly for information when planning your visit. For larger events check the access available when making your booking.

There are several options for getting around. These are listed below.

### Travelling in your own car as a driver or passenger

*Driving*

When you are driving you are using your neck, upper limb and lower limb muscles for movement and posture. If MND is affecting one or more of these muscle areas it may impact on your ability to drive safely.

Just because you have a medical or physical condition, it does not automatically mean that you can't drive. It may just mean that you need to undertake regular medical reviews with your doctor to ensure that you remain medically fit to drive.

Your doctor may recommend that you have a driving assessment conducted by an occupational therapist. Driver trained occupational therapists assess all areas of driving including cognition, memory, reflexes, judgement, driving behaviour, motor function, knowledge of road rules, application of road rules and response times.

If you think muscle weakness is affecting your ability to safely control your vehicle, or if your doctor recommends that you do not drive then it is important that you stop driving. Other than the danger this may present to yourself and others, you may be not covered by insurance and may be liable for prosecution.

*Getting comfortable in the car*

Your physiotherapist can advise on head, neck, body and limb support aids and strategies.

**Tips for car comfort**

- Recline the seat back and consider using a neck support such as a neck brace, inflatable neck support or rolled towel
- Use back cushions or a pillow to support your upper limbs
- Seek the advice of your physiotherapist or occuptional theapist about the most appropriate type of seatbelt for your needs
- Items that can make it easier to transfer in and out of a car include
  - pieces of silk or satin, a plastic bag or sailcloth placed on the seat
  - turntable, swivel seat or slide board
  - cushion to fill the 'dip' in the seat
  - car hoist
  - car personal support handle
  - features of particular car models including a height-adjustable car seat, keyless entry and keyless start

### *Getting in and out of the car from and to a wheelchair*

**Getting in the car from a wheelchair:**

- Position car on flat ground with adequate access on passenger side
- Roll down window on passenger side
- If using a wheelchair, position it, swing footplates out of the way if possible and then lock brakes
- Stand, then place your left hand on the open car door and your right hand on car roof until you get your balance
- Manoeuvre your feet around so that your legs are against the car seat. You may have to place both hands on the door
- Place your right hand on the car seat or your left hand on the back of the car seat and lower yourself slowly into the car seat. Make sure you tip your head forward to avoid banging your head against the car as you get in
- Wriggle back towards centre of car, then lift your legs into car

**Getting out of the car to a wheelchair:**

- Have wheelchair close by, brakes locked, footplates swung out of the way, if possible
- Swing your legs out of the car until your feet touch the ground
- Wriggle your bottom forward so you are sitting on the edge of the car seat
- Place your right hand on door and your left hand on the car seat or back of the car seat. Bring your head and shoulders forward and stand up Try not to pull on the door if it is not fixed open by a person or wheelchair
- Once standing, move your left hand onto the car door
- Check the wheelchair brakes are on
- Turn around until your bottom is facing the wheelchair. Making sure your legs can feel the wheelchair behind you, place hands on the arms of the wheelchair and sit down

### *Packing a wheelchair into the car*

Before lifting a wheelchair into a car, first check brakes are on and then remove all removable wheelchair parts such as footrest, armrests and wheels.

### *Converting an existing vehicle or purchasing a wheelchair accessible vehicle*

Converting to or purchasing a vehicle that can accommodate a person remaining in their wheelchair in the car requires very careful consideration. The cost is considerable and the period of time that people with the most common forms of MND are able to use the vehicle may be insufficient to justify the expense. Conversion or purchase may be more viable for people with the more slowly progressive forms of the disease. Popular vehicles allowing modification for wheelchair access include the Mercedes Vito, Toyota Hiace and Town Ace.

If you are considering the purchase of a vehicle that can accommodate a person in a wheelchair it is most important to carefully research all measurements and details. Particular attention should be given to the measurement from the top of the head to the ground when the person is seated in the wheelchair. Allowance should be given for 1200mm clearance from the top of the head to the roof of the van. Wheelchair width has to be taken into account with a width clearance of at least 1270mm. Your occupational therapist can advise.

For details of conversion suppliers and websites advertising sales of second hand disabled vehicle see the MND Association resource *Living with motor neurone disease: services and resources*.

### Taxis

There are taxi subsidy schemes that provide a discounted taxi rate for people who are unable to use public transport because of a qualifying severe and permanent disability such as MND. If you can, book your wheelchair accessible taxi in advance. For more details see the MND Association resource *Living with motor neurone disease: services and resources*.

### Disabled vehicle hire

Several companies provide wheelchair accessible vehicle hire. For more details see the MND Association resource *Living with motor neurone disease: services and resources*.

### Parking concessions for people with mobility disabilities

There is a national parking concession scheme for people with mobility disabilities. Cardholders are entitled to park in spaces showing the symbol for people with disabilities and to extended parking limits that are defined by the scheme. For more details see the MND Association resource *Living with motor neurone disease: services and resources*.

### Community transport

Many local councils, particularly those in regional and rural areas provide a level of community and/or volunteer transport for people with a disability.

### Trains, buses and ferries

For more information about train, bus and ferry facilities for people with a disability see the MND Association resource *Living with motor neurone disease: services and resources*. You may need to notify the facility about your needs before your trip.

### Keys for disabled toilets

Many local councils in Australia have introduced specialised locked toilets for the disabled. These are accessible only by using a Master Locksmith Access Key (MLAK). For more details see the MND Association resource *Living with motor neurone disease: services and resources*.

## Holidays and travelling longer distances

### Research

Research prior to travelling can make the difference between your next holiday being a disaster or your best ever. The success of your journey can depend on the initial effort you put in to your enquiries.

Think about your needs and check before you book. If you are planning your holiday several months in advance you may need to 'over-specify' your needs. Avoid overcrowding your holiday itinerary and plan restful days before, during and after travel days.

The Internet can be a great source of holiday information. In general, searching online for the location you want with '+ disabled' as your other search term will be a good start.


Figure 4 Michael (seated in passenger seat of car) out and about with MND

### Useful aids for travel

There are many useful aids for travel including portable hoists and pocket sized urinals. For more details see the MND Association resource *Living with motor neurone disease: services and resources*.

## Access

Access can mean different things to different people. As everyone's access requirements are different contact the accommodation facilities and places you are visiting prior to booking to ensure they meet your specific requirements. This avoids disappointment and unnecessary stress.

## Accommodation

Even if the hotel or motel advertises accessible facilities it is important to contact the facility to make sure they are adequate for your particular needs. This is particularly important before travelling overseas because the exact nature of accessible facilities can vary considerably from country to country.

The quality of disabled access is not necessarily related to the cost of accommodation. Some cheaper chains offer excellent facilities.

When you are researching and booking your holiday destination or cruise, list some of your essential accommodation needs and then check with the particular facility to see if it meets your needs.

### Accommodation checklist

☐ Is the accommodation close to the locations you will be visiting?

☐ Is there parking close to the room?

☐ Access into the accommodation - the room and reception and dining areas.
  - Are there any steps or ramps?
  - Are there any small steps or lips that might catch a walker or wheelchair, or cause a trip?

☐ Are there any small steps or lips from one area in your room to another area in your room, or to the bathroom?

☐ Is there enough room around the furniture and the bed for a walker or wheelchair?

☐ Are the bathrooms suitable?
  - Is the doorway wide enough?
  - Does it have grab rails?
  - Is there a shower hob that might get in the way?
  - Is there a hand held shower?
  - Is there a shower chair available?

☐ Are the facilities in the room easily accessible, for example access to light switches and the kettle?

☐ If using a hoist - is there sufficient clearance under the bed to take a hoist?

☐ Is there somewhere nearby where you can rent any necessary equipment if needed?

☐ If travelling alone, are there are any nursing or caring agencies available? What is the cost and do you need to pre-book?

## Transport

If you do not have your own transport, will there be wheelchair-friendly transport on arrival? Try to find out how locals in the same situation get about. If you need to take transport from your accommodation, can it take a wheelchair? Are there disabled taxis available? Can you hire a wheelchair-accessible vehicle if necessary?

### *Rail travel*

The rail system is gradually improving access for those with mobility difficulties, with special wheelchairs provided on most trains and ramps providing access from train platforms to carriage. However, check with the facility before you travel.

The Indian Pacific from Sydney to Perth, and the Ghan from Adelaide to Darwin, have specially designed cabins providing full wheelchair access, sleeping accommodation for two and an ensuite bathroom and toilet suitably modified for the purpose.

### *Coach travel*

With advanced notice, coach companies are generally happy to arrange special seating, assist you in getting on and off the coach, and provide storage for equipment such as wheelchairs. Unfortunately, most coaches do not have lifts or lowered floors.

### *Air travel*

#### ***Disability Access Facilitation Plans***

Many domestic and some international airlines and airport operators publish Disability Access Facilitation Plans (DAFPs). The aim of each plan is to provide detailed information on how they (the airlines and the airport operators) intend to meet the needs of customers with disabilities.

By knowing what help airlines and airports can provide may help you plan your journey in relation to managing departure, transfer and arrival processes including check in, security screening and using wheelchairs in airport and on board.

#### ***Booking***

**Tips for making airline reservations**

- Make your reservation as far in advance as possible
- Tell the reservations person if you will be travelling with a wheelchair
- Inform them if you need assistance with boarding
- Ask if there are concession fares available for an accompanying person
- If it is a long flight and you are able to use a standard restroom but are unable to walk to the restroom, ask that an aisle chair* is available to you during the flight
- Confirm that the airline has a record of your requests 48 hours prior to departure

Some planes have lift up armrests on some aisle seats. You can request to be seated in one of these if available to make it easier to transfer from the aisle chair (*see *Using an aisle chair* p. 61). Airlines are very helpful with special dietary needs including modified food consistency. You will need to ring the airline in good time to discuss and arrange your requirements. Prepare yourself with all the information you need before heading off.

### *At the airport*

Be sure to arrive early and make certain you get a gate check tag during check in. This tag, which is attached to your chair, lets the ground crew know to bring your chair to the gate when your plane arrives rather than to the baggage claim area.

You will generally be the first to board the plane and the last to disembark although flight personnel may ask if you wish to disembark before or after the other passengers.

If you use a fold up manual wheelchair you can request that it be stowed in the on board coat closet, if the plane has one, but this is purely at the discretion of the flight crew and space may not always be available.

All electric chairs must be stowed as checked luggage so it is important to minimise the possibility of damage during transit. Remove seat cushions and any other parts that could easily become separated from the chair. Disconnect and remove any battery wires that may be visible to the ground crew. Electrical connections may make them nervous and they have been known to remove them before they load the chair into the cargo hold.

Have details available of the type of battery installed. For transporting ease airlines much prefer gel or dry cell batteries to traditional acid filled ones. Confirmation that a particular type of battery has been tested to meet the criterion to be classified as a 'non-spillable' battery will usually be available from the selling agent or the manufacturer. It should be noted that many 'gel-cell' batteries are sold as 'non-spillable' but have not been subjected to the tests necessary to be legally classified as 'non-spillable' for transport by air. For spillable batteries, if the wheelchair cannot travel upright in the cargo hold, the battery must be removed and transported in a container specifically designed for the purpose. Procedures adopted by the airlines can differ, specific advice is best sought from the airline you intend to travel with.

Some physical disassembly of the wheelchair may be required for transport so it may be a good idea to attach some 'how-to' instructions to your chair. Remember it also has to be reassembled at the other end by a different ground crew who may not be experienced in such procedures. For this reason it's probably a good idea to travel with some basic maintenance tools for your wheelchair

### *Using an aisle chair on the plane*

If you are unable to walk from your wheelchair to your seat in the aircraft, you'll transfer to a carry-on or aisle chair for the trip down the aisle. You can't ride your chair onto the plane - it will not fit.

An aisle chair is a tall, skinny, high-backed chair designed to fit down the narrow aisle of an aircraft. It has retaining straps to hold you in and is quite stable. Even so it might be a good idea to take your own leg strap just in case you need to strap your legs into the chair.

Most planes are fitted with some aisle seating that has a movable or lift up armrest. This enables an easier transfer from the aisle chair. If you require assistance transferring to the plane seat, explain to the staff how to help you. The staff are often helpful and well trained but you are always safer not assuming anything.

If an aisle seat was requested but not allocated, ask the cabin crew to swap your seat for another. Being stuck sitting in a middle seat could make it very difficult to get to a toilet during a long flight.

### *During the flight*

Some planes have a privacy curtain that includes the aisle to allow a companion to help you with personal care. Aircraft toilets are small and not all aircraft have disabled facilities in their toilets. Ask the booking officer for as much information about the facilities on the type of plane you will be flying on. Some planes have restrooms that have outward swinging doors and handrails that are large enough to fit an aisle chair inside, making it possible to transfer to the toilet.

## Tips when travelling overseas

If you have a disability and are planning to travel overseas, remember Australia and New Zealand's arrangements for people with disabilities are among the best in the world. It is unlikely that you will find similar facilities in many countries overseas, so it is important to plan ahead.

Tips for travel from smartraveller.gov.au[10].

### Tips for travellers with disabilities

- Make reservations for transport, accommodation, tours and hire equipment well in advance, and confirm all bookings and arrangements 48 hours beforehand
- Notify others about your needs. Inform your travel agency or companies you are using, including your airline
- Book direct flights where possible and when making bookings allow plenty of time for any necessary transfers between planes or other forms of transport
- Call airports and airlines well ahead of time to find out about services, including seating arrangements, special meals and shuttle services
- Contact the local tourist authority to find out if the public transport system accommodates your disability
- Be very specific about your needs and confirm that operators can meet your requirements
- Do not make assumptions. If you have checked that the bathroom is wheelchair accessible, also ask about the front steps. Try to speak to somebody who has actually seen the facility
- If any of your aids need electricity or if you need to recharge batteries, check the voltage used in the country you are visiting. Also check what adaptors are needed -the plug configuration can change
- Check health care arrangements
- Options for travel insurance* should be explored prior to your departure

* For more details about travel insurance see the MND Association resource *Living with motor neurone disease: services and resources*.

---

[10] Edited from Tips for Travellers with Disabilities smartraveller.gov.au

## Some ideas for maintaining interests and hobbies

Play music files or digital radio through a computer, phone, tablet or TV

Videos/DVDs and on demand internet TV are a flexible way of having movies and TV series at home when you have the energy to watch

Audio books can be borrowed from your local library, purchased online or purchased from book shops

Art galleries and museums usually have easy ramp and lift access

If going out to dinner is too difficult, consider going out to lunch or having a ‘special’ dinner or lunch at home

If playing sport has been important, you may get enjoyment by being a spectator and/or armchair critic - major venues have ramp and lift access

Sharing your craft, hobby or gardening knowledge with others can give you the opportunity to get pleasure from watching others learn new skills

Use email, blogs, Facebook, Skype and other web-based tools

Compile memoirs and personal histories through photographs, on tape or using the computer

Bushwalking and camping can be difficult, but bush picnics and holidays where there is bush may provide rewarding alternatives

Plant bird attracting plants in the garden and having a bird feeder will bring native birds nearer to you

Video games can be accessible using a switch with the controller

Visiting friends and going to religious services is likely to become difficult, have your friends and religious leader visit you

Many galleries, museums, theatres and sporting venues offer discounted entry for the companion* of a person with a disability

* For more details see the MND Association resource *Living with motor neurone disease: services and resources*.

## Staying connected

In their daily lives, people’s most enjoyable moments are those spent socialising with family and friends, whether in person or online. If you can’t get out as much as you previously have, consider staying connected with others through:

- participating in online communities of particular interest to you (see *Linking up with others,* page 7)
- making video calls through your mobile phone, tablet or computer to link up with family and friends
- getting involved in social networking and online gaming
- using email and text messages.

# The later stage of MND

Some people may find it too painful to talk about what lies ahead. For others, talking about what lies ahead is a way of maintaining control over their future care and even their death. They may want to plan the ceremony or service to be held after their death, including the venue, type of ceremony or service, music to be played and photographs to be used. This may help to give them a sense of control, a feeling of peace of mind and allows them to fully participate in their leave-taking from the people who are important to them.

Many people prefer to die at home and the local palliative care team, your GP and other community services can provide you and your family with support during this time.

For some people, the nature of their disability, the symptoms being experienced and lack of available community care may mean that an admission to hospital, hospice or residential care will be necessary towards the end. These facilities may be able to offer a calm and peaceful alternative to home and help to allay stress and strain for all concerned.

## How will I feel?

Nothing is more individual than how people feel in the months, weeks and days before death. You may have a sense that time is very limited.

> *"I mourn my dwindling time, but I cherish the chance it gives me to put things right"*
>
> Morrie Schwarz, *Tuesdays with Morrie*

Some people want lots of people coming and going or just those closest to them. Others may have unfinished conversations they are anxious to address. Those with young children might write special letters or collect keepsakes together.

You may feel the need to reminisce, to feel connected to others, to focus on things that are important to you and your family and to have reunions with people who have shared your lives and experiences.

If you are feeling anxious, concerned or worried it can be helpful to talk to someone who is not involved with you directly, such as a doctor, MND Association advisor, counsellor, social worker, palliative care team, clergy or others living with MND.

## Organ and tissue donation

People with MND are not automatically excluded from general organ and tissue donation programs (except for corneal tissue).

However, it is important for you to discuss how you feel about organ and tissue donation with your family. This is because when a person dies, the family is asked to provide their consent for the person’s donation decision.

Less than 1% of deaths in hospitals are in the particular circumstances where organ donation is possible. However, tissue may be able to be donated even if someone dies at home.

Some MND and related disease research centres specifically seek and accept brain and spinal cord donations from people with MND. However, there are very specific criteria that need to be met.

For more information see the MND Association resource *Living with motor neurone disease: services and resources*.

## The days before death

During the days before death a person may:

- Not want to eat or drink
- Not want to talk or participate in activity/conversations happening around them
- Have increased sleepiness and weakness
- Have a reduction in chest expansion
- Have a quietening of the breath sounds
- Have irregular, noisy breathing
- Have colour changes in the hands and feet
- Have a cooler skin temperature

These signs may be noticed by a person in the family or by a member of the multidisciplinary team.

Morphine is frequently prescribed for breathlessness, anxiety and/or pain. Morphine may be given orally as a liquid, or tablet, or a continuous injection of small doses via a self-managed syringe driver (a needle is placed under the skin and left in place for a couple of days attached to a small machine). The dose is carefully monitored by the general practitioner, palliative specialist, community nurse or palliative care nurse.

There are a number of other medications such as Lorazepam, Diazepam (valium) or Midazolam - which may be prescribed to treat anxiety and restlessness. Oxygen is sometimes prescribed to minimise the feeling of breathlessness. The palliative specialist or general practitioner prescribe and advise on medication dosage and how the medication is taken.

In summary, medications in the very final stage of MND often include:

- opioid analgesics - reduce cough reflex, relieve dyspnoea, control pain and help to reduce fear and anxiety
- anti-cholinergics - such as hyoscine hydrobromide and glycopyrrolate - reduce saliva and lung secretions
- sedatives - such as diazepam, midazolam, clonazepam and chlorpromazine - reduce anxiety
- oxygen - can be used to relieve the sensation of breathlessness
- haloperidol - for restlessness.

For most people there will not be a dramatic moment of death but rather a gradual lapse into unconsciousness with perhaps some moments of lucidity. However, there are many uncertainties in MND and it is not unusual for a respiratory infection to occur, with death coming quite suddenly and unexpectedly, leaving the family and friends experiencing many mixed emotions. There may be feelings of relief or feelings of being cheated of time they expected to share with the person who has died.

> *"As long as we can love each other and remember the feeling of love we had, we can die without really going away. All the love you created is still there. All the memories are still there. You live on - in the hearts of everyone you have touched and nurtured while you are here."*
>
> Morrie Schwarz, *Tuesdays with Morrie*

## Publications in the Living with Motor Neurone Disease series

### Living with motor neurone disease: aspects of care

- provides an overview of MND and strategies for symptom management

### **Living with motor neurone disease: day-to-day**

- **provides strategies for living at home with MND, more in depth information and day-to-day tips**

### Living with motor neurone disease: services and resources

- provides contact details for organisations that provide services and information that may be of interest to people living with MND

### Living with motor neurone disease: for carers

- for family and friends caring for a person with MND - provides information about looking after yourself

# Index

## For more information contact the MND Association

### MND New South Wales

Gladesville Hospital Victoria Road,
Gladesville NSW 2111
(Locked Bag 5005, Gladesville NSW 1675)
Ph: 02 8877 0999
Freecall: 1800 777 175
Fax: 02 9816 2077
www.mndnsw.asn.au
admin@mndnsw.asn.au

### MND Queensland

PO Box 1039
Inala East QLD 4077
Ph: 07 3372 9004
Freecall: 1800 777 175
Fax: 07 3278 9871
www.mndaq.org.au
info@mndaq.org.au

### MND South Australia

302 South Road
(PO Box 2087 Hilton Plaza)
Hilton SA 5033
Ph: 08 8234 8448
Freecall: 1800 777 175
Fax: 08 8351 9524
www.mndsa.org.au
admin@mndsa.org.au

### MND Tasmania

PO Box 379
Sandy Bay TAS 7006
Freecall: 1800 806 632
www.mndatas.asn.au
info@mndatas.asn.au

### MND Victoria

265 Canterbury Road
(PO Box 23)
Canterbury VIC 3126
Ph: 03 9830 2122
Freecall: 1800 806 632
Fax: 03 9830 2228
www.mnd.asn.au
info@mnd.asn.au

### MND Western Australia

Centre for Neurological Support
The Niche, B/11 Aberdare Rd
Nedlands WA 6009
Ph: 08 6457 7355
Freecall: 1800 777 175
Fax: 08 6457 7332
www.mndawa.asn.au
admin@mndawa.asn.au

### ACT and Northern Territory contact:

Locked Bag 5005,
Gladesville NSW 1675
Ph: 02 8877 0999
Freecall: 1800 777 175
Fax: 02 9816 2077
www.mndnsw.asn.au
admin@mndnsw.asn.au

### MND Association of New Zealand

Yarnton House, 14 Erson Ave
(PO Box 24036)
Royal Oak, Auckland 1345
New Zealand
Ph/Fax: 09 624 2148
www.mnd.org.nz
admin@mnda.org.nz