

# NeuroNews

The Neurological Council of WA (Inc)

## Diagnosed with Myasthenia Gravis: My Story!

In my early 70's to my horror, I found that I was rapidly losing my ability to sing, and after ruling out any "nasties" my GP told me it was ageing muscles.

Next, I experienced frightening episodes of choking, even waking up at night choking on my saliva. Off to the GP again, my trouble thought to be asthma related. Some treatment ordered.

A couple of years on I found I had extreme difficulty opening my eyes. The question was asked "Do you mean they are sticky?" "No. I just find it difficult to open my eyes".

"If I could sit and talk to folk with my eyes closed, life would be easier". This time I was thought to be depressed. I knew I was

not depressed. I had realised that there would be some effects from ageing but was shocked that it was racing on.

I did not take the anti-depressants prescribed but paced myself and got on with my life.

Some time later I experienced double vision. This time it was off for a Brain Scan. This ruled out brain tumours or any affects of strokes.

Next step, a Neurologist. In five minutes this man told me he felt I was suffering from Myasthenia Gravis.

It was not ageing muscles which was affecting my speech and stopping me from singing, not asthma which was making me choke, and not depression that made it difficult to open my

eyes. All these symptoms were related to MG. *It is no reflection on the GP who was treating me that he had failed to recognise the symptoms, as I now know MG is difficult to recognise.*

No treatment was prescribed until I had blood tests, underwent a Tensilon test and a test where the muscle was repetitively stimulated (shocked).

In the words of the Neurologist "Chinese Torture". These tests confirmed the diagnosis of MG.

Despite feeling totally shocked and miserable at the thought that I had this rare disease for which there is no known cure I have stamped indelibly on my mind the day of the Tensilon Test.

*(Continued on page 5)*

June/July 2005

Volume 2, Issue 2

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### Breakfast with Dr Neale Fong

A/Director General of Health

'What the WA Health Service will look like in 2010'

Wednesday 31st August (see page 2 for details)

The Neurological Expo and Conference 2005 will be held in November. If your organization is interested in participating, please contact the Neurological Council of WA on 9346 7533.

### Board Members

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Unit 3/ 10 Victoria St, Bunbury  
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*NeuroNews* Editor: Del Weston

# **BREAKFAST WITH DR NEALE FONG**

## **Acting Director General of Health**

### ***'What the WA Health Service will look like in 2010'***

**31st August 2005, 7.15 am for 7.30 am start**

**Cost: \$35.00**

**Bells Function Centre, Perth**

**(between the Bell Tower and the Swan River)**

**RSVP and payments to the**

**Neurological Council of WA**

**24th August 2005**

West have identified the need for dementia / memory clinics in our area,  
Phone: 9346 7530 or Email: del.ncwa@cnswa.com  
at our office in unit 3/10 Victoria Street Bunbury.

GP, specialist referrals, service providers etc. The assessment will be free  
**Disabled Access**

**Parking available on South side of Perth Concert Hall**  
f memory loss with a tool called the ADAS Cognitive Assessment (Australian

### **NCWA networking morning tea**

ill receive a copy of the report (GP's, specialists etc).  
About 20 people attended the morning tea held at the Niche on June  
1st. It was an opportunity for the NCWA to briefly give an overview of  
what is happening in the Council that is of relevance to the membership  
and also an opportunity for member organizations to meet, briefly say  
what their organization does and what they would like to do as a group  
in future.

as the need arises.  
Some constructive ideas emerged and in general, it was agreed to hold  
quarterly morning teas. There was very little representation from the  
health organizations which was unfortunate as there is much good will  
in supporting all members of the Council and such networking is very  
positive, unifying and empowering for the sector.

This newsletter welcomes all submissions relevant to the neurological sector — whether research, personal experience stories, events, comments and opinions. The views expressed in articles in *NeuroNews* are not necessarily those of the Neurological Council of WA. The deadline for copy for the next newsletter is the beginning of September 2005.

# Neurological Expo and Conference 2005

The NCWA Board has decided that the Neurological Expo and Conference be separate events this year. The Expo will be held during Neurological Awareness Week, on Tuesday and Wednesday 15<sup>th</sup> & 16<sup>th</sup> November in Sir Charles Gairdner Hospital (Watling Street).

The NCWA will organize sponsorship, display boards and publicity for the event.

If you would like to be involved in contributing to the organization of the Expo, please contact the NCWA CEO.

The Neurological Conference will be held at The Niche on the 21<sup>st</sup> and 22<sup>nd</sup> November 2005. It will be a bi-annual event, alternating with the Symposium of

Western Australian Neuroscience (SWAN) conference.

There will be three or four streams to the conference: scientific research and clinical; community (including regional); allied health; social and ethical issues.

The main theme will be 'The Living Experience: neurological disorders in the 21<sup>st</sup> century' - unless other preferred suggestions

Funding will be sought to cover overheads incurred by the Expo and Conference to enable these events to be accessible to all organizations and members of the community. Every attempt will be made to provide all member organizations opportunities for participation in the event. A conference web page will be 'launched' by July/ August (funded by Perth Convention Bureau). The conference

web page will be linked to a revamped NCWA web page.

Conference papers will be by invitation, abstract submission and member organisation's contributions. Details of abstract submission will be found on the web conference page by early August at [www.cnswa.com](http://www.cnswa.com)

For further information about the Expo or Conference,

phone 9346 7533

or email: [del.ncwa@cnswa.com](mailto:del.ncwa@cnswa.com)

## Symposium of West-

The Symposium of Western Australian Neuroscience (SWAN) is a one day meeting that aims to facilitate exchange between basic researchers and clinicians.

Invited speakers this year will address the themes of Stroke (Prof Neil Sims, Dr Bruno Meloni), and the use of Viral Vectors as a tool in Neuroscience (Prof. Pirooska Rakoczy, Prof Alan Harvey).

In addition, research students will be invited to submit abstracts for poster and oral presentations. The Symposium will be held at The Niche with the support of the Neurological Council on the 30<sup>th</sup> of September, 2005. Members of the Neurological Council are welcome to attend the seminars free of charge.

### 'The CNS Workstations'

The NCWA Board is currently considering setting up a workstation in the Centre for Neurological Support for use by non tenant organisations. If your organization would be interested in the use of such a facility, please let the Council know to assist with the planning. It is envisaged a workstation would consist of a computer and printer and access to photocopying.

Global Motor Neurone Disease Day (MND) was celebrated on 21st June.

See the next issue of Neuronews for a story about MND.

# Virtual Neuro Centre.com

## Background

Doctor Andrew Dean FRACP and Mr Wayne Hughes founded the Virtual Cancer Centre (VCC) three years ago. Virtualcancercentre.com's primary professional aim is to improve, inform and educate medical professionals in the very latest treatment knowledge, enabling the best clinical outcomes possible for patients, their families and carers.

Due to early successes of VCC and the reaction of the key stakeholders within the organisation the idea has been expanded to a bigger picture and a new entity known as the Virtual Medical Centre (VMC). Virtual Medical Centre has now become the central hub of the group of 12 specialist centres that not only addresses cancer but eleven other specialist centres which include bone, renal, gastro, blood, cardiac, pain, respiratory, neuro, psych, endocrine and infection. (Refer to *Figure 1* below)

## *Figure 1 – The future evolution of virtualmedicalcentre.com*

VMC believes that many patients are currently under treated because of poor communication, myths and misconceptions about treatment and a lack of knowledge about the availability of new treatments. Our online resources help dispel myths through the information supplied and believe that more patients, when they have their concerns addressed, will be willing to undergo treatment once they understand the benefits.

## Operations

Virtual Medical Centre.com is a free service provided to the community and offers a patient profiling service enabling users to request breaking information about specific cancers.

The websites offer comprehensive information on treatments and how they work; explanation on biology;

new and emerging therapies; patient support groups; clinical trials; and symptom management. The sites also offers a bulletin board, links to other sites and breaking news about new treatments as they become available.

One of the key directives of the founders is to maintain high ethical standards and to always foster good clinical practice. To support this directive, the company ensures its web site meets the stringent standards of the HON accreditation of Switzerland for the supply of medical information on the Internet.

The company's General Manager Tom Maher, manages a team of twenty skilled people experienced in medical and information portal development fields. Starting costs have been high, the company continues to invest in research, and development to improve the web site as it grows.

The company derives its income by selling sponsorship space on the web site to major pharmaceutical companies. This is an attractive proposition for the pharmaceutical companies as legislation currently prevents them from advertising their products directly.

The Virtual Medical Centre receives on average 1.2 million page requests a month for medical information. The breakdown for information is 40% Doctors, 40% Public & 20% Allied Health Professionals.

The virtual Medical Centre is the successful recipient of an ITOL grant, from the Federal Government, to develop an Online Patient Managed Health Record known as MY Quest. A consortium formed by the Virtual Cancer Centre has been working on My Quest for more than 10 months. Members of the consortium include:

- Virtual Cancer Centre
- Hollywood Private Hospital – a member of Ramsay Health Care Australia
- St John of God Health Care –

Subiaco

- Silver Chain Hospice Care Service
- Sir Charles Gairdner Hospital – Radiation Oncology Department

The purpose of My Quest is to provide patients with an on-line system to store information regarding their illness and its treatment. Patients are able to provide their medical practitioner with a summary report on demand, thereby significantly enhancing the quality of the consultation.

Virtual Medical Centre is accredited by the Royal Australian College of General Practice (RACGP) as a Continued Medical Education (CME) provider.

Virtual Medical Centre has recently been awarded the Prime Minister's award for small business Excellence in Community Business Partnership for Western Australia by the Prime Minister the Hon John Howard and been announced as a finalist in the "Secrets of Australian IT Innovation Competition 2004" by AUSTRADE.

## The Management Team.

The Management Team is lead by **Dr Andrew Dean**, Medical Director, has twenty years medical experience as a Physician and Associate Professor of Medicine. Dr Dean is nationally respected for his passion for continuing medical education and patient empowerment. He has practised medicine in Sydney and Perth in both the Public and Private Health Care Systems.

(Continued on page 6)

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## Diagnosed with Myasthenia Gravis: My Story! *(cont. from p 1.)*

I duly reported at the hospital and was put in a bed. After some preliminaries the Neurologist entered accompanied by five medical students, white coats flapping and stethoscopes around their necks.

As I responded to requests to flap my arms and raise my leg – turn my eyes etc. as my strength resistance was tested, it seemed to me that there should have been music striking up and the students breaking into a song and dance routine as it resembled a scene from a Gilbert and Sullivan show. Tensilon administered, and then strength tests repeated. The excitement obvious in the eyes of the students and the words of the Neurologist “That’s positive” told me that I did have Myasthenia Gravis.

Because I am elderly, it is sometimes confusing to know whether it is MG or old age that makes me feel like I do. The Neurologist tells me that he should be able to control the symptoms and avoid a life-threatening crisis, and that I will die of old age. Cheerful thought.

The anger has subsided. Of course I get annoyed and a little sad at times at the restrictions the disease places on me, but this is my life and I am grateful to my parents for that fact, and as I approach my eightieth birthday I look forward to enjoying quite a few more wonderful years.

*Information submitted by Rona J. Okely*

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## What’s new on the Myasthenia Gravis Front?

**Myasthenia Gravis (MG) is a little known** neuromuscular disorder which, based on world figures, could affect up to 250 people in Western Australia.

The Myasthenia Gravis Friends and Support Group WA Inc have made contact with some fifty-five Myasthenics and have been working to raise awareness of the disease and the existence of the support group amongst health professionals and in the community generally.

The Group has written a “Handbook for Myasthenics”, new hand out pamphlets and have established a website.

The Book, materials and website are to be launched early August with the venue and date still to be determined.

Those who would like more info on the launch are invited to ring the Support Group on (08) 9459 7168.

Ron Okely

Hon. Secretary

Myasthenia Gravis Friends & Support Group WA Inc

## What's On.....

### Looking for information on Muscular Dystrophy?

Mark your diary

MD2005 [www.md2005.info](http://www.md2005.info)

Perth, Western Australia

15th & 16th July 2005

The Neurological Council of WA will be conducting the following workshops for its members during the second half of 2005:

- Risk Management and Insurance
- Cross Cultural Awareness
- Advocacy Training and Consumer representation
- Quality Assurance and Quality Improvement

If you or members of your organization is interested in any of these workshops, please contact the NCWA on 9346 7599 and register your interest.

## Parkinson's Western Australia, Committed To Caring!

*Committed to Caring*, our new motto, was submitted by one of our members, and will be officially launched later in the year. A new community service announcement *Parkinson's knows no boundaries* will go to air during the next month. This is part of our strategic plan to increase awareness of the condition and the services we offer.

The bi-monthly seminar series in April featured a session on *Nutrition and Oral Hygiene* for people with Parkinson's and their carers. This coincided with the revision of a very popular book, *Eat Well, Stay Well with Parkinson's Disease* - now available in the office.

Throughout the state our fifteen Support Groups, mainly coordinated by volunteers, provide support and social activities for people with Parkinson's, friends and carers. Support Groups are in Albany, Armadale, Bullcreek, Bunbury, Busselton, Geraldton, Kingsley, Mandurah, Morley, Narrogin, Northam, Rockingham and the western suburbs. We are working towards establishing two new Support Groups in the metro area. The Support Group Leaders will hold a workshop in June to share ideas on activities and media promotion.

### Coming Events:

**25<sup>TH</sup> June - Seminar:  
Vision, Driving and  
Parkinson's Disease**

**20<sup>th</sup> August - Seminar:  
Parkinson's and Sexuality**

**For further information  
please contact the  
association on 9346 7373  
or email: [pawa@cnswa.com](mailto:pawa@cnswa.com)  
Toll free 1800 639 331**

# Corporate Governance and the NGO Sector

*The following document is an excerpt from a workshop on corporate governance presented by Tony Bevan, Director, Horwath Audit (WA) Pty Ltd for members of the not for profit sector.*

## Liability Officers, Introduction

There are three main types of organisations involved in the non-government not for profit sector in Australia. They are:

- unincorporated associations.
- companies limited by guarantee
- incorporated associations.

In each case, directors or officeholders of those organisations can be personally liable for certain debts (liabilities) incurred by the organisation.

## Unincorporated Associations

An unincorporated association does not have the power to enter into contracts or be sued in its own name. Generally speaking, **third** parties, when dealing with unincorporated associations contract with members of that association's committee directly. Consequently, the committee members become personally responsible (liable) for the performance of that contract. They may also become personally liable for any other debts incurred by that organisation.

The potential liability for members of committees of unincorporated associations is enormous. Any such organisation should immediately take steps to incorporate, to give the association the ability to contract in its own name and to offer limited liability to the association's members and office holders.

## Companies Limited By Guarantee

A company limited by guarantee is a corporation created under the Corporations Act. The members of such a company instead of contributing share capital provide a guarantee (usually for a nominal amount) that they will meet any outstanding debts of the company on winding up. The constitution of a company limited by guarantee also prohibits the payment of dividends to its members.

Directors of a company limited by guarantee have the same responsibilities and risks of a public company director. Obligations are imposed by the Corporations Act and at common law. The common law duties of a director can be summarised as follows:

- to exercise a proper level of due care, diligence and skill in acting for the company
- to act in good faith
- to act honestly and be loyal to the interests of the company.
- to exercise their powers for the purpose which they are conferred and not for any collateral and improper purpose.
- not to fetter the future exercise of their powers.

- to avoid being placed in a position where their individual or collective interests conflict with those of the company.

The Corporations Act imposes personal liability on directors for:

- Failure to take reasonable steps to comply with the requirements of the administrative obligations of a company.
- Failure to prevent insolvent trading by the company.

## Incorporated Associations

Most not for profit organisations (including member based organisations) are incorporated associations under their relevant State legislation - in WA this is the Associations Incorporations Act (1987).

Incorporated associations are entities in themselves, separate and distinct from their members in the same manner as companies. They have perpetual succession, the rights to acquire and hold property and are capable of suing and being sued. Incorporated associations are prevented from distributing their income or assets to their members.

As a general statement, the common law obligations imposed on directors of companies limited by guarantee apply equally to committee members of incorporated associations.

There is little authority in the application of common law duties of directors to situations involving incorporated associations. In principle however, the positions are very similar and it seems that the committee members of associations would have the same obligations of those of a director of a company.

## Conclusions

There is still some degree of uncertainty as to where the "line in the sand" will be drawn for personal liability of directors and office holders of not for profit organisations. However it is becoming increasingly clear that in a more litigious society with increasing community expectations that issues involving the potential liability of office holders are more likely to be tested in the courts. In those circumstances the potential for personal liability of officeholders is likely to increase.

To combat this risk officeholders and directors must:

- ensure that they are aware of what is going on in their organisation and that they are not just "along for the prestige", "the post meeting fellowship" or "filling the numbers".
- ensure that they carefully consider any document which they are asked to sign in their capacity as an officeholder
- ensure their club or organisation has put in place procedures or protocols which will ensure compliance with statutory requirements, limit risks and ensure that proper reporting is made to directors and officeholders.
- insist upon directors and officeholders liability insurance.

## A Corporate Governance checklist is available from:

Tony Bevan, Director Horwath Audit (WA) Pty Ltd  
128 Hay Street, Subiaco Phone 9380 8400

## Home and Community Care Programs (HACC)

The Neurological Council of WA is funded to provide Home and Community Care programmes throughout the Perth metropolitan area, the Great Southern region based at Albany and the South West Region, based at Bunbury.

**The Perth Metropolitan HACC** programme provides a brokerage service which ensures the best services are provided and tailored to meet the specific needs of people with neurological

disorders. Services which can be obtained include:

- Respite
- Social Support (outings, shopping, etc)
- Personal Care (assistance with showers, etc)
- Counselling
- Information and advocacy.

A Respite Care Co-ordinator will make an assessment in your home of your

needs and develop a care plan. Services needed for the care plan will then be put in place in consultation with the patient and carer.

Perth has two Care Respite Co-ordinators, Sue Nash and Dianne

Melville who can be contacted at the Neurological Council on:

**9346 7533**

Monday to Friday 8.30–4.30pm

## South West Neurological Nurse Specialist Service

**Bunbury Neurological Nurse  
Specialist Service**

**Unit 3, 10 Victoria St**

**Bunbury Phone: 9792 4073**

## Great Southern Neurological Nurse Specialist Service

A Parkinsons support group meeting is held in Narrogin on the last Friday of the month. next one is 28th July. Ann Weaver, the Neurological Nurse Specialist will also attend a Seniors disability meeting in Narrogin .

Ann will also be in Katanning on last Wednesday of each month.

The Neurological Support Group in Albany is on the 3rd Tuesday of the month, at Lotteries house, North

Road, Albany.

The Parkinsons Support Group in Albany meets on the first Tuesday of

**Albany Neurological Nurse  
Specialist Service**

**Lotteries House, North Rd, Albany**

**Phone 9841 5233**

the month at Lotteries House, North Road, Albany.

If you have any queries about the Neurological Nurse Specialist Service in Albany, contact Ann Weaver on

9841 5233

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# Petrol Sniffing, A National Disgrace

## Petrol Sniffing: A National Disgrace

Associate Professor Dennis Gray

National Drug Research Institute

Curtin University of Technology

In the first issue of this newsletter, Professor Gavin Mooney discussed the inequalities in Aboriginal health status. Here, I look at one aspect of this inequality – the prevalence of petrol sniffing (inhalation) and its harmful consequences.

Petrol sniffing is not a discrete behaviour. It is an element of the use of a wide range of psychoactive substances that is found – to varying degrees – in all societies. However, substance use at harmful levels is particularly marked in Indigenous minority populations where it is, in large part, a consequence of dispossession and continuing economic and social marginalisation.

### Petrol

It is important to distinguish between types of petrol and the effects of inhaling them. *Leaded petrol* – the use of which has now been phased out – contained relatively large amounts of ethyl-lead as well as a number of volatile hydrocarbons including benzene, toluene, xylene and n-hexane (substances that are also found in a number of commercially available products such as glues, paints and cleaning fluids). All of these substances are psychoactive and toxic – including being neurotoxic. *Unleaded petrol* contains the same hydrocarbons as did leaded petrol but not the ethyl lead. Aviation fuel or *avgas* – which is currently being phased out for environmental reasons – contains high levels of ethyl-lead but low levels of volatile hydrocarbons and is un-sniffable. In order to discourage its use and to recoup some of the costs of environmental damage, avgas was subject to high levels of excise duty making it considerably more expensive than unleaded petrol. In addition, a new highly refined fuel called ‘Opal’ is now being produced which contains no lead and extremely small proportions of volatile hydrocarbons. Opal is also considerably more expensive than unleaded petrol because of high refining costs.

### Patterns of use

Petrol sniffing – as opposed to other inhalant use – is generally confined to remote Aboriginal communities; often where the communities themselves have prohibited the sale or consumption of alcohol and the availability of other psychoactive substances is limited. Fifteen years ago, petrol sniffing was largely confined to remote communities in Arnhem Land and desert communities in Central Australia and the tri-state border region of the Northern Territory, South Australia and Western Australia. However, since that time it has spread over a wider geographic range.

It is difficult to enumerate accurately the extent of the problem. In terms of the larger Australian population, the public health impact of the problem appears small. However, when the numbers of sniffers and the size of the communities in which they reside is taken into account, sniffing is of epidemic proportion. In some remote communities, petrol sniffing and related harms occur at a rate that would not be tolerated in the wider community and which would initiate a major public health intervention.

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*In some remote communities, petrol sniffing and related harms occur at a rate that would not be tolerated in the wider community and which would initiate a major public health intervention.*

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### The effects of petrol sniffing

The acute symptoms of intoxication that are valued by sniffers are feelings of euphoria and hallucinations. Other acute symptoms may include feelings of aggression, impaired motor responses including slurring of speech and diminished muscular coordination, impaired cognitive function, elevated heart rate, nausea, and/or loss of consciousness.

Chronic, long-term petrol sniffing can result in permanent cognitive impairment and neurological damage. Further, the accumulation of lead can result in severe encephalopathy (damage to both the structure and function of the brain) and it is generally agreed that much of, though not all, chronic damage from the sniffing of leaded petrol was caused by the lead component. Although it has now been phased out, in many remote communities there are people who are permanently disabled as a consequence of sniffing of leaded petrol.

In those communities where it is endemic, the direct and indirect effects of petrol sniffing consume significant amounts of health, policing (that is, where there is a police presence) and other resources.

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## Petrol Sniffing, A National Disgrace

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*Many families and communities must bear a heavy burden of care and responsibility for those who suffer permanent cognitive and neurological impairment as a consequence of petrol sniffing. By and large people in remote communities must bear this burden of care in the face of an almost total absence of appropriate services and professional support.*

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### The response

At a policy level, the response to petrol sniffing has been largely sporadic. A comprehensive approach to the problem must incorporate harm, supply and demand reduction strategies. As well as focusing on individuals and families, such an approach should also address the social structural factors that underlie supply and demand.

While the introduction of unleaded petrol reduced – but not eliminated – some harm, a more sustained national government response has been to assist communities to reduce the supply of sniffable petrol by switching to avgas. As of 2004, over 30 communities that were part of that scheme.

The same approach is now being adopted to subsidise the use of Opal fuel.

As well as these harm and supply reduction strategies, communities have initiated, and have been funded by government to pursue, a number of demand reduction strategies, including the provision of sporting and other recreational activities. Some communities have introduced by-laws against the practice and established night patrols and warden schemes in an attempt to control it.

### And the Neurological Council's role?

I believe that the Neurological Council can play a three-fold role in helping to address petrol sniffing. First, it can reach out to Indigenous Australians, listen to their views on the issue, and work towards a solution with them. Second, it can raise awareness about the nature of the problem and its consequences. Third, the Council can ensure that the needs of people in remote Indigenous communities are not forgotten.

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Professor Rosemary Tannock a leading Canadian Educationalist, has suggested (In Educational Leadership 2001) that findings from her studies indicate that AD/HD is a learning disorder rather than a behavioural disorder. Thus, teaching strategies that target cognitive weaknesses may be more effective than behavioural management techniques in promoting academic success for students with AD/HD.

#### **Rosemary Tannock**

**will be visiting Perth 25<sup>th</sup>, 26<sup>th</sup> August for Parenting and Teacher workshops to be held at the venues below.**

**Parenting Workshop: August 25<sup>th</sup>, 7.00 –9.00pm, The Niche Cost: \$11.00 members, \$44.00 non members of LADS**

**Teacher workshop: August 26<sup>th</sup>, 9.00am – 3.00pm, Health Dept Lecturette, Royal St Perth.**

**Cost \$133.00**

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## Doctor, Doctor will I die?

Yes old man; and so will I. An old rhyme from the 18<sup>th</sup> century when medical techniques and technology were not what they are to-day and death was probably a more natural and everyday event. And in 2005 we are living longer and the forecasts for life expectancy continue to increase. In 2000 it was forecast that the incidence of cancer will increase by close to fifty per cent not because we face an epidemic but primarily due to the rapid ageing of our population. Forecasts across the western world have also indicated that more and more people will not be cured of their cancer but live with the disease for 15 or more years, surviving on 'maintenance therapy' probably until another disease of old age claims them. The same applies to other conditions. Yes, the advances in medical management are superb and startling with more to come. Patients who would have died 20 years ago of a disease or a tragic accident are saved and sustained to-day as a commonplace procedure. But who decides when the 'time has come'? Does the patient have a say?

In Western Australia, the answer is no. Whereas in other states Living Wills or

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### Medical Treatment for the Dying- Workshop

Palliative Care WA (Inc) is running a 2 hour workshop in order to refine its submission to the WA Government's discussion paper on 'Medical Treatment for the Dying'.

**On:** Thursday 7 July 2005

**Time:** 5.00pm for 5.45pm start (refreshments provided before meeting starts)

**Where:** University Club of WA, Seminar Room 2, Hackett Drive, Crawley, UWA Campus

For more information , call : Clive Deverall (PCWA President) on 0417 933 554  
lor Stephen Carmody at Silver Chain on (08) 9242 0282

Please RSVP

## The Neurological Council of WA (Inc)

Centre for Neurological Support  
The Niche, Suite B  
11 Aberdare Road  
NEDLANDS WA 6009

Phone: 08 9346 7533  
Fax: 08 9346 7534  
Email: [ncwa@cnswa.com](mailto:ncwa@cnswa.com)

An estimated one in eight people suffer from a neurological disorder. There are more than 4000 neurological disorders, many of which are degenerative.

We are also on the web:  
[www.cnswa.com](http://www.cnswa.com)

*The Neurological Council of WA was established in 1992 to promote the common aims of the member organizations.*

*These aims include:*

- To alleviate sickness, suffering and distress*
- To provide support for people suffering from neurological conditions, their families and carers*
- To advance research and other work towards developing and applying methods to prevent, control or cure such disorders.*

*The Neurological Council also manages a Home and Community Care programme which provides services specifically to people with neurological disorders. This programme provides clinical neurological nurse specialist services in the Great Southern Region, based in Albany, and in the South West Region, based in Bunbury. Respite and personal support services are available throughout the metropolitan area. Further information on these services can be found on page 8 of this newsletter.*

## Members of the Neurological Council of WA

Alzheimer's Australia WA Ltd  
Anxiety Disorders Foundation of WA Inc  
Anxiety Self Help Association Inc  
Australian Huntington Disease Association (Inc) WA  
Australian Neuromuscular Research Institute  
Carer's Association of WA Inc  
Continence Advisory Service WA Inc  
Elba Incorporated  
Epilepsy Association of WA Inc  
Guilliam-Barre Syndrome Association  
Headache and Migraine Western Australia Inc  
James Crofts Hope Foundation Inc  
Learning & Attentional Disorders Society of WA Inc  
ME/ Chronic Fatigue Syndrome Society of WA Inc

Motor Neurone Disease Association of WA Inc  
Multiple Sclerosis Society of WA Inc  
Muscular Dystrophy Association of WA Inc  
Myasthenia Gravis Friends Support Group  
Neurofibromatosis Association of WA Inc  
Paraplegic Benevolent Fund Australia Ltd  
Parkinson's WA Inc  
Periodic Paralysis Society of Australia  
Spina Bifida Association of WA (Inc)  
Spinal Cure Australia  
Traumatic Stress Recovery Association Inc  
Trigeminal Neuralgia Support Group WA Inc  
WA Blue Sky Inc  
WA Stroke Foundation Inc

