

NOgIN News



Issue 2 - March 09

Co-ordinators Comment

Welcome to our second edition of NOgIN News. Since the inception of our support group for Western Sydney Area in July 2006 we have been keen to reach more of our patients, so have embarked on the task of posting the newsletter to reach over 400 patients.

Yes, you are not alone and we encourage you to attend our information nights or write us a short story about your experience, you will be surprised how many people have the same questions as you do.

We have included a patient's journey in this issue, along with a summary of points discussed at our most recent information nights, with questions and answers presented by participants. We hope this helps those who are unable to attend our meetings.

2009 Meeting Dates:

3rd February

7th April

2nd June

Carers Only - 9th July

4th August

6th October

1st December

7pm - 9pm Conference Room
Westmead Private Hospital

NOgIN Fundraising and International Brain Tumour Awareness Week

(26th October-1st November)

On Thursday 30th October, 2008 nursing staff of Westmead Private Hospital and Westmead Hospital held an inaugural awareness BBQ at Westmead Private Hospital to help raise awareness in the community and raise much needed funds for NOgIN.

Raffle tickets and purple 'NOgIN' pens were sold on the day and during the week leading up to the BBQ.

Many staff donated items for the raffle and food supplies, and gave up their own time on the day to assist with the event. In all we sold 280 sausages, used 200 bread rolls and 10 loaves of bread and sold 175 drinks in the space of 3 hours. 900 raffle tickets were sold and many purple pens. We raised \$1000 just selling raffle tickets in the lead up to the BBQ and in total raised \$3350 for our very own Brain Tumour Support Group.

A huge thank you to all the staff, patients, local businesses and the executive of Westmead Private Hospital for supporting this event.

For more information on International Awareness Week go to www.theibta.org.

With specific recognition and thanks to our sponsors:

- Westmead Private Pharmacy
- The Flower Factory
- Sodexo
- Westmead Private Physiotherapy Services
- Cookie Man
- Bungaree Butcher
- Peppers Manor House
- Stella Group
- Greater Union Parramatta
- Morffew Photography
- BWS
- Merrylands Bowling & Sports Club
- Wax Works
- Nohra Small Goods Distributors Pty Ltd
- The Watercart Specialist
- Thyssenkrupp Elevator Australia Pty Ltd



Maricel Soliman, Emma Everingham, Harry Harrison & Doug Kelly lend a helping hand

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NOgIN Information Nights

December 2008 - Session 1

Neuroanatomy and Physiology

Presented by: **Dr Tom Pitham**
(Neurosurgical Registrar)

The brain is made up of billions of nerve cells and supporting cells including astrocytes, oligodendrocytes, ependymal cells and microglia which are the primary causes of brain tumours. It is divided into two hemispheres (halves) and five different lobes.

The brainstem is the most important part of the brain and is responsible for wakefulness, heart and respiratory rate and breathing, hearing and vision.

The cerebellum is primarily responsible for coordination of movement.

The speech areas are: Brocas in the frontal lobe (ability to speak) and Wernickes in the temporal lobe for understanding speech.

Q. How does the surgeon know which part to resect if all the brain looks the same?

A. We conduct pre operative testing to ensure eloquent brain is not removed. Imaging studies and experience also assists.

Q. How much space is there between the brain & the skull?

A. After your 20's brain cells start to die, it may not affect the way you function, but the amount of space increases. The space is filled with brain fluid.

Q. Does the right side of the brain control the left side of the body?

A. Yes. Nerves pass from the motor cortex in the brain and cross over in the brainstem.

Q. Does radiation affect the eyes?

A. The eyes are very sensitive. Radiation is planned to give the maximum dose to the tumour with very little irradiation to other areas of the brain.

Q. Does normal tissue heal faster than the brain tumour tissue after radiotherapy?

A Radiotherapy is toxic, however surrounding brain is minimally exposed. (Sometimes the side effects of radiotherapy take years to be exposed.) Radiotherapy affects the DNA.

December 2008 - Session 2

Complications of Brain Tumours

Presented by: **Dr Tom Pitham**
(Neurosurgical Registrar)

The overall risks for cranial surgery for brain tumours is 1-2% mortality with a 20% risk of a post operative deficit. Other risks include:

Infection- requires oral antibiotics, deeper infection may affect the bone or brain fluid causing meningitis and long term intravenous antibiotics.

Bleeding - one of the biggest concerns post operative. Ensure all blood thinning medications (Aspirin, Warfarin, Clopidogrel) have been stopped before surgery.

Stroke - injury to the brain or a major blood vessel supplying the brain resulting in not enough oxygen to a particular part of the brain. Symptoms may be temporary or permanent. (Epilepsy, hydrocephalus deep venous thrombosis (DVT) or pulmonary embolus (PE).)

Epilepsy - approximately 20% of neurosurgical patient's will have a seizure, they can either be caused by a tumour or surgery. Seizures are controlled by anticonvulsants such as dilantin, tegretol or epilum. The RTA rules are, patients are not to drive following neurosurgery for 3 months and following a

seizure or seizure free for 12 months, this must be signed off by a neurologist.

Q. Can you be weaned off anticonvulsants completely?

A. Depending on the type and location of the tumour. If you have not had a seizure for 6 months your neurosurgeon will consider weaning the anticonvulsants.

Q. What is the most frequent time for a seizure?

A. Most patients who have a seizure it is in the first week following diagnosis or surgery. This does not mean you will have further seizures or long term epilepsy.

DVT / PE - A blood clot in the deep veins usually in the leg and may dislodge and travel to the lungs. Patients may notice a painful swelling in the calf, but some DVT's are clinically silent with no symptoms. Risks include bed rest, prolonged surgery, obesity, leg weakness and a past history of DVT. Prevention includes early mobilisation, stockings and blood thinning agents

Hydrocephalus - an excess of the fluid (CSF) that surrounds the brain and spinal cord. Blood can cause scarring of the absorption apparatus causing blockage or a tumour may cause a blockage preventing the fluid from draining from the brain to the spinal cord. This may need to be treated by a shunt, which is a thin tube inserted into the ventricle in the brain, then tunnelled to the lining of the abdomen for reabsorption.

Q. What are the complications of shunts?

A. Blockage and infection. Approximately 20% of shunts will need replacing in the first 6 months and 50% in the first 5 years.

Q. Can the fluid cause blindness?

A. Rarely, as the brain enlarges with the build up of fluid the

nerves of the eyes may become squashed and damaged causing vision impairment.

Other Topics Presented in August and October 2008

- Treatment methods for brain tumours - Dr Vanessa Perotti (Neurosurgical Registrar)
- Overcoming Communication Changes - Colleen Kerr (Speech Pathologist)
- Radiotherapy and Treating Brain Tumours - Dr J Jayamohan (radiation oncologist)
- Quality of Life / How To Cope - Sally Carveth (NSW Cancer Council)

February 2009 - Session 1

Meeting The Needs of Brain Tumour Patients and Their Carers

Presented by: Sally Carveth (NSW Cancer Council) Ph: 131120

The extensive variety of support services were outlined.

This included:

- One-to-one telephone support
- Online chat rooms
- Online support for cancer carers
- Living with Cancer Programs
- Financial support
- Brain Tumour Booklet



Sally Carveth - NSW Cancer Council providing support

February 2009 - Session 2

Radiotherapy and The Treatment of Brain Tumours

Presented by: Dr Jayamohan (Radiation Oncologist)

Q. What is radiotherapy?

A. High energy x-ray treatment which disrupt the DNA of the abnormal cell. It prevents the cancer cells from dividing in the specific area where the treatment is delivered.

Radiotherapy and chemotherapy can be given together to maximise the benefits in some tumours.

Q. What are the most common side effects of radiotherapy?

- Tiredness for 4-6 weeks following and during treatment
- Loss of hair. It usually takes about 6 months for hair to regrow.
- Nausea

Q. If you irradiate a small tumour how long does it stay hot?

A. It depends on the tumour. Treatment is given from different points. It does not heat the tumour, it destroys the DNA. It does not kill the cell, it stops it from dividing and multiplying.

Q. On the CT scan the area of tumour bed is larger, what does this mean?

A. It may be oedema/swelling around the tumour which is a common reaction to the radiation treatment. After 12 months it can form scar tissue (gliosis)

Q. Can you have radiation a second time to another area?

We can give a second treatment to a different part of the brain as long as the first area is not in the way, or overlapping. During the treatment we treat a larger area than the tumour due to tumours having tentacles. In rare circumstances we may re treat after discussing all the advantages and disadvantages with the patient.

Q Is the gamma knife available in Australia?

This is also called radiosurgery and is a high dose of radiation treatment to a specific area using a linear accelerator. We use a similar treatment here in Australia using a different technique.

Q. How do you determine the length of the course of radiation treatment?

A. Radiation is dose dependent. That is some fast growing tumours will need high doses quicker. It also depends on how the patient will tolerate the treatment and their quality of life.

Q. Is chemotherapy helpful?

A. Recent research has shown it to be helpful when given with radiation treatment. Elderly patients do not always tolerate this as well.

Q. Are there any specific vitamins or food that are helpful?

A. There is little scientific evidence to base specific benefits of alternative treatments. It is important that you are careful and do your own research. Often people want to try different things, most importantly you need lots of support and love from your family and friends. Learning coping skills, positive thinking and meditation are all things that may help you.



Dr Jayamohan (left) answers patients questions during break

Upcoming Course (Feb-April 09)
with Cancer Council

Mindful Meditation for Cancer
Patients and Carers

At two locations

- Rouse Hill ph: 9354 2070
- Penrith: 9354 2060



Rick enjoying himself at one of our
Information Nights

A Patients Journey

Penny's Story

2006 has been my most forgettable year yet, because in July of that year I was diagnosed with a malignant glioma, essentially a brain tumour. I was at work when I felt dizzy, sick and the vision in both my eyes became so blurred that I was unable to see properly.

Thankfully, within an hour it had passed, but it meant that I ended up at the doctor's surgery, then admitted to hospital where they did an MRI scan and found the tumour. From there I was transferred to a larger hospital to see a neurosurgeon to discuss having it removed.

It was at that point that the "chicken" in me emerged. I put off surgery for three weeks. Doing this gave me time to organise my family, make a will and to get used to the idea of having someone mess with my brain, my personality, my intelligent matter, my thoughts and my dreams.

With 2 teenage kids and a husband, the future seemed uncertain. However, surgery went well and I was relieved to

wake up talking and moving arms and legs.

Six weeks later, I was having radiation therapy in yet another hospital closer to home. I was grateful for this as I was unable to drive and public transport would have been a real challenge with the fatigue I was experiencing.

I was offered chemotherapy after the radiation therapy, but chose not to have it. It was the right decision for me.

I feel very blessed because here I am 2½ years later and I am working 2 days a week and managing to keep up with my family (just!). Thank you to all my family and friends, the Cancer Council and NOgIN, other brain tumour patients, my church community and the hospital staff who walked the journey with me and made me feel appreciated and strong.

NOgIN would like to thank Penny for sharing her story with us. We hope others may also like to share their experience. Please contact us.

Regards Diane & Emma

**Disclaimer: This newsletter does not intend to replace individual treatment prescribed by your physician.
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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.

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