NOgIN News

NOgIN
Neuro Oncology Information Network
Westmead Private & Westmead Hospital working together to support adults with brain tumours

Issue 6 - Aug 15

Co-ordinators Comment

Welcome to our 6th edition of NOgIN News, the official newsletter for NOgIN.

This successful support network has been expanding over the past nine years and we look forward to celebrating our 10th anniversary in 2016. We are open to any celebration ideas!

The ongoing demand to provide much needed support for our patients and their carers has been the driving force behind our brain tumour network. We believe our group continues to provide a unique environment for patients and carers to meet like-minded people, exchange ideas and challenges and build relationships, whilst expanding their knowledge. As NOgIN is a nurse co-ordinated group this stimulates a relaxed, supportive and professional atmosphere.

This edition is a combination of information presented by our expert speakers at our NOgIN sessions, including questions and answers. In addition, we are excited to include a patient story and photos from recent events. We have attempted to cater for the needs of our diverse group, including newly diagnosed patients and care givers, to long term survivors.

If you have not attended one of our meetings, we would like to extend a warm welcome to you and your family to accept our invitation, as we assist you along your brain tumour journey.

Recent achievements

- Information Nights continue to be well attended every second month at Westmead Private Hospital.
- Annual International Brain Tumour Awareness Week activities.
- NOgIN presentation at the World Federation of Neuroscience Nurses Congress, Gifu, Japan.
- NOgIN presentation at the Australasian Rehabilitation Nurses Conference, Sydney
- NOgIN poster presentation at the Co-operative Trials Group for Neuro-oncology Annual Scientific Meeting, Sydney
- Commenced Annual NOgIN Participants Consultative Group, this group provides essential feedback about the progress of NOgIN and ideas for future planning.

Go to: www.westmeadprivate.com.au/Our-Services/NOgIN.aspx. for programs, newsletters, events.

Finally, once again we acknowledge the support of all of our presenters, who give up their time and expertise to present at NOgIN meetings.

We also receive ongoing support and funding from Westmead Private Hospital, for our venue and catering. A big thank-you to our executive team, we couldn't do this without your commitment.

Thank you

Emma & Diane

NOgIN Coordinators

(see back page for contact details)

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NOgIN Websites

www.westmeadprivate.com.au
www.westmeadneurosurgery.com.au

Brain Tumour Awareness Week

Last year for Brain Tumour Awareness Week, my mum and I had the privilege of volunteering for the NOgIN's barbeque fundraising day. Dressed in our purple NOgIN shirts, which we proudly wore I must say, we sold lots of sausage sandwiches, cakes and other treats. We worked alongside, and had so much fun with hospital staff and other volunteers. It was amazing to see how many staff members gave up their personal time for this cause.

It was a beautiful day, not just the weather, but to see the compassion and generosity of complete strangers. It truly renewed my faith in human kind. And as a patient which has gotten so much support from NOgIN myself, I cannot wait to volunteer for NOgIN again.

Thank you

Sharon Lowery

Joan & Sharon helping out at the registration desk

Bungaree Butchery Donation for NOgIN BBQ

Once again, Steve Carlaw very generously donated all of the sausages for our Brain Tumour Awareness Week barbeque. This time we visited Steve and his team to personally thank them for their help. Our event would not be the success it is without these very tasty sausages. Every year our barbeque is a sell out! Thank-you so much for your support Steve.

Emma, Steve, Diane and Harry at Bungaree Butchery, 22 Bungaree Road, Toongabbie. Phone: 9631 0721

NOgIN Nursing Scholarship

In March 2014 I was fortunate to receive a NOgIN nursing scholarship to attend the Neurosurgical Study Day at Macquarie University Hospital. As a registered nurse at Westmead Private Hospital, attending this study day allowed me to expand my knowledge and implement better care to the neurosurgical patients, specifically patients having surgery for brain tumours.

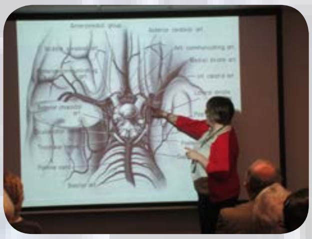
Thank-you NOgIN - Gail Williams

Information Session Summaries

Session 1

Cranial Anatomy

Presented by: Dr Ruth Mitchell (Neurosurgical Registrar)



Q. Why does it hurt to chew after your operation?

A. The temporalis muscle which assists in chewing is cut to access the brain for certain operations causing pain in the area.

Q. How thick is a normal skull?

A. Different portions of the skull differ in thickness with some areas up to 1cm.

Q. How long does it take for the scar to feel normal and not numb?

A. Some of the nerves are cut during the operation and depending on the size of the nerve and the blood supply will depend on the time for the scar to feel normal. This is normal and not dangerous. Radiotherapy to the area can sometimes slow the healing process down.

Q. What area of the brain controls thinking?

A. Thinking involves input from many different areas in the brain.

Q. Where is the blockage of CSF when you require a shunt?

A. The blockage is not always caused in the same area, sometimes the problem is with absorption rather than a blockage.

Dr Gordon Dandie with patient & partner at a NOgIN meeting

Session 2

Types of Brain Tumours

Presented by: Dr Gemma Olsson (Consultant Neurosurgeon)

What is a brain tumour?

A group of cells which have an abnormal pattern of growth or located in an unusual location of the brain. Some lumps are not tumours such as infection, infarction (dead cells as in a stroke) or inflammation such as multiple sclerosis (MS).

Benign – non cancerous, slow growing, most common meningioma, schwannoma, pituitary adenoma – only treated if symptoms are present

Malignant – cancerous, fast growing, likely to spread elsewhere

Management

Patients undergo an operation for 2 reasons

- To find out the pathology so the appropriate treatment can be commenced
- To treat symptoms

Symptoms

Due to pressure on the brain, vomiting, mood swings, cognitive decline, decreased hearing, headache, speech problems, seizures, or other specific symptoms depending on the area involved.

Primary tumours V Metastasis

Primary – arise from structures (tissues) within the brain, can be benign or malignant

Metastasis – cancers which have spread from another site in the body via the blood stream

Meningioma

- 20% of all brain tumours
- Arise from the covering of the brain and spinal cord (dura)
- Surgery is the primary treatment
- Can be cured or controlled for life

Acoustic Neuroma / Schwannoma

- Tumour of the 8th cranial nerve
- 90% arise from the balance portion of the 8th cranial nerve
- Usual presentation is a decrease in hearing

Pituitary Adenoma

- 1 in 10 people will have a pituitary adenoma and may only be found incidentally on autopsy
- Benign and only treated if causing symptoms

Cavernoma

- Tumours of abnormal blood vessels
- May cause seizures

Gliomas

- Primary brain tumour
- Account for 50% of all brain tumours
- Arise within the brain and behave aggressively
- Cause is unknown, but in rare cases may be genetic or inherited
- Tumour of the glial cells which support the nerves cells
- Astrocytes – provide nutrition for the nerves
- Oligodendrocytes – make myelin to insulate the nerves
- Ependymal cells – line the fluid spaces in the brain

Grades of gliomas

- There are 4 grades of gliomas classified by the World Health Organisation (WHO)
- Grade 1 is the slowest growing and considered benign
- Grade 4 is the fastest growing and considered malignant / cancerous
- Other gliomas are brain stem gliomas and gliomatis cerebri

Grade 1 – Pilocytic Astrocytoma – often occurs in children, can be cured with surgery

Grade 2 – Diffuse Astrocytoma/ Oligodendroglioma – usually in adults and often presents with seizures

Grade 3 – Anaplastic Astrocytoma – fast growing and more invasive than the lower grade astrocytoma

Grade 4 – Glioblastoma Multiforme (GBM) – aggressive and the most common type of brain tumour in adults

Ependymoma

- Can be cured with surgery but may be aggressive
- Arise from the choroid plexus, the lining of the ventricles
- Usually benign

Medulloblastoma

- Usually found in children
- Aggressive requiring surgery, radiotherapy and chemotherapy

Pineal region brain tumours

- Benign to aggressive
- Include pineal tumours and germ cell tumours

Cerebral Metastasis

- 50% of other cancers will spread to the brain, usually via the bloodstream
- Can be removed surgically if solitary and causing symptoms

Q. Can a brain tumour change grades?

A. Some grade 2 and grade 3 tumours will progress to a higher grade. A grade 1 tumour will not change.

Session 3

Seizure Management and Resources

Presented by: Carol Welsh (The Epilepsy Association)

The Epilepsy Association was founded in 1952. Research and new treatments for epilepsy continue to evolve. 70% of patients have good management of seizures.

Services

- Surgical management planning
- Indirect service programs
- Training for professionals and carers
- On line self management tools
- Advocacy and consultancy

What are seizures

Sudden discharges of abnormal electrical activity in the brain that disturb it's normal function. Clinical features depend on where the seizure starts and spreads in the brain.

What is epilepsy

A condition of recurrent, usually unprovoked seizures requiring medical management

Who gets epilepsy

- Most common <20 years and >65 years of age
- In Australia 1 in 200 people are affected
- 1 in 20 people will have a seizure in their lifetime

What causes epilepsy

- Family, inherited, developed from a head injury, disease or infection
- Many people with epilepsy have no known cause for their seizures

Seizure triggers and threshold

Something that stimulates the brain that can make you more likely to have a seizure

Seizure threshold – minimum stimulation required to trigger a seizure, people with epilepsy have a lower seizure threshold

What can trigger a seizure - sleep deprivation, missed medications, hormonal influences in women, stress, alcohol and drug abuse, photosensitivity, metabolic changes

Diagnosis and Treatment

- Epileptologist for an accurate history and examination
- Diagnostic procedures – EEG, MRI, CT scan
- Treatment – anti epileptic drugs (AED), surgery, alternative and complimentary therapies, ketogenic diet

Types of seizures

- Focal – seizure starts in one area of the brain. Awareness may either be altered or retained
- Generalised – seizure activity involves both hemispheres of the brain.
- Atonic/Tonic
- Myoclonic
- Tonic/Clonic
- Absence

Tonic/Clonic seizures - Immediate loss of consciousness, tonic phase where muscles stiffen and changes in breathing, clonic phase with rhythmic jerking of the muscles. Generally no recall of events.

Things to remember:

- Most seizures last 1-3 minutes
- You can not stop or slow down a seizure
- The person may be confused after the seizure, sometimes for several hours
- The person may be extremely tired after a seizure and need to rest
- The person may remember very little of the seizure

Overall impact of epilepsy

- Psychological effects sometimes worse than the seizure
- Stigma and misconceptions still exist
- Good seizure management is important
- Physical or social problems vary with seizure frequency and severity

Keys to managing epilepsy

- Regular review with your doctor
- Avoid seizure triggers
- Take medications as prescribed
- Healthy lifestyle, reduce stress
- Learn about seizures and epilepsy

Fact sheets are available on the Epilepsy Action website including safety checklist and first aid. www.epilepsy.org.au

Session 4

Radiotherapy for brain tumours

Presented by: Dr Najmun Nahar (Radiation Oncologist)

- All tumours are not malignant
- Aim of treatment, cure, symptom control, prevent deficits, quality of life plays a role in treatment
- Definite treatment (cure), adjuvant (with other treatments), palliative (for symptom control).

What is radiation?

- Use of high energy electromagnetic radiation (x-rays, gamma rays)
- Ionising radiation damages DNA and kills the cancer
- Having gaps between treatments means healthy cells have a chance to recover

Steps to Treatment

- Simulation
- Fitting of mask, CT scan
- Mesh that is moulded to your head and neck shape
- CT simulator for scan, planning in 3 dimensions, use the planning, computers
- MRI & PET can be used, fused with CT
- When planning the treatment, there is an extra 1-2mm margin to make sure all of the tumour is treated
- It is important that treatment involves preserving important structures in the brain, where possible
- Stereotactic treatment - specific software to target very small tumours <3.5cm
- Can be one dose or multiple doses

Important - no evidence that it actually improves survival rates

Doses

- High grade tumours receive 54-60 gray over 6 weeks
- Low grade tumours 50.4 gray
- Benign tumours 45-50 grays
- Machine only on for 2-3 minutes, but you need to be positioned
- You are not "radioactive"
- We are able to verify that everything is matching up with what treatment is being delivered

Toxicities

Acute: Tiredness, somnolence syndrome, scalp redness, alopecia, headaches, nausea

Long-term: Neurological dysfunction, endocrine dysfunction, neurological impairment, short-term memory loss - common

Advances

- Improvements in imaging eg MRI
- More chemotherapy eg Temozolaimide
- New anti-angiogenic agents
- Multidisciplinary team
- New proteins in the brain and targets for gene therapy

Session 5

Nutrition During Treatment and Recovery

Presented by: Samantha Rand (Dietician & Nutritionist - Western Sydney Nutrition & Dietetics)

As we progress through different life stages and encounter different obstacles, our nutritional goals and requirements change; what was working for us previously, may not be appropriate for us during stages of treatment and recovery. The nutrition presentation covered; general nutrition goals, nutrition concerns through treatment, supplement usage and food safety concerns.

The overall goals of nutritional care for patients should be to prevent or resolve nutrient deficiencies, achieve or maintain a healthy weight, preserve lean body mass and support treatment. Minimising nutrition related side effects and maximising quality of life can also be assisted through food.

Nutritional supplements should be limited to those needed to prevent/treat a deficiency and should always be discussed with your doctor; there is no current evidence to say that blanket dietary supplements can reduce the risk of recurrence or survival of oncology patients.

Food safety is a key concern for those undergoing treatment, especially if immunity is compromised; the take home messages regarding food safety are; keep it cold, keep it hot, keep it clean and check the label.

Overall, nutrition can impact the body's resilience. Specific nutrition recommendations can be made through an appointment with an Accredited Practising Dietitian.

Contact: 9633-1045

Session 6

Resources for Carers

Presented by: Ros Richardson (NSW Carers Association)

- In Australia there are 2.7 million carers
- In NSW, there are 857,200 carers (12% of NSW population)
- In a class of 25 students, estimated 1-2 are carers for an adult parent

Hidden Carers / Unrecognised Carers

- People who don't identify themselves as a carer or prefer not to disclose their role to others and/or they don't appear in statistics and data relating to carers
- 66% of primary carers and 56% of all carers in NSW are female
- Care is mostly for a partner 44%, child 25% or parent 21%

Value of Care

- Estimated 74% of all care needs are provided by carers in the community
- Unpaid care for adult family and friends is worth $40.9 billion across Australia

NSW Carers (Recognition) Act 2010

- Supports the social inclusion of carers
- NSW Carers Charter - advocacy eg flexibility
- NSW Carers Advisory Council
- Carers NSW: Carer Culture surveys being conducted in a number of large organisations currently

What Does a Carer Do?

- Assist with tasks of ADLS
- Support with transport or finances
- Emotional support
- High/low level
- Advocacy

Physical

- Back injuries common

Emotional

- Anxious, overwhelmed

Financial

- eg superannuation
- Changes to income

Social & Cultural

- Connectedness, life changes and priorities change
- Love and commitment is the heart of caring
- 'What Carers Want' Carers NSW Survey 2014
- Carers need to take care of themselves
- Care Line 1800 242 636
- Advocacy, First stop

National Carer Counselling Program

- Can be face to face or over the phone
- Counselling
- Managing stress
- Changes in care relationship
- Anxiety
- Depression
- Isolation
- Coping skills

Young Carer Program

- Children and young people <25 years

Older Parent Carer Program

- Adults >60 (or ATSI >45+)
- Caring for child with disability or long-term illness

Other things of interest:

- The "Together" Program
- Carers NSW Conference Homebush 2015
- www.carersnsw.org.au

Session 7

Financial Planning and Returning to Work

Presented by: Dr Alka Bisen (NSW Cancer Council)

- Experiencing financial hardship may be a new experience, an unexpected consequence of cancer
- On average, cancer patients in NSW can have out-of-pocket expenses - $8000 (access economics)
- There is help available, there are resources available

Managing Financial Issues

- Financial problems are common, speak up about your concerns'
- Don't wait until situation is desperate, overcome shame and embarassment
- Social worker is first point of contact in the hospital
- Financial assistance services offered by Cancer Council NSW for eligible applicants
- Emergency assistance with unpaid utility bills
- No interest loans
- Pro bono financial planning and legal services

Managing Financial Issues

- Understand your income sources and expenses

Centrelink

- Accessing payments - intent to claim
- DSP, sickness allowance, carers allowance

Accessing Super

1. 55+39 weeks , income support +>26 weeks, able to demonstrate financial hardship
2. >55yrs +39 weeks, income support +>39 weeks
3. Terminally ill (<12 months)

Most superannuation funds have income or disability insurance attached.

www.superseeker.com

Understand Your Expenses

- Be aware of concessions, rebates or emergency assistance schemes you can access
- Apply for hardship variations on credit cards and loans, home loan, personal loan, credit card loan
- Request debit release or other debt management solutions from creditors
- When bills increase, debts increase, seek advice, avoid high interest high risk loans

Managing Services

- Financial counselling is a free community service
- Financial counsellors can act as an advocate on your behalf
- FCAN website search fcan.com.au
- Financial planning normally costs
- Hotline 1800 007 007 Mon-Fri 9.30am-4.30pm
- www.financialcounsellingaustralia.org.au
- Cancer Council 131120
- Lifeline 131114

The three generations of the Patel family attending a NOgIN information seminar

Tony's Story

By Joy Gardiner

During the early part of 2011 my husband Tony Gardiner who was 68 at the time, started having spasms in his left leg. It would twitch involuntarily.

Doctors did tests to determine if his prostate cancer had returned. These proved negative.

The general thought was that his chronic lymphocytic leukaemia (CLL) and subsequent swollen lymph nodes, pressing on the spine were the cause of the problem.

Gradually the spasms crept up to his stomach & you could actually see his insides convulsing.

In July 2011 we were preparing to go on a long fishing trip to the top of Cape York. By now the spasms were becoming more frequent and intense and our G.P. advised as a precaution we see a neurologist to eliminate any other cause.

I had started keeping a record of the time of the attacks and what Tony had been doing eg. walking, sitting, driving etc.

On the 25.7.11 we saw a neurologist and I showed him the list and my husband also informed him that the attacks had become more intense and had progressed up the left side of his face and down his left arm. Immediately the neurologist said the problem was not emanating from the spine.

The next week wires were attached to Tony's head and tests were carried out. Then he went to Westmead

Private Hospital for an M.R.I. The neurologist rang and said he wanted to see us.

When we went into his room Tony's M.R.I. scans were up on the wall. The large white mass was clearly evident even to our uninformed eyes. He told us that the M.R.I. showed that Tony had a very large meningioma on the right side of his brain & that the so called spasms were actually focal seizures. He then informed us he had made an appointment for us with

Dr. Mark Dexter (neurosurgeon at Westmead Private & Public Hospitals.)

On 25.8.11 Dr. Dexter confirmed the diagnosis & said that the meningioma had to be removed straight away.

Unfortunately owing to Tony's CLL his platelet count was very low and bleeding is a major concern in brain surgery.

After consultation with our haematologist steroids were used to try and improve the platelet count. This did not work.

Dr. Dexter then sent us to see Dr. Hertzberg (haematologist at Westmead Hosp.) To allow the surgery to proceed he said he would attend the operation and if necessary would administer a platelet infusion.

The week prior to surgery Tony and I attended the pre-operation clinic at Westmead Public where we spoke to most of the people involved in his operation. Over and over the procedure was explained to us and what would happen post op.

On the 10.10.11 we arrived at Westmead Public at 6 a.m. accompanied by two good friends. Tony was to be Dr. Dexter's first patient for the day.

Our friends waited downstairs and we went upstairs to be admitted to his room. He put on the gown and the assisting neurosurgeon came and stuck discs on his head and again asked us did we have any questions. Then he was wheeled down for a 3D M.R.I. I waited outside while this was done, kissed him good luck & he was wheeled off for his surgery.

I went back downstairs to join my friends and wait for a call from the recovery nurse whom we had already met at the pre-op. clinic. She had advised us to leave once he was admitted and that she would ring when he was settled in recovery. I had said that I would be staying till I saw him again.

Time drags slowly but the nurse rang about 1.30 p.m. to say he was now in her care and that she would ring again when he went to intensive care.

More hours passed & eventually about 5 p.m. I was allowed into his intensive care room.

At first glance I was alarmed to see all the equipment in the room and thought it looked like a mini operating theatre. I immediately thought that things had not gone well and that that was the reason he was taking so long to be moved.

I need not have worried. About 20 minutes later they asked me to wait outside his room.

When they wheeled him in he could not see me till I walked round the trolley. Then the first thing he said was to the nurses

"Has she been bossing you around and telling you what to do?" I knew straight away he was alright.

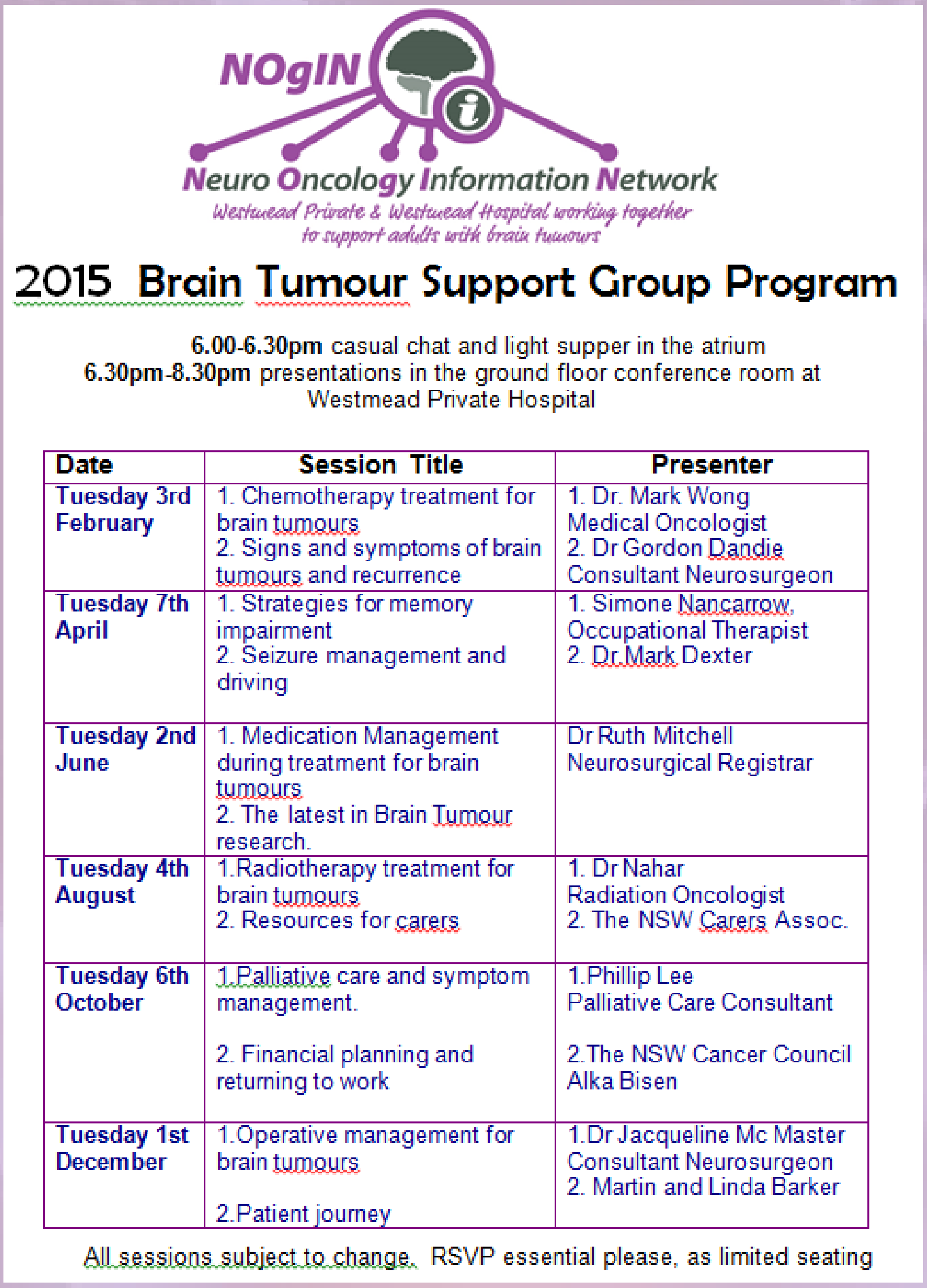
I waited outside his door till they got him settled in his bed. When I went in he kept asking me did he have a helmet on as his head was so heavy. I said no, just a lot of bandages and tubes. He would not believe me till I showed him in my mirror.

He stayed in intensive care for two days then he was transferred to the neurological ward. The large cut on his head had been resealed with staples. After 5 days as a consequence of his CLL the wound had not healed as quickly as it should have. It was decided to send him home with a set of staple removers for his G.P. to do the job when he deemed the time right. Eventually this was accomplished and on our return to Dr. Dexter he happily informed us that the meningioma which had turned out to be the size of a duck egg and had grown partly into his brain and skull had been successfully removed. MAJOR RELIEF !!

For a further 3 months while Tony was on Keppra he was not allowed to drive.

It has now been 3 years since his operation and except for a slight memory lose, numb left foot and not quite so good at Suduko he has come out the other end very well.

We cannot thank Dr. Dexter and the staff at Westmead Public Hospital enough. They are truly remarkable people. Thanks should also go to Diane Lear & Emma Everingham, Clinical Nurse Consultants at Westmead Public and Private Hospitals for their instigation and the forming of NOgIN. The information nights held every 2nd month are very informative and a wonderful opportunity to Learn more from the speakers and meet fellow patients. I would recommend the friendly and casual meetings to all patients & their carers.



NOgIN

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2015 Brain Tumour Support Group Program

6.00-6.30pm casual chat and light supper in the atrium
6.30pm-8.30pm presentations in the ground floor conference room at Westmead Private Hospital

Date	Session Title	Presenter
Tuesday 3rd February	1. Chemotherapy treatment for brain tumours 2. Signs and symptoms of brain tumours and recurrence	1. Dr. Mark Wong Medical Oncologist 2. Dr Gordon Dandie Consultant Neurosurgeon
Tuesday 7th April	1. Strategies for memory impairment 2. Seizure management and driving	1. Simone Nancarrow, Occupational Therapist 2. Dr Mark Dexter
Tuesday 2nd June	1. Medication Management during treatment for brain tumours 2. The latest in Brain Tumour research.	Dr Ruth Mitchell Neurosurgical Registrar
Tuesday 4th August	1.Radiotherapy treatment for brain tumours 2. Resources for carers	1. Dr Nahar Radiation Oncologist 2. The NSW Carers Assoc.
Tuesday 6th October	1.Palliative care and symptom management. 2. Financial planning and returning to work	1.Phillip Lee Palliative Care Consultant 2.The NSW Cancer Council Alka Bisen
Tuesday 1st December	1.Operative management for brain tumours 2.Patient journey	1.Dr Jacqueline Mc Master Consultant Neurosurgeon 2. Martin and Linda Barker

All sessions subject to change. RSVP essential please, as limited seating

WESTMEAD PRIVATE HOSPITAL

NOgIN

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NSW GOVERNMENT Health Western Sydney Local Health District

NOgIN would like to acknowledge Westmead Private Hospital Executive Team for their ongoing support

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