

For those who care:



A PRACTICAL GUIDE

for families of people with

NEUROLOGICAL CONDITIONS

or ACQUIRED BRAIN INJURY

BrainLink

Reducing the impact of acquired brain disorders in our community.

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INTRODUCTION

When a family member has acquired brain injury (ABI), there are many questions to be answered, much new information to absorb and many decisions and details to sort out.

ABI usually occurs as a result of serious trauma to the brain, such as a severe blow to the head or lack of oxygen or due to a neurological condition, such as Alzheimer's disease, Parkinson's, Motor Neurone Disease, Muscular Dystrophy, Multiple Sclerosis, Huntington's Disease or a Brain Tumour.

In most cases, the role of caring for someone with ABI usually falls to family members, yet there is often little time to adjust to the situation and learn how to cope. We have developed for those who care: *A Practical Guide for Families of People with Acquired Brain Injury* to help you navigate your way through this time and beyond it.

These fact sheets aim to provide a general overview of the many different aspects of caring, some useful contacts and some strategies to guide you through issues and situations that may arise. The kit does not need to be read from beginning to end, just read the parts that appear helpful.

Remember, the doctors and health care professionals supervising the care of your family member, and the support organisations dedicated to their condition

See Contacts page 7, have a wealth of information, support services and resources to offer you. Do seek their assistance.

There is also a very large network of government, community and private support services that can meet your needs as carers – everything from support groups, respite care and long-term accommodation to counselling and equipment aids.

We also have fact sheets available on a number of neurological conditions. Call us (BrainLink, Tel: 9845 2950 or free call: 1800 677 579) or email info@brainlink.org.au to request any of the following fact sheets:

- > Understanding Stroke
- > Understanding Alzheimer's
- > Understanding Parkinson's
- > Understanding Multiple Sclerosis
- > Understanding Muscular Dystrophy
- > Understanding Huntington Disease
- > Understanding Motor Neurone Disease

For contact details of these condition-specific organisations and many other useful services, **refer to page 7**.

Remember, we're here to help.



REVIEW TEAM

For Those Who Care: A Practical Guide for Families of People with Acquired Brain Injury is a joint initiative led by BrainLink, in conjunction with the Multiple Sclerosis Society of Victoria (MSSV), the Motor Neurone Disease Association (MNDA) of Victoria, the Muscular Dystrophy Association (MDA), Parkinson's Victoria, the Australian Huntington's Disease Association (AHDA) (Vic) and Alzheimer's Australia, Victoria (AAV). This compilation has undergone significant review since its original production, with the aim of making it easier to use and more relevant to our clients.

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National Dementia

Helpline:

1800 100 500
Email: alz@alzvics.asn.au
Website: www.alzheimers.org.au

Australian Huntington's Disease Association (Vic.) Inc.

PO Box 60, Holmesglen, 3148
607 Warrigal Rd,
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Tel: (03) 9563 3922
Fax: (03) 9563 3489
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Website: www.ahda.com.au

Motor Neurone Disease Association Vic.

PO Box 23, Canterbury, 3126
265 Canterbury Rd,
Canterbury, 3126
Tel: (03) 9830 2122
Free call: 1800 806 632
Fax: (03) 9830 2228
Email: info@mnd.asn.au
Website: www.mnd.asn.au

Multiple Sclerosis Society

54 Railway Rd,
Blackburn, 3130
Tel: (03) 9845 2700
Free call: 1800 287 367
Fax: (03) 9845 2777
Email: Blackburn.Reception@msaustralia.org.au
Website: www.msaustralia.org.au

Muscular Dystrophy Association (Inc)

GPO Box 2200, Nth
Melbourne, 3051
111 Boundary Rd, Nth
Melbourne, 3051
Tel: (03) 9320 9555
Free call: 1800 656 632
Fax: (03) 9320 9595
Email: info@mda.org.au
Website: www.mda.org.au

Parkinson's Victoria Inc.

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Cheltenham, 3192
Tel: (03) 9581 8700
Free call: 1800 644 189
Fax: (03) 9583 9952
Email:
info@parkinsons-vic.org.au
Website:
www.parkinsonsvic.org.au

Carers Association Victoria

Level 1, 37 Albert Street,
Footscray, 3011
Tel: (03) 9396 9500
Free call: 1800 242 636
Fax: (03) 9396 9555
Email: cav@carersvic.org.au
Website: www.carersvic.org.au

Carer Respite Centre

Information on respite care.
Free call: 1800 059 059

Lifeline

Emergency telephone
counselling.
Tel: 13 1114

Mensline

Crisis support service.
Tel: 1300 789 978

Suicide Line

Crisis support service.
Tel: 1300 651 251

Centrelink

Department of Human
Services, pension enquiries.
Tel: 13 2300
Website: www.centrelink.gov.au

Office of the Public Advocate

Information and advice on
disability, guardianship and
financial issues.
Tel: (03) 9603 9500
Free call: 1300 309 337
Website: www.publicadvocate.vic.gov.au

Elder Rights Advocacy

Advocacy for older people
through out Victoria.
Freecall: 1800 700 600
Tel: (03) 9602 3066
Email: era@era.asn.au
Website: www.era.asn.au

Pharmaceutical Benefits Scheme

Free call: 1800 020 613



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SECTION ONE

Medical Issues

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Understanding the Nervous System

THIS FACT SHEET tells you about the different parts of the nervous system — the brain, spinal cord and nerves. It explains briefly what each part does, how the different parts of the nervous system communicate with each other and the rest of the body, and discusses the effects of disease or damage to it.

The Brain

The brain is the body's control centre. It may only weigh about 1.5kg but it is estimated to have about 100 billion cells. It controls everything we do from basic body functions, such as breathing, heart beat and blood pressure to our movements, speech, senses and aspects of our personality.

Cerebral Hemispheres

The brain is divided into two cerebral hemispheres — the left hemisphere and the right hemisphere. Each hemisphere tends to specialise in certain functions but the two hemispheres work seamlessly together, sharing information.

Right hemisphere: The right hemisphere tends to be more visual, thinking in pictures. It sees, recognises and organises information for the left side to analyse and process further. Generally speaking, the right hemisphere controls muscles on the left side of the body.

Left hemisphere: The left is mostly responsible for speech, language, calculations, maths and logical abilities. It generally controls muscles on the right side of the body.

Lobes

The brain is divided further into "lobes" that handle specific areas of function.

Frontal lobes: The frontal lobes look after planning, organising, reasoning, decision-making, judgement and the emotions.

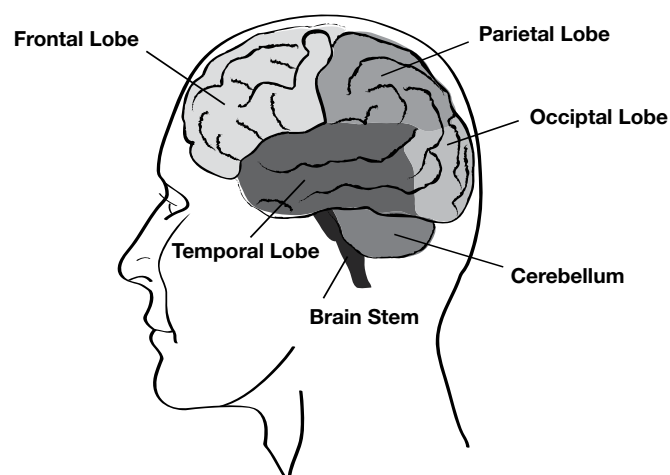
Parietal lobes: The parietal lobes are concerned with the perception of sensations, such as touch,

pressure, temperature, pain and the understanding of words and sentences, reading and writing and sometimes the ability to use numbers. They deal with spatial awareness, such as our ability to find our way around a house, to drive a car and to reach for objects

Temporal lobes: The temporal lobes also have a role in language, particularly in the ability to hear and understand it. They are concerned with memory, the emotions, the ability to enjoy music and to recognise and identify things we see, such as faces or objects.

Occipital lobes: The occipital lobes are primarily concerned with vision but also with our ability to recognise what we see in terms of identifying colours, locating objects in the environment and seeing objects accurately.

You can see how damage to the brain can affect many different functions and abilities.



Cerebellum and Brain Stem

Below the cerebral hemispheres are the cerebellum and the brain stem, which connect with the spinal cord.

Cerebellum: The cerebellum is involved in “doing” rather than “thinking” activities. It carries out orders from the cerebral hemispheres above and keeps a number of vital but routine functions kicking over, such as maintaining balance and ensuring our muscles move in a smooth, coordinated way.

Brain stem: The brain stem controls many vital functions including breathing, blood pressure, blood circulation, swallowing, appetite, body temperature and digestion, as well as the need for water, staying awake and sleeping, among other things. It is also the main route for nerve fibres running between the cerebral hemispheres and the spinal cord. Any damage in the brain stem can produce widespread and profound effects.

The Nervous System

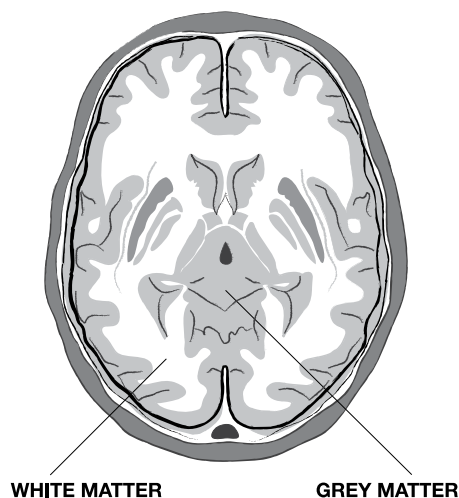
The brain communicates messages through a complex network of nerves that travel throughout our body.

Nervous system: Together, the brain and nerves are known as the nervous system.

Central nervous system: The spinal cord and the brain make up the central nervous system.

Peripheral nervous system: On their own, the nerves that run throughout our body are called the peripheral nervous system. They relay information from our brain through our spinal cord to the body, and back again.

Autonomic nervous system: This is part of the peripheral nervous system. It conveys messages from all of the organs in our chest, abdomen and pelvis. For example, it manages our “fight and flight” responses, our “rest and digest” responses. It looks after the automatic activities of our heart and blood vessels and plays an important part in sexual response and bladder control.

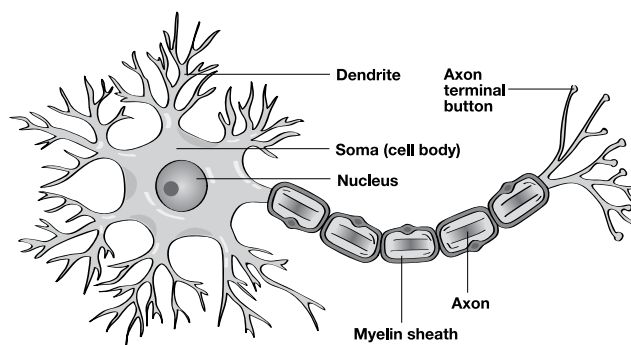


Neurones – Basic Building Blocks

The basic building blocks of the nervous system are nerve cells or neurones. We are born with about 100 billion neurones that must last a lifetime. Unlike all the other cells in the body, neurones do not replace themselves if they die or are damaged.

Grey matter: When neurones cluster together, they form grey matter on the outer part of the brain and inner part of the spinal cord.

White matter: White matter is found on the inner part of the brain and outer part of the spinal cord. It is made up of bundles of nerve fibres called axons, which are really just the long, thin extensions of neurones. These axons are covered by a white, fatty substance called myelin (hence the term “white matter”), which insulates them, like the plastic coating of an electric wire. The axons then bundle together, like the individual telegraph wires in a cable, to form a nerve.



How it all Works

The brain is in constant contact with all parts of the body, sending instructions and receiving feedback from the senses. The axons carry these messages as tiny electrical currents or nerve impulses.

Outgoing messages: motor neurones Messages sent from the brain to activate the muscles of the body travel along the motor pathways. The neurones that make up these pathways are called motor neurones.

Incoming messages: sensory neurones Messages sent from the senses back to the spinal cord and brain come along the sensory pathways. These are called sensory neurones.

How Change Affects the Nervous System

Various conditions from illness (encephalitis) and incidents (heart attack, stroke) to accidents (near drowning, a skateboarding fall) can cause brain damage, which affect the way the nervous system functions by:

- > Affecting brain function itself.
- > Affecting the brain's ability to communicate with the rest of the body.
- > Affecting the ability of muscles to respond to the brain's orders (nerve impulses).

Acquired brain injury (ABI): Damage to the brain is called acquired brain injury. An accident, illness or incident can cause direct injury to the brain cells and any interruption to the blood supply to the brain may also cause damage. Without a constant blood supply, the brain is unable to maintain its extraordinary level of functionality.

For example, a lack of oxygen (hypoxia) during near drowning affects blood supply to the brain, as does severe bleeding in other parts of the body or any excessive pressure within the skull, which might occur due to brain swelling or bruising.

Changes to the brain and nervous system can lead to the following kinds of issues.

Medical problems: Headache and epilepsy are two of the most common.

Sensory difficulties: Sight, hearing, touch, smell, taste, body-temperature control and awareness of body position can be affected. For example, some people may become hypersensitive to sound, heat or cold. Others may lose awareness of body position, which creates problems with buttoning shirts, using a spoon or stepping off a curb safely.

Physical difficulties: The most obvious problems are paralysis and limb weakness or problems with coordination, balance and tremor. Fatigue is also very common.

Thinking abilities: Poor concentration, memory loss and difficulties in planning, organising, problem-solving, abstract thinking and responding effectively may arise. Slowness in thinking is very common.

Communication and speech difficulties: Speech may be affected by becoming slurred or difficult to understand. Some people may have trouble swallowing. Others have difficulties using language, such as finding the right words or understanding sentences.

Behaviour: A person may become aggressive, lack initiative or be poorly motivated. They may have difficulty regulating their own behaviour in a way that is socially acceptable. For example, a person with ABI may make inappropriate jokes.

Personality: Personality changes can occur as a result of damage to the brain. One example is having difficulty regulating emotional responses: a person may become irritable or they may laugh or cry too easily.

Personality change can also be the result of a person's reaction to having ABI, which is often the case with depression.

Some of the effects of ABI are obvious and profound while others are subtle, yet disabling. The effects will vary widely from person to person and the recovery process may continue over many years.

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Getting the Best from the Health Care Team

THIS FACT SHEET describes the roles of health care professionals you may meet. It discusses strategies for getting the information you need and related matters such as confidentiality, seeking second opinions, managing difficult communications and guardianship issues

Health Care Team

When a family member suffers a brain injury or neurological condition, there is much new information to absorb. It can be difficult to know who the best person is to answer your questions.

The following professionals are typical members of a health care team whom you may meet while at hospital, during rehabilitation or back at home.

If you need assistance from an interpreter to speak to a doctor or therapist, just contact this free service:

The Translating and Interpreting Service:
telephone 131 450.

Consider keeping a diary of problems, symptoms and past treatments – the team can make better decisions when it has an accurate medical history and record of a person's progress.

Case manager: Case managers plan and coordinate many aspects of a person's care, link people to appropriate services, locate funding and help reintegrate them into the community.

Dietitian: Dietitians tailor diets according to a person's capabilities (e.g. difficulty eating and swallowing) and to other short and long-term issues associated with their condition.

District or community nurse: These nurses provide a range of services to people in their own homes. Your general practitioner can refer you to this community service.

General practitioner (GP): A GP is often the first point of contact after leaving hospital and may coordinate visits with other members of the health care team.

Neurologist: Neurologists specialise in conditions that affect the brain or the nervous system. They diagnose conditions, decide on appropriate treatment and monitor progress.

Neuropsychologist: Neuro- psychologists understand how brain damage can affect thinking, memory, behaviour and personality. They perform assessments to identify which functions have changed and suggest strategies to help manage changes.

Neurosurgeon: Neurosurgeons operate on the brain and spinal cord.

Occupational therapist: An occupational therapist assesses a person's ability to manage daily tasks and recommends any home modifications or physical aids they may need. They also help people to re-learn skills, such as how to dress, prepare meals or maintain hygiene.

Physiotherapist: Physiotherapists work on a person's ability to move, coordinate and balance. They can help relieve muscle stiffness, develop exercise programs and can also assess the need for mobility aids.

Psychiatrist: Psychiatrists deal with disorders of the mind. Some are experts in the personality and behaviour changes caused by brain damage. Treatments may involve counselling and medication.

Psychologist: Psychologists help people manage their reactions to things like anxiety or challenging situations. In the case of brain injury, they help people to manage problems that are an emotional reaction to having acquired brain injury.

Rehabilitation specialist: These specialists aim to prevent or reduce disability after brain damage through various physical therapies and activities. They help a person to become as independent as possible so that they can re-establish their life at home and community connections.

Social worker: Social workers help people locate special accommodation needs, useful community and government services, support groups and provide advice on welfare benefits.

Speech pathologist: Speech pathologists help people overcome problems with speaking and swallowing.

Confidentiality between Doctors and Patients

Getting the information you want is not always a straightforward process. Families sometimes feel challenged by the confidential bond between a doctor and patient.

A person undergoing treatment can tell their doctor not to give out any information about their condition to relatives, which can be difficult for family members involved in the person's care. The doctor must respect that wish unless the carer or relative is also the person's legal guardian.

A relative or carer can make an appointment to see the doctor and share any concerns they have, however. The doctor may then consider those concerns when treating the family member.

Obtaining Information

These tips can help your family get the information you need:

- > Make a list of questions and book an appointment of sufficient length to answer them.
- > Make appointments for the time of day when the person with acquired brain injury is most alert if fatigue is an issue.
- > Families, be sensitive if discussing issues about a person's unusual new behaviour in their presence or make a separate appointment to discuss your concerns.

- > Take notes at appointments or bring someone along who can help to remember information and take notes too.
- > If you don't understand something, ask the health professional to explain again.
- > Ask for printed material on the condition or where to get information and support.
- > Ask the health professional to write a list of medications and what each does.
- > Ask for the results of any test, procedure or diagnosis and for explanations of each.
- > Before leaving hospital or rehabilitation, ask each member of your health care team to write down the treatments that will be required at home.

Seeking Second Opinions

Some patients may want to seek a second opinion but feel uncomfortable about doing it.

It's perfectly OK to seek a second opinion on a person's condition from another health care professional.

Doctors and therapists are normally happy to suggest someone else or to provide a referral to any specialist you name. Ask for the medical records to be sent to the second doctor. After seeing the second doctor, you are free to choose your preferred specialist.

Making Decisions

The person with the brain injury usually deals directly with the health care team. Sometimes however, family members or carers end up being the main point of contact.

If a person's brain injury affects their capacity to make informed decisions or provide informed consent about their treatment, you need to find out if they have appointed – or whether there is a legal order in place that allows – someone to act on their behalf at unexpected times like these.

Enduring Power of Attorney: An Enduring Power of Attorney (Medical Treatment) is a legal document in which a person appoints someone to make medical treatment decisions on their behalf in the event that at some point in the future they lose their capacity to make those decisions themselves.

If there is no formal order in place, the closest relative is legally allowed to consent to health care treatment and is expected to make decisions that – to the best of their knowledge – reflect the known wishes of the person.

Legal Guardian: If there is difficulty in establishing the appropriate decision-maker or there are doubts about the injured person's wishes or if there are differences of opinion about what course of action to take, the Victorian Civil and Administrative Tribunal (VCAT) can help you to appoint a legal guardian.

Administrator: VCAT can help you to appoint an administrator if a person is not able to manage their own legal or financial affairs. For further information on these matters, contact:

VCAT

telephone (03) 9628 9911 or free call:
1800 133 055.

The Office of the Public Advocate

Tel: (03) 9603 9500 or freecall 1300 309 337
Website: www.publicadvocate.vic.gov.au

Handling Difficult Communications

It's important that you remain well informed by gathering information and maintaining effective communications, but at times you may feel frustrated by the process.

Client relations manager: All hospitals have a staff member called a "client relations manager" or "patient-client advocate" whose role is to assist patients and their relatives with concerns or complaints about treatment or care. Ask to see them if you are having difficulties.

If you feel angry or upset, you gain little by directing your frustrations at a health professional. Here are two communication strategies that encourage helpful responses by avoiding blameful tactics.

Try using "I feel" statements and "I" statements, rather than "you" statements.

How to use "I feel" statements

Instead of: "You people don't tell me a damn thing!"

Try saying: "I feel so frustrated because I don't understand this. Can you recommend someone for me to speak to?"

Instead of: "If you'd slow down I might understand this mumbo jumbo!"

Try saying: "I feel overwhelmed with all this new information. It would help a lot to hear that again more slowly."

How to use "I" statements instead of "You" statements

Instead of: "You're just drugging Dad to the eyeballs!"

Try saying: "I'm worried about the effect of the drugs. What other options are there?"

Instead of: "You've got to do something. She's driving me crazy!"

Try saying: "I need help. I'm really struggling to cope with Mum at this point."

Contact

Major hospitals, rehabilitation centres and GPs can supply contact details for all these health care professionals or ask for a referral from the medical centre where main treatment occurs.

Australian Physiotherapy Association

Tel: 1300 306 622

Australian Psychological Society

Tel: (03) 8662 3300.

Australian Association of Social Workers

Tel: 03 9602 5097

Occupational Therapy Australia, Victoria

Tel: (03) 9481 6866.

Speech Pathology Australia

Tel: (03) 9642 4899.

Nurse-on-Call

This 24-hour, 7-day service puts you in touch with a registered nurse for professional health information and advice for the cost of a local call.

Tel: 1300 60 60 24.

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Tests and Technology

THIS FACT SHEET covers the various tests that are used in diagnosing and assessing patients who have acquired brain injury or a neurological condition.

Angiography

Angiography describes different ways of looking at the blood vessels of the brain. In catheter angiography, the radiologist (an X-ray specialist) inserts a catheter (a long, thin, flexible tube) into an artery in the groin. The radiologist moves the catheter through the arteries to the carotid artery in the neck, guiding the progress on X-ray. The catheter then releases a special dye and X-rays are taken as the dye flows through the blood vessels of the brain. This gives a very good picture of the blood vessels.

This is usually done as a day procedure in hospital. It takes about half an hour but you need to rest at hospital for a few hours afterwards because sedation or anaesthetic is required for the procedure. People occasionally stay overnight.

Catheter angiography is uncomfortable and there is a slight risk that it may cause a stroke or other less serious side effects. A less invasive procedure is Magnetic Resonance Angiography (MRA), which uses Magnetic Resonance Imaging technology (see MRI). MRA has no side effects but the picture it provides is not as good as the one produced by catheter angiography.

CT Scan

A CT scan (a Computerised Tomography scan, sometimes called a CAT scan) uses a scanner that encircles the person's head or body without touching it (it looks a bit like a very large doughnut). It takes X-ray pictures from many angles. A computer then uses these images to build cross-sectional pictures of the brain or another part

of the body. To make the detail clearer, a dye may be injected into a vein (usually in the arm), which may make the person feel briefly hot all over.

The test takes up to half an hour to complete and is painless. Most people can go home straight afterwards.

Spiral CT: Spiral CT is a new technique still being developed. The process for the patient is the same as the CT scan but the computer creates a three-dimensional, rather than two-dimensional, image on the screen that can be viewed from various angles.

EEG

An EEG (electroencephalogram) is a test to detect abnormalities in the electrical activity of the brain. Brain cells communicate by producing tiny electrical impulses. In an EEG, electrodes (flat metal discs) are placed on the scalp over different areas of the brain to detect and record patterns of electrical activity.

EEG is used to help diagnose the presence of several types of seizure disorder, such as epilepsy, and to look for causes behind unclear or confused thinking. It is used to evaluate head injuries, tumours, infections, degenerative diseases and metabolic disturbances that affect the brain.

The test is performed by an EEG technician in a specially designed room that may be in your health care provider's office or at a hospital. You will be asked to lie on your back on a table or in a reclining chair.

The technician will apply between 16 and 25 electrodes at different positions on your scalp.

The discs are held in place with a sticky paste and are connected by wires to an amplifier and a recording machine. The recording machine converts the electrical signals into a series of wavy lines that are drawn onto a moving piece of graph paper.

You need to lie still with your eyes closed, as any movement can alter the results. You may be asked to do certain things during the recording, such as to breathe deeply and rapidly for several minutes or to look at a bright, flickering light. This test causes no discomfort.

EMG

An EMG (Electromyography) measures electrical activity in muscle and can look in detail at small areas of muscle. It involves putting an electrode (in the shape of a fine needle) into the muscle at different points. It can be slightly uncomfortable but it has no after-effects. Sometimes a flat electrode is used on the person's skin.

Lumbar Puncture

In this procedure, a needle is inserted between vertebrae in the lower back to draw off some of the cerebrospinal fluid – the special fluid that bathes and cushions the central nervous system (the brain and spinal cord). A local anaesthetic may be given and some discomfort may be felt as the needle is inserted. This test can be used in conjunction with other tests to confirm a diagnosis of multiple sclerosis.

MRI

MRI (Magnetic Resonance Imaging) is similar to a CT scan but uses magnetism instead of X-rays to build cross-sectional pictures of part of the body. The magnetism comes from a large metal cylinder, which is open at both ends. The person lies on a couch inside this cylinder. Safe, low-energy radio waves are then passed into your body and absorbed by some of the tissues, which reflect back the radio waves. The magnet is turned on and off and reads these radio waves while the computer records this information and generates a two- or three-dimensional picture. Diseased tissue gives

off a different signal to healthy tissue, which the machine detects.

The test may take up to an hour to complete. MRI is painless and the magnetism is harmless but the cylinder makes some people feel claustrophobic. MRI cannot be used on anyone who is pregnant or who has a pacemaker.

Muscle Biopsy

This involves removing a small piece of muscle under a general or local anaesthetic, which is then sent to a laboratory for examination. It is used to confirm a diagnosis of muscular dystrophy.

Nerve Conduction Studies

Nerve Conduction Studies (NCS) look at how nerves are functioning. Electrodes (small flat discs) are placed over a nerve or muscle that is then stimulated using a small hand-held stimulator. The person will feel a mild prickling sensation. The electrodes pick up the resulting muscle activity. The test is quick, simple to do and is pain free.

PET Scan

A PET (Positron Emission Tomography) scan is another technique used to build cross-sectional pictures of the body. The person is injected with a glucose solution containing a very small amount of radioactive material. The scanner can "see" the radioactive substance and this shows the areas where cells are using the glucose. Healthy cells in the body pick up and use the glucose but damaged cells show up as areas where the glucose is ignored. Other than a minor injection, the scan is painless. The radioactivity fades quickly and has no known after-effects.

SPECT

SPECT (Single Positron Emission Computed Tomography) is similar to a PET scan but uses two cameras to build a three-dimensional image that can be studied from different angles on a screen.

Ultrasound

Ultrasound involves the use of very high frequency sound waves, higher than the human ear can hear. It is often used to investigate the arteries in the neck (carotid arteries) in relation to stroke. The person doing the test (an ultrasonographer) moves a small probe over the part of the body being investigated. When ultrasound is directed at the body part, the soundwaves “echo back” at different rates according to the different types of tissue detected. The computer measures these differences in tissue to build a picture that is displayed on a TV monitor.

The process takes about 15 or 20 minutes, is painless and has no after-effects. Ultrasound can also be used to generate heat in body tissues to relieve muscle tension or strain.

Videofluoroscopy

This is an X-ray of someone swallowing. The person is X-rayed with a video X-ray camera while swallowing spoonfuls of food or drink that contain a special substance that shows up on X-rays. The moving image is recorded on videotape. It shows clearly how the swallowing muscles are working and if any food or liquid is escaping into the lungs. The procedure takes 10 to 20 minutes.

Visual Evoked Response

The Visual Evoked Response (VER) test assesses brain function – particularly those parts involved in vision – by measuring electrical activity in the brain. A number of electrodes (small flat discs) are placed on the person’s scalp using a clear jelly (the hair may need a wash afterwards) and are held there by something that looks like a rubber hair net. The electrodes pick up and record brain activity while the person watches a flashing light or a changing pattern of lights. VER is painless and has no side-effects.

Managing Medications

THIS FACT SHEET discusses the information you need to know about medications being taken, problems that can occur and how to manage medications safely.

As people get older, they often end up taking a range of medications for various conditions. Medications can have side effects that differ from person to person or with age, because the body processes them differently. Depression and confusion are common side effects.

Drugs can also interact with each other. The interactions can be difficult to predict and may cause unexpected side effects: one or other drug may become less effective, for example. The more medications a person takes, the more likely such interactions are.

Reducing distress and agitation can also help to reduce the number of medications a person needs. Encourage the person you are caring for to have a social life, to get out and about, to be involved in activities that hold their interest and to stay as physically active as possible.

Medication Don'ts

Don't stop using a prescribed medicine unless the doctor tells you to. Some medicines are not effective unless they are used all the time and for a long period.

Don't use other people's medicines.

Don't use medicines that are out of date. They may no longer be effective.

Don't keep old or unused medicines. Your pharmacist can dispose of them for you.

Don't change the dose or the time the medicine is taken without the doctor's advice.

Questions You Should Ask

Do ask questions of your doctor, pharmacist or nurse. If you don't understand something, ask

for it to be explained in simpler terms. If you need an interpreter, ask for one. It is important to understand the following points about any medication.

Checklist

- > What is the name of the medicine and what is it for?
- > Are there any possible side effects? Will they fade with time or continue as long as the person is taking the drug? What should you do if there are side effects?
- > How long should the person be taking the medicine?
- > What should you do if a dose is missed?
- > Will the medicines interfere with others being taken? Take a list of all the person's medicines or all the medicine containers with you.
- > Will the medicine affect other medical problems the person has?
- > Is there anything the person should avoid doing or taking while on this medication? (e.g. alcohol)
- > Is there a lower priced brand? Often the same medicine is available more cheaply packaged under a different name by another company.

Using Medicines Safely at Home

Use a "dosette" box: These plastic containers come in different shapes and sizes and have compartments labelled by days of the week and meal times. A dosette enables you to organise the week's medications and prevents uncertainty about whether or not a medicine has been taken. Pharmacists carry them. If you are unsure about

organising tablets, your district nurse or pharmacist may be able to help.

Follow the directions: Follow directions given by the doctor, pharmacist or those on the bottle. Directions should include how much of the medicine to take (e.g. 2 tablets), how often to take it (e.g. once a day), how to take it (e.g. by mouth) and when to take it (e.g. with meals).

Take medicines at the correct time: Some medicines work best on an empty stomach, others should be taken with food. The doctor or pharmacist can advise.

Obey warnings on the label: For example, it is dangerous to drink alcohol or operate machinery while taking many medicines.

Take note of side effects: Make a note of any side effects that occur, such as drowsiness, forgetfulness, confusion or nausea, and discuss these with your family member and/or your doctor.

Keep a record: Make sure you keep a record of what is being taken. Sometimes new drugs are prescribed without the doctor being aware of what other medications the person is on. Taking a newly prescribed drug on top of other tablets can cause serious side effects.

Use a "Medi-list" form, available from your pharmacist, to keep record. It allows you to list all the drugs, when to take them and the dosages. The pharmacist can help you fill it out and keep it up to date. Take it whenever you go to see any health professional (doctor, pharmacist, specialist, dentist etc).

Inform your doctor: Make sure your doctor knows *all* the medications, preparations and supplements being taken and whether these are prescribed by a doctor, bought over the counter or provided by another practitioner.

Label bottles: Make sure bottles are labelled properly. A bottle labelled "as before" or "take as directed" can be dangerous for a person who does not remember the previous instructions.

Keep medicines away from children: Keep medicines in a child-proof cabinet. *Never*

store medications in a container that could be mistaken for something else – use the correctly labelled and dated container. Likewise, don't use the empty medicine bottles to store other things.

Storage: Read the label to find out how the medicine should be stored. Heat, in particular, can affect medicines.

Lack of response: Go back to the doctor if the medicine does not seem to be working.

Cost of Medicines

If the person you care for has one of a number of concession entitlement cards, they pay \$4.70 for each PBS medication. Ask your pharmacist if they are eligible. If your family member spends more than \$253.80 in a calendar year on medicine, any further prescriptions during that year will be free. For people without concession cards, PBS medicines cost no more than \$29.50. If a family spends \$960.10 within one year, any further medicines that year will cost no more than \$4.70 each. If the person you care for has one of a number of concession entitlement cards, they pay \$4.70 for each PBS medication. Ask your pharmacist if they are eligible. If your family member spends more than \$253.80 in a calendar year on medicine, any further prescriptions during that year will be free. For people without concession cards, PBS medicines cost no more than \$29.50. If a family spends \$960.10 within one year, any further medicines that year will cost no more than \$4.70 each. To be eligible for the "safety net", the pharmacist or hospital must list each medicine you buy on a "Prescription Record Form". You can get a form from your pharmacist. Keep it with the Medi-list and take both lists with you whenever you visit a pharmacy or hospital.

This information is correct as of May, 2006.

For up-to-date information, contact your pharmacist, condition-specific support organisation or Centrelink Pharmaceutical Benefits Information: free call 132 468 or visit website: www.humanservices.gov.au.

Nurse-onCall

Tel: 1300 60 60 24

Assessing Complementary & Alternative Treatments

THIS FACT SHEET discusses the difference between conventional, complementary and alternative treatment. It suggests how to assess these treatments and their practitioners, and offers a range of issues to consider and questions to ask

There are many practitioners offering therapies and treatments outside mainstream medicine and Australians are turning more and more to these approaches.

You and the person you care for are likely to receive lots of advice and information about treatments and remedies from many sources – doctors, friends, family, pamphlets, workmates, magazines, newspapers, books, shops, the radio and the internet. Some of it will be sound and useful. Some may be confusing or misleading. We offer the following information as a guideline to help sort through your options and make the best choices.

What are Complementary and Alternative Treatments?

Broadly speaking, in our society there are three main types of treatment and therapy available:

- Conventional treatment
- Complementary treatment
- Alternative treatment

You may hear a variety of terms used to describe treatments: “mainstream” and “conventional” refer to the same approach, while the words “complementary” and “alternative” are often used interchangeably for treatments, when they are not.

“Holistic” and “integrated” are also popular terms. Generally speaking, these terms most often refer to complementary approaches that take into account the whole person and influencing factors on their health such as diet, their emotional, mental and spiritual states, and the environment in which they live and work.

Conventional treatments: These are the basis of the Western health system. Mainstream treatments are generally based on scientific evidence and the

benefits and side effects are usually well known.

In the case of acquired brain injury, your family member might undergo conventional treatments such as surgery, medication, physiotherapy, speech therapy, occupational therapy or psychotherapy.

Complementary treatments: These are used in conjunction with conventional medicine and are generally based on more natural methods. These treatments are often well established in other cultures that have successfully used them for hundreds or even thousands of years.

Complementary treatments might include traditional Chinese medicine, naturopathy, homeopathy, herbalism, acupressure, acupuncture, chiropractic, kinesiology, Reiki, reflexology and iridology. They are offered by non-medical practitioners.

In addition, complementary therapies might include meditation, massage, yoga, tai chi, dance, other forms of exercise, spiritual practices, relaxation techniques, music, nutrition, aromatherapy, hypnotherapy and certain activities, such as gardening and art and crafts.

Alternative treatment: Alternative treatments are used instead of conventional treatments. These tend to be approaches about which little or nothing is known from a scientific perspective.

People who use alternative therapies have generally done their own research by speaking to the practitioners and their clients and reading whatever information is available about the approach. Examples of treatments include ozone therapy, taking large doses of vitamin supplements, taking special vegetable or fruit juices or a radical approach to diet and nutrition.

Issues to Consider

Complementary therapies can make a wonderful difference to a person's quality of life and overall well being and many are proven in these capacities.

Alternative approaches can also be useful and some may claim to offer anything from dramatic improvements in a condition (or for particular groups of patients) to cures, although there may be no scientific evidence to support this.

With conventional, complementary and alternative approaches, miracles do happen – so do mistakes. People may use one or a combination of these approaches with varying levels of success. It is important to make well informed choices. This is your body, your health, your life and how you choose to handle it is your responsibility.

When we are ill or challenged however, it can be very difficult to maintain clear thinking and motivation. Researching your options and settling on treatment and therapy that *feels right for you* is part of the journey – do enlist trusted family and friends to help you gather all the information you need.

Check qualifications: It helps to know what level of training your practitioner has had and how much experience they have had treating people. Also, check to see whether they belong to a professional association that has a charter or code of ethics and ask how many practitioners belong to that organisation. Remember, the title “doctor” does not necessarily mean they are a medical doctor.

Assess the environment: Make sure you are comfortable with the practitioner's working environment. Does it appear hygienic, professional and well equipped for the task? Are any remedies or treatments used prepared in accordance with some standard of practice or quality assurance?

Talk to your doctor: If you decide to try other treatments while continuing mainstream approaches, it is very important to keep your doctor and/or specialists informed. New treatments may interfere with conventional treatments or even exacerbate their effects, as can happen when taking large amounts of vitamin supplements, for example. Your doctor or specialist may also have additional information on

the proposed treatment and be aware of other benefits, possible side effects or its potential to cause harm. The better informed you are of the proposed treatment, the better able your doctor is to advise you.

Some people find it difficult to discuss non-mainstream treatments with their doctor. If you feel uncomfortable, try this approach:

“I keep hearing about the ____ treatment. Can you tell me why some doctors don't accept it? Why do some people think it works and others believe it doesn't? Can it help me at all?”

You have simply asked for information. You have not attacked the treatment you are receiving or the people treating you.

Costs: Some therapies and treatments can be very expensive at a time when the illness may already be placing you under financial strain. Ask if there will be extra costs, such as further courses of treatment, living-away-from-home costs, travel, further tests etc.

Independent sources of information: When assessing complementary or alternative therapies it is best to consult a range of people. It may be possible to speak with some of the practitioner's clients, for example, but try to find others who have considered the treatment who are not nominated by the practitioner.

For example, condition-specific support groups (either local or internet-based) can be excellent sources of well researched information. Ask whether anyone has assessed the approach and their reasons for going with it or deciding against it. Your condition-specific support organisation may have further information, too. Or you may feel more comfortable asking a trusted specialist for advice.

A biased approach: The health industry provides vital services but like any other, it also exists to make a profit. Be aware that some practitioners you consult (conventional, complementary or alternative) may receive some kind of benefit from supporting a particular treatment or product associated with that treatment. As a result, you may not be offered the widest selection of treatments available.

Questions to Ask

How can this treatment maintain or improve my quality of life and general health?

What does the treatment involve?

Are there any known side-effects?

What is the cost and the duration of the treatment?

What evidence is there that it works?

Has the practitioner worked with others who have the same condition as you (e.g. Parkinson's or Multiple Sclerosis)? Can you speak to any of them?

How many people has it helped? (Claims can be made on the experience of one or two people.)

Is there any information on the number of people who used the remedy but received no benefit from it?

Will it affect mainstream treatments?

If the treatment is only offered overseas, can it be brought back through Australian Customs?

If the person uses the title "Doctor" or "Professor", do the titles refer to medical qualifications recognised in Australia?

Resources

The disability division of the Department of Human Services has a website that contains a range of very useful health information fact sheets on complementary therapies. Visit www.disability.vic.gov.au



SECTION TWO

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Changes in Thinking and Behaviour

THIS FACT SHEET describes the types of changes that can occur in thinking and behaviour due to acquired brain injury (ABI) and suggests some strategies to help manage or compensate for those changes.

After a diagnosis of acquired brain injury (ABI), changes often occur in a person's thinking and behaviour that can be very challenging to live with for the person concerned and their carers and family.

It's sometimes more difficult to adjust to these changes than the physical ones because they are harder to perceive and to associate with a condition. For example, irritability and sitting around the house all day could become common behaviours for someone with ABI. Someone with multiple sclerosis might cry easily and often be exhausted.

A brain injury can alter a person's personality quite dramatically too.

Friends, relatives, employers, even a spouse, may not understand or readily accept these sorts of changes. But there are plenty of management and coping strategies to help your situation. A neuropsychologist can make an assessment of changes that have occurred and devise a plan for both the person and their carer.

In general, the best approach is to help the person help themselves; to do things independently.

Attention and Concentration

When it is difficult to pay attention and concentrate on one thing, it's hard to take in information and to learn, such as working out how to use a new mobile phone. Be realistic about a person's abilities to learn new skills and routines. These strategies may help them to focus.

- > Repetition helps, going over the same thing again and again.

- > Minimise distracting background noise, such as radio, TV, or people talking nearby.
- > Tackle new or difficult things when the person is fresh. Stress and fatigue make concentration more difficult.
- > Say things as often as necessary and think of ways to help the person remember. For example, to help remember people's names, try associating a new person's name with a physical feature – "Carole with the curls".
- > Try to avoid saying – "I've just told you that" – it's very disheartening.
- > Say things simply, one at a time – "Do you want porridge?" wait for the answer then, "Do you want a cup of tea?".

Memory

If short-term memory is a problem, the person may not be able to remember a string of requests, follow directions or remember how to pay a bill on the internet, but their old memories remain intact. Consider these strategies.

- > Use a large calendar that shows the day and date.
- > Keep a daily routine. If you break the routine (e.g. going to visit friends), give the person a written list or timetable to refer to so they feel more in control.
- > Help the person to use a daily planner to write down jobs and routines, keep it in the same place. Encourage its regular use.
- > Help to jot down names of new acquaintances, old friends, and details of important conversations to remember.
- > Talk about things from the past that the person does remember.

- > For people with severe memory problems, use labels on rooms, drawers, shelves and objects.
- > Use existing skills and abilities and try to find activities that don't require much learning.
- > Minimise stress and fatigue – these can hamper memory.

Planning, Organisation and Problem-Solving

If the brain loses its capacity to plan, organise or solve problems effectively, a person may have difficulty making decisions, organising their time and working out how to do things like cooking a meal. They may also have trouble knowing when, where and how to ask for help.

Some people cope with familiar tasks but need help with new or complex ones. Others need help organising the simplest tasks, such as changing clothes. Some people become unable to see the consequences of their actions and find it difficult to learn from their mistakes. Others have trouble applying their knowledge in different circumstances – they learn to manage the toilet at the rehabilitation centre, but not at home. Keep the following suggestions in mind:

- > Use a daily planner and stick to a routine.
- > Help write down things that need to be done over days/weeks and use a diary for important events.
- > Encourage the person to do one thing at a time.
- > Break tasks into small steps to be completed every time. Rehearse the steps, talking through them, one by one. Then remind them gently of each step as they come to it – “Fill the kettle, now plug it in. Switch it on, right. Get the tea cups ...”
- > Keep things needed for everyday tasks in the same place.
- > Encourage the person to do things independently. Don't complete tasks for them.
- > Minimise distractions and let them do things in their own time.

Spatial Difficulties

A person's understanding of how things relate to each other in space may be affected. For instance, they may have difficulties moving through a doorway, putting on a shirt, setting the table or finding their way to the bathroom. Once they can understand the problem, some people compensate well, others will always need their carers to help them. Visual perception difficulties have a similar impact and are discussed in Fact Sheet 12: Vision Problems.

It may help to:

- > Talk through activities as you do them – “Come into the hall, walk straight ahead...” – arrows on the floor can also help at home.
- > Draw attention to objects or activities on the affected (non-seeing) side.
- > When moving about, encourage the person to set orientation landmarks that are meaningful to them.

Insight and Awareness

Brain injury or an illness that affects the brain, like dementia, can leave some people with little understanding and awareness of their disabilities. This can lead to someone attempting things beyond their capabilities, for example or being less able to monitor their behaviour or understand its effect on others (e.g. speaking too loudly).

A person may find it difficult to understand social niceties and other people's feelings. Others may not pick up on the usual indicators that you are tired or unhappy. A person's personality can change in a variety of ways too, becoming more self-absorbed perhaps, or withdrawn.

- > As difficult as it can be, try to be reassuring toward the person. These changes are the result of their condition and are often very disturbing for them too.
- > Allow the person to make decisions (as much as possible).
- > Be clear about their ability to take risks. Set clear limits and communicate these to them in a simple, straightforward manner.
- > If the person's behaviour is annoying, try to distract them with something else to do.

Use positive statements like “Try this”, instead of “Stop that”.

- > Explain the effect their behaviour has on others by using clear, straightforward words. Dropping hints won’t work.
- > Accept their comments – arguing only makes matters worse.
- > If the person is confused easily, maintain a quiet, familiar environment and limit visitors.

Loss of Control or Disinhibition

When people experience loss of control or disinhibition in their behaviour, it can be disturbing and taxing on carers and families. It’s hard when a loved one’s condition causes them to become an incessant talker or to have aggressive outbursts regularly. Perhaps they are restless, fidgeting and pacing or wandering off and getting lost. They may be impulsive in new ways from spending money to overeating. Disinhibition can also lead to making persistent sexual demands on a partner or inappropriate sexual remarks. Try these tips when managing behaviour:

- > Become aware of situations and triggers that can provoke unacceptable behaviour and avoid them.
- > When awkward moments occur, it’s best not to react. Simply say “this is not the place for that” and move on to another topic. Ask others to do the same.
- > Occasionally, actions may cause emotional hurt or distress. Encourage people not to take it personally.
- > Remember, arguing only makes matters worse.
- > Create a safe environment so that outbursts won’t result in injuries – remove yourself from the situation if necessary.
- > If possible, allow the outburst to pass, but don’t ignore or trivialise behaviour that might harm others – take steps to defuse it.
- > When addressing the person’s behaviour, be assertive and confident. Use clear “I” statements and provide an alternative:
- > “I don’t want you to do that, I want you to do this...”

- > Always reassure the person that you understand their response is part of their condition.
- > Respond in a positive manner to behaviour that is appropriate and acceptable.
- > Try to highlight what the person can do, rather than what they cannot do.

Loss of Motivation or Drive

Brain injury sometimes causes people to experience a loss of motivation, drive and the ability to get things started. This person may seem lethargic, disinterested or uncooperative. They may not wash or eat without prompting. They may fail to initiate conversations or they may sit on the couch all day. It often helps to provide cues, structure and direction.

- > Establish tasks and activities as part of a familiar routine, and provide checklists for tasks.
- > Involve them in everything that is happening, encourage them to contribute and give praise often.
- > Encourage them to do easy things that provide some stimulation – music, TV, reading, talking, crafts.
- > Find activities that are relevant and meaningful to them. Join in or ask others to participate sometimes.
- > Remember, it is okay to do nothing at times.

Other Common Effects

Fatigue and depression are both very common effects of brain injury that can make other symptoms appear worse. Fatigue is discussed in more detail in Fact Sheet II: Managing Fatigue.

Depression can be caused by a person’s condition or their psychological reaction to it. Counselling, therapy (e.g. Cognitive Behaviour Therapy) or medication can make a huge difference to a person’s mental well being. It’s important to see your doctor if you suspect depression is an issue. Sometimes changes in mood are part of a grief response or the frustrations of dealing with the situation. These are discussed in Fact Sheet I8: Grief and Loss and Fact Sheet I9: Coping with Stress.

Speech and communication difficulties, such as difficulty expressing thoughts, finding words and reading body language, are discussed in Fact Sheet 7: Speech and Communication Problems.

Seeking Support

There is no need to bear hurtful or inappropriate behaviour beyond reasonable limits.

Neuropsychologists can assess these changes and help develop behaviour management programs. Some people benefit from having a neuropsychological assessment done every few years. Occupational therapists can also help with management strategies at home or work. Speech therapists can help with communication strategies.

Respite: Carers and family members, do consider using respite care for regular breaks to ensure your own well being. Your health is important too! (See Fact Sheet 15: Respite and Residential Care).

Contacts

Try your local doctor or your condition-specific support agency (See Contacts pg 7) who can help you to decide which specialists might assist with your situation.

Specialists such as neuropsychologists, occupational therapists or speech pathologists are usually found through large hospitals or rehabilitation centres. Ask at your regular treatment centre for referrals. Or try the ABI Behaviour Consultancy, Tel: (03) 9490 7366

Speech and Communication Problems

THIS FACT SHEET describes the effects that acquired brain injury, dementia and hearing loss can have on speech and communication, and provides strategies that may assist when there are difficulties.

A brain injury can affect communication in many different ways. For example, a brain injury may lead to weak or uncoordinated muscles resulting in slurred speech or a soft, hoarse voice. The language centres of the brain may be affected, resulting in difficulty using words, forming sentences, and understanding what others say. Changes in thinking and memory may also occur.

Hearing loss can also affect a person's ability to communicate, while poor eyesight can limit reading and writing.

A speech pathologist can assess a person's communication difficulties and suggest strategies to help. A neurologist, rehabilitation specialist or condition-specific support organisation can put you in contact with a speech pathologist.

When Muscles of Speech are Affected

Dysarthria results from weakness or incoordination of the muscles involved in speech and breathing.

A person's speech may be slurred, slow and difficult to understand. Their voice may be harsh, strained, breathy, too loud or too soft. It may lose its melody and sound "flat", with little variation in tone. A person may sound expressionless, disinterested and depressed, but this may not necessarily reflect how the person is really feeling.

Because the same muscles involved in speech are involved in swallowing, a person with dysarthria may also have difficulties with eating and swallowing. (see Fact Sheet 8: Eating and Swallowing Problems).

Dyspraxia is a difficulty in planning and initiating muscle movements to form the sounds and words of speech. This may occur even when there is no paralysis or weakness of the muscles. A person with dyspraxia may have trouble finding the correct sound for a word, or moving smoothly between sounds and words.

Dysphonia is a voice disorder that results from impairment to the strength and coordination of the muscles that help to produce voice. A person with dysphonia may have trouble controlling the volume of their voice or it may tire easily. Their voice may be weak and hoarse.

Speech aids: For some people with acquired brain injury, speech becomes all but impossible. There are various aids that can help, from simple alphabet boards or whiteboards to electronic communication aids.

For more information, talk to your speech pathologist or contact equipment specialist, ComTec (Tel: (03) 9362 6111).

Strategies for Speech Difficulties

Be aware that talking may be frustrating for your family member – give them time to respond.

If you do not understand what they have said, say so. Repeat the words you have understood so they do not need to say them again.

Ask your family member to speak more slowly.

Encourage them to use shorter phrases or single words, if that makes it easier to understand them.

If soft voice is the problem, ask them to “feel as if they are shouting”. They may not be aware how soft their voice is, and what feels like shouting may be about right for the listener.

Show when you have understood –nod your head and say “I see” or repeat and rephrase the message.

It is usually best to let the person finish their sentence. Don’t anticipate what they are going to say.

If repeated attempts fail, be honest, say: “I’m sorry, I don’t understand. Let’s try again later”.

Writing may be simpler for some people. If the person cannot use a pen, see whether they can use an alphabet card to point to letters and to spell out words or a communication chart to point to pictures.

When Language Centres are Affected

Dysphasia or aphasia results from damage to the centres in the brain that control language – the way we understand and use words and sentences. These language centres are typically on the left side of the brain.

A person with dysphasia may have difficulties understanding, talking, writing, reading and using and interpreting body language.

Understanding: A person may not be able to recognise or understand words or the meaning of speech. They may not remember information they are told.

A person may become confused when too much information is presented at once, eg when more than one person is talking or when listening to a conversation.

Talking: A person may know the name of an object but not be able to find the correct word. Some people may have particular difficulty saying the small, connecting words – “the”, “and”, “to” etc. Others may use long sentences, but not use key words. Jargon or meaningless strings of words and sounds may also be present. Words may slip out unexpectedly, but the person may not be able

to repeat them. Others can use simple words and sentences well, but have trouble explaining things more complex things. Some people cannot control swearing.

Reading: A person may have trouble recognising letters, reading words or understanding sentences or paragraphs.

Writing: Apart from any weakness in the hand, a person may have trouble forming letters, writing words, constructing sentences or writing down ideas. The person may become confused when a lot of information is presented at once, such as a long sentence or a full page.

Gesture or body language: A person may have difficulty using gestures or “reading” body language. For example, they may not be able to nod their head for “yes” or hold up three fingers to indicate “three”.

Strategies for Dysphasia

Use short, simple sentences.

Use gesture to complement what you are saying e.g. point to relevant objects.

Check to see if the person has understood you. Repeat, rephrase or simplify your message if necessary.

Give the person time to speak. Don’t rush them or complete their sentences. Encourage the person to communicate, even if this takes time.

Listen for the message the person is trying to convey, not just how the words sound. It is the message that matters, not how they get it across. Any method is good if it works.

Avoid background noise and interruptions.

Encourage the person to be as independent as possible, but be there to help if needed.

If the person is upset or frustrated, acknowledge the difficulty they are experiencing and continue to support and encourage their communication attempts.

If you are encouraging the person to use, for example, gestures or a communication board, use

the same strategies yourself when communicating so they can mirror what you are doing.

If the person swears inappropriately, ignore it. It may be something they are unable to control.

Include the person in conversations and encourage friends to do the same, even if the person is unable to respond.

If Dementia is a Problem

As dementia progresses, words may become jumbled and confused and a person may gradually lose the ability to use and understand speech. This is part of a much wider loss of thinking and memory skills. They may be able to indicate needs in other ways, such as facial expressions (smiling, frowning), gestures (pointing, touching, arm waving), eye contact, behaviour (such as walking away, crying), or tone of voice (speaking loudly, softly).

Strategies for Dementia

Look for meaning in the person's behaviour. What are they trying to tell you?

Be aware of body language – facial expression, tone and pitch of voice, posture.

Make contact with the person – use gentle touch, smile and humour as appropriate.

Speak gently, clearly, at an even pace. Wait for a response before continuing.

Ask one question at a time – avoid two in one sentence.

If possible, use a statement rather than a question – “We’re having dinner now”, rather than “Would you like to have dinner now?”

Reinforce your words with your gestures and facial expression.

Repeat or rephrase if you get no response.

Enjoy memories together – favourite photographs, music, foods, a “this is your life” album.

Don't talk across or about the person as if they are not there.

Hearing Loss

Many older people are hard of hearing, which can make communication difficult. These tips may help:

If your family member has a hearing aid, make sure it is switched on and the batteries are working.

When speaking, position yourself where they can see you.

Place yourself at eye level with the person when talking or listening to them.

Get the person's attention before speaking – use their name.

Reduce background noise – turn off the radio or television.

Remaining Part of the Family

No matter what type of communication difficulty your family member is experiencing, it is vital that they still feel part of the family and contribute in whatever way possible. Here are a few ideas to help this happen and to support the flow of communication.

Have a visitors' book and ask people to jot down what they have talked about, to give some sense of continuity to communications.

It is the give and take of communication that is important, not just what is talked about. Chat about ordinary things – the supermarket, mowing the lawn, the kids, and about things in the past when you know the subject and you can interpret their responses.

Share old photos and memories together or find picture books on things that interest, or used to interest, your family member.

Use the retail catalogues to help them choose presents they would like to give to others for birthdays or Christmas.

Even though dealing with writing or figures may be difficult, they may still be able to contribute to broad decisions about finances*, with someone else organising the details. For example, they may be able to sign a form that someone else has filled out or have an opinion about a household expense.

*A social worker can help you with the legal aspects of assisting someone with financial decisions (See Fact Sheet 16: Legal and Financial Matters).

Contacts

Speech pathologists are usually available through your local hospital, rehabilitation centre or community health centre.

Speech Pathology Australia is the national body for the speech pathology profession in Australia.
Website: www.speechpathologyaustralia.org.au

Contact Speech Pathology Australia for the names of speech pathologists in your area.

Tel: (03) 9642 4899

Email: office@speechpathologyaustralia.org.au

ComTec

A company that provides electronic speech aids (part of Yooralla).

Tel: (03) 9362 6111

Eating and Swallowing Problems

THIS FACT SHEET discusses how acquired brain injury can affect swallowing, nutrition and hydration. It suggests strategies for safe swallowing and discusses how specialists can help further.

As a result of an acquired brain injury, the muscles of the mouth or throat may be weak or uncoordinated. A person may have difficulty eating, drinking and swallowing saliva. Difficulty swallowing is called dysphagia.

We swallow so often that most of the time we never think about how it happens. However, swallowing involves a complex series of movements. In a normal swallow, the lips are closed, food is mixed with saliva and the tongue moves food around the mouth while we chew. The tongue then moves the food back into the throat to trigger a swallow.

When we swallow, the food is moved downward towards the oesophagus (food pipe). To stop the food going the wrong way (into the lungs), the larynx (or voice box) acts as a valve to close off the airway. At the same time, the soft palate (the back part of the roof of the mouth) lifts and closes off the nasal cavity to stop food moving upwards into the nose.

What are the Effects of Dysphagia?

Swallowing difficulties: Swallowing can be interrupted at a number of different points or the sequence of movements may be uncoordinated. For example,

A weak tongue may make it difficult to move food about the mouth and it may collect in the cheek or under the tongue.

Sometimes a person may find it difficult to get a swallow started.

If the larynx does not close off and move out of the way at the right moment, food or drink may get into the airway. This should set off a strong cough

to clear the airway. If the person is unable to cough or their cough is weak, bits of food or liquid may collect in the lungs and cause a chest infection.

A person's desire to eat can be affected if eating becomes too much of a struggle. Sometimes the condition itself or their medications may cause their appetite to become depressed or food to taste different.

Assessment

Swallowing problems should be assessed by a speech pathologist. A speech pathologist will take a careful history, look at how the muscles of the mouth and throat are working, and observe a person swallowing different foods and drinks. The speech pathologist will also assess how much the person can swallow, how quickly they tire, and will provide strategies for making swallowing as safe and efficient as possible.

Tests: A special X-ray called a videofluoroscopy may be ordered. Your family member will be X-rayed while swallowing spoonfuls of food or drink that contain barium sulphate, which shows up on X-rays and allows the specialist to see how the muscles move and where the food goes. The moving image is recorded on videotape.

Managing Swallowing Problems

Specialists can help:

A speech pathologist can advise on safe swallowing strategies including diet modification.

A dietician can help plan an interesting, well balanced diet to ensure that a person receives optimal nutrition and hydration.

A Physiotherapist may advise on positioning.

An Occupational Therapist may recommend modified utensils e.g. shallow spoons, lightweight or spouted cups, a non-slip mat, a plate guard or special bowls. Various special utensils are available through the Independent Living Centre (see Contacts below).

Eating Strategies

The speech pathologist will tailor strategies to suit an individual's swallowing abilities. These may include:

- > Keeping mouthfuls reasonably small
- > Ensuring one mouthful has been swallowed before taking the next. Allowing time for rest between swallows, if necessary
- > Allowing more time to eat and drink. It may assist to provide a number of smaller meals or snacks if larger meals are too difficult.
- > Ensuring the person is sitting in the position that ideally assists their swallowing
- > Recommending modified foods and fluids.

Alternative Methods of Feeding

If swallowing is very difficult or tiring, the speech pathologist may recommend that a person use other methods to meet their nutritional needs.

Nasogastric tube: This is a thin, plastic tube that passes down the nose and throat to the stomach. Liquid food is fed directly into the stomach via the tube. The tube can only stay in place for a limited time and can sometimes irritate the nose and throat.

PEG tube: A person with longer term feeding difficulties may choose to have a PEG (Percutaneous Endoscopic Gastrostomy) tube inserted on the advice of your doctor or specialist. This tube is surgically inserted into the stomach under light anaesthetic. Food, usually a liquid, is fed directly into the stomach via the tube.

Management of saliva

Some people have trouble swallowing saliva that builds up in the mouth and throat, while others may have thick, ropery saliva that makes swallowing difficult. A speech pathologist will be able to suggest strategies to help reduce the amount or type of saliva. Assisted coughing may help to clear secretions in some people – a physiotherapist can advise on this.

Contacts & Resources

Speech pathologists are usually available through your local hospital, rehabilitation centre, community health centre, or your condition-specific organisation

Speech Pathology Australia is the national body for the speech pathology profession in Australia. Website: www.speechpathologyaustralia.org.au

Contact Speech Pathology Australia for the names of speech pathologists in your area. Tel: (03) 9642 4899

Email: office@speechpathologyaustralia.org.au

The Independent Living Centre

The centre has occupational therapist advisors, aids and equipment. Visit weekdays from 9am to 4.30pm, by appointment.

705 Princess HWY, Brooklyn, Victoria
Tel: (03) 9362 6111 Fax: (03) 9314 9825

Also at:

54 Railway Rd Blackburn, Victoria Tel: (03) 9362 6111 or 1300 885 886

Motor Neurone Disease Association, Victoria.

The association has a helpful video available for sale or hire: Swallowing Difficulties – A Guide for Carers. free call: 1800 806 632

Continence Problems

THIS FACT SHEET explains the different types of incontinence, causes, diagnosis and treatments. It also explains how a person's environment and physical health can be managed to minimise the problem.

Incontinence is the accidental or involuntary loss of control of either the bladder (urinary incontinence) or bowel (faecal incontinence). It can be an embarrassing condition, it is certainly inconvenient and it can be very hard to accept. Some people are so troubled by their incontinence that they cut themselves off from friends and become very isolated.

What people don't know is that incontinence can often be managed so well that dramatic improvement is possible. In some cases, incontinence can even be cured.

Urinary Incontinence

Urinary incontinence affects about four million Australians of all ages and is most common in older people. It may be caused by brain or nerve damage, by other physical changes (e.g. prostate enlargement or infections) or the environment may contribute (e.g. difficulty finding public toilets). There are several different types of urinary incontinence:

- > Stress incontinence
- > Urge incontinence
- > Overflow incontinence
- > Reflex incontinence
- > Functional (Age and disability-related) incontinence

Stress incontinence: Stress incontinence is when small amounts of urine leak while coughing, sneezing, laughing, straining or lifting. It is usually related to changes in the pelvic floor muscles as a result of childbirth, being overweight, chronic constipation, chronic coughing, menopause or prostate surgery.

Urge incontinence: This type occurs when a bladder contracts without warning and the person gets a sudden, strong urge to urinate. This may result in some loss of urine. People with urge incontinence visit the toilet very often. It's common in people with stroke, Parkinson's disease and other conditions. Alcohol, caffeine, cold weather and anxiety make it worse.

Overflow incontinence: Overflow occurs where the bladder does not empty properly and urine spills out without warning. The cause is usually something obstructing the flow of urine. It is common in men with an enlarged prostate but constipation can also contribute. Sometimes a neurological problem can make the person unable to feel a full bladder, causing overflow incontinence.

Reflex incontinence: When certain nerves in the spinal cord are damaged, the messages they send from the bladder to the brain are disrupted. When full, the bladder takes action and empties itself. Reflex incontinence is particularly distressing because it results in flooding, rather than leaking, without warning.

Functional incontinence: Older people or people with a physical disability cannot always reach the toilet in time. They may have difficulty in moving fast or in undoing clothing. The problem may be complicated by dementia, poor vision, or a toilet that is difficult to reach in time.

Bowel Incontinence

Bowel control problems are less common than bladder problems but still affect many people of all ages. Poor diet, not enough to drink and

lack of exercise are key contributors to bowel incontinence. A well balanced diet, good fluid intake, and regular exercise can help prevent it.

What Causes Incontinence?

There are many causes of urinary and faecal incontinence. It might be a neurological problem, a urinary tract infection, prostate problems, diabetes, constipation, or even a chronic cough, but most causes can be treated.

Medications are sometimes the culprit. For instance, some sedatives reduce a person's awareness of body signals, while blood pressure pills can occasionally cause stress incontinence. Other drugs may cause constipation, which can lead to bladder or bowel incontinence. Talk to your doctor about any problems you are experiencing.

In the case of bowel incontinence, severe constipation is often the problem. This causes the back passage to become stretched and weakened over time and the person loses control over it. Loose stools can also be difficult to control, especially if your pelvic floor muscles are weak or the sphincter muscle has been damaged. Loose stools may be caused by eating too much fibre, highly spiced foods or other food intolerance, some medications or bowel surgery.

Diagnosis

Your doctor might order tests, such as a urinalysis to check for a urinary infection. A bladder ultrasound may be required to check if the bladder is emptying fully. Sometimes an X-ray may be required to detect severe constipation.

Treatment

Treatments can range from losing weight and bladder retraining to curing chronic constipation, physiotherapy and for a few, surgery.

Where medication is contributing to incontinence, your doctor may be able to reduce the dose, spread the pills out over the day or change the medication. For urge incontinence, medicines are

available to slow down the bladder, which doesn't cure the problem, but it can improve things significantly. There may be side effects however.

Physiotherapists can help with stress and urge incontinence by providing simple exercises to strengthen the pelvic floor muscles that need to be done regularly.

Your doctor might need to refer you to a continence advisor – a nurse, physiotherapist or medical specialist working in continence management. Sometimes a referral to a urologist (a specialist in urinary problems), a urogynaecologist (for bladder problems related to gynaecological issues) or a geriatrician (a specialist in aged-care) is appropriate.

Managing Incontinence – the Environment

Incontinence often results when a toilet is not easy to find or use. An occupational therapist or advisors at the Independent Living Centre can help you assess your environment for practical purposes and set it up to help prevent accidents. Are any of the following issues in your home?

Getting to the toilet: Can the person readily walk the distance to the toilet? Is the lighting good enough? Are there mats to trip on? Would it help to leave a night light on? A label on the toilet door may remind someone with memory problems where it is.

Setting up the toilet: Do steps create access issues? Is the doorway and room big enough for a wheelchair or walking frame? Can the person balance at the toilet? Grip rails may help. If access can't be improved,

a urinal or commode chair may be the best solution. Is the toilet too low? Devices are available to raise the toilet seat. Can the person reach the toilet paper? Does poor balance or restricted movement in shoulders, elbows or hands make it difficult to use the toilet paper?

Clothing: Is clothing easy to get on and off? Lots of layers can be a problem. Use stretch fabrics, elastic waist bands and Velcro rather than zips or

buttons. For easy laundering, buy non-iron clothes or consider using a linen service if constant washing of sheets is an issue.

Public facilities: When out, look for places with disabled toilets as these have space for a wheelchair and two people. See the Melbourne Central Business District Mobility Map, published in the Melway Street Directory or available free from the City of Melbourne Hotline: (03) 9658 9658. Also check the National Public Toilet Map website at www.toiletmmap.gov.au to locate toilets by town, suburb or postcode.

When memory is a problem: Establish a routine and remind the person to use the toilet at regular intervals (every two or three hours) or at the times you know they usually go.

Managing Incontinence – Physical Health

Diet, fluid intake and exercise are all key elements for managing incontinence well.

Diet: Constipation can make bladder problems worse and sometimes leads to faecal incontinence. A regular bowel pattern depends on a healthy, high-fibre diet, which means lots of fruits (fresh, stewed, dried), vegetables, wholegrain and wholemeal cereals and breads (oatmeal, rice, rye, wheat, barley) and nuts and lentils.

Fluid intake: We need about 1.5 to 2 litres of fluid a day – six to eight glasses. Fluid intake includes foods with high fluid content, such as jellies, soups and yoghurt. In the case of faecal incontinence, adequate fluid helps to soften constipated stools or thicken loose stools.

Often people with bladder problems try to drink less for fear of becoming wet, but this only makes matters worse. Firstly, it can cause constipation. Secondly, urine becomes concentrated, which can irritate the bladder, leading to infection. Thirdly, the bladder learns to hold less fluid, resulting in more frequent trips to the toilet. It's important to drink enough, but sensible to refrain from lots of fluid before bedtime or social outings.

Exercise: Regular exercise is important because it improves blood flow throughout the body, including the gut, which helps to prevent constipation. If walking isn't possible, arm, leg and body exercises will help.

Weak pelvic floor muscles can often also contribute to both bladder and bowel incontinence. Continence Physiotherapists can assist with pelvic floor exercises.

Managing Incontinence – Aids and Appliances

Absorbent pads and special pants are available that are designed to absorb urine or contain faeces. These come in a range of sizes and levels of absorbency. Some pads are disposable, some are reusable and they are held in place by special pants.

For mild incontinence, some women can use thin continence pads or even panty liners. Menstrual pads are not effective because they are not designed to hold urine and they do not eliminate odour.

Urinary incontinence in men can be managed through condom drainage – a sheath over the penis, with a tube attached that leads to a leg bag or overnight bag. Some people use condom drainage as a back-up on outings, for example.

For men or women, urine can also be collected via a catheter – a tube inserted into the bladder. Long-term catheters need careful management however to minimise infections and other complications. A bag to collect the urine is strapped to the leg under the clothing. A larger bag can hang on the bed at night. Ask your doctor about this method.

Other continence aids include absorbent bed sheets and chair covers (reusable or disposable), bed pans, commodes and non-spill urinals for use in bed or on car journeys.

Financial Assistance

Most people must pay for their continence aids. Some assistance is available in some states and territories through government-funded schemes, such as the Aids and Equipment Scheme in Victoria. Some people on a disability pension may be eligible for the Continence Aids Assistance Scheme (CAAS). Ask your doctor, the National Continence Helpline (see Contacts below) or another health professional about this.

Contacts

National Continence Helpline (NCHL).

The Continence Foundation of Australia manages the NCHL on behalf of the Australian government. NCHL has trained continence nurse advisors who can provide you with advice, send written information and direct you to local services. free call: 1800 33 00 66

Australian Physiotherapy Association (APA)

Both the APA and the NCHL can help you contact a physiotherapist with relevant expertise, or visit the website www.physiotherapy.asn.au (go to Find a Physio, Your State, Continence) to locate one in your area. Tel: 1300 306 622

Independent Living Centre

The centre has occupational therapist advisors, aids and equipment. Visit weekdays from 9am to 4.30pm, by appointment.

705 Princess HWY, Brooklyn, Victoria

Tel: (03) 9362 6111

Fax: (03) 9314 9825

The Nerve Centre

54 Railway Rd, Blackburn, Victoria

Tel: (03) 9362 6111 or 1300 885 886

Other sources of help include continence services and clinics, general practitioners, local community health centres or community nursing services. Your doctor can refer you to a nursing service.

Intimacy and Sexual Activity

THIS FACT SHEET discusses how intimacy, sexual activity and sexuality can be affected by chronic conditions that involve brain damage. It offers suggestions on how partners can communicate their needs, approach difficult issues and adapt their lives.

When a condition is first diagnosed, there are so many things to work through that sex is often low on the list of concerns. Eventually, the urge to return to intimacy and a sexual life is likely to be important for most people – of all ages.

Then the questions begin: Is it possible? Is it safe? Am I being selfish even considering it? Will he or she still find me attractive? Can I be a good lover? Will my erection last? Can I have an orgasm? What if I lose bladder control during sex? How can I have a sex life when I'm always tired? Will my partner continue to love me? How do I get interested in sex when I'm dealing with everything else?

Keeping channels of communication open and discovering appropriate avenues for sexual expression can have significant benefits to your overall feelings of happiness and wellbeing.

If you are having problems, do ask your doctor or condition-specific support organisation for advice or more information.

How Brain Injury Affects Sexual Activity

Many types of acquired brain injury (ABI) and neurological conditions can affect a person's sexual response directly. Some progressive conditions only affect sexual abilities as time goes on.

Stroke: A common worry for people after stroke is whether sexual activity will cause another one. The concern here is blood pressure. We all experience a sudden rise in blood pressure as excitement increases but if it is already high, this can cause problems. Check with your doctor. It also helps to make having sex more effortless – the well partner may need to take the more active part.

A partner with high blood pressure is also likely to be on tablets to control it. These may affect their ability to have intercourse. If this is a problem, talk to your doctor. There are tablets that do not have this side effect.

Motor Neurone Disease (MND): MND does not generally prevent men from having erections or women from reaching orgasm, but a person with MND gradually becomes frail from muscle wasting and weak joints. The well partner may become fearful of causing pain or damage. Adapting the positions you use to accommodate physical difficulties may help.

Parkinson's: The combination of physical and cognitive (thinking and behavioural) changes that affect people with Parkinson's over time often affects their sexual response. Some men experience impotence, anti-Parkinson's medications can have an impact and disruptive symptoms, such as tremor, can be intrusive.

Multiple Sclerosis (MS): MS may damage nerves that control sexual response. Men may have changes in sensation and experience difficulties with erections and orgasm. A number of medical procedures and medications can assist to gain an erection. All have advantages and disadvantages – discuss them with your doctor.

Women may have less vaginal lubrication, less genital sensation and difficulty reaching orgasm.

Vaginal lubricants, available from the chemist, will help with dryness.

How Chronic Conditions Affect Sexual Activity

Often it is only as chronic neurological conditions progress that difficulties arise, such as:

- > Physical changes
- > Cognitive changes
- > Fatigue
- > Incontinence
- > Emotional responses
- > Personality changes
- > Self-esteem and self-image

Physical changes: For example, symptoms such as paralysis, weakness, spasticity, poor balance, muscle wasting or pain may require couples to adjust their positioning or types of sexual activity.

Cognitive changes: Brain damage can affect cognitive (thinking and behavioural) abilities that have an impact on a person's sex life. For example, emotional instability, which is often part of ABI, and poor communication due to speech difficulties, which is often the case with Muscular Dystrophy, can be disruptive.

People with Alzheimer's speak of forgetting to have sex or forgetting it has occurred. It may look to the unaffected partner as if the person is no longer interested. Yet a simple reminder may be all that is needed.

Fatigue: Fatigue can have a significant impact but if you know when it is most likely to occur, you can plan time together around it. Medications can also increase or decrease tiredness or change muscle function, which you may need to take into account as well. (See Fact Sheet II: *Managing Fatigue*).

Incontinence: The fear of bladder or bowel accidents makes some people uneasy but there are ways to minimise the likelihood: going to the toilet immediately before love-making, adopting positions that minimise the chance of reflex-emptying of the bladder (particularly with Multiple Sclerosis) and having towels and a sense of humour on hand, just in case.

Emotional responses: Depression, anxiety and stress that occur either as a result of changes in the brain or in reaction to illness can also reduce

sexual desire. If depression is an issue, treatment can make a huge difference. Do talk to your doctor. Strategies for reducing stress may also help. (See Fact Sheet 19: *Coping with Stress*).

"If circumstances hadn't forced us to develop our sexual relationship, we might never have discovered the depth and variety of feelings and experiences that are now part of our entire life, not just our sex life."

Personality changes: When brain injury affects aspects of someone's personality, it can feel like you are living with a stranger. Occasionally, demanding or inappropriate sexual advances are an issue. This area is also discussed briefly in the Fact Sheet 6: *Changes in Thinking and Behaviour*, but a neuropsychologist can help with strategies that minimise difficult new behaviours. (See also Fact Sheet 19: *Coping with Stress*).

Self-esteem and self-image: Sexual response is also tied up with our self-image and self-esteem. Both depend on our ability to accept ourselves and to not be influenced negatively by the perceptions of others, but both are challenged when someone becomes chronically ill.

Self-image can take a battering when a person's physical appearance changes. Self-esteem can falter if the person is less physically able to engage in sexual activities. If these are serious issues for you, consider seeing a sex counsellor or joining a support group. Your doctor or condition-specific group can help with referrals.

The well partner: Well partners often experience guilt, frustration, resentment, anger, exhaustion, depression or combinations of these states. It's hard to switch from the role of carer to the role of lover.

Some carer-partners play down their own concerns for fear of seeming selfish or complaining to a loved one whose ego may already be fragile. All these elements can generate anxiety and dampen interest and pleasure in sex. (See Fact Sheet 19: *Coping with Stress*).

Discussing Sex

Many couples feel embarrassed talking about sex – telling each other what they like and what they

don't like. It's important to try to get past this. How can you help your partner to enjoy sex if you don't know what gives them pleasure?

Timing: Find out from your partner when he or she would be most comfortable talking. Right after an unsatisfying encounter may not be the best time for some, but right for others.

Approach: Think through what you want to say and use "I" language. Don't accuse or criticise. For example: "I'd like to spend more time kissing and cuddling before we have sex" is more helpful than, "You seem to be in a hurry without thinking about my enjoyment".

Topics to try: Different people will want to talk about different things – how often you have some type of sexual activity, what activities you can both manage and enjoy, the use of fantasy or a need for more emotional intimacy. Try to talk together about any problems you have and share your feelings and needs with each other.

Depending on your situation, you may need to discuss changing what you have done together in the past – perhaps less focus on intercourse and orgasm and more on intimacy. Touching, tenderness and gentleness, the reassurance that you are loved and needed are equally important.

Speech problems: When a person's speech is affected, showing affection physically will be even more important

for both of you. Similarly, you may need to show, rather than tell, each other what you find pleasurable.

Discussion don'ts: Try not to talk when you are angry, have had too much to drink or have too little time or privacy – it only makes matters worse.

Strategies to Improve Intimacy and Sex Life

There are no magic answers to improving your intimacy levels and sex life, but certain strategies may help.

It's important that couples do not lose their sense of physical intimacy – it can be such a wonderful way of comforting each other and expressing feelings.

Role awareness: Be aware of the role each of you plays in your relationship and how your partner's condition may change this. Be flexible and ready to shift roles. For example, which of you usually initiates sex? Would it help to change this?

Respect boundaries: We must all balance the need for closeness with the need for independence and privacy. A disability can disrupt this by throwing you together more than usual. Make sure you get time alone.

Broadening horizons: There are many ways of achieving intimacy, warmth and sexual satisfaction without intercourse or orgasm. Touching, kissing, stroking and cuddling provide the physical contact we all need and can be immensely reassuring and satisfying.

Mutual masturbation: This simply means stimulating each other to orgasm. Some couples have never done anything like this before and find the idea difficult to accept. But people of all ages find sexual satisfaction together through this method. It is never too late to learn.

For most women, rubbing or kissing the clitoris – where the folds of flesh come to a point above the opening to the vagina – is the easiest way to help them reach orgasm. Some may prefer vaginal stimulation. A holistic approach is generally best, which might include the above, music, body-kissing and massage. Every woman is different.

A man's partner can bring him to orgasm/ ejaculation by stimulating his penis. Even without a chronic illness, older men need more direct penis stimulation than younger men to become erect. Try using lubricant or saliva to make this easier.

Express sensuality: Looking good helps. Wear clothes that you both find attractive. Consider sensual triggers such as perfume, aromatherapy or massage oils. Try setting the scene with music and candles. Talk about and enjoy the sexual experiences you can have. Try not to concentrate on what you can no longer do.

Sex isn't everything: Make sure you have enough time simply to enjoy each other's company.

Counselling

If talking together about sexual issues is too difficult or it is not solving the situation, consider seeking outside help, either together or separately.

For some people, talking about their sexual relationship with a stranger can be difficult. Often however, a few sessions with a capable therapist can help you to see problems in new ways and to find workable solutions.

Seeking the advice of a counsellor or therapist does not mean you are “sick” or that you need prolonged treatment. If you feel uncertain about professional help, remember that you are doing the hiring and firing – you can stop the therapy any time you wish.

Caring for Family Members

If the person you care for is a family member or friend, be aware that they may have sexual needs that are not being met. This can apply particularly to older people, such as parents. It can be very difficult for this person to express their sexual needs to a family member. Find someone they trust who can broach this subject with them.

Contacts

To find a suitable therapist or counsellor, ask your own doctor or contact your condition-specific support organisation (see Contacts pg 7).

Managing Fatigue

THIS FACT SHEET explains the symptoms and triggers of fatigue and provides some strategies to minimise and manage it.

Fatigue is a common and very disabling symptom experienced by people with acquired brain injury (ABI) or neurological conditions. Some people with multiple sclerosis, for example, describe an overwhelming sense of general fatigue that can occur at any time of the day. It happens without warning and the person needs to rest immediately before the symptoms get worse.

Fatigue is also a problem among carers as they find themselves managing increased workloads and greater responsibilities. Members of the rehabilitation team understand your position and can recommend support services, such as respite care, and coping strategies. Do consult with your GP or a trusted team member before your own health is affected.

What is Fatigue?

The fatigue associated with brain injury or neuromuscular damage often appears more suddenly, lasts longer and takes longer to recover from than ordinary fatigue. Make no mistake, *it is real*, and not a case of mind over matter.

What Causes Fatigue?

Fatigue can occur for no apparent reason or after relatively mild exertion. It may be caused by physical activity, but is just as likely to occur as a result of mental activity.

Planning the week's errands, organising a work schedule, calculating a weekly budget or simply reading, can be very draining. We all experience this to some extent but for the person with brain injury, it happens more easily and much more frequently.

Strategies

Fatigue can be managed with good planning and rest periods, but first carers and the family member affected need to acknowledge that it is *real*.

Symptoms

The following symptoms may all suggest fatigue:

- > Withdrawal.
- > Loss of appetite.
- > Shortness of breath.
- > Slower movement and speech.
- > Short answers, quieter voice, a dull tone of voice.
- > Irritability, anxiety, crying episodes.
- > Increased forgetfulness.
- > Lack of motivation to plan for each day.
- > Lack of interest in things the person normally considers important (e.g. appearance, grooming).

Fatigue also intensifies symptoms experienced because of ABI or a neurological condition, such as:

- > Poor vision.
- > Slurred speech.
- > Difficulty finding words.
- > Poor concentration.
- > Cramps or weak muscles.
- > Poor coordination or balance.

The next step is to work out what triggers it and what factors make the symptoms worse, such as holding a demanding conversation for more than 10 minutes or watching a film with a complicated plot. You can then work together to develop strategies to conserve energy.

Contingency plans: Fatigue may occur at the least convenient times – on public transport or during a meeting. You need to negotiate ways of coping when this happens. You can use specific strategies or call in extra support. Work out contingency plans with your family member. Your neuropsychologist, occupational therapist or physiotherapist can help with suggestions.

Assess your environment: Provide an environment that is easy to move around and work in. Think about how and where things are stored, bench heights, entrances, types of furnishing, lighting. For example, some people may find fluorescent lighting or dim lighting more tiring.

Assess best hours: Some people function best in the mornings, so complete demanding tasks then. Others function better in the afternoon or the evening. Organise your routine accordingly.

Schedule rest periods: Make a daily or weekly schedule and include regular rest periods. “Rest” means *do nothing at all*.

Use aids: Use mechanical aids to conserve energy for when it really counts. One man spared his legs extra effort by using his wheelchair to get from his house to the car, then from the car to the church, before walking his daughter, the bride, down the aisle.

Break it down: Break down activities into a series of smaller tasks. This provides opportunities to rest while allowing the person to complete the task. Encourage sensible shortcuts.

Set priorities: Focus on things that must be done and let the others go.

Medication highs & lows: Be aware of changes throughout the day that relate to medication. Is the person better or worse immediately after their tablets? Plan their activities around these times.

Sleep: Encourage a regular sleeping pattern. Some people may also need a regular nap – or two – during the day.

Fitness: Your family member should maintain fitness within their individual ability, that is,

enough exercise to stay fit, but never to the point of causing tension, overtiredness or cramps.

Weight: Maintaining a healthy weight helps. If your family member’s condition affects their ability to eat, consult a dietician and speech pathologist to ensure they have a nutritious diet that is easy to manage (See Fact Sheet 8: *Eating and Swallowing Problems*).

Weather: Hot weather can also increase fatigue. Plan around this.

Seek support: Ask for advice. In particular, an occupational therapist can visit your home and advise on an energy-conserving plan of action.

Contacts

For more information, talk to your doctor or condition-specific support organisation (See Contacts pg 7).

Vision Problems

THIS FACT SHEET describes the ways in which a neurological condition or acquired brain injury (ABI) can affect a person's vision and suggests some strategies and therapies to assist.

Our ability to see and to understand what we see relies not only on our eyes, but on many parts of our brain. Damage to a particular part of the brain or to the optic nerves (the nerves that connect the eyes to the brain) can affect our vision in many different ways.

Some possible problems include: partial vision, seeing double, hazy or blurred vision, an inability to recognise or interpret what you see, being able to see only one side of your surroundings, tunnel vision (as if looking down a tunnel), trouble seeing in dim or glary light.

Three common problems that may occur after acquired brain injury, stroke or tumours are hemianopia, visual neglect and visual agnosia.

Hemianopia

Hemianopia (hemi – an – o – pia) is a type of blindness. It affects the same half of each eye, either the left half or the right half ; or a person may have a hemianopia of one eye only dependant on the lesion site. It occurs as a result of damage to the connections and wiring of the visual system of the brain.

In medical terms, the person loses half (sometimes less) of their "visual field". It's like losing a wedge of sight or a portion of your vision.

People with hemianopia can be affected in various ways, and in varying degrees; they may bump into things on one side, knock over drinks on one side and can be startled by objects that "suddenly appear" on their affected side. Reading can be very difficult, as the person may not see one side of the page unless they turn their head.

Carer strategies: Usually the person has an understanding or insight into their sight difficulty and some people learn to compensate well for these difficulties. Carers can help a great deal by drawing attention to objects or activities on the affected (non-seeing) side.

Approach the person from the non-seeing side or encourage the person to turn their head to you when talking to them or helping them to dress so that they become more aware of it.

Reading and writing are easier if there is a clear edge down the affected side of the page – a ruled black or red line or a brightly coloured strip of cardboard might help to direct attention to the start or end of a line of text.

Compensation strategies can include teaching the person to turn their head to scan the environment and to place objects in their field of vision.

If the brain damage is significant or as the neurological condition advances, you may need to approach your family member *only* on their non-affected side and always assist them with activities, such as dressing, on their affected side.

Visual Neglect

While hemianopia is a *sensory loss of vision* to one side, visual neglect is a *loss of attention* to one side of the body. It is a spatial inattention disorder, usually caused by damage to the parietal lobe of the brain, which deals with spatial awareness and the perception of sensations, the person may not have an insight into the problem.

A person with visual neglect may not shave one side of their face or not eat the food on one side of the plate, for example.

Carer strategies: It is more difficult to overcome the effects of visual neglect because the person's ability to *perceive* that part of their world has been damaged. They usually need persistent prompting to attend to all things on their affected side.

The person may sit slumped towards their good side. Encourage and help them to sit up straight, in the midline.

Visual Agnosia

Visual agnosia is when someone is unable to recognise things. While their eyes still "see" the world, their brain is not able to interpret the information sent from the eyes. It is a processing problem.

A person may look at a cup but have no idea what it is. If they pick it up however, their fingers may recognise it. They may have trouble identifying objects in a cluttered pantry or on a supermarket shelf. For a few people, pictures or faces may become meaningless or unrecognisable.

Visual agnosia can be very frightening because the person's world no longer makes sense to them. Activities we take for granted like moving through busy environments, crossing the road or catching public transport may become terrifying to them.

Carer strategies: Carers can help by recognising the problem and reassuring the person that they are not going mad! You can gradually help them to recognise objects again.

Encourage the person to use other senses, such as sound and touch, to make sense of visual information.

When moving about, encourage the person to set orientation landmarks that are meaningful to them.

Don't always assume they are coping, especially in busy environments. Ask if they would like physical guidance and then offer your arm – don't take theirs – and link arms if they need a stronger grip.

Therapies

Ideally, your family member will work through these problems with a rehabilitation team appointed at the time of their diagnosis or assessment.

Rehabilitation therapists can develop helpful strategies to manage many vision problems. For example, an occupational therapist can teach people how to use what vision they have to scan the environment, enabling safety and independence with tasks such as food preparation and dressing. A person can also be taught how to read labels and recognise signs more effectively.

Loss of vision can affect a person's ability to maintain their balance and gait. A physiotherapist can teach them how to use their remaining vision to scan the environment, without losing their balance.

The Guide Dog Association of Victoria runs an Acquired Brain Injury Mobility Service for people with vision problems that are caused by acquired brain injury. The team of orientation and mobility officers assesses your family member's vision and how it affects their ability to move about in their home and local community. The team then devises a program that develops the person's other senses and some compensatory skills that use their remaining vision.

Contact

Acquired Brain Injury Mobility Service

Guide Dog Association of Victoria

Private Bag 13, Kew, VIC 3101

Tel: (03) 9854 4444

Fax: (03) 9854 4500

email: referrals@guidedogsvictoria.com.au

web: www.guidedogsvictoria.com.au



SECTION THREE

Section 3 Practical Assistance

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Adapting your Home

THIS FACT SHEET describes ways in which you can make your home a safer and easier to manage environment for a family member with disability.

Planning and making home alterations can take time so it's wise to start as soon as possible. Remember that any significant alterations, such as rails or ramps, need to comply with Australian Standards.

Around the House

- > Occupational therapists can assess your situation and suggest the most appropriate equipments and aids, such as the need for wheelchair ramps or handrails near the stairs, outside steps and in the bathroom.
- > Arrange the furniture so that it is easy to move about. Some people need a clear passage. Others may need supports along the way.
- > Install smoke detectors in all rooms.
- > Keep the temperature inside the house comfortable for someone who cannot move about.
- > Remove extension leads or loose cords and don't use loose rugs or mats on floors.
- > Keep outside paths free of loose things you could trip on.
- > Room-to-room communication and alarms can be arranged with plug-in baby alarms or more sophisticated alarms. A buzzer or doorbell could be wired to a light-touch switch. Ask your occupational therapist.
- > A hands-free phone makes it possible to talk without lifting the handset. Choose one with a memory function for frequently used numbers. Phones are also available with large numbers for people with poor vision.

- > Get a "pick-up stick" – a metal stick with a lifting claw at one end that is closed by a trigger at the other end –for picking up things out of reach.

In the Bathroom

- > A plastic chair or stool in the shower allows your family member to sit down. A long-handled sponge, soap on a rope and a suction cup to keep soap in place may be useful. If possible, it is best to have no step into the shower.
- > Use a non-slip bathmat. Stick anti-slip adhesive shapes on the bottom of the bath.
- > Try a raised toilet seat or a mobile commode that can be wheeled over the toilet.
- > Install hand rails beside the toilet and shower.
- > An electric toothbrush is ideal for people who have difficulty cleaning their teeth.
- > Consider installing individual hot and cold taps or a hot water system that is thermostatically controlled to prevent hot-water burns.

In the Bedroom

- > A person should be able to sit on their bed with their feet flat to the floor. If the bed is too high, consider having its legs shortened. If too low, sit the bed on special raisers.
- > Bed sticks or "monkey poles" are available that provide something to hold on to so a person can swing themselves upright in bed.
- > A commode or urinal may overcome the problem of toileting at night. A plastic sheet on the bed is useful when someone has incontinence.

- > Special mattresses to increase comfort in bed are available: airbeds, waterbeds, net beds, deep mattresses. Mattress elevators raise a person from lying to sitting.
- > Consider satin sheets. They make it easier to move in bed.

Dressing

- > Use clothes that are easy to put on and quick to fasten – front-opening dresses, skirts or trousers with elastic waist bands, track suit trousers, clip-on ties, cardigans rather than jumpers, slip-on shoes, elastic shoelaces, stretch fabrics without zips or buttons.
- > Aids for dressing include devices for putting on socks, long shoehorns, gadgets for doing up shoes and foot stools.

In the Kitchen

- > Benches and tables should be the right height for the person to work at or have meals at while sitting – with room for a wheelchair if necessary.
- > Useful gadgets include: steel-pronged, wooden boards that secure vegetables for cutting; pot stabilisers that secure saucepans to stove tops during stirring; a tap “turner” for someone who cannot easily grasp a tap.
- > Special bowls, cups, knives, forks and spoons are available for people with restricted hand function.
- > Plastic is more practical and safer than china and glass if the person has difficulty holding objects.
- > A plate guard that attaches to the side of the plate stops food escaping and gives the person something to push against.

Financial Assistance

Talk to your occupational therapist or social worker to see if your family is eligible.

Victorian Aids & Equipment Program: This program provides funding for aids, equipment and home modifications for people who are not eligible for help under other government services. An occupational therapist, physiotherapist, your

condition-specific support organisation or the Independent Living Centre (below) can help to organise your application for funding.

Home and Community Care: This program can arrange maintenance and home modifications, such as the fitting of handrails. Contact your local council.

The Home Renovation Service: This service provides free home inspection and advice to those with a disabled family member.
Tel: (03) 9616 6170 or
free call: 1800 134 872.

Equipment loans: Contact your condition-specific support organisation to enquire about equipment loans or hire services.

Contacts & Resources

Occupational therapists: These can be contacted through your doctor, hospital, community health centre or your condition-specific support organisation. Occupational Therapy Australia, Victoria, can provide the names of therapists in private practice: telephone (03) 9481 6866.

The Independent Living Centre: The centre has occupational therapist advisors, aids and equipment. Visit weekdays from 9am to 4.30pm, by appointment.
705 Princess HWY, Brooklyn, Victoria
Tel: (03) 9362 6111
Fax: (03) 9314 9825

Telstra Disability Inquiry Hotline: Ask Telstra about its range of telephone aids and services.
Free call: 1800 068 424.

Lifting and Moving

THIS FACT SHEET describes techniques for helping a person with physical disabilities to walk, sit, stand and move.

There are correct techniques for lifting and moving a person with disabilities.

By using the right technique, you can **avoid damaging your own back** and causing great discomfort – and possibly permanent harm – to your family member. Each person has different needs and disabilities, so before attempting any lifting or moving it is *essential* that you talk to your occupational therapist or physiotherapist first about the best ways to lift and move your family member. They can also give advice on aids and useful equipment. The information here is a general guide only.

Lifting

- > Make sure the things you may need – walking stick, frame – are close at hand.
- > Let your arms and legs take the strain, not your back.
- > Stand close to the person so that you can use your body to support them. Have your knees slightly bent, feet slightly apart and back straight.
- > Just before you lift, tuck your chin into your chest to stabilise your spine.
- > Try to coordinate your actions with the person you are helping. Counting may help – “One, two, three, up!”
- > Lift by straightening knees and hips. Use whatever movement the person has to help you.
- > Support the person using the palm of your hand so that your fingers do not dig into them. Support them gently under the elbow.

- > If using only one hand, put the other on a firm surface, or your knee, for extra support.
- > Allow the person to lean on you as they need to. Don't push up on them.

Lifting don'ts: Never pull on the person's weak or paralysed arm or under the shoulder. This can seriously damage a weak shoulder or tear a ligament, causing considerable pain. It can also be very slow to heal.

Standing Up and Sitting

This guide is also relevant to helping someone onto the toilet.

Choosing chairs: Avoid low, deep chairs. Choose a chair that is relatively high that has arm rests. You could raise the height of a chair on wooden blocks or a platform. Make sure the chair is stable. Special frames and seats are available to raise the height of a toilet.

Have aids ready: To help someone stand from a chair, have their stick or walking frame ready.

Think first: If the person has difficulty organising tasks or remembering, you may need to go over this routine many times, step by step. Encourage them to think the moves through before they start.

Get your family member to:

- > Move to the edge of the chair.
- > Ensure their feet are firmly on the ground, about 25 cm apart, well under the body, and that their hands are placed on the armrests or on the sides of the chair seat.

Fig. 1

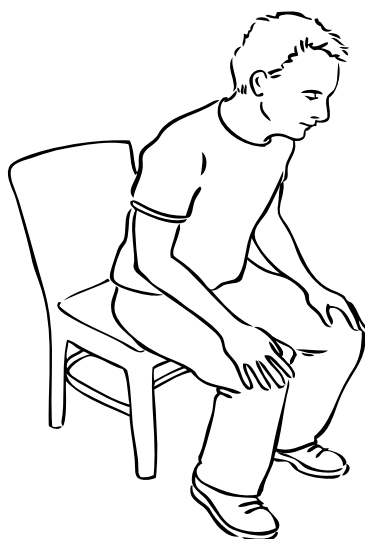


Fig. 2



- > Get them to lean well forward from their hips – “nose over toes” – and to press down on their feet, and forward and up on their arms. (See Fig. 1)
- > Straighten the knees.
- > If the person is moving from wheelchair to toilet or to another chair, they will need to turn, then sit again. Stepping around, using small steps on the spot, is safer than swivelling.
- > Before the person sits down, get them to stop in front of the chair and feel for the chair arms, placing one hand on each, before lowering themselves in a controlled way, bending slowly from the hips and knees.

- > You could also use a Mayfield belt, a special belt available for lifting and moving people. Ask your physiotherapist or the Independent Living Centre

Moving Back into a Chair

Ask the person to lean forward then shift their buttocks backward. If the person needs help to slide the bottom backwards, hold underneath their buttocks or use a Mayfield belt.

Getting out of Bed

It is generally easiest to help the person to roll onto their better side first, then they can use their arm/s to push up into a sitting position. Then they, or the carer, can move their legs over the edge of the bed.

Moving in Bed

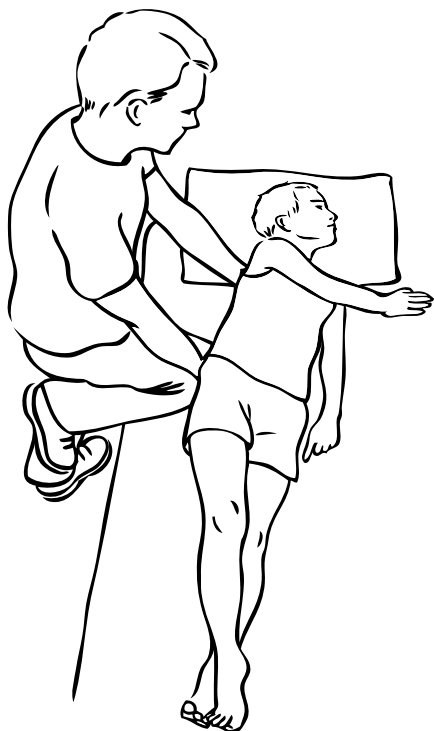
A firm mattress and satin sheets can help your family member to turn in bed.

- > Stand facing the direction they want to turn (let's say, the right side).
- > Get them to turn their head to the right, stretch their left arm across their body towards the right edge of the bed, and cross the left leg over the right leg.
- > Put one knee on the bed behind the person's back. Keep your other leg, knee slightly bent, firmly on the floor.

The carer must:

- > Use the lifting technique outlined earlier.
- > Help the person by supporting them under the forearm, held close to their trunk. (See Fig. 2)
- > Use your own foot to stop the person's foot from sliding forward as they stand.
- > Make sure the person is standing as straight as possible and is balanced before they take any steps.
- > It is usually easier for them to begin moving towards their stronger side, putting their strongest foot forward.

Fig. 3



- > Put one hand under the person's right shoulder and the other under their right hip. (See Fig. 3)
- > Leaning forwards, but keeping your back straight, turn the person onto their right side, straightening the leg you are standing on to help you lift.

Help When Walking

Practise walking with your family member under a therapist's supervision before trying it alone. A Mayfield belt can be used to support the person – ask your therapist.

- > A walking stick should always be held in the better hand.
- > The person should move the walking stick or frame first, then the weaker leg, then the stronger leg.
- > The helper should stand on the weaker side and should never pull on a weak arm. Support them gently under the elbow with the palm of your hand.
- > Keep a watch on your family member's balance and fatigue levels.

When Someone Falls

Reduce the risk of falls by getting rid of loose rugs, turned up carpets, and loose-fitting slippers or shoes.

After a fall, make sure your family member is not hurting. Give them time to calm down and collect themselves before you start helping them to move.

- > They must turn onto their side.
- > Then get onto their hands and knees. Assist them if necessary.
- > Crawl to a heavy piece of furniture (table, bench etc).
- > Place their good hand or both hands on the table/bench.
- > Bring their better knee up and place the foot firmly on the floor.
- > Push up through the hand and straighten the knee to get into standing position.

If your family member is unable to get themselves up off the floor and you can't move them, make them comfortable by placing a pillow under their head and covering them with a blanket. Then contact someone for help – a neighbour, a relative or an ambulance if necessary.

Getting Up and Down Stairs

Check with your physiotherapist for the method that best suits your family member. Some people find it easier to use a rail and step up with the better leg, then down with the weaker leg (or vice versa). Get the person to lean forward after stepping with the first leg. Some people prefer to go sideways.

Getting from Wheelchair to Car

- > Place the wheelchair beside the car next to the front seat. Have the front seat moved well back.
- > Make sure the chair brakes are on and move the footplates out.
- > If the person is using a sling, Mayfield belt or walking aid, make sure that they are in position.
- > Help the person to stand up as noted earlier.
- > Support the person as best you can to step around to the car seat.

Fig. 4



- > The person should feel the seat with the back of their legs, then bend forward and gently sit down, without using the car door for support. (See Fig. 4)
- > Lift their legs into the car, one at a time.
- > To get out of the car, reverse this process.

Speak to the Independent Living Centre about gadgets that can assist getting someone in and out of vehicles.

Contacts

If you don't already have a physiotherapist or occupational therapist, you can locate one through your doctor, hospital, community health centre or your condition-specific support organisation (see Contacts pg 7). Occupational Therapy Australia, Victoria, can provide the names of therapists in private practice: telephone (03) 9481 6866.

The Independent Living Centre has a wide range of aids and equipment on display. Occupational therapists and physiotherapists are available to answer questions, give advice and provide equipment-supplier details.

The Independent Living Centre

The centre has occupational therapist advisors, aids and equipment. Visit weekdays from 9am to 4.30pm, by appointment.

705 Princess HWY, Brooklyn, Victoria

Tel: (03) 9362 6111

Fax: (03) 9314 9825

Respite and Residential Care

THIS FACT SHEET describes the different forms of respite care and how to access them. It also discusses permanent residential care – making the decision and finding the right hostel or nursing home.

Respite Care

Carers often don't like to admit they need time off but respite care allows someone else to step in and give you that break for a few hours, a day, a week or more. It's essential to have time to revitalise yourself so that you can go on caring for your family member.

Giving yourself permission: Carers often feel they must be doing something "important" or "useful" to warrant using respite – the whole point is to ensure you get time off from being useful! Placing your loved one in respite so you can relax by reading a magazine or going on a day trip is just as good a reason as any. Don't wait until you feel stressed. You need regular breaks so that you remain healthy too.

Besides, most people being cared for enjoy a new face, new conversation and new activities. Even if this is not the case, stand up for your right to respite. It will be good for both of you in the long run.

Sometimes family and friends can provide some respite but other services are available, such as government-subsidised or commercial. For information on all types of respite, contact the Commonwealth Carer Respite Centre (free call: 1800 059 059).

In-home respite: This is when someone comes to your home and looks after your family member while you go out and do things you can't do while caring. If there is a charge, it will be at an hourly rate.

Day centres: Day centres offer activities, company and stimulation for people in need of care.

They are often used on a regular basis – perhaps a full-day or a half-day each week – and some services offer weekend care. There may be a fee per session. Most can organise transport to and from the centre. Contact your local council or community health centre for details.

Residential respite care: Some residential care facilities – nursing homes and hostels – admit people for a short stay while you have a holiday or break. In some areas, especially smaller country towns, the local hospital may also be able to provide this service. Nursing homes and hostels charge standard fees. Other services range widely in cost. Some have a sliding scale, depending on your income.

In theory, you may use these residential respite services for up to nine weeks a year, usually in blocks of two or three weeks. It depends on availability however, which is based on priority and need. This is assessed by an Aged Care Assessment Team (ACAT, see below). Bookings need to be made well in advance.

Centrelink allows you to have up to 42 days away from care-giving while still receiving the carer's pension.

Emergency respite: This is not available in all areas so check first with a Commonwealth Carer Respite Centre. If emergency respite is not available, it may be important for your peace of mind to have a back-up plan. This could include family, neighbours or a local service, but it is best discussed in advance.

Permanent Residential Care

There are many reasons why people move to a hostel or nursing home. Deteriorating health and physical abilities may mean the person can no longer be managed at home. Sometimes their behaviour can be the trigger. For instance, a person's condition may cause them to become aggressive. Maybe your health has deteriorated and you need to go into hospital or you are no longer physically capable of caring. Perhaps there are other family demands, your back-up help is no longer available or the services you need are not available locally.

Making the decision: Whatever the reason, making the decision about permanent residential care is difficult and feelings are often mixed. Carers describe feeling relief and guilt, pride in what they have done, yet a sense of failure that they can no longer continue. There may be a sense of freedom but also a sense of loneliness, and worry about the care their family member will now receive.

Involve your family member: If possible, it is best to consider and plan this move together with your family member before relocation becomes necessary. A person who is mentally alert should always be involved in this planning. Even where thinking skills and insight are blunted, it usually helps to involve the person as far as possible. Preparation and planning make the transition easier for everyone, though this is not always possible. The most difficult situations occur where a person has to be moved suddenly because of a crisis.

The rewards: Many carers find that once the move is made, it opens a new dimension in their relationship with the person. Without the physical burden of caring, you are free to relax and enjoy each other's company. If it is physically possible, the person can still go out with you to visit home, have a meal or go to a movie.

Issues to explore: You may consider visiting potential nursing homes or hostels and find out more information about them. Issues you might want to consider include:

- > What nursing home or hostel care is available nearby?

- > What information and advice will help in making the decision? Where do I find it?
- > How can I make sure that my family member receives the best care?
- > How will we know when the time is right?
- > How can I continue to be a carer when he or she goes into residential care?

You will have the opportunity to discuss these issues with an ACAT member (see below) when your family member is assessed for residential care. Otherwise, you can call a Commonwealth Carer Respite Centre, residential care staff, community care workers, or your condition-specific support organisation (see Contacts page7).

Hostels: Hostels are available for people who need some help with everyday living. Each person has their own room with a private or shared bathroom. Meals are served in a dining room and other services are provided. Qualified staff are available to help with activities such as dressing, laundry, medication and bathing.

Hostels usually charge fees based on the person's financial situation, and these fees are limited to make sure that the person retains set amounts of assets and income.

Nursing homes: Nursing homes are for people who need full-time nursing and substantial help with personal care. Nursing homes are run by private companies, government departments and church groups.

An ACAT (see below) will be able to give you up-to-date information on any charges involved, while Residential Care Rights (free call: 1800 700 600, Tel: (03) 9602 3066) can provide broad information on nursing homes and the rights of residents.

Aged-Care Assessment Teams (ACATs)

Before a person can enter a hostel or nursing home or receive certain community services, they must be assessed by an Aged-Care Assessment Team (ACAT). ACATs are independent teams who assist frail, older people and their carers to identify what kind of care will best meet their needs.

They are multi-disciplinary teams that include health professionals, such as medical officers, social workers, nurses, occupational therapists and physiotherapists, who conduct comprehensive, medically based assessments. Some younger people who have age-related disabilities are also eligible for an ACAT assessment.

An ACAT will assess the person at home or in hospital and discuss the results with you together, so that you can decide on the right move. ACATs can also arrange nursing home or hostel care if needed, or refer you to local community services to support your care at home. You can find your nearest ACAT through your doctor, regional hospital or health centre.

Choosing a Nursing Home or Hostel

Single or shared room: Choosing the right hostel or nursing home will be different for everyone. In newer nursing homes, the trend is to provide single rooms, while older ones have larger shared rooms. Don't dismiss shared rooms without consideration. In a shared room, staff are about more often, visitors are shared and there is more company and stimulation. A single room preserves privacy, but it can be very isolating too.

Privacy issues: If you are choosing a nursing home for your partner, bear in mind that a lack of privacy may seriously restrict your opportunities for intimacy and touching. Some nursing homes address this issue better than others.

Quality of service: The standard of care in all nursing homes and hostels is monitored by teams from the Aged Care Standards and Accreditation Agency and their reports are available to the public. If you want to check on a particular nursing home, contact the Agency (Tel: 1800 288 025 or website: www.accreditation.org.au).

Checklist: Here are some issues you may want to consider and some questions to ask when choosing a nursing home or hostel.

- > Are the managers and workers interested in you – do they listen and ask for information?
- > Does the place feel friendly, welcoming and caring?
- > Do other residents appear well cared for?
- > Is there somewhere to sit together privately?
- > Is it acceptable for you to come and feed and shower your family member?
- > What is the diet provided? Are you satisfied with the quality of food and nutrition? Do the meals look appetising?
- > What training does staff have?
- > Are you satisfied with medical and specialist services available? Can the person have his or her own doctor?
- > What is the medication policy?
- > Are therapies provided – speech therapy, physiotherapy, occupational therapy?
- > Are you satisfied with environment issues, such as heating/cooling of the building, bathroom access, maintenance of rooms, buildings, grounds?
- > Are there procedures in place in the event of a fire?
- > Is there at least one person on duty at all times? What level of training does this person have?
- > What are individual residents' rights regarding their privacy, belongings, pets, mail, telephone, religious beliefs?
- > Are you satisfied with the range of activities and choices for recreation?
- > Are you satisfied with visiting times and access for family members?
- > Can outings, overnight stays and holidays with family members be arranged easily?
- > Does anyone speak the language of your family member?
- > Are other services provided, such as hairdressing or massage?
- > Is there assistance for you and the person in preparing for the move?
- > Will you be asked for suggestions and comments?
- > Is there a policy for addressing any of your complaints or concerns?
- > Can you join a residents' and relatives' committee?
- > Has the fee structure been fully explained? Are there extra costs?

Contacts

Your local council can also put you in touch with a number of relevant agencies who deal with respite services.

Commonwealth Carer Respite Centres

free call: 1800 059 059

Elder Rights Advocacy

Advocacy for older people through out Victoria

Free call: 1800 700 600

Tel: 03 9602 3066

email: era@era.asn.au

website: www.era.asn.au

Centrelink Retirement Services Line for carers' pension enquiries.

Tel: 13 2300

website: www.humanservices.gov.au/customer/services/centrelink/age-pension

Legal and Financial Matters

THIS FACT SHEET highlights a number of legal and financial matters that may need tending, such as making wills, powers of attorney and guardianship, managing finances and financial assistance. Carers may take over these matters or assist a family member with them.

Attention to a number of legal and financial matters can make life easier for you and your family member, and can ensure that their wishes continue to be carried out up to and after their death.

If dementia is a concern, there comes a point where a person is considered legally to be mentally incapable of making decisions. At this point, carers, family, friends or a legally appointed third person take over these responsibilities on the person's behalf.

Planning ahead eases this process, ensuring that all legal and financial possibilities are considered while your family member is still capable, able to participate in discussions and able to sign documents.

Getting Started

Consider the following issues and try to determine what legal and financial areas you may need to start addressing.

Bank accounts: Can your family member's bank, building society or credit union accounts be accessed by you or their spouse or partner?

Financial situation: Have you discussed their financial affairs with them or their financial advisor, such as a bank manager or accountant?

Locate important documents: It is important to know where they keep the following documents: wills, house and land titles, mortgage documents, birth and marriage certificates, insurance policies, superannuation documents, Centrelink and Veterans' Affairs documents, share market certificates, Enduring Power of Attorney form.

Entitlements: Have you consulted Centrelink's Financial Information Service (FIS) Appointment Line to discuss your eligibility for benefits? An FIS Officer (Tel: 132 300) will make appointment for you to speak with an advisor in your area.

Wills

A will gives instructions as to how the estate of a deceased person should be distributed. If a person dies without a will, there is no guarantee that his or her wishes will be carried out. This can cause conflict, stress and even hardship for family members.

Encourage your family member to establish a will and to update it regularly so that it expresses their current wishes. To be legal, a will must be made and signed while the person is capable of understanding its effects and its full import. For more information, the Victoria Legal Aid Legal Information Service has an excellent publication available free with information about will-making – Securing their Future for Parents of Children and Adult Children with a Decision-Making Disability (Tel: (03) 9269 0210; country callers 1800 677 402; downloadable from website: www.legalaid.vic.gov.au).

If you require a solicitor to make a will, the Law Institute of Victoria Referral Service (Tel: (03) 9607 9550) can put you in touch with one.

Guardianship

A guardian is a person appointed by the Victorian Civil and Administrative Tribunal (VCAT) to make personal and lifestyle decisions for someone with a decision-making disability – an adult who

is unable to make reasonable decisions because of their disability and for whom important decisions need to be made. The guardian is responsible for making decisions that respect the person's wishes and that are in the person's best interests. Where possible, VCAT prefers to appoint a relative or friend of the person as their guardian. The initial application for guardianship is handled by the Office of the Public Advocate (Tel: 1300 309 337) before being handed over to VCAT.

Administrators: VCAT can also appoint an administrator to make financial and legal decisions for a person, such as managing their day-to-day finances. For more information, call the Office of the Public Advocate (Tel: 1300 309 337).

Enduring Powers of Attorney and Guardianship

While a person is still mentally capable, they can sign Enduring Powers of Attorney and/or Guardianship to appoint someone they trust to look after their affairs in the event that they lose the capacity to make decisions, either temporarily or permanently. "Enduring" means that the power continues (endures) for as long as the person is unable to make decisions.

The powers granted by the Enduring Powers of Attorney may give the attorney (the person appointed) the right to do most things necessary to ensure the person is well cared for. Conditions can be imposed however, such as preventing the attorney from selling the person's house.

There are three different powers, each with its own area of decision-making:

- > **Enduring Power of Attorney – Financial:** This is for making financial and legal decisions, such as managing a person's banking, property or paying their bills.
- > **Enduring Power of Attorney – Medical Treatment:** This applies to making medical treatment decisions, such as agreeing to medication or surgery on a person's behalf.
- > **Enduring Power of Guardianship:** This authority governs personal and lifestyle

decisions, such as where a person lives and the sort of health care they will receive.

As a carer, you might consider arranging Enduring Powers of Attorney and Guardianship for yourself to ensure that your affairs, and the affairs of your family member, are managed in the event that you also become incapacitated.

Enduring Powers of Attorney and Guardianship are simple to make. The Office of the Public Advocate has produced the publication *Take Control – A Guide to Powers of Attorney and Guardianship*, which contains all the forms you need and easy instructions to complete each form. Forms are also available from most newsagents and legal stationers.

Office of the Public Advocate (Tel: 1300 309 337).

Disability Services Legislation

Any disability and aged-care services funded by government are required to achieve certain standards and to protect a person's human rights. The Australian Human Rights Commission (General enquiries and publications: 1300 369 711. Complaints Info line: 1300 656 419) and the Victorian Equal Opportunity And Human Rights Commission (Enquiry Line: 1300 292 153) have jurisdiction to conciliate complaints about discrimination in areas such as disability services, employment and many other services.

Financial Assistance

Below is a summary of financial assistance that is available under a number of government schemes and programs. To find out which ones apply to your situation, contact the Department of Human Services Disability, Sickness and Carers Service (Tel: 13 27 17; Website: www.humanservices.gov.au.)

Carers' Pension: Available to a person providing personal care and attention or constant supervision to a person with a severe physical, intellectual or psychiatric disability. Eligibility depends on a number of criteria, including assets, income and other benefits received.

Carers' Allowance: This is paid by Centrelink to a person caring for someone at home. It is not means tested or taxable and it does not affect entitlements to other pensions or benefits.

Disability Support Pension: Available to people who have a physical, intellectual or psychiatric impairment that prevents them from working for 15 hours per week over the next two years and who are unable to undertake educational or vocational training that would equip them to work within the next two years.

Health Care Card, Pensioner Concession Card: These cards entitle the holder to a wide range of concessions covering health, transport, household bills and recreation. Anyone on a Disability Support Pension automatically receives one of these.

Mobility Allowance: Available to people who cannot use public transport and who are engaged in employment, training or volunteer work for a minimum of 32 hours every month.

Rent assistance: Available to some people who receive payments from Centrelink and some people who live on low-incomes or in government-funded residential care or in disability or rehabilitation accommodation.

Pharmaceutical allowance: This is automatically included in a pension payment.

Telephone allowance: Assists with the cost of telephone rental and is available to pensioners who are telephone subscribers.

Bereavement payment: Available as a lump sum to the surviving partner of a pensioner couple.

Reduced charges and tariffs: People who receive Centrelink benefits may be able to receive reductions on their electricity, gas, council rates and car registration under two Department of Human Services schemes – The Utility Relief Grant Scheme and the Non-Mains Utility Relief Grant Scheme (anything that is not connected to mains power, such as bottled gas, alternative fuel

sources). For more information on either, call the Concessions Unit Information Line (free call: 1800 658 521).

Department of Veterans' Affairs: If your family member is part of the veteran community, he or she, and their spouse and dependents, may be entitled to benefits. For more details, contact the Department of Veterans' Affairs (Tel: 13 32 54).

Driving

THIS FACT SHEET discusses specific problems that can affect driving, how to get a driving assessment and suggests ways of handling a family member who is no longer safe to drive.

Not all medical conditions affect driving performance in the same way and not all individuals with the same condition will be affected in the same manner. A person's fitness to drive depends on their cognitive (thinking and perceptual) and physical abilities, and their ability to cope with unusual and emergency situations. Some people are able to compensate for changes in their abilities while others may not. The effects of acquired brain injury (ABI) can sometimes be subtle and difficult to detect and may also creep up over time, affecting a person's ability to drive safely.

Conditions that Affect Driving

Physical changes: A person with ABI may experience physical weakness or poor coordination that comes and goes unpredictably, for example, affecting their control of the car.

Cognitive changes: These are changes in a person's thinking or perceptual abilities. For example, difficulties with perception may cause problems judging gaps in traffic. Changes in vision and attention may leave them unable to see potential hazards in their peripheral vision.

They may have slowed response times, trouble concentrating or experience confusion, all of which are dangerous when driving.

If there are doubts about your family member's ability to drive, you need to encourage them to discuss this with a doctor or occupational therapist.

Stroke: After stroke or serious head injuries, doctors normally recommend that a person wait at least three months before driving again.

The decision about if and when to return to driving should be made in consultation with a doctor and where appropriate, a driving assessor.

Driving assessment and other specialist referrals:

A detailed assessment by a specialist occupational therapist driving assessor can detect subtle problems that affect driving ability. It may also be necessary to refer the family member to another specialist – to have their vision tested, for example.

The Carer's Dilemma

Having a driver's licence gives a person independence. Being forced to give up this independence can have a big impact on the person's self esteem and well being. This is a sensitive issue that carers of people with ABI need to handle carefully.

It is important to discuss your safety concerns with your family member in a sensitive but straightforward way. Some people will understand the problem clearly, others may deny there is a problem, especially if their condition has deteriorated slowly and they do not realise they are no longer safe to drive.

Specialists can help: Some people will accept advice more readily from their doctor than a family member. You could ask your doctor to tackle the subject with your family member or see the doctor together and bring up the subject yourself. You or the doctor or an occupational therapist might suggest that the person has a driving assessment. When the person decides to have an assessment themselves, it helps them to feel that the decision remains in their control.

If this is not possible however, it may be necessary to write directly to VicRoads, or ask your doctor to do so.

Involving VicRoads

A doctor, health professional, friend or relative can write to VicRoads to express their concern about a person's driving skills that have deteriorated as a result of a medical condition. This letter is dealt with by VicRoads' Medical Review Section, which writes to the person to outline its concerns, and asks them to obtain a medical assessment from their doctor.

Depending on the doctor's report, VicRoads may then require a Review Driving Test or an Occupational Therapy Driver Assessment by an occupational therapist (it provides a list of approved occupational therapists).

Occupational Therapy Driver Assessment: This involves an off-road assessment that looks at the driver's medical and driving history, their physical, sensory and cognitive abilities and their knowledge of road law. This may be followed by an on-road assessment in a dual-control car.

The Medical Review Section then considers the reports from the doctor and occupational therapist. In its final decision, it may allow your family member to retain a full licence with annual medical reviews. Or it may grant a conditional licence that specifies modifications to the car or that allows daylight driving only. Or it may suspend or cancel the licence but agree to review these terms if their condition improves.

If the person is unwilling to be assessed, VicRoads may automatically suspend their licence.

Legal obligations: Drivers have a legal obligation to advise VicRoads of any permanent condition or illness that may impair their ability to drive safely. VicRoads has available a useful checklist to assist drivers (and their spouse or carer) to review and monitor their ability to drive safely (*see the VicRoads' Victorian Older Drivers' Handbook, 5th Edition*). It is also the driver's responsibility to advise their private

insurance company about any condition that may compromise driving abilities. Failure to do so may compromise the person's insurance coverage in the event of an accident.

Transport Options

If driving is no longer an option, help your family member to plan others ways to travel, such as by public transport, community services or taxis. Try to arrange activities that don't involve the use of a car and discuss positive reasons why these options work – they are more relaxing, quicker and there are no parking problems!

Multi-Purpose Taxi Program: This program is available for people with a permanent disability who cannot use public transport. Members pay half the metered taxi fare.

Contact

VicRoads Medical Review Section

PO Box 2504, Kew, 3101

Tel: 13 11 71

Fax: (03) 9854 2307

Source: Information sourced from VicRoads' Victorian Older Drivers' Handbook, 5th Edition.



SECTION FOUR

Section 4 Emotional Issues

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Grief and Loss

THIS FACT SHEET discusses the many losses associated with chronic conditions that challenge people with these conditions, their families and their carers. It describes the grief they can cause, emotional reactions that occur such as anxiety and depression, and presents ways to cope.

Grief is the emotional pain that we feel when we lose something or someone we value. It is a natural and normal reaction. Death is one such loss, but illness also brings the experience of loss for the person with the condition and for their carer. There is no single way to grieve, no clear set of “steps” in a grieving process.

Friends often don’t know how best to support you and grief can sometimes stretch relationships to breaking point. The most important thing is that people are allowed (and allow themselves) to grieve in their own way, in their own time.

For the Carer and Family

Families almost always experience grief over the loss of the life they had before. Grief may be felt over the changes in the person you care for or in confronting their imminent death. Many carers feel they can’t admit, even to themselves, how terrible they feel.

Diagnosis: The diagnosis often brings shock and confusion. You may be so focussed on the person that you have little time for your own feelings or reactions. Your relationship with the person may be changing, and your own needs may be neglected.

Too close for comfort: A carer looking after a parent may find their roles reversed – carer becomes parent – which can be awkward and difficult to come to terms with on both sides. Caring for a spouse often means taking over their responsibilities in the relationship. In both cases, you may be losing your greatest source of comfort and support.

Carers speak of loss in many ways:

- > Loss of the person you once knew, the things you did together, sharing good times.
- > Lack of intimacy and closeness.
- > Loss of independence, freedom, time for yourself, pursuing things you enjoyed, and employment.
- > Loss of communication and mutual support.
- > Losing a sense of normality and future, loss of dreams, goals and plans.
- > Loss of predictability, control, and financial security.
- > Loss of religious faith.

Feeling stuck: Each small setback can trigger grief. Where the condition is clearly progressive, you may feel you can’t start to move on until the person’s death, yet even to think like that opens up more grief and guilt. It can be a very drawn-out process.

For the Person with the Condition

Your own grief will be paralleled in the person you are caring for. Consider some of the losses they are dealing with: loss of the ability to move about easily, to work, to play, perhaps even the ability to communicate.

There is loss of their authority and place in the family, loss of decision-making abilities, family security and predictability, loss of self-esteem, religious faith, privacy and dignity.

When we are well, we have a sense of invulnerability that somehow the bad things in life will pass us by. Chronic or progressive illness shatters this sense

and brings grief that anticipates losses yet to come – loss of control, of family support and the fear of further illness and of becoming a burden. For those with an inherited condition, there may be the added fear that their children may face the same experience.

Feelings and Reactions

People react in many different ways and at different times. It's important to remember that these are all *normal reactions* to serious loss. You are not falling apart, cracking up or failing to cope.

Feelings: Feelings like these listed below may come over you in waves, often without warning. They are part of the process of adjusting to the changes.

- > Denial and shock – “Not us/me!”, it hasn't happened, it can't be true.
- > Anger and resentment – “Why us/me?” It's someone else's fault, blame the doctor, blame God.
- > You may feel sorrow, numb, miserable and many other negative emotions.
- > Guilt – at your anger, because you couldn't prevent the illness, because it didn't happen to you or because you no longer feel the same about the person.
- > Despair at the words “no cure”.
- > Depression, sadness, sorrow, helplessness hopelessness – feeling you can't cope, it's not worth it, there's nothing to live for, a continued grief with no end in sight.
- > Anxiety or panic – over the intensity of your feelings, about your future, about the present.
- > Self-doubt and blame – a sense of inadequacy, insecurity, “I'm doing a rotten job”, “It's my fault”.

Reactions: These feelings may cause people to behave and react in all sorts of ways. Each person's response is unique, but carers have described:

- > Tension, crying, fatigue, exhaustion.
- > Sleeping problems.
- > Changed eating habits.
- > Poor concentration and memory, loss of motivation, difficulty making decisions.
- > Poor health – headaches, stomach aches, indigestion.

- > Refusing help and withdrawing from social outings.

Managing Grief

Ignoring grief won't make it go away, but there are certain approaches that might help you to find a path through it and to adjust to your losses.

Recognise your feelings: Become aware of the feelings you have and learn to recognise why you have those feelings. Keep a diary if necessary.

Help yourself: Adopt a problem-solving approach. What can you do to help deal with these feelings or to defuse them?

Care for yourself: It's essential that you take care of your own needs as well as those of the person you care for. Acknowledge to yourself that you are grieving – it's OK to grieve.

Talk it out: Find someone you can talk to, perhaps a friend who will listen without giving advice. Consider seeing a grief counsellor who can give you skilled help in dealing not only with your own grief, but with that of the person you care for.

Find hope: You need hope. With hope, there is a future. While one part of you needs to acknowledge the difficulties you face, there is always something to hope for, however small or large it may be – don't let anyone talk you out of it. It might be an event, it might be a relationship or the knowledge that this time, too, will pass.

Other strategies that carers have found helpful include:

- > Seeking respite care (see Fact Sheet 15 : Respite and Residential Care).
- > Actively trying to maintain a positive state of mind.
- > Faith in a higher spirit or religion.
- > Treating yourself once in a while – to the movies, shopping with a friend, buying yourself something special.
- > Keeping informed, knowing what to expect in the future.
- > Avoiding isolation.
- > Holding on to a sense of humour.
- > Keeping a journal to write down fears, hopes, concerns, joys.

- > Joining a carers' support group.
- > Nurturing activities like yoga and tai chi.

Depression, Anxiety and Insecurity

Anxiety and depression are common and understandable reactions in a person who has a serious and disabling condition or in someone caring for that family member.

Depression is more than the sadness we all feel at times. It may be an overwhelming feeling of blackness that persists and deepens over weeks and months. Depression saps motivation and energy.

Grief may look a bit like depression, and for some people, the two may merge if grief becomes a sense of chronic sadness and hopelessness.

Symptoms of depression: Typical symptoms of depression include difficulty sleeping, crying a lot, overwhelming tiredness, a general loss of interest, changes in eating patterns, poor concentration, forgetfulness and confusion, difficulty in getting going, slowed movements, and a sense of worthlessness and guilt.

Affecting behaviour: If you are depressed, you may begin to neglect yourself, avoid things that have brought you pleasure, even blame yourself for your situation. You may begin to resent and neglect the family member you are caring for and feel there is no end to the despair.

Depression and anxiety coupled with the insecurity of illness can make a person with a chronic condition very reluctant to be left alone, even from room to room. This can be very demanding on the family. Even small changes make some people anxious.

Treatment: Chronic depression needs to be treated professionally. Speak to your doctor about your feelings so he or she can recommend a course of treatment. Both medication and talking about your concerns with someone such as a psychologist can help to overcome the depression. Likewise, if you feel the person you are caring for is depressed, talk to your doctor about it. You can help by treating the person as normally as possible. Be chatty and positive, but show them that someone still cares.

Preparing for Death

We all know we are going to die, yet in our society, we tend not to think about death or to prepare ourselves for it. Watching a person you love slowly approach death as they move, perhaps, from home to hostel to a nursing home, can therefore become a painful and confronting process for carers. But by thinking about how you might feel and doing some preparation, you can make this process a little easier.

Acknowledging death: For many people, the grief is there long in advance. It may start when the person is diagnosed, or before, and continue throughout their illness. Some people may begin grieving only after their family member dies.

Grief is unique: There are no rules about how to grieve – what you do, how long you are sad, when you stop crying – each of us deals with this in our own way. Do not expect those around you – family members or friends – to behave or feel as you do. We all react differently.

Just be yourself and allow yourself to grieve in your own time, in your own way, whether that is publicly or privately, but do grieve.

Before or after death: Talk about your thoughts, feelings and memories – it helps to sharpen memories, to remember the good times and the bad. Accept offers of support – this can help you to express your feelings, to reflect and to talk it out.

Professional help: If you can't seem to come to terms with the loss or if after several months you are not sleeping, not eating properly and are sad much of the time, seek professional help. A trained grief counsellor can make a difference.

Moving on: For many people, caring has defined their lives for so long that life beyond it can seem a challenge. There are usually decisions you can make and actions you can start that will help you move toward a new future. Try planning things you might do now, or in a few weeks, months or further down the track. These might include finding someone to help sort out a large house and financial affairs, thinking about friendships you would like to

rekindle, looking into TAFE courses, volunteering, employment or community work, or planning a break.

There is a time to move on that comes when you are ready, but occasionally, a person needs the help of a good counsellor to get there.

Contacts

National Association for Loss and Grief (NALAG) (Vic) Inc.

Provides information, advice and can refer you for further help if necessary.

Tel: (03) 9329 4003

Grief Line

Trained telephone counsellors provide anonymous help and support for grief and loss.

Tel: (03) 9935 74009

Carers Victoria

Carers Victoria has a counselling program and support groups.

Tel: (03) 9396 9500

free call: 1800 242 636

Coping with Stress

THIS FACT SHEET helps carers to recognise the symptoms of stress and provides strategies on how to avoid and manage stress. It discusses ways in which carers need to look after themselves.

Carers and Stress

We all encounter stress as part of our daily living. While a certain amount acts as a healthy, motivating force, too much stress over a prolonged period leads to physical and emotional exhaustion. Carers are very vulnerable to stress. They often report feeling utterly overwhelmed. Looking after someone day-in and day-out can be thankless, lonely, exhausting work, with no end in sight. Many carers also feel great sadness at the loss of their loved one's capabilities and let down by friends and family who don't want to be involved.

Too close for comfort: Caring for someone full-time or part-time is an intense experience that places strain on close relationships. If the person you are caring for is a partner or parent, it often means you have also lost your main source of emotional support and companionship.

It can also upset the normal roles we play in life. For example, a partner may need to take on many new roles such as cooking, managing finances and looking after the children. It's also quite an adjustment to feel comfortable "parenting" a once formidable mother or father who has become frail.

Add to this your family member's pain and frustration with their illness, which can cause irritability, even hostility, and you feel a bit like a punching bag. It's only natural to feel hurt when aggression is directed at you, the only person around to hear it.

Financial strain: Illness may also bring extra expense at a time when the family has less income, which adds to the tension.

The rewards: Yet, even under the most difficult conditions, carers speak of shared feelings of love and affection, of their personal satisfaction, of small successes, of mutual pleasures and appreciation, and cherished moments of happiness and closeness. Sometimes, helpers appear from the most unexpected corners and become wonderful friends.

Respect your needs: You need to make sure that you don't overcommit yourself or work too hard for too long – for your own sake, as well as the sake of the person you care for. Otherwise, who is going to care for you? You must learn to respect and meet your own needs. It's the only way to avoid breakdown or burnout.

Symptoms

Stress triggers a physical reaction in the body and prolonged stress weakens the immune system, making us less resistant to illness. When the body is placed in a state of high energy, all that energy needs to go somewhere. You might experience:

- > Short-temperedness and irritability.
- > Muscle tension, causing headaches.
- > Shallow breathing – the brain/body cannot function at its best with reduced oxygen intake.
- > Jumpiness or overactivity – unable to sit still or eat slowly, having scattered thoughts.
- > Constant fatigue, even after sleep, accompanied by foggy thinking.
- > Physical symptoms – stomach aches, indigestion.
- > Difficulty sleeping.

- > Increased heart rate, blood pressure, blood-sugar levels and palpitations.
- > Emotional symptoms – anxiety, overemotional responses, feeling trapped, crying easily, trembling, depression

Coping Strategies

Almost all carers experience some level of these symptoms and often feel guilty about not coping. But ignoring your own health and needs only makes matters worse.

Share your feelings: It is much easier to see a problem clearly and find a new way of dealing with it when you share the load. Find someone who can share your feelings, fears, frustrations and joys – a family member who understands, a friend or another carer.

Support groups: Consider joining a carers' support group where you can talk to others in similar situations and find out how they manage. It can be a great relief just talking with someone who understands what you are going through. You may also gain some useful, down-to-earth strategies. Call Carer's Australia (Vic) for support group details.

Counselling: A few sessions with a counsellor or psychologist may also be helpful, particularly if you are feeling overwhelmed or depressed about your situation. Ask for a referral from your doctor, contact your local council for services in your area or try the Australian Psychological Society's telephone referral service:

Telephone (03) 8662 3300 or free call 1800 333 497.

Laugh: Laughter is a tremendous stress release. Try not to take insults personally. Let yourself see the funny side and the absurdity in situations. A good belly-laugh performs magic on the mind and body.

Time off: You cannot care for someone 24 hours-a-day, seven days-a-week without serious consequences to your health. Plan time to yourself every day – at least thirty minutes – perhaps when the person you are caring for is watching TV or asleep or when someone else is home. Sit down

with a drink and read a magazine. Don't fill the time with housework.

You have probably forgotten what it's like having a weekend off. You need at least two half-days off a week. Plan a regular outing with a friend, attend a class or join a group.

Many councils offer services to look after a person in their own home and have day programs, if the person is well enough to attend. Have you asked family members or friends if they can help? They may be happy to help some of the time.

Don't try to do everything. Do the things that really matter and forget about the rest. Is all the housework you do really important? Could someone else manage the garden? Make lists of the most important things to be done.

Respite care: Respite care allows you to have a holiday to renew yourself physically and mentally. Respite care services recommend that you have at least two consecutive weeks in a break to allow yourself time to relax fully and gain maximum benefit. Fact Sheet 15: Respite and Residential Care tells you how to access these services.

Ask for help: Don't battle on alone. With support, you'll get some rest, be able to think more clearly and be in a better position to cope. You'll feel better about yourself and you'll be better able to go on caring.

Call your local council to find out what services are available in your community. Councils and local hospitals employ social workers who are a great source of support and information, as are Carers Australia (Vic) and your condition-specific support organisation, who understand your position well. Talk to your local doctor about stress management or call the Australian Psychological Society for a psychologist in your area. (See Contacts below) Don't forget to ask friends and acquaintances. People are often happy to help on a limited basis. Or ring a member of your carer support group.

If things suddenly become too much, call a crisis support service:

Lifeline: 13 1114

Mensline: 1300 789 978

Suicide Line: 1300 651 251

Commonwealth Carer Respite Centre:
1800 059 059

Caring for Yourself

Rule number one: Try not to put unrealistic demands on yourself. It is only natural that you will feel grumpy, tired and frustrated at times. Don't give yourself a hard time. No one is perfect. Just look at what you are achieving – you are doing an invaluable job.

Vitality = diet: Make sure that you eat well. Good nutrition gives us our health, our ability to cope and our energy. Choose a diet with lots of fresh fruit and vegetables, grains and legumes (beans, nuts, seeds), protein (meat, fish, eggs) and plenty of good fats (avocado, olive oil, butter, coconut milk). Try to avoid processed foods as much as possible.

Relaxation therapy: Research proves that relaxation therapies (tapes, classes, do-it-yourself techniques in books) and meditation dramatically reduce stress. This can be as simple as sitting in a park or really engaging with nature on a walk. A relaxation tape is available free from the Carers' Association. Many other tapes and books are available commercially.

Exercise: It simply is one of the best ways to reduce stress and it doesn't have to take long. Get some exercise each day. Walk around the block or to the shops or along the beach. Take up exercise you can do at home like yoga or tai chi. Try a new activity, like bowls or golf.

Indulge yourself: Pamper yourself within your budget. Go to the hairdresser, buy new clothes, go to a film, have a massage or sit in the sun with a good book.

Keep up social contacts: It's easy to lose social contacts but it's very important to keep up your own identity, separate from your caring role. Make sure

you do things that you are passionate about: films, reading, eating out.

Organise to see friends over a coffee and speak regularly with them over the phone. As simple as it seems, having stimulating conversations with people about a wide variety of topics temporarily takes your mind away from your role as a carer. It also gives you something to talk about together with your loved one.

Zzzzz: Try to get enough sleep. If your nights are interrupted, can you nap during the day? Can family members help, even one night a week? A relaxing activity before bed is an excellent idea.

Contacts

For more information, you might also contact your condition-specific support organisation (see Contacts page7).

Carers Australia (Vic)

37 Albert St,
PO Box 2204,
Footscray, 3011

Tel: (03) 9396 9500
free call: 1800 242 636
Fax: (03) 9396 9555

email: reception@carersvic.org.au
website: www.carersvic.org.au

Australian Psychological Society Ltd

Tel: (03) 8662 3300
free call: 1800 333 497

Supporting Children and Grandchildren

THIS FACT SHEET describes how to help children cope with the illness of a parent or grandparent, including how to communicate with them, common reactions to chronic illness, how to involve them and how to maintain a stable environment.

Children have the right to know about things that affect the family. Adults often think they can protect children from unnecessary distress by not discussing serious illness but it can do more harm than good. Children know when something is wrong. They see that adults are upset or behaving differently and they overhear conversations. They see physical changes in their loved one. It is best to talk through the issues with them.

Children have an amazing ability to deal with the truth. Even very sad truths relieve anxiety over uncertainty. Once they understand what is happening, they can also be a support and comfort to you.

Keeping Kids in the Dark

This is what happens when we keep the truth from children:

- > If they are not given a clear and accurate explanation, children often imagine something far worse than the real situation.
- > Someone may tell them anyway or they will gather misconceptions from TV, magazines or other sources.
- > Children can feel very cut-off, forgotten or misunderstood. They may feel they are not important enough to be included.
- > It is very common for a child to think that they have somehow caused or contributed to the illness. Young children feel they have magical powers and that what they wish will come true. For instance: "I got mad at Dad. Now he's sick. Maybe I made him sick."

Delivering the News

- > Explain what is wrong and about any treatment your family member is having.
- > Don't give too much information at one time.
- > Use words that are clear and precise.
- > Don't lie, but don't talk unnecessarily about frightening medical or financial concerns. Do discuss how the child will be affected.
- > Answer questions clearly, truthfully and in an age-appropriate manner.
- > If there are questions you can't answer, don't be afraid to say, "I don't know".
- > Don't make promises you can't keep - "Mummy will be fine, I promise".
- > Reassure young children that nothing they have said, thought or done could cause the illness.

Typical Responses of Children

Chronic illness means that parents have less time and attention for their children. Meanwhile, children are often asked to carry extra responsibilities. All these changes turn a child's world upside down. There can be great frustration and anger, with the responses to match.

Guilt: Some children will feel sorry for themselves when a parent is sick, then feel guilty because they are not feeling sorry for the parent. Some will feel angry at their parent for being sick and wish they weren't there, and feel guilty about that too. Other children try to make up for their guilt feelings by being super-good and setting unrealistically high standards for themselves.

Resentment: Children can resent having to help a sick parent when they are so used to being looked after. Children may act out their resentment and fears by running away or dropping out of school.

Regression: Children of any age may regress in behaviour. Know that it's just their way of saying, "I'm still here!" and "I'm just a kid. I need someone to look after me".

Inappropriate behaviour: Some children laugh or behave badly to cover up their real feelings, their lack of understanding or their discomfort.

Attention seeking: Children sometimes act sick to get attention. Some may also begin to compete for the healthy parent's attention. Some children become clingy, afraid that something bad will happen to their parent when not there.

Confusion of roles: Teenagers face a tough time – just when they are trying to be independent, a parent may need to depend on them. Suddenly the roles are reversed. Some teenagers rebel, some may regress, some are too embarrassed to bring friends home, others may take on heavy responsibilities and mature too quickly. Sometimes kids withdraw, subconsciously trying to become more independent.

Communication breakdown: All children find it difficult to grasp how illness could cause someone they love to treat them differently. Carers have described children who become frightened of their parent's behaviour and who can no longer communicate with them. Some avoid visiting their family member because they can't cope with the changes.

As the Illness Progresses

Keep them well informed: As the symptoms or effects of brain injury appear and progress – personality changes, physical disability, inability to participate, speech and memory problems – explain and discuss these changes with the child. Help them to understand that even if grandpa's face or voice changes, it's still grandpa underneath.

If death is an issue, you need to talk about it. What you say will depend on the age of the child.

Remember that a child's understanding of "soon" and "later" is very different to an adult's. Talk about and share the sadness and the happy memories that will remain.

Some children may need reassurance about how people die. For many, their only knowledge is the violence they see on television. Contact a grief counsellor for suggestions if you feel uncertain about how to discuss death.

Give the child answers about their practical concerns – Who will take them to school if Mum can't? Where will the money come from if Dad isn't working?

Children's fears run easily out of control, so the truth may seem much less frightening. You may find children have concerns you never considered, but no worries about the things you thought would trouble them.

If a child seems worried, ask about their fears or what they think might happen and correct any wrong impressions.

Emotional support: Try to instil children with feelings of hope – while there are things to be sad about, there will still be lots of good times. Reassure them they will always be loved and cared for.

Children will let you know how much they can handle and what they want to know. Remember to listen well and to keep your ears open.

Talk about your feelings, the feelings of the person you are caring for and the child's feelings. Share feelings of sadness and happiness. And don't be afraid to cry in front of children or to let them know that you cry. They need to know that it's part of how we cope.

Involve them: Children need to be told how they can help. For instance, they might visit or talk with the grandparent or parent. You may need to suggest things that they could do together. The child might be able to help the carer in some way, which helps them to feel that they are contributing.

Maintaining Stability in Change

Reassure: The most important thing you can do is to let the child know you understand that things are difficult for them and that you love them as they are.

Routine: Keep things as normal as possible. Stick to a daily routine if possible.

Be flexible: If plans need to be changed because of an emergency, try to be relaxed about it and involve the children as much as possible in the changes.

Inform supervisors: Let the children's teachers and perhaps the school counsellor know about the home situation. Their suggestions and understanding will help if there are any problems.

Flow-on effect: Serious illness in the family can have a flow-on effect, creating disturbances in other areas, such as eating, sleeping, schoolwork or even friendships. Be on the lookout for these.

Maintain discipline: Disciplining children may be difficult, particularly when they are acting up to get some much-needed attention. But a breakdown in discipline can convince a child that something is very wrong at home. Set firm limits and find ways to enforce them, for your sake and the child's. Let the child know that you understand, love and accept them – but not their misbehaviour. Reward good behaviour and let them know how much you appreciate their cooperation.

Express feelings: Keep talking about feelings. If you don't, your children will also bottle up theirs. Children can shut down their feelings if sharing or expressing them is made to seem unnatural. Don't be afraid to express sadness – it's part of life. Sharing feelings can also strengthen the bond between you and your children.

Seek support: There is no need to battle on alone. If problems persist, help is at hand. Talk to people at your school, hospital, church or seek out professional counselling, either for individual members or the family as a unit.

Genetic Testing

Older children may be concerned about the possibility of inheriting their parent's condition.

Some conditions are inherited directly or there may be a genetic predisposition. These possibilities are discussed in fact sheets on each specific neurological condition that can be obtained from BrainLink (Tel: 9845 2950 or free call 1800 677 579). See the introduction to this booklet for a list of fact sheets available.

Genetic testing is available for some conditions. Because the results can be upsetting and create difficult decisions, anyone who chooses to have it must first see a genetic counsellor. Counsellors map out the family tree to identify the pattern of genetic inheritance and to determine a person's risk level before discussing the possible outcomes of testing.

Your condition-specific support organisation (see Contacts pg 7) can provide more information or phone the Victorian Clinical Genetics Service at Monash Medical Centre, Tel: (03) 9594 2026 or Genetic Health Services Victoria at the Royal Children's Hospital, Tel: (03) 8341 6201.

Notes:



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BrainLink

Reducing the impact of acquired brain disorders in our community.