

GP Booklet

MNDAA

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PRESENTATION

Motor Neurone Disease is an uncommon degenerative disorder of motor neurones, which leads to progressive paralysis of cranial and skeletal muscles. The onset is insidious. First symptoms include stumbling, weakened grip, hoarse voice, cramp and muscle wasting. The condition is incurable and leads to death within a few years of diagnosis, generally 1-5 years. Death is most commonly due to respiratory muscle weakness and ventilatory failure.

Incidence: 1.8 per 100 000 per year

Male/female ratio: 1.26/1

Distribution: worldwide

Average age of onset: 50 years

Motor Neurone Disease is characterised by progressive degeneration of motor neurones:

- Anterior horn cells in the spinal cord - resulting in lower motor neurone lesions [LMN]
- Skeletal muscle wasting and fasciculation
- Reduced muscle tone and stretch reflexes
- Weakness of limb, trunk and respiratory muscles

Cranial motor nuclei in the brain stem - resulting in lower motor neurone weakness of the facial jaw and bulbar muscles [bulbar palsy]

Upper motor neurones in the motor cortex - resulting in degeneration in cortico bulbar and corticospinal pathways [upper motor neurone lesions]

- Spastic weakness of cranial and bulbar muscles [pseudobulbar palsy]
- Spastic weakness of limb and truncal muscles
- Exaggerated jaw, gag and cough reflexes plus emotional lability
- Exaggerated limb stretch reflexes and extensor plantar responses

It is typical for patients to present with symptoms in one muscle group, for example, weakness and wasting of one hand or a unilateral foot drop. Lower motor neurone [LMN] or upper motor neurone [UMN] signs may be present elsewhere on examination. It is also typical to find evidence of LMN and UMN features in the same limb, for example, leg muscle wasting and fasciculation in combination with increased muscle tone, exaggerated reflexes and an extensor plantar response. As the disease progresses, other motor segments become involved.

Sensory symptoms or signs are rare and should lead to review of the diagnosis. Fronto-temporal cognitive changes have been associated with MND and are prominent in 5 -10% of cases.

The motor nuclei controlling eye movements and the voluntary pelvic sphincter muscles remain intact.

Clinical Categories

The disease can be categorised on the basis of sites of involvement at presentation and the balance between LMN and UMN features.

Amyotrophic Lateral / Sclerosis - ALS

Most common form affecting about 65% of patients
Mixed LMN and UMN signs beginning in the limbs
Bulbar involvement later
More common in men than woman

Progressive Bulbar / Pseudobulbar Palsy.

About 25% of cases at onset, especially women
Progressive dysarthria and dysphagia
Limb, neck and trunk involvement later
Usually show mixed UMN and LMN features although one type may predominate

Progressive Muscular Atrophy.

Progressive lower motor neurone muscle wasting and weakness, without convincing UMN features
Relatively uncommon form of MND
Other causes of motor neuropathy need to be carefully excluded in these patients

Primary Lateral Sclerosis.

Least common pattern of disease, about 1% of cases
Progressive upper motor neurone syndrome with limb spasticity and weakness accompanied in time by a pseudobulbar palsy

AETIOLOGY AND TREATMENT

Sporadic MND

This form of the disease occurs randomly throughout the world and was first described in the medical literature in the mid 1800's. Studies specifically designed to analyse any association between work or environmental factors and MND have failed to demonstrate any entity, which may be related.

Familial MND

Familial MND accounts for about 10% of all MND cases. A specific genetic defect has been detected on chromosome 21 in 20% of the familial cases. The defective gene is responsible for the production of the enzyme superoxide dismutase or SOD1 (this enzyme is involved in the removal of cytotoxic free radicals).

Current Research:

Environmental and Toxic triggers. Epidemiological and cellular research is continuing to try and identify specific factors, which may be responsible for motor neurone damage. This not only includes cytotoxic free radicals but also heavy metals and Neurotransmitters like glutamate, which in high concentrations can be neurotoxic.

Genetic. SOD1 accounts for only 20% of all the familial cases, leaving 80% unexplained. Analysis of the families with non-chromosome 21 linked MND is ongoing but as yet no specific gene has been identified.

Neurotrophic factors. Neurotrophic factors are known to influence the growth, differentiation and survival of neurones. As a consequence a number of recently discovered Neurotrophic factors have been tested as to whether they can alter the clinical course of motor neurone disease.

Viral Infections and Autoimmune Mechanisms continue to be areas of active analysis but have never indicated a likely aetiology or treatment alternative.

Possibilities for Treatment (December 1997)

Clinical tests have been focused on finding treatments that slow disease progression, resulting in longer survival and maintaining quality of life measures. As yet no single agent has been found which substantially improves these end points.

Therapy remains focused on appropriate palliation with patient and carer orientated support.

Riluzole (Rilutek); prolonged survival by 3 months but did not result in significant improvements in muscle strength. Currently not approved for use in Australia.

IGF-I (Myotrophin); North America trial indicated that progression of functional disability was reduced and survival increased, the European trial showed similar trends but they were not statistically significant. As of May 1997 IGF-1 was rejected by the FDA in the United States as a drug in motor neurone disease.

BDNF (Brain derived Neurotrophic factor); Phase 111 trials failed to demonstrate any significant benefit when this drug was given subcutaneously. A further study is still in progress in which the drug is delivered intrathecally; the results as yet have not been published.

CNTF (Ciliary Neurotrophic factor); Initial trials of subcutaneous injection were halted due to adverse outcomes. Research is continuing into alternate mechanisms of drug delivery.

DGNF (Glial derived Neurotrophic factor); A trial using direct intrathecal delivery is currently in progress in the United States.

Gabapentin (Neurontin); Initial trials did not indicate any statistically significant benefit; however further larger studies are currently being completed in North America.

Antioxidants (Vitamin E, C, Carotene); As yet no scientifically performed clinical trial has been performed to test the effectiveness of these compounds.

DYSARTHRIA

Cause

Weakness and paralysis of the lips, facial muscles, tongue, larynx and pharynx resulting from affected trigeminal, facial, glossopharyngeal, vagus, accessory and hypoglossal cranial nerves.

Effect

Impairment of speech production (Dysarthria) may begin with slurring, hoarseness and weak voice. This may progress to total loss of speech (Anarthria).

Treatment

Early referral to a **Speech Pathologist** for

- advice on strategies for communication
- assessment for and provision of communication aids and training in their use

The Speech Pathologist will work with an **Occupational Therapist** who can advise on scaring, positioning, wrist supports, switches, pointers, mobile arm supports and tables, and access to communication aids

Useful strategies

- Encourage to slow down and carefully articulate words
- Establish gestures or signals for yes and no first. Ask questions which only need a yes/no answer
- Positioning - face to face, watch lips, eyes, gestures
- Take time to create a relaxed atmosphere
- Avoid interruptions or trying to finish sentences

Communication can be aided by:

- Writing
- Alphabet board
- Perspex eye pointing frame (ETRAN BOARD)
- Hands-free telephone
- Call bells
- Personal alarms
- Computerised communication aids, LIGHTWRITER(tm)
- Telephone typewriter

Emotional response

- Isolation communication inadequate or avoided
- Frustration difficult or impossible to be understood, need time which may not be available
- Increased fear and anxiety because unable to discuss these fears and anxieties
- Low self esteem others assume deafness and shout or assume intellectual impairment
- Loss of control because misunderstood or opinion ignored or not sought
- Increased sadness isolation and frustration felt by patient, carer and family

NOTE: Referral to the Motor Neurone Disease Association in each State, or a similar specialist Dysarthria centre may be of benefit, e.g. Bethlehem Hospital, Victoria.

PAIN

Pain and discomfort in MND arise as complications of muscle weakness, stiffness and immobility

Causes

- Loss of muscular control to stabilise large joints and maintain spinal posture
- Passive injury to joints when controlling muscles are weak, e.g. shoulder joint damage during assisted transfers
- Muscle cramps
- Spasticity
- Skin pressure
- Constipation

Management

- Postural discomfort and joint pain
- Careful positioning to support head, trunk and weight of limbs
- Regular repositioning for patients unable to reposition themselves
- Passive limb movements to prevent muscle and joint stiffness
- Allied health professional advice on most appropriate positioning and transferring techniques and pressure relieving equipment

Analgesia - simple analgesics may be ineffective.

- non-steroidal anti-inflammatory drugs if there is an arthritic or inflammatory component to pain
- intra articular injection, especially into shoulder joint
- small doses of oral morphine are often very helpful. Start with very low doses e.g. 2-4mg nocte and increase gradually if necessary. The dose may be repeated on a 4 hourly basis. Consider slow-release morphine preparations if regular analgesia is required

Muscle Cramps

More common early in the disease course

Drug treatment: Quinine bisulphate ~300mg nocte
Diazepam
Baclofen

Start with very small doses, e.g. Baclofen 5-10mg BD or Diazepam 1-2mg BD. Only bedtime doses may be required.

Spasticity

Anti-spasm drugs are well worth considering in the treatment of MND. However, it must be stressed that careful assessment of the effect of spasm medication is essential. Co-ordination with a physiotherapist is essential to determine the relative role of medication and regular physiotherapy e.g. passive stretching of limbs. Advice should be sought from the physiotherapist regarding optimal positioning in bed and chair.

Drug therapy: Baclofen, starting with 5-10mg BD. Gradually increase dose as required. It is seldom worth exceeding a total daily dose of 75mg.

Side effects: drowsiness increased muscle weakness, rash

Benzodiazepines, e.g. Diazepam, Clonazepam.

Patients seldom tolerate more than small doses during the day because of unwanted drowsiness.

More helpful at night.

DYSPNOEA

Shortness of breath is a common symptom at some stage in the course of MND. Usually respiratory muscle weakness occurs late in the disease and is the most likely cause of death. However ventilatory failure can develop at any stage and occasionally is the presenting feature of MND.

Clinical Features

- Breathlessness on exertion, sometimes just the exertion of speaking or eating.
- Sleep disturbance, anxiety, and panic.
- Orthopnoea - breathless lying flat. Most patients find a semi-recumbent position most comfortable. This position allows the intercostal muscles and the diaphragm to work to greatest advantage.
- Hypoventilation is worse during sleep. Upper airway may also be partially obstructed due to bulbar and laryngeal muscle weakness.
- Increasing CO₂ levels in the blood result in headaches, nausea, somnolence, encephalopathy, especially on waking.
- Hypoxia, especially if there is coexisting lung disease. Oxygen therapy in the setting of CO₂ retention is likely to lead to increasing hypercarbia, coma and death.

Management

- Relieve anxiety - reassurance and/or medication [see below]
- Correct posture in chair and bed. Beds with adjustable back supports and recliner chairs may be helpful.
- Improve accretion control. Retained secretions in the mouth and pharynx further compromise the airway and add to the patient's discomfort and panic. [See under dysphagia]. The physiotherapist may also be able to reduce anxiety by teaching controlled breathing exercises and assisted coughing techniques.

Consider:

- Measuring arterial blood gases, pO₂, and pCO₂. This gives some guidance to prognosis and also indicates whether oxygen therapy would be appropriate.
- Referral to a specialist Respiratory Unit if some form of assisted ventilation is appropriate and is desired by the patient.
- Intermittent non-invasive positive pressure ventilation by mask - BIPAP at night
- Life support continuous ventilation via tracheostomy.

Implications

- Quality of life issues
- Advanced medical directives - at which point should ventilatory support, be withdrawn?
- Increased dependency on family and carers

Palliation

Breathlessness is one of the most frightening symptoms of MND. Few patients choose the option of mechanical ventilation, although some achieve good palliation of symptoms of CO₂ retention and dyspnoea using Intermittent Positive Pressure Ventilation at night. These benefits are often sustained for many months or years. Ultimately, however, the breathing difficulties become life threatening.

Palliation of dyspnoea and anxiety are best achieved using opiates

Starting dose: Morphine ~2mg orally or subcutaneously. Increase gradually as required.

The dose can be repeated 4 hourly if necessary.

Usually patients benefit from a bedtime dose, but may use it intermittently in the daytime. When anxious or distressed by breathlessness or retained secretions in the throat, a small dose 45 minutes before meals can improve symptoms of dyspnoea while eating.

More regular doses of Morphine may be required in the more terminal stages of the disease for control of symptoms. The use of slow release Morphine preparations or subcutaneous delivery via a syringe driver may need to be considered in these late stages, particularly if the patient chooses to die at home.

It should be stressed that death caused by choking attacks is almost unknown and that the final stages of MND are usually peaceful and dignified.

Other drugs:

Benzodiazepines

Small doses of Diazepam or Clonazepam may be added to help control anxiety.

Hyoscine, Atropine

Anticholinergic drugs reduce secretions in the airways of dying patients.

They can be used more cautiously in the earlier stages of the disease in-patients with copious watery secretions. Excessive use leads to thick, tenacious oropharyngeal secretions, which are more difficult to manage, increase dysphagia and compromise the airway.

DYSPHAGIA AND NUTRITION

Causes of Dysphagia

- Weakness and paralysis of the lips, facial muscles, tongue, larynx and pharynx resulting from affected trigeminal, facial, glossopharyngeal, vagus, accessory and hypoglossal nerves

Effect

- Impaired ability to chew, form a bolus and propel food/fluid with the tongue
- Impaired swallow reflex
- Impaired airway protection during the swallow

Resulting in:

- Drooling
- Dehydration and malnutrition
- Aspiration and resultant chest infections - which contribute to impaired respiratory function

Treatment

- Requires a rapid, co-ordinated, multidisciplinary approach
- Assessment and monitoring of swallow, advice concerning food and fluid consistency, modified drinking utensils,
- Facilitating techniques (eg. vibration and icing) - consult **Speech Pathologist**
- Assessment and advice concerning nutritional intake - consult **Dietician**
- Head and neck support and positioning, training carers to perform assisted cough - consult **Physiotherapist**
- Advice concerning modified plates, cups, cup holders, cutlery, non slip mats - consult **Occupational Therapist**

Secretions

A range of problems may occur:

- **Drooling and pooled secretions** - anti-cholinergic medication will reduce and thicken saliva. Regular and excessive dosing may result in tenacious oropharyngeal secretions, consider PRN.

Drug therapy - starting doses:

Tricyclic antidepressants, eg Imipramine 10 mg

Probanthine, 15 mg

Atropine, 0.03 mg

- **Thick tenacious saliva** - mucolytic agents: papaya enzyme (eg. Kordells Enzymex, available from Health Food Shops), juices and ice cubes - grape, apple, pineapple and papaya. Frequent swabbing of the mouth: using plain water, especially after meals (avoid harsh mouthwashes).

Nutrition

As the disease progresses eating may become difficult and exhausting, and cause anxiety. Some people opt for alternative feeding via a Percutaneous Endoscopic

Gastrostomy (PEG). It is important that the patient be aware of such options in good time in order to obtain maximum benefit. Advice concerning nutritional intake - consult Dietician. Some weight loss is an inevitable consequence of muscle wasting.

Constipation

The sphincter muscles themselves are not weakened by MND. Incontinence is therefore not a common problem in this disease. Constipation is, however, a frequent problem and is caused by a number of factors:

- Immobility
- Modified diet and poor fluid intake
- Medications - especially analgesics and Anticholinergic drugs
- Inability to strain due to weak abdominal, diaphragmatic and glottic muscles.

Management:

- Optimise fluid intake if possible
- Faecal softeners if stool is hard, eg Coloxyl tablets or Lactulose syrup
- Bowel stimulants if bowel transit still slow, eg Senna, Duro lax
- Regular rectal evacuant to overcome weak muscles of defaecation, eg suppositories.
- Microlax enemas, usually given three times per week.

PSYCHOLOGICAL SUPPORT

People with MND, their families and carers often suffer considerable psychological and emotional distress. Much can be done to alleviate this distress, help people to adjust and make the most of their coping skills.

Before the diagnosis

Anxiety can increase as a result of:

- onset of worrying symptoms
- difficulty in identifying cause
- a protracted period of investigation
- the need for the doctor to be sure before giving the diagnosis

Telling the diagnosis

Preparation

- taking time to convey the potential seriousness of diagnosis & prognosis

Time and place

- quiet, relaxed, private and away from external distractions
- choice of who will be present - partner /family members

Amount of information

- initial shock often limits the ability to absorb information
- need the doctor to give written information, e.g. Motor Neurone Disease - Some Facts, Motor Neurone Disease - More Facts. (Copies available from the MND Association of Australia).
- need opportunities to return for more information and to set own pace
- need an identified person to provide ongoing support

Telling the truth

- honesty is important but avoid leaving the person feeling alone and unsupported
- prolonging uncertainty can exacerbate fear of the unknown, deny support and the opportunity to come to terms with mortality and make decisions
- telling relatives in isolation puts strains on relationships and families

Emotional Responses

Fear

- of increasing dependency and becoming a burden
- of the unknown, of death and the process of dying

Allowing time and opportunities to discuss these concerns can alleviate these fears and produce practical solutions to some of them.

Denial is a coping mechanism that sometimes operates alongside awareness of the condition and its implications. This should be accepted by professionals unless or until it is inhibiting appropriate support or palliation.

Both denial and anger are normal reactions and are associated with a refusal to accept help or to use equipment, which can be very frustrating for professionals and carers.

Depression is not always easy to diagnose or differentiate from sadness and recognition that many of life's expectations can no longer be realised. Treatment of depression is likely to have a positive effect on ability to cope.

Upper motor neurone involvement is associated with **emotional lability**.

Acceptance/adjustment: Coming to terms with reality is constantly challenged by proliferating impairments and increasing severity of symptoms.

Families and Carers

Motor Neurone Disease forces changes in roles and relationships. Consider ways of

- balancing the needs of the patient & other family members
- counteracting isolation of individuals and promoting awareness of each other's needs
- creating opportunities for expressing negative feelings without feeling guilty

The feelings of people with MND are often mirrored by their carers although not always at the same time.

Physical exhaustion from the caring role is coupled with powerlessness to prevent suffering.

Impact on professionals

MND frequently arouses strong emotional and ethical challenges:

- attitudes to issues such as disability, quality of life, euthanasia and measures taken to prolong life
- frustration with the seeming inability of individuals or the system to provide solutions to complex problems.

Strong teamwork is necessary to provide support and encouragement.

PALLIATIVE CARE

Palliation should apply from diagnosis. The illness is characterised by a series of losses with the accompanying issues of grief and bereavement. Hence it may be advisable to link up with supporting services such as:

Palliative care team:	hospices and domiciliary palliative care services.
Home care:	expert help for patients and carers in collaboration with the District or Community Nurse.
Day care:	provides respite, social activities and access to therapy services.
In-patient care:	provide respite, assessment, and opportunities for monitoring and review of symptom management.

Working with the Palliative Care Team

Establishing links at an early stage can provide the primary health care team with a useful source of advice and support. Initially this may be resisted by the patient and/or carer who may need additional time to come to terms with the terminal nature of the disease.

The terminal stage

The terminal stage is recognised as progressive weakness and sudden deterioration over a few days or hours.

Following such sudden deterioration only 2% survive more than one week.

The commonest cause of death is respiratory failure, usually following upper respiratory tract infection.

Action

Check all symptoms control:

- pain
- dyspnoea
- dysphagia
- salivation
- insomnia
- anxiety / depression
- bowels & bladder

Reassess needs of carer and family.

Medication

- Refer to preceding sections of this booklet.

Communicating with the patient

This may become extremely difficult but eye pointing or single response answers to closed end questions can be maintained.

- **Dry mouth** (often related to mouth breathing during sleep) - oral Lubricants: Oralbalance(tm) gel, 100 parts grapeseed oil to 1 part peppermint oil. Anticholinergic medication, especially at night, can exacerbate the problem-
- **Thick tenacious saliva** - mucolytic agents: papaya enzyme (eg. Kordells Enzymex, available from Health Food Shops), juices and ice cubes - grape, apple, pineapple and papaya.

The carer

The carer will need practical and emotional support. Care plans and information must be shared by all members of the care team, and adequate nursing cover maintained.

Good symptom control is essential in the management of a peaceful and dignified death.

COORDINATING CARE

Needs of people with MND

Information and support

- from the onset of symptoms
- during the often protracted period of uncertainty prior to diagnosis
- Ongoing in response to progressive deterioration and impact on family life

Access to the skills of experts from a variety of agencies

- assessment of needs
- rapid response
- co-ordinated action
- regular review

The multidisciplinary team

Provides a breadth of expertise but access to all these services is a daunting prospect. The number of agencies, referral criteria and complexities of communication place additional burdens on the person at the centre, often still reeling from the shock of diagnosis.

A Key Worker can

- develop a relationship as trusted family confidant
- co-ordinate the activities of other team members
- interface with other service providers
- alert team members and initiate effective and timely response to changing needs

Anticipating & avoiding crises depends on:

- building and maintaining trust
- confidence in a rapid response to requests for help
- communication within the team and effective delegation of responsibility

General Practitioners rarely see a case of MND,

but the primary health care team does have a great deal of experience of caring for people with terminal disease. This booklet aims to outline some of the particular problems encountered by people with MND and to provide signposts to sources of expert help.

The Primary Health Care Team:

The anticipatory care approach now emerging in modern primary health care provides the ideal supportive framework to retain dignity and autonomy for the individual during the relentless progression of this devastating disease.

The Primary Health Care Team can consist of a number of health care professionals delivering a range of supports to optimise the quality of life for the person with MND. These may include

general practitioner (following diagnosis by a neurologist or physician), speech pathologist, occupational therapist, physiotherapist, and nurse, depending on the individual situation

EQUIPMENT

1. The Motor Neurone Disease Association in each State of Australia is able to advise General Practitioners and other professionals regarding the local source of supply of equipment, which will enable people living with Motor Neurone Disease (MND) to enjoy the best possible quality of life. Advice may also be obtained from the Motor Neurone Disease Association of Australia during business hours.
2. An Independent Living Centre (ILC) operates in every State, although these Centres may be named differently from State to State. Aids and appliances are available for inspection, but cannot be bought directly from the ILC. Skilled staff are available to advise people on a large range of aids (including clothing) and equipment which could be helpful.
3. Before decisions are made regarding specific equipment, it is essential that accurate assessment be carried out by an Occupational Therapist, Physiotherapist, Speech Pathologist or Nurse, depending on the area of expertise and the availability of professionals in any particular locality.
4. Equipment that can be helpful for people living with MND includes the following aids, which can maximise their quality of life and allow them to remain in their own homes for longer periods, thus avoiding hospitalisation.

Aids for Daily Living:

Feeding utensils including:

- modified cups, plates and cutlery
- non-slip mats
- cup holders
- collars
- splints

Pressure care:

- cushions
- mattress overlays

Chairs and beds:

- reclining
- adjustable height
- electrically operated for individual comfort
- modification of existing furniture

Mobile arm supports:

- wheelchair attached
- free standing or table attached

Grooming aids:

- Velcro for assistance with clothing including shoes.

Environmental controls:

- personal alarms
- remote operation of lights/electrical equipment
- book rest
- page turner
- talking books
- Wheeled trolley

Aids for carers:

- Turntables
- Hoists
- lifting belts

Mobility Aids:

- walking sticks,
- walking frame
- rails/ramps
- Splints
- Wheelchairs
- Manual/electric - carer or patient operated.

Communication:

- hands-free telephone
- call bells
- personal alarms
- computerised communication aids incl. –
 - light touch key boards
 - voice synthesisers
 - magic slates

Bathroom aids:

- grab rails for bathroom and toilet
- Chairs –
- Shower
- over toilet
- commode

FINANCIAL HELP

Extract from "Carer Support: Practical Information on caring at Home."
Commonwealth Department of Health, Housing and Community Services, 1993.
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There are a number of pensions, allowances and benefits available from the Commonwealth Government for people who are aged or disabled. In addition, there is help available for full-time carers of these people. Unless noted otherwise, payments are made through the Department of Social Security (DSS). Apply at your local office. To receive most pensions and allowances you must be an Australian citizen or permanent resident (or come from a country which has a reciprocal agreement with Australia -check with DSS). Your income and assets and those of your partner must be below certain limits. There are different types of assistance including a financial information service, concessions, and from April 1993, home equity conversions loan.

Carer Payment

You are eligible for a Carer Payment if you are looking after someone who:

- has a physical, intellectual or psychiatric problem which means your help is needed for everyday tasks or constant supervision is needed to prevent injury to the person or to someone else
- is getting a pension or benefit from DSS or Veterans' Affairs
- is living at home.

The problem must be long-term. You must not be receiving any other pension. You must be personally meeting the daily needs of the person being cared for and be living in the same house or in an adjacent home. The carer payment is both income tested and assets tested.

From 1 July 1993, you may also be eligible for a Carer Payment if the person you are caring for is 16 years or older, but not getting a pension from DSS or DVA because they have not lived in Australia long enough.

Child Disability Allowance

This allowance is paid for persons providing care for a disabled dependent child in their home. Payment is not tied to the level of disability or to the cost of care provided, but to the level of care required. The allowance is not income or assets tested.

Domiciliary Nursing Care Benefit

This benefit is paid by the Commonwealth Department of Health and Family Services, not by the DSS. It is not means tested and is tax-free.

It gives financial assistance to those caring at home for a person who has been assessed as requiring nursing home level of care.

To receive this benefit the person you are caring for must:

- need help with the activities of daily living such as bathing, dressing, toileting and mobility
- be at least 16 years old
- be living with you

- Have a long-term illness/disability.

You must be providing continuing care. Both a doctor and a registered nurse must sign the application form to certify that the person being cared for is in need of continuing nursing care and that adequate care is being provided.

Age Pension

Generally available to women over 60 and men 65 who have been residents of Australia for at least 10 years (there are exceptions to this - check DSS). The Age Pension is income tested and assets tested.

Disability Support Pension

This used to be called the Invalid Pension. Available to men aged 16-64 or women aged 16-59 who is unable to work for a prolonged period because of a disability.

If you get compensation or third party damages because of your disability your DSS or DVA income support payments may be affected. Check with DSS.

Health Concession Cards

Four health concession cards are currently available through DSS. These are a Pensioner Health Benefits Card, a Pharmaceutical Benefit Card, a health Benefit Card and a Health Care Card. All cards provide concessions on Pharmaceutical prescriptions. Some may also give you discounts from State, Territory and Local Government services.

For further information contact your local DSS office.

Mobility Allowance

Mobility allowance helps meet the extra cost of travel for disabled workers or trainees.

To be eligible, a person must:

- be unable to use public transport without substantial help
- be at least 16 years old
- spend at least 8 hours each week in a paid or voluntary job or doing courses which will help in finding paid work
- not be undertaking a rehabilitation program with the Commonwealth Rehabilitation Service
- not have a 'gift car' front Veterans' Affairs
- be living in Australia
- Not have received two years sales tax exemption for the purchase of a motor vehicle.

For Veterans

Other benefits are available to veterans and their widows. Contact the Department of Veterans' Affairs.

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Motor Neurone Disease: Some facts
Motor Neurone Disease: More facts

MOTOR NEURONE DISEASE ASSOCIATIONS:

are charitable organisations that aim to bring together all people concerned with MND including people with the disease, their carers and professionals.

Their objectives are:

- To ensure that people affected by MND secure the care and support they need
- To promote research into causes and treatments

Their funds are used to:

- Support research into the disease and its management
- Support the care of people with MND by:
 - providing information and advice to people with MND and their carers and to professionals involved in their care
 - offering equipment on loan in cases where this is not available front local statutory services

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