



Brain Tumour Australia Information

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Second Opinions - Rights & Choices

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When a person arrives for their first consultation with either a neuro-surgeon, a medical oncologist or a radiation oncologist, they bring a multitude of problems. They may arrive at an oncology office in a state of distress, uncertainty and anxiety. They may also have serious questions about their mortality and their future.

A brain tumour diagnosis produces a strong emotional reaction. Everyone is shocked and devastated, needing more time to fully comprehend the seriousness of the diagnosis.

When a diagnosis of a brain tumour is received, there is much fear, lack of knowledge, and many questions about treatment. All these factors impinge on issues of life and death therefore it is not unreasonable for the person diagnosed with a brain tumour and their family to want to have a second opinion.

A second opinion can be very helpful, even though most patients are reluctant to offend their treating specialist by obtaining one. It is very important for the patient and their family/friends to give themselves time to learn what the diagnosis means. Information about treatment options (surgery, radiation, or chemotherapy) needs to be discussed and thought about. The prognosis that may have been mentioned by the specialist will effect the immediacy for the patient/family of commencing treatment.

Today where many people have access obtained from the internet, newspapers, magazines or from well-meaning friends, this information can be overwhelming and confusing.

If at any time patients/families wish to seek a second opinion, as is their right, they need to obtain copies of records, test results, x-rays and pathology reports before attending the second appointment. Many consultants will refer the patient 'on' if a request is made. A phone call from one consultant to another can also assist in navigating the 'health system' quicker where time may be thought to be of the essence.

Commencing the brain tumour journey is terrifying. This is a journey that no-one wants to travel. People feel that they are being treated differently by family, friends, and work colleagues. The future seems bleak, and hope which is so

important may suddenly seem difficult to obtain. Life changes overnight.

People want to know 'yesterday'

- what is happening
- how bad the diagnosis is?
- what part of the brain will be effected?
- can it be all 'cut' out?
- Will it spread?
- What are the choices for treatment?
- How soon can treatment begin?
- How successful are the different treatments?
- What are the risks and side effects of treatment?
- Does one have a better outcome than others?
- How do I make a choice?
- And am I going to die?

How do you find answers to these questions to enable you to make a make decisions about what to do?

You need to find a specialist who deals with brain tumours and their treatment. How do you find out if the information that you found on the web or the advice that has been given to you by friend and family is right for you?

When making a decision about treatment for a brain tumour, listen to the information that the specialist is giving you.

Ask questions, and if possible allow time to think about the options given to you.

No one wants major surgery, and people usually do not want to even think about radiation therapy or chemo-therapy treatment. All the tests that you may need, CT scans, MRI's, blood tests, injections, overwhelming and terrifying.

At any doctors appointment, not just your second opinion, take a notebook, have someone write notes, keep a record. Always have a significant other, a family member/friend with you. Write down questions that you want addressed during your visit to the consultant.



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Second Opinions & Communication with Health Professionals

Second Opinions - Rights & Choices *cont.*

Mention to your treating specialist about the second opinion, it is to your advantage to share all the information. Know what the choices are and what the risks and complications are.

Your second opinion may assist with the following:

- Allow you to make the choice that makes the most sense
- Reassurance that your first specialist has suggested the best treatment plan for you .
- Introducing a clinical trial or treatment that may not be generally known or available
- Allowing you to follow a treatment plan that a previous consultant made not have agreed with (eg. Surgery, a particular type of chemo therapy)

A second opinion is one way of clarifying your choices and helping you decide what is right for you.

You need to feel comfortable with your treatment team and establish a sense of trust. It is your right, your body, your treatment and your decision to follow the treatment path that you feel is the best option for you. A second opinion may provide a different perspective on the outcome of a treatment plan

Australian Professional Groups

Australia Neurosurgical Society of Australia -Serving Australia, New Zealand, and parts of South East Asia. <http://www.nsa.org.au/>

Australia Australasian neuroscience Nurses Association <http://www.anna.asn.au/>

Australia The Medical Oncology Group of Australia (MOGA) is a Special Society of the Royal Australasian College of Physicians (RACP) and a sub-group of the Clinical Oncological Society of Australia. <http://www.moga.org.au/>

Australia COSA is the peak national body representing health professionals whose main is the treatment of Cancer <http://www.cosa.org.au/Home.htm>

Australia OSWA is the national professional body of Australian social workers who work in Oncology <http://www.oswa.net.au/>

The Brain- Communication with your Health Professional

Be Aware That There May Not Always Be Definitive Answers.

You have the right to ask questions, and should never be afraid to approach any health care professional for information about your diagnosis, treatment and prognosis

Guidelines

- Never be afraid to ask and to keep asking until your questions have been addressed
- Remember, it is your body and you have the right to know what is happening to it
- Write down your questions in advance so that they will not be forgotten. This will make you feel more confident
- Write down things that the doctor may say, or ask for a note to be written for you
- Take someone with you to appointments. They can help keep track of what is said
- Do not be afraid to interrupt to ask about technical terms or words that you do not understand
- Take your time. Let the professional know if you need to arrange a longer appointment
- Encourage family members to be involved and communicate with the health care professional

Remember, do not expect the health care professional to know what you want. ASK!