NOgIN News

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

Issue 1 - July 08

Co-ordinators Comment

Welcome to all our new NOgIN News readers. Yes that includes all of you, as this is our inaugural edition. We finally made it , our first newsletter.

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 this newsletter to reach over 200 patients currently on our data bases. 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.

In future issues we hope to include some of those stories. Please contact us if you would like to contribute to the newsletter.

In this issue we will introduce 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.

Finally, this July we hope to see an improved response rate to our annual questionnaire that will be posted to all our patients. Last year we posted our first annual questionnaire to 143 patients with only 21 returned. Please help us to continue to provide a small piece in the gap of services for people who have had surgery for a brain tumour, by giving us your feedback.

Historical Happenings

- 49 people attended the first 3 information nights in 2006
- 90 people attended 2007 sessions
- 65 people have already attended the 3 information nights in 2008

What is NOgIN?

The Neuro Oncology Information Network is a brain tumour information and support group developed as a joint initiative between the Clinical Nurse Consultants at Westmead Private Hospital and Westmead Hospital, Sydney.

As a non profit organisation, we aim to provide specific education and support for adults diagnosed with a brain tumour.

Brain Tumour Australia Inc. has supported the development of the group along with The Cancer Council of NSW.

www.bta.org.au

BTA BRAIN TUMOUR AUSTRALIA Inc.

NOgIN Information Nights

February 2008: Session One Overview of Brain Tumours Presented by: Dr Gordon Dandie, Neurospinal surgeon

- 0.5 to 1% of the population will have a brain tumour, this means a general practitioner rarely sees patients with brain tumours.
- Metastasis (secondary tumours that have spread from another part of the body to the brain) are the most common brain tumour.
- Gliomas (tumours that start in the brain) are the next most common. Patients commonly present with seizure, headache and/or a neurological deficit (arm weakness).

Above: NOgIN member with neurosurgeon Dr Gordon Dandie at the inaugural NOgIN information night July 2006

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- There are many different types of tumours and it is best for your surgeon to obtain the formal pathology results to confirm your type of tumour. 11% of masses seen on CT scan are incorrectly diagnosed.
- Treatment after surgery may include radiotherapy and chemotherapy depending on the tumour type.

Questions asked:

Q. Where does an acoustic neuroma grow?
A. Along the nerve used for hearing, it's a benign slow growing tumour.

Q. Does "lesion" mean tumour, are these terms used interchangeably?
A. Yes, lesion means or refers to a tumour.

Q. Is it better to find out you have a tumour by a seizure or headache?
A. Usually presenting with a seizure means the lesion is smaller before the mass effect of the tumour on the brain causes bad headaches. If you present with a weakness on one side of the body, treatment may be able to reduce the weakness.

February 2008: Session Two Medications commonly used in the treatment of Brain Tumours Presented by: Dr Gordon Dandie

- Dexamethasone (decadron) most powerful type of corticosteroid reduces swelling/ oedema caused by tumours. Side effects: hypertension, obesity, peptic ulcers, diabetes, impaired wound healing, immunosuppression.
- Zantac reduces the incidence of gastritis/peptic ulcers from steroid use. Side effects: (slow heart beat).
- Dilantin reduces the risk of seizures. Side effects: drowsiness, tremor, unsteadiness, mental slowing, blurred vision, rash, low blood pressure, acne, hair growth.
- Analgesia: may include paracetamol, codeine, tramadol (tramal), endone, to reduce pre and post operative pain.
- Laxatives: coloxyl, senna, duphalac, movicol, metamucil reduces constipation and straining. Side effects: diarrhoea, electrolyte imbalances, nausea and vomiting, thirst, reliance.
- Anti-seizure medications: may include dilantin (phenytoin), tegretol (carbamazipine), epilim (sodium valproate).
- Temozolomide (temodol): is an oral chemotherapy agent. Side effects: fatigue, headache, nausea and vomiting, anorexia, rash, hair loss, shortness of breath, fever, myelosuppression.

April 2008: Session One Managing Changes To Cognition/Memory Presented by: Matthew Sproats, Occupational Therapist, Westmead Hospital

- To assist with memory difficulties practice breaking down steps and making a "mind map". This was explained by asking someone in the group to explain what their home was like. The person described their home as if they were walking in the front door from one side to the other. This is an example of a mind map.
- To assist with completing tasks write down the steps to completion (the mind map) to help you become more efficient at completing the task.
- Use natural and external cues to trigger memory. For example you may have trouble remembering what to do when needing a shower. Walk into the bathroom to assist memory, shower at a consistent time so it becomes more automatic and then requires less cognitive effort. When behaviours or tasks become a habit they don't tire you as much.
- Having lots of rests throughout the day helps to maintain your energy levels. Choosing to do more tiring tasks earlier in the day or after a rest makes it easier on you. For example cook the dinner in the morning rather than in the evening when you are more tired.

Q. What do people do to help complete tasks at home?

A. Write a list every night of jobs to do and cross off when done, choose even the smallest goals.

April 2008: Session Two The role of chemotherapy in the treatment of brain tumours Presented by: Dr Tom Pitham, Neurosurgical Registrar, Westmead Hospitals

Q. What is a high grade tumour?

A. A World Health Organisation (WHO) grade 4 tumour and some mixed or grade 3 tumours are classed as high grade.

Q. When should I call a doctor?

A. Whenever you are worried or unsure about something you

should notify your local doctor or present to the Emergency Department. Particularly if signs of infection, bleeding, severe nausea and vomiting, skin rashes,a decrease in urine output are present.

Q. Why does Temodal affect me differently each time I take a cycle?
A. There is no significance in this, Temodal can produce a very different and individual reaction each time.

Q. What is the duration of chemotherapy (Temodal)?
A. It can be a lifetime treatment depending on your individual circumstances and reaction to the treatment.

Q. How long should you stay on Dexamethasone?

A. There are no limitations only guidelines, and you should be guided by your treating doctor. A small dose should be continued during radiation and chemotherapy treatment. Following this it may be reduced to the smallest dose (0.5mgs) or ceased indefinitely.

June 2008: Session One Management of Headaches and Pain
Presented by: Dr Mark Dexter

A very wet and wintry evening on 3rd June saw our largest ever attendance at an information session. Two very informative sessions on management of headaches and pain and seizure management and driving was presented by Dr. Mark Dexter, Consultant Neurosurgeon. The conveners Emma and Diane would like to take this opportunity to thank Dr. Dexter for his valued time and informative presentation. Below is an overview of the information as well as some frequently asked questions.

Q. What happens during my surgery.
A. The scalp incision and hole in the bone is no larger than the size of the tumour (keyhole surgery).
Some of the things listed below are the causes of headaches.

High intracranial pressure - which is worse in the morning due to an increase (retainment) in carbon dioxide whilst sleeping causing the cerebral blood vessels to dilate. Treatment includes the steroid Dexamethasone (Decadron) which decreases the swelling around the brain, removal of the tumour and possibly an external ventricular drain or shunt to remove some of the brain fluid and decrease the pressure.
Dural irritation - the dura is the covering of the brain, this becomes irritated when there is blood in the brain fluid. Another symptom may include sensitivity to light.
Healing of the bone and muscle - incision pain and bone pain is worse on movement the same as any healing fractured bone. Treated with simple analgesia, anti inflammatory medication or small doses of valium to minimise muscle spasm.
Cranial nerve involvement - neuralgic or nerve pain is described as burning or stabbing and is treated with anticonvulsants such as Tegretol or Epilim. Antidepressants (valium) in small doses are also useful for nerve pain.
Tension headaches - are common. They are usually worse at the end of the day, often include eyestrain, and are described as a tight band across the forehead. Treatment is relaxation and a mild analgesic.

June 2008: Session Two Seizures and Brain Tumours
Presented by: Dr Mark Dexter

Seizures are the presenting symptoms in approximately 26% of patients diagnosed with a brain tumour.
Seizures may occur prior to diagnosis or following surgery.
Temporal lobe seizures may go unnoticed as they may sometimes appear as a blankness or not listening or not concentrating.
The chance of having a seizure following surgery is less than 10%.

Q. What is a seizure.
A. A change in the electrical activity in the brain.

Factors that lower the seizure threshold: ie. means you are more likely to have a seizure
sleep deprivation, hyperventilation, infection and fever, head trauma, metabolic imbalance after surgery, alcohol consumption, flashing lights.

Q. Does it do any damage to the brain.
A. A brief one off seizure does not cause any damage to the brain.

Q. Can you have a seizure in your sleep.
A. Yes, it may not be a full blown convulsive seizure and may go undetected. Your partner may notice breathing

changes. Often seizures that start in the frontal lobe occur at night.

Antiepileptic drugs

Prophylactic (to prevent seizures) - the night before surgery and up to 3 months following surgery.
Therapeutic (to treat seizures)- given if a seizure occurs prior to surgery and up to 12 months following surgery if more than one seizure occurs.

Common drugs

Phenytoin (Dilantin)
Carbamazepine (Tegretol)
Valporate (Epilim)
Clonazepam (Rivotril)
Phenytoin - you need to have regular blood levels taken by your local doctor. If a rash develops ensure your local doctor ceases Dilantin and commences another drug such as Epilim.
Most patients will develop a skin rash on Tegretol if they have previously developed a rash on Dilantin.

Q. What sort of cognitive changes can you expect on Dilantin?
A. More fatigued, slow in thinking, short term memory problems.
Q. Will it affect my liver if I use Dilantin long term?
A. If it does it will be almost immediate and reversible.

Driving following brain tumour surgery.

There are RTA guidelines for driving following brain tumour surgery. If the surgery is on the top part of the brain eg; the frontal, parietal, temporal or occipital lobes there is a risk of having seizures and you cannot drive for 3 months from surgery. If the surgery is on the back part of the brain eg; cerebellum, you cannot generate a seizure.
If you present to hospital following a seizure there is a minimum of 6 months not driving depending on where the tumour is. Driving must be ceased if you are weaning your anticonvulsant medications. There may be an increased time frame for not driving if you have a neurological deficit such as problems with forward planning or a limb weakness. There are specific RTA guidelines for visual deficits and you may be required to undergo formal visual field testing by an opthalmologist. If the visual loss is more than 1/4 or 90 degrees (often from damage to the occipital or temporal lobes) you are not able to drive.

Q. What if your license comes up for renewal during the 3 months.
A. Notify the RTA and defer from reapplying. You can obtain a letter from your local doctor.

Q. Are the RTA guidelines available.
A. Yes, they are available on the RTA website www.epilepsy.org.au/fact_sheets

Above: Dr Dexter talking with one of his patients during the supper break, June 2008

Below: Mairead and Yvan, winners of the lucky door prize at the June 2008 meeting

Flowers kindly donated by the Flower Factory at Westmead Private Hospital.

NOgIN would like to thank Westmead Private Hospital Executive Team for their ongoing support, providing the conference room, supper and free parking.

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