

# MANAGING CHALLENGING BEHAVIOURS AFTER BRAIN TUMOUR

*A resource for patients, carers and health providers*

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ABSTRACT

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Managing challenging behaviours after brain tumour

Cancer Institute NSW

## **Managing challenging behaviours after brain tumour: A resource for patients, carers and health providers**

### **Purpose**

Between 17-50% of people with brain tumour (BT) display some degree of challenging behaviour (CB) including executive impairment, behavioural disturbance, or social/emotional dysfunction. However, little information on management strategies is available for patients and/or their carers to assist in coping with these problems. A web-based review identified 17 key English language information resources (web-based or hard copy) on BT from across Australasia, North America, and the United Kingdom. Although 47% contained lists of cognitive/behavioural impairments, 71% provided either no or minimal information (1-2 sentences) on management strategies. This project aimed to develop patient/carer oriented Fact sheets to address this information gap.

### **Methods**

A literature review regarding behavioural / cognitive impairments after BT was conducted. Resources developed for other neurologic groups were reviewed. Combining data from these sources with the clinical experience of the project team, draft fact sheets were devised and presented to a focus group of patients and carers for feedback. Drafts were also circulated to a state multidisciplinary health provider BT network convened by the New South Wales Cancer Institute. Readability statistics were also calculated to ensure that the resources met public health standards for comprehension.

### **Results**

Sixteen Fact sheets (web-based and hard copy) were developed addressing apathy, anger, stress/anxiety, fatigue, high level thinking problems (executive impairment), inappropriate social/sexual behaviour, lability, perseveration, disorientation/confusion, egocentricity, impulsiveness, depression, neglecting personal care, memory difficulties, attention/concentration and communication. Each sheet contains a definition of the problem, prevalence statistics, symptom list, de-identified case-study, management strategies for the person with BT and carer(s), key questions to ask health professionals and web-links to further information. After only three months of release, substantive requests for these resources from across Australia have been received.

### **Conclusion**

Results suggest that these Fact sheets fill an important information gap, an important resource for patients, carers and health providers.