

## Co-ordinators Comment

Four years ago NOgIN was launched to support patients and their families whose lives are affected by brain tumours. With thanks to all of our presenters who have given up their time to present at our information nights we are excited to continue to provide this service in Western Sydney.

### 2010 Developments

- **"Inaugural Carers Only Night"** In June we held our first specific session for carers. The evening was highly evaluated as carers had the opportunity to engage with our panel of experts in a relaxed setting, with an amazing buffet sponsored by Sodexo. Some comments from the evening included: "The social setting was conducive to open discussion", "Learning that we are not alone", "Finding out more about palliative care was most beneficial". With specific thanks to our expert panel: Dr Mark Dexter (Consultant Neurosurgeon), Dr Phillip Lee (Palliative Care Specialist), Matthew Sproates (Occupational Therapist) and Diane Lear (Clinical Nurse Consultant). Please see page 8 for details on the next Carers Night.
- **Information Nights** continued every second month at Westmead Private Hospital. Topics included: The Benefits of Massage, Coping Strategies, Management of Seizures and Headaches, Current Research

and Causes of Brain Tumours, Radiotherapy, Basic Anatomy, Tumour Recurrence and Medication Management. Our final session was extremely successful with two presentations from patients. I am sure the audience will agree that both patients (and husband) did an amazing job sharing their experiences with the audience. The program for 2011 will be posted to all patients on our data base and available on the websites.

- **Nursing Scholarship:** Nurses in Western Sydney can now apply to NOgIN for education assistance to enhance their knowledge and skills in the care of patients with brain tumours.
- **Nursing paper published:** Diane Lear and Emma Everingham published a 'NOgIN: Three Year Review' paper in the Australasian Journal Of Neuroscience Nursing Vol 20 No 1 May 2010. Copies available on the websites.

## 2011 Meeting Dates:

1st Feb  
5th April  
7th June  
2nd August  
1st Sept "Carers Only Night"  
4th October  
6th Dec

7pm - 9pm Conference Room  
Westmead Private Hospital

## Fundraising

During International Brain Tumour Awareness week, 1st to 7th November 2010, we once again held our primary annual fundraiser. Staff across the Westmead hospitals wore their bright purple "NOgIN" polo shirts throughout the week whilst volunteering to assist with our raffle and BBQ. This is the third year we have held this event, with our raffle prizes growing each year. The first prize was once again a \$1500 glass splashback donated by DecoGlaze. Our thanks go to Mr. Bill Lockett, Wendy Kelly and Denis Trimble, associates of our support group, who either donated goods or volunteered their time to help. Many other local businesses also donated goods to support the raffle and food for the BBQ. With the amazing efforts of all these people and the local businesses that supported us, we were able to raise funds for our NOgIN trust fund, held at the Westmead Medical Research Foundation.



"NOgIN fundraising BBQ at Westmead Private Hospital November 2010".

## Useful Web Addresses

[www.westmeadprivate.com.au](http://www.westmeadprivate.com.au)  
[www.westmeadneurosurgery.com.au](http://www.westmeadneurosurgery.com.au)

## April 2010 - Session 1

### Coping After A Brain Tumour

Presented by: **Diane Whiting**,  
Clinical Psychologist, Brain Injury  
Rehabilitation Unit, Liverpool  
Hospital

There are varying emotions experienced during the three stages of a disease process, following diagnosis, during treatment and during the recovery phase as either a survivor or during palliation. Patient's often experience behavioral, emotional and cognitive changes which may be extreme.

#### Stage of Grieving

- Denial (the refusal to face the reality of the loss)
- Anger (protest against the reality)
- Bargaining (attempt to negotiate the reality)
- Depression (mourning the reality)
- Acceptance (making peace with reality)

#### Behavioural Changes

Create a positive lifestyle and control external factors (EASE)

- Eating – the right foods and the right portion helps to maintain energy and control weight.
- Activity – remain active helps to enjoy life, such as maintaining contact with friends and doing day trips.
- Sleep – poor sleep can lead to tiredness and irritability, rest when you need to.
- Exercise – can generate a sense of well being and reduce stress and tension.

#### Emotional Changes

- Cognitive strategies
- Relaxation
- Formal counseling through a social worker or psychologist

#### Memory or Cognitive Changes

- Use lists

- A place for everything and everything in its place (eg; use the same place to hang up keys)
- Use "post it" notes
- Mobile phone – use as a diary for appointments or contact list
- A diary or calendar
- Don't be afraid to be creative or use different strategies (eg; whiteboard timetable)

#### Attention/Concentration Changes

Following treatment for a brain tumour, most patient's can only concentrate on one thing at a time and have difficulty multi tasking. Fatigue and emotion can make it harder to concentrate and maintain attention.

- Acknowledge the problem exists
- Organise your environment
- Use a cue card
- Know your limitations (eg; reduce external noise, restrict visitors if overwhelming)
- Undertake important tasks when you are most awake and can concentrate better
- Don't overload or try to take too much in at a time, keep stimulated, boredom can affect your ability to think
- Take several breaks
- Break things down into smaller tasks
- Don't schedule too many activities on the same day

#### Language Disorders

- Word finding difficulties "tip of the tongue"
- Use of the wrong word
- Going blank during a conversation
- Difficulty understanding what people are saying
- Try to describe what you want to say or use a similar word

#### Summary

- Use your support networks – don't be too proud or afraid to ask for help

- Be selfish – don't take on other people's problems, put yourself first
- Limit other stressors in your life if possible
- Try to maintain normal routines as closely as you can

## Session 2

### Radiotherapy for Brain Tumours

Presented by: **Dr Jayamohan.**,  
Radiation Oncologist, Westmead  
Hospital

#### Some Facts

- With brain tumours each patient is different, therefore each treatment is different. Well meant comments from family and friends are not always factual.
- Radiotherapy is high energy x rays (1000 times more than a normal xray), that damage the DNA of the tumour cells stopping the cells from dividing. However it is difficult to deliver radiotherapy to just the tumour cells and the normal cells in the brain may receive some radiotherapy but these normal cells have the capacity to repair.
- Radiotherapy is usually given in small fractions on a daily basis normally over 6 weeks Monday to Friday, although dose and duration may vary depending on the size and type of the tumour. The daily doses allow the normal cells to repair and gain function, tumour cells do not repair.
- Radiation effects continue 3-4 months after the completion of treatment.
- If you are receiving radiotherapy and chemotherapy together you will need to closely monitor your blood count as you are more prone to infections.
- It is very unusual for a brain tumour to metastasise to another part of the body.
- Prior to commencing



radiotherapy treatment, a mask is made to keep the head still during treatment and also to enable the radiation oncologist to mark the targeted area. The mask may cause claustrophobia in some patients, if this is the case, notify your radiation oncologist.

- There are other types of radiotherapy used world wide such as, the gamma knife which is not available in Australia. However radiosurgery is the same as the gamma knife and is available at Westmead Hospital. In Australia radiotherapy is as up to date and effective as anywhere in the world.
- Side effects of radiation include:
- immediate – tiredness, hair loss, sore or blocked ears, nausea and vomiting is unusual and more common with chemotherapy.
- long term – loss of short term memory, occurrence of secondary tumours although this is extremely rare.

**Q. Is the short term memory loss permanent?**

A. It is very unusual for a return of short term memory, learning strategies for coping mechanisms are very useful.

**Q. Is the short term memory loss because the radiotherapy damages the brain?**

A. One of the functions of the cerebral cortex is storage of memory and the cerebral cortex receives the majority of the radiotherapy during treatment.

**Q. Are there different types of radiotherapy?**

A. Radiotherapy is given in two different ways.

Conventional – usually given over a period of six weeks on a daily basis.

Radiosurgery – given stereotactically where the specific area is targeted by

localising the area using MRI scan images. Primarily used for small benign tumours less than 2cms in size such as acoustic neuromas.

**Q. Why is a course of radiotherapy given only once?**

A. Following radiotherapy the normal cells have reached their maximum repair capacity, therefore we do not repeat a radiotherapy course. There may be a few exceptions such as a long survival since the original radiotherapy course.

**Q. Why do normal cells repair and tumour cells are unable to repair?**

A. Tumour cells have an unstable DNA and therefore are unable to repair. Radiotherapy may control aggressive brain tumours but not completely remove the tumour cells, therefore the tumour may remain dormant and reoccur.

**Q. Can meningiomas be treated with radiotherapy?**

A. Meningiomas are usually benign and ideally treated by surgery. Some meningiomas are atypical and may require follow up with radiotherapy.

**Q. Is a glioblastoma multiforme (GBM) one of the tumours treated for cell control?**

A. A GBM is a difficult tumour to cure, however studies have shown increases in duration of living when treated in conjunction with surgery, radiotherapy and chemotherapy.

**Q. Should you exercise during treatment?**

A. It is best not to do too much as you will tire easily, taking a long daily walk is preferable.

**Q. What is whole brain radiotherapy?**

A. Whole brain radiotherapy is usually used for metastatic disease.

**Q. Do brain tumours cause other cancers?**

A. Primary brain tumours do not metastasise (spread) to other parts of the body, however other cancers can cause metastasis in the brain.

**Q. Are there areas in the brain better able to tolerate radiotherapy than other areas?**

A. The main part of the brain or cerebrum can take larger doses of radiotherapy. Some parts of the brain e.g.; the visual pathways are more sensitive to radiotherapy. Each patient's treatment is individualised where the brain and the tumour is mapped to determine the amount of radiotherapy they will receive.

---

June 2010 - Session 1

**Management of Headaches and Pain**

Presented by: Dr Mark Dexter, Consultant Neurosurgeon, The Westmead Hospitals

**Classification of tumours**

Primary – gliomas, meningiomas, schwannomas, pituitary adenomas, other

Secondary – metastasis from lung and breast

**Grading of tumours**

Graded according to the World Health Organisation (WHO) grades 1-4

**Investigations**

Clinical review, imaging (CT scan, MRI, PET scan)

**Management**

Surgery, medications, chemotherapy, radiotherapy

**Headaches**

Headaches may be caused by

- increase in the pressure in the brain (intracranial pressure/ICP),

- irritation of the coverings of the brain (dural irritation)
- healing of the bone and muscles following surgery
- cranial nerve involvement (usually the 5th or trigeminal nerve)
- tension and/or stress
- Pain sensitive structures are the skin, skull bone, dura or covering of the brain and the blood vessels supplying the brain.

### Increased intracranial pressure (ICP)

Headache is typically worse in the morning and may be associated with nausea and/or vomiting and visual changes. The headache is due to brain swelling from the tumour, associated oedema and possibly blockage of the brain fluid (cerebrospinal fluid).

### Treatment

- Swelling – steroids such as Dexamethasone (decadron) or mannitol
- Removal of the tumour
- Drainage of the cerebrospinal fluid with an external ventricular drain (EVD) or shunt

### Dural irritation

A constant headache associated with photophobia and a sensitivity to noise, often caused by blood products in the cerebrospinal fluid.

### Bone/Muscle

Pain at the incision site or the site of the attachment of muscle, which is associated with movement. Treated with mild analgesia and anti inflammatory medication.

### Cranial nerve involvement

A burning or stabbing pain in the distribution of a nerve (neuropathic pain). May be due to pressure on a nerve. Treated with anticonvulsants, anti depressants and sometimes radiotherapy.

### Tension/Stress

Headache is worse at the end of the day, described as a band like

pain across the forehead with a sensation of eye strain. Treated with relaxation and simple analgesia, avoid narcotics.

### Q. Is it common to suffer headaches after surgery?

A. Headaches are dependent on the site of the operation and most painful when the neck muscles have been involved.

### Q. Is Amytriptyline used for depression?

A. Often used for headaches with a low starting dose of 10mgs, when used for depression the doses are higher. Medication needs to be weaned slowly to prevent a reactive depression. The same applies when certain anticonvulsants such as Epilum are used for headaches.

### Q. Can you take Epilum with other anticonvulsants?

A. Yes, Epilum is metabolised differently and won't interact if you are taking it for headaches.

### Q. What is the incidence of recurrence of meningiomas?

A. This will depend on the grade of the tumour and the completeness of the removal. In a grade 1 meningioma it is unusual for a recurrence, in a grade 2 meningioma there is a recurrence rate of 75%, a grade 2 tumour is usually treated with radiotherapy after surgery. If there has been complete removal the recurrence rate is 7%.

## Session 2

### Seizures and Driving

Presented by: Dr Mark Dexter, Consultant Neurosurgeon, The Westmead Hospitals

Seizures are the presenting symptom in 26% of all patients admitted with a brain tumour, and may also occur following surgery. They may be focal (affecting one part of the brain), generalised or both.

### Post operative

- Usually focal, close to the brain tumour or surgical site
- Usually self limiting (stop by itself)
- Usually short in duration
- Usually occur in the first 7 days after surgery

### Factors that lower the seizure threshold

- Sleep deprivation
- Hyperventilation
- Photic (light) stimulation
- Infection
- Fever
- Head trauma
- Alcohol
- Metabolic disturbances

### Seizure first aid/What to do if you witness a seizure

- Relax/don't panic
- Avoid injury to the patient
- Place the patient on their side
- Call an ambulance

### Q. Do you know when a seizure is going to happen?

A. Some people will get an aura or sensation such as a smell or feeling sick in the stomach

### Q. Are panic attacks the same as seizures?

A. No, panic attacks are often called pseudo seizure

### Q. Can seizures be controlled by drugs?

A. Yes, in approximately 75% of cases

### Anti epileptic drugs/ anticonvulsants

Prophylactic - to prevent seizures

Therapeutic - following a seizure

75% of seizures can be controlled with medication

Common drugs – Phenytoin (dilantin), Carbamazepine (tegretol), Epilum, Rivotril and Keppra



## Keppra

- Can be administered intravenously or orally
- Not metabolised by the liver
- Routine blood levels are not required
- Choice of anticonvulsant for patient's taking Temodal as the Temodal level decreases with patient's taking Dilantin and Tegretol

## Side effects

- Headache
- Drowsiness
- Insomnia
- Depression
- Dose required up to 3000mgs per day

**Q. If you are taking 3000mgs a day, how do you know if it is enough if there are no blood levels taken?**

A. If you are seizure free

**Q. Do you always lose consciousness in a tonic/clonic seizure?**

A. Yes, the patient will lose awareness in a generalised seizure

## Duration of therapy

**Prophylactic** – sometimes only given for the first 7 days following surgery. Often six weeks to 3 months.

**Therapeutic** – ceased following 1 year of seizure free period

**Variable** – individualised dependent on your particular pathology and whether radiotherapy was given after surgery. You will need to discuss this with your neurosurgeon/neurologist.

## Driving

- Refer to the RTA guidelines for specific instructions
- The time you are not permitted to drive following surgery is dependent on the location of

your surgery. There is no seizure capacity in the brainstem and cerebellum, therefore patient's with acoustic neuromas and pituitary tumours are exempt

- You are not permitted to drive for 6 months following a seizure, or for 12 months if you have had many seizures or if you are an epileptic
- If you have neurological deficits such as memory loss or decreased concentration you are not permitted to drive

## August 2010 - Session 1

### Current Research in the Treatment of Brain Tumours

Presented by: Prof Brian Owler  
Consultant Neurosurgeon  
The Westmead Hospitals, Sydney  
Adventist Hospital & Norwest Private Hospital

Research is based on the prevention, surveillance/epidemiology and treatment and management of brain tumours.

### Who conducts the trials

Trials are typically multi centred and conducted both within Australia (COGNO) and overseas.

### Benefits

- Care is provided by leading physicians
- Patients have access to new drugs and interventions
- There is close monitoring of health care and side effects
- You play a more active role in your own health care
- Opportunities to make a valuable contribution to research
- If the study approach is found to be of benefit you may be one of the first to benefit from the treatment

## Risks

- New drugs and treatments may have unknown side effects
- The drugs or treatment may be ineffective

**Q. How many CT scans would be too many in a lifetime?**

A. You need to look at the necessity versus the risks. Current scanning techniques have improved and are much quicker and therefore less radiation. There is however a cumulative risk, particularly in young people.

**Q. If you have had a removal of a meningioma what are the chances of it growing back?**

A. There are different types of meningiomas. 90% are grade 1 tumours with a very minimal chance of recurrence if the tumour has been completely resected. The risk of recurrence increases if there has been only partial resection because of the location of the tumour. Atypical meningiomas (grade 2) require additional radiotherapy because there is a risk of recurrence.

**Q. Is it safe to have another course of radiotherapy?**

A. The general rule is a certain dose of radiotherapy as it affects the normal tissue also. This will depend on the dose and the time frame between treatment. Patients may be able to have an extra focused boost (stereotactic) of radiotherapy.



Westmead Private Nurses with Ruth  
Neurosurgical patient

## August 2010 - Session 2

### Aetiology of Brain Tumours

Presented by: Prof Brian Owler  
Consultant Neurosurgeon The  
Westmead Hospitals, Sydney  
Adventist Hospital & Nowest  
Private Hospital

### Epidemiology

- There are currently approximately 450 new cases of brain tumours per year, and they account for 1.4% of all cancers in males and 1.2% in females.
- Brain tumours are the most common solid tumours found in children.
- Brain tumours are formed by cells that grow out of control and keep growing
- It is very rare for a brain tumour to spread (metastasise) to other parts of the body, but cancers from other parts of the body, such as the breast, lungs or kidneys can spread to the brain.

### Risk Factors

- Male - most common tumours in males are gliomas
- Female - most common tumours in females are meningiomas
- Race – mainly Caucasians
- Age – most common in the over 70 years
- Family history – brain tumours are not considered genetic, but the risk is slightly higher if there is a family member with a brain tumour
- Radiation - increased risk if you are exposed to radiation at work
- Formaldehyde – pathologists and embalmers who work with formaldehyde are at increased risk
- Mobile phones – there have been a lot of studies published in regards to the use of mobile phones and the incidence of brain tumours, which have been inconclusive. A study in

the International Journal of Oncology 32: 1091-1103 in 2008 reviewed a meta analysis of long term mobile use and the association with brain tumours. Another inter phone study conducted in 2000-2004 established there was no increased risk unless phones had been used with high use for greater than 10 years.

Q. Why were there so few numbers from France in the study?

A. Some centres did not choose to participate in the study.

Q. I have a cousin with two daughters both diagnosed with a meningioma, do you see a correlation in this?

A. We often see families with clusters of tumours, but there is no evidence to prove they are familial.

Q. Would you suggest screening tests for families?

A. Depends on the test. There is a risk of tumours developing from radiation in young people from having multiple CT scans, MRI scans are safer but not always available.

Q. Is Avastin a good drug with good results?

A. Your medical oncologist can provide you with more information on certain medications. In my experience there have been good benefits for a long time. It has been used in other types of cancers but the results have not been as positive as hoped.

Q. What is Gamma Knife?

A. Gamma knife is a form of stereotactic radiotherapy, which is focused to a small target. It is used for small tumours and has exactly the same effect as the linear accelerator machines that are used in most hospitals.

## October 2010 - Session 1

### The Wonders of the Brain - Neuroanatomy

Presented by: Dr Gordon Dandie,  
Consultant Neurosurgeon  
Westmead Hospital & Westmead  
Private Hospital

The brain is a complex organ divided into two hemispheres and four main lobes. Most tumours develop in the main part of the brain which is called the cerebrum.

A tumour and swelling in these lobes will cause deficits as outlined below.

The **frontal lobes** are responsible for movement and power of the limb's, the expressive speech area, personality, sense of smell and regulation of behavioral and social skills.

The **temporal lobes** control memory, hearing, receptive speech or interpretation of speech and part of the visual pathways.

The **parietal lobes** control geographical sense, ability to dress and spacial orientation as well as part of the visual pathways.

The **occipital lobes** major function is vision.

---

## October 2010 - Session 2

### Tumour Recurrence and Grading

Presented by: Dr Gordon Dandie,  
Consultant Neurosurgeon  
Westmead Hospital & Westmead  
Private Hospital

Tumours are defined as either **benign** where they compress the surrounding tissue but do not invade it. **Malignant** tumours have a tendency to invade the surrounding tissues and spread to distant sites in the body. It is very unusual for a brain tumour to metastasise to another part of the body. Tumours are classified according to location, grade and histology.



**The World Health Organisation (WHO)** is used to standardise the description and aggressiveness of tumours.

**Grade 1** – benign and slow growing.

**Grade 2** – can be malignant or non malignant. Relatively slow growing but can sometimes recur as a higher grade tumour.

**Grade 3** – malignant tumours and often recur as a higher grade tumour.

**Grade 4** – malignant and very aggressive, reproduce their cells rapidly.

---

December 2010 - Session 1

### Common Medications in Brain Tumour Treatment

Presented by: **Dr Jacqueline McMaster, Consultant Neurosurgeon Westmead Hospital & Westmead Private Hospital**

Medications are used to treat a symptom or complication.

**Seizures** (anti epileptic medications) are administered if you have had a seizure or if you are prone to having a seizure for a minimum of three months following neurosurgery, dependent on the location of the tumour.

#### Phenytoin (Dilantin)

- Prevents spread of abnormal electrical activity
- Most common drug
- Used for most seizure types
- Can be given intravenously or orally
- Side effects – cognitive (slow thinking, slowing of memory), liver disturbance, hypersensitivity (rash)
- Blood levels need to be checked regularly

#### Carbamazepine (Tegretol)

- Unknown mechanism of action
- Mainly used for focal seizures
- Avoid if there has been a previous reaction to Phenytoin
- Blood levels need to be checked regularly
- Side effects – low sodium levels in the blood, hypersensitivity (rash)

#### Valproate (Epilum)

- Less common
- Modifies transmitter levels in the brain
- Useful in partial or absence seizures
- Side effects – decreased platelet function (clotting function)

#### Keppra

- One of the newer anti epileptic drugs
- Unclear action, may block nerve conduction
- Best for partial seizures
- Better tolerated than most anti epileptic drugs
- Side effects - drowsiness

#### Dexamethasone

- Steroid 20-30 times stronger than natural steroids
- Decreases the fluid in the abnormal blood vessels of the brain tumour
- Two primary roles in neurosurgery:
  1. Decreases brain swelling before and after neurosurgery and during radiotherapy
  2. Anti nausea actions related to brain swelling and treatment induced
- Variable dosage, initially high doses (e.g. 4mgs/ 4times a day), slowly weaned to a maintenance

dose whilst receiving radiotherapy

- Side effects – upset stomach, increased appetite, insomnia, weight gain, altered blood glucose levels

#### Paracetamol

- Simple analgesia
- No anti clotting effects
- Well tolerated

#### Gastric Protection

Ranitidine (Zantac)

- Prevents acid production
- Protects against gastric erosions, stress ulcer formation

#### Omeprazole (Losec)

- Acts in the stomach to block acid production
- Interacts with other drugs such as Warfarin, anti fungals and anti depressants

#### Anti Nausea agents

##### Maxalon

- Increases stomach emptying
- Acts on the brain receptors to inhibit nausea and vomiting

**Q. Can you have vomiting without nausea?**

A. Yes, this is caused by pressure on the vomiting centre in the brainstem.

**Q. What can be done to prevent it?**

A. There are a lot of newer anti nausea medications that act on the vomiting centre.

**Q. Can you stay on steroids continuously for a long time?**

A. Yes, usually on a lower maintenance dose. Being on high dose steroids for a long time can lose their efficiency.

**Q. Can you take Tegretol and Panadol together?**

A. Both of these medications are metabolised in the liver. If

you have a normal functioning liver, you can still metabolise both safely. Taking these two medications together is only a contraindication, your Doctor will need to monitor your liver function.

**Q. What are the long term side effects of Keppra?**

A. Keppra is a relatively new drug with no long term studies, however all drugs are rigorously tested and controlled by the TGA prior to availability.

**Q. How quickly should Dexamethasone be weaned?**

A. The rate of weaning is dependent on how long and at what dose you have been taking Dexamethasone. For example the higher the dose and duration, the longer or slower the weaning process. Patients are often kept on a low or maintenance dose for a long time.

**Q. What should you do, if you forget to take your anti seizure medication?**

A. This is dependent on the type of medication and how long you have been taking it. Take the medication as soon as you remember if it is only a couple of hours or for a daily medication, only one day late. Missing multiple doses of a medication such as Dilantin, will cause the blood levels to drop and will take a long time to become therapeutic again if you just continue to take your regular dose. If you are unsure call your local doctor, the Neurosurgical Registrar at Westmead Hospital or the nursing staff from the ward where you were cared for recently.



The NOgIN Nursing Team at the Inaugural Carers Night, June 2010

## Linda's Story

This is Linda's story as prepared by Martin and is a condensed version of a talk given by Linda and Martin at the NOgIN meeting on 7th December 2010. Linda's attitude always prevails in situations of adversity and while there is light-hearted style used here, this does not deny the seriousness of this situation. This story is not meant to be frivolous, nor make light of anyone else's situation.

Linda was diagnosed with a brain tumour on the morning of March 27th 2007. We knew something serious was going on when three doctors came into the bed cubicle at Westmead Hospital. Linda had been referred to Westmead the previous evening by our family GP, after a few days of flu like symptoms. No one expects to hear that news – Linda reacted by saying to the doctors "It's just a headache, give me some panadol. Treat the guy in the next bed, he's really sick."

That afternoon, we arrived at Westmead Private Hospital to be admitted for surgery the next day. First step, however, was a head MRI, and this was a problem! Linda is claustrophobic and head MRIs are probably one of the most confining medical procedures a person can have. After some 90 minutes of trying to convince Linda that it would be alright, the radiographer gave up. We were grateful for her patience, but it just wasn't going to happen. We then attended reception at about 6 pm for admission. The next day an MRI with sedation was arranged. Linda was still apprehensive and I was allowed to stay in the MRI room, while the MRI was underway. Fortunately the sedative worked and Linda successfully completed the MRI.

Later that day, Linda underwent surgery to remove the tumour from her temporal lobe – this operation was 5 ½ hours long, and went well. Linda was in ICU overnight after surgery, and

caused a 'stir' shortly after arriving in ICU by setting off alarms on the monitoring equipment. Nurses rushed over to ascertain what was going on – her arms and legs were moving up and down in the bed. Linda simply said "I'm alright! I'm just checking to make sure everything still works." She was simply moving all her limbs to make sure. Linda was quickly despatched to a ward the next day and after 5 days in hospital, recuperating, Linda was allowed home. However before discharge came the news that the pathology of the tumour was not good – it was malignant, and she was in for a 'fight'. Treatment with both intensive radiation and chemotherapy were her next steps.

Six weeks later Linda started radiotherapy and chemotherapy – this lasted for 6 weeks. While various conversations leading up to these treatment, mentioned various side effects, it is hard to appreciate these until they occur. For Linda they occurred "in spades", she became very nauseous, requiring considerable anti nausea medication. That in turn brings its own side effects. For me, it was just a case of 'hang on for the ride'. I was lucky in regard to my work situation – my employer was very understanding, allowing me basically to work 'part time' about 4 hours a day. This allowed me to attend to Linda in the morning and complete some household chores, going to work mid morning but also leaving work around 2pm to transport Linda to radiation therapy. Being a knowledge worker, most of my work activity is email and phone conversations. I don't need to be at work. There were many times I sat outside the radiation suite at The SAN Hospital, reading and sending work emails while Linda was being treated. Linda completed the radiotherapy in early June, but chemotherapy continued for a further 6 months, until just prior Christmas when she refused to continue – the side



effects were making her too ill and miserable, and she wanted to enjoy the Christmas period with her family. After Christmas, with the agreement of her doctor, she did not resume chemotherapy.

The next episode in this story concerns Linda's experience with Dexamethasone (dex). Most other people are on 'dex' for a number of months after surgery and while receiving radiotherapy, and then taper off the drug. Linda tapered off and ceased taking it just before Christmas. Unfortunately her adrenal glands were very 'relaxed' and did not kick back in again to make the natural steroid. This affected Linda after a busy Christmas day by making her very tired – she slept about 20 hours a day for a week. It took a little while for me to realise something was wrong and it wasn't just a simple case of a very exhausting Christmas. Linda restarted the dex. After another failed attempt to taper of dex during 2008, she was referred to an endocrinologist. This doctor moved Linda from Dexamethasone to Cortisone – this allowed a gentler taper over many months, avoiding her earlier issues. She had almost completed this alternate approach to wean off artificial steroids, when the next event in Linda's story occurred.

Linda suffered a seizure in October (2008). A scary event when never experienced before. Linda was admitted to hospital to be assessed after the seizure, going home again after 2 nights with a Tegretol medication regime.

Unfortunately Linda was referred back to hospital four days later with a massive reaction to the Tegretol – she looked as if she had 'gone 5 rounds in a boxing ring' – swollen face, red skin over her body like bad sunburn. There was a real concern that the swelling may affect her breathing, and she was admitted to hospital again for observation and treatment. The treatment for such an inflammation in the body is .... large doses of artificial steroids.

This immediately set her long steroid taper program 'back on its heels'. It took some time for the Tegretol reaction to work through Linda's body – taking about 3 weeks. During this time, all her skin peeled off - even the soles of her feet! Linda has since ceased her dependency on artificial steroids.

Since then Linda has been 'well' and I am pleased to say all her scans for the past 3½ years have been clear. We sincerely hope that Linda's Story continues like this forever!!

---

Some reflections on this story from Martin's point of view. I learnt the contemporary source of information in our society – the Internet, is not a good place to go for information about cancer and cancer treatment when you are personally involved. The statistics are stark and the many individual testimonials (or memorials) don't help – they plant negativity in your mind. I learnt (some would say the obvious) statistics on life expectancy don't translate well to individual cases - every case is different. Doctors do tell you a lot of information, but ask any questions anyhow. The trick is to write it all down while you sit in front of them – take the time (they are patient). Lastly as Linda often said in situations like this – "Take each day as it comes (don't think too far ahead)".

A brief comment on NOGIN, to those who may not have attended a meeting yet. For Linda and I, NOGIN has provided a venue to meet people in a like situation to ourselves. Getting the right information is sometimes difficult especially when you are vulnerable and apprehensive of what is going on. I have no hesitation in recommending NOGIN to other people and their carers – it is a wonderful arrangement, run by Emma and Diane, in a very caring and professional manner.

As a final word, I wish to

acknowledge the wonderful work of the many health professionals who have been part of Linda's story, all of her doctors (I won't name them all here), the nursing staff, various radiographers, and a special mention to our dear friend Vicki who we've known for many years and who, coincidentally, was a specialist nurse in the "neuro ward" at Westmead Private Hospital when Linda was first diagnosed. Vicki was an immense support for Linda and I during this time, and a wonderful "resource" with her knowledge and background.



Guest speakers Martin & Linda at NOGIN Meeting December 2010

## International Brain Tumour Awareness Week

1 - 7th November 2010

Recognition of our sponsors:

- DecoGlaze, Seven Hills
- Bungaree Butchery, Toongabbie
- Westmead Private Physio
- Fernwood, Blacktown Club
- Catherine Hardman
- Rydges Parramatta
- Cumberland Country Golf Club
- Officeworks, Castle Hill
- Arthurs' Restaurant, Kellyville
- Archangel Gabriel Consultancy
- Sodexo
- The Flower Factory, Westmead
- Reliable Corporate cars
- Nepean Motor Group
- Price Attack, Castle Hill
- Coca-Cola Amatil (Aust) Pty Ltd
- Gloria Jeans
- Westmead Private Pharmacy

# Information Session Dates for 2011

Westmead Private Hospital, Conference Room

(Ground Floor) - light refreshments are provided

6.30 - 7.00pm

Casual chat and supper

7.00 - 9.00pm

Presentations

DATE	SESSION TITLE	PRESENTER
1st Feb	Benefits & Demonstration of a seated massage. Participation encouraged	Tony Wilson Oncology Massage
5th April	1. Managing changes to thinking and behaviour after diagnosis of a brain tumour 2. Chemotherapy for brain tumours	Diane Whiting Clinical Psychologist  Dr Mark Wong Medical Oncologist
7th June	1. Current research on the treatment of brain tumours 2. Are there any causes of brain tumours?	Dr Mark Dexter Consultant Neurosurgeon
2nd Aug	1. Palliative Care Options 2. Radiotherapy & treatment for brain tumours	Dr Phillip Lee Palliative Care Consultant Dr Jayamohan, Radiation Oncologist
1st Sep	"Carers Only Night" Panel Discussion - RSVP 1st Aug	
4th Oct	1. Managing memory & cognitive changes 2. Financial Advice	Matthew Sproates Occupational Therapist Cancer Council TBA
6th Dec	1. Management of seizures 2. Patient & partner stories	Dr Andrew Bleasel Consultant Neurologist

## Save the date!

Friday 13th May 2011

The Menzies Hotel

A free information day for brain cancer patients and their families presented by the Cancer Institute NSW Oncology Group Neuro Oncology.

The day features educational sessions presented by brain cancer clinicians and professionals involved in all spectrums of care throughout the patient journey. There will be both adults and paediatric programs.

For further information contact Julie MacDonald on 8374 5683 or [julie.macdonald@cancerinstitute.org.au](mailto:julie.macdonald@cancerinstitute.org.au)

## "Carers Only Night"

Book your seat for dinner with a panel of experts!

**When:** Thursday 1st  
September, 2011

**Where:** Conference Room  
Westmead Private  
Hospital

**Time:** 7.00pm

Bookings are essential as numbers are limited

RSVP to Emma on 837 8926 or email: [everingham@ramsayhealth.com.au](mailto:everingham@ramsayhealth.com.au) by 22nd August

Disclaimer: This newsletter does not intend to replace individual treatment prescribed by your physician. No part or whole of this newsletter may be reproduced without permission of the NOGIN coordinators/editors ©

NOGIN would like to thank Westmead Private Hospital Executive Team for their ongoing support, providing the conference room, supper, free parking and making the publication of this newsletter possible.

## Contacts:

Diane Lear  
Clinical Nurse Consultant  
Westmead Hospital  
**02 9845 5555 Page: 09113**  
[diane\\_lear@wsahs.nsw.gov.au](mailto:diane_lear@wsahs.nsw.gov.au)

Emma Everingham  
Clinical Nurse Consultant  
Westmead Private Hospital  
**02 8837 8926**  
[everingham@ramsayhealth.com.au](mailto:everingham@ramsayhealth.com.au)