



## **The Brain– Coping- Gain Control**

### **If you are the person diagnosed with a tumour**

#### **What To Do**

the following points are a guide to regaining some control in your life

#### **Helpful hints/tips/strategies**

- Firstly, take one day at a time
- Keep a diary; keep track of your diagnosis; the name, type and grade of tumour; in which part of the brain the tumour is situated; treatment options offered and accepted; drugs offered and taken; side effects; medical tests and results; doctors seen and dates of appointments; and what was spoken about in your consultation with your doctor
- List your feelings; fears; anger and uncertainty; this may help you cope
- Always bring someone to your consultations with your doctor; it is difficult to remember everything that is discussed. A family member or friend can help ask questions, and provide you with support
- Ask if you are able to record your consultations on a tape
- Ask for and keep copies of reports, scans, and any tests
- You are entitled to obtain second, third, and even fourth opinions if you desire, it helps you find a doctor you can feel comfortable with and trust. It also expands your treatment options

**It will give you peace of mind to know you have exercised all options**

## **The Brain—Communication**

The brain tumour can lead to individuals becoming inflexible

- In their thought processes
- Being unable to change their train of thought
- Tending to repeat themselves
- Having difficulty accepting others points of view
- Not coping well with changes in routine

### **If you are the person diagnosed with a tumour**

#### **Helpful hints/tips/strategies**

- Listen to what is being said
- Ask for things to be repeated if you don't understand

### **If you are a family member**

#### **Helpful hints/tips/strategies**

- Try to listen the first time
- Provide clear feedback that you have heard and understood the message
- Try to ignore repetition
- Ensure involvement for everyone in the decision making process about changes in routines
- Forewarn of change by the use of diaries, notice-boards, letters etc
- Talk about the planned changes

Communication may be difficult

- Speech may be slowed or slurred
- Some may talk excessively
- Conversations may not make sense

**Give clear, consistent feedback (this can help change behaviour)**



## **The Impact of a Brain Tumour Diagnosis**

### **The Impact of a Brain Tumour Diagnosis— Seizures— Use of medications**

#### **If you are the person diagnosed with a tumour Helpful hints/tips/strategies**

- Keep a diary
- Take the medication as prescribed and at the time of day/night recommended
- Write the name of any medication in a diary and note what it is used for
- Have regular blood tests ( if advised by your treating specialist)
- Contact your pharmacist or medical practitioner if you have any issues of concern

Taking medications may result in different side effects being experienced. The following strategies have been generalised. Not all side effects occur with each medication.

#### **Anticonvulsant Medication Side Effects & Suggestions to assist**

- swelling of gums – use a soft tooth brush for tooth care
- a rash – seek medical advice for the correct skin care
- nausea/vomiting - seek medical advice
- constipation - seek medical or dietary advice
- tremors - seek medical advice
- tiredness – take regular rest periods
- insomnia - relaxation or meditation can assist with obtaining a better sleep
- feeling on 'edge' or 'worked up' – relaxation or meditation can assist with calming down
- poor coordination, feeling off balance – remember 'slow and steady wins the race'
- concentration problems - take time doing tasks, ask for assistance if necessary

#### **Use of Medication**

- It may be necessary to take medication for a lengthy period
- Discuss your care plan with your doctor
- Do not reduce your medication or take it in different dosages without medical advice

#### **What To Do**

##### **Helpful hints/tips/strategies**

If you are the person diagnosed with a tumour

- You may be very tired after a seizure so take time to rest
- If temporary confusion occurs, take time to reorientate

- Speaking may be difficult , indicate that this is not easy
- Walking may be tiring due to limb weakness, so give yourself time to readjust
- Allow for a period of time to regather energy (it may take minutes to hours)
- Ask family/ friends for assistance. This will only be a temporary measure
- When showering or bathing you may at times require some supervision or assistance
- Do not drive or ride a vehicle without checking with your doctor
- Restrict strenuous physical activities, and be aware that some may require a medical reassessment before participation eg, scuba diving, abseiling etc
- Participate in certain activities with a "buddy" (eg. swimming, bike riding)

#### **If you are a family member**

##### **What to do in event of a seizure**

- Stay calm and if possible provide privacy
- Lower the person gently to the floor and loosen any clothing if it is restricting breathing or comfort
- Do not attempt to restrain the person experiencing the seizure while it is occurring or immediately after it has ceased. Restraint may injure the person physically or initiate an aggressive response
- Remove any items that might injure the person
- To allow saliva to flow freely from the mouth, move the person onto their side and direct their movements to ensure injuries do not occur; however remember, do not use restraints
- Do not attempt to force anything into the mouth
- Seizures can be exhausting so after a seizure when the person awakes, allow for a period of reorientation and rest
- If possible do not leave the person alone during an attack
- If a series of successive convulsions occurs (lasting more than 10 minutes), seek immediate medical assistance
- During a grand mal seizure, it may be necessary to protect the people from hurting themselves if they appear to be repeatedly knocking their head. (Use hands to support and protect)
- Remove dentures etc if possible but do not force removal
- Discuss the seizure events with treating medical professionals if appropriate