

GETTING THE BEST FROM YOUR HEALTH CARE TEAM

If you, a friend, or family member have an acquired brain injury or neurological condition, many different health care professionals are likely to be involved in your treatment. 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 (see Making Decisions). With so much new information to gather and absorb, it can be difficult to know who the best person is to answer your questions. This fact sheet includes information on:

- > Making decisions
- > How to go about obtaining information
- > Handling difficult communications
- > Your health care team – who they are and what they do

If you need help from an interpreter to speak to a health care professional, contact:

The Translating and Interpreting Service (telephone: 131 450). This is a free service.

MAKING DECISIONS

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 whether they have appointed - or whether there is a legal order in place that allows - someone to act on their behalf at unexpected times.

Powers of Attorney: Powers of Attorney are documents in which a person appoints someone to act on or make financial, legal,

medical treatment or lifestyle decisions on their behalf. An Enduring Power of Attorney (Medical Treatment) appoints someone to take control in the event that a person should at some point in the future lose their capacity to make those decisions themselves. A person must be considered to have the capacity to make decisions at the time of appointing a Power of Attorney.

In medical treatment decisions, 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.

A Legal Guardian: If there is difficulty in establishing the appropriate decision-maker or there are doubts about the injured person's wishes or 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.

An 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: 9628 9911 or toll free: 1800 133 055)

The Office of the Public Advocate (telephone: 9603 9500 or toll free: 1800 136 829 or website: www.publicadvocate.vic.gov.au)

OBTAINING INFORMATION

These tips can help you and 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 you are most alert.
- > Bring someone to appointments who can help to remember information or take notes
- > If you don't understand something, ask the health professional to explain again
- > Ask for printed material on your condition or where to get information and support
- > Ask the health professional to write a list of your 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 treatment you will need at home
- > Carers: be sensitive if discussing issues about a person's unusual new behaviour in their presence or make a separate appointment to discuss your concerns

Getting the information you want is not always a straightforward process. For example, families sometimes feel challenged by the confidential bond between a doctor and patient. Also, some patients may want a second opinion but feel uncomfortable seeking it.

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

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

Seeking Second Opinions: It's perfectly OK to seek a second opinion on your 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 your medical records to be sent to the second doctor. After seeing the second doctor, you are free to choose your preferred specialist.

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.

All hospitals have a staff member called a **patient-client advocate** or **client relations manager** 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
- > **I** statements, rather than **you** 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 bloody mumbo jumbo!”

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

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?”

YOUR HEALTH CARE TEAM

The following professionals are typical members of a health care team. You may meet them while at hospital, during rehabilitation or once you are home. Consider keeping a diary of problems, symptoms and past treatments – your team can make better decisions when it has an accurate medical history and record of your progress.

Case manager: Case managers plan and coordinate many aspects of your care, link people to appropriate services, locate funding and help you reintegrate into the community.

Dietician: Dieticians help those who have difficulty eating or swallowing. They suggest the most suitable foods and give advice to those who are overweight, underweight or diabetic.

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

General practitioner: Your 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 your progress.

Neuropsychologist: Neuropsychologists 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 those changes.

Neurosurgeon: Neurosurgeons operate on the brain and spinal cord.

Occupational therapist: Occupational therapists assess your ability to manage daily tasks and recommend home modifications or physical aids you may need to perform tasks. They also help people re-learn skills, such as how to dress, prepare meals and maintain hygiene.

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

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 damage, they help people manage problems that are an emotional reaction to brain damage.

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 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 you overcome problems with communication, speaking and swallowing.

FOR MORE INFORMATION

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 you had treatment.

Australian Medical Association

(telephone: 9280 8722 or 1800 810 451)

Australian Physiotherapy Association

(telephone: 9429 1799)

Australian Psychological Society

(telephone: 8662 3300)

Australian Association of Social Workers

(telephone: 9388 1499 or 1800 630 124)

Occupational Therapy Australia, Victoria

(telephone: 9481 6866)

Speech Pathology Australia

(telephone: 9642 4899)

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