

Update on BTAA Cancer Australia project – June 2016

In April 2016, the BTAA received funding from Cancer Australia for a three-year project to 'create information resources to help brain tumour patients improve the health and quality of life outcomes for people from culturally linguistically and diverse communities, including Arabic, Greek, Chinese, Vietnamese and Easy English'.

We will be seeking input from our members, and from brain tumour patients, families and caregivers over the coming months to identify what information resources are most needed by people with tumours from culturally and linguistically diverse (CALD) communities.

The BTAA CA Project Steering Committee will hold its first one-day meeting on 2 August 2016 in Melbourne. Its second meeting will be held on 11 September 2016 in Sydney.

The members of the Steering Committee are: Dr Danette Langbecker (U Qld), Dianne Legge (Austin Melbourne), Sally Payne (IBTA Sydney), and Dr Jonathon Parkinson (UNSW Sydney).

The CA project team will also attend the 2 August 2016 meeting. Members of the Project Team are: Tricia Berman, Susan Pitt, Janet Micallef, Rigoula Roussakis, Philip Steel and Annabelle Wilson (representing Cure Brain Cancer Foundation). We are yet to identify a multicultural member of the project team.

The 4th national BTAA Summit (14 September 2016) will include a session on the CA project.

Melbourne and the Sydney Brain Cancer Week forums in May

There was discussion of the CA project at the Melbourne and the Sydney Brain Cancer Week forums. The Melbourne forum included questions about the CA project in its end-of-forum questionnaire - we are awaiting the outcome of the questionnaire from Dianne Legge.

Separate meetings were held with Annabelle Wilson (Cure Brain Cancer Foundation) and Danette Langbecker (University of Queensland) in Melbourne on the same day as the forum.

NSW Neuro Oncology Group meetings

The April and June meetings of the NSW Neuro Oncology Group discussed the CA project (Dr Parkinson chairs that Group). In April, it was suggested by the Group that the MSD information package 'Temodal Patient Support Resources' would be a good information resource to translate for CALD.

The 2013 MSD package includes: DVD for patients and carers, The Way Ahead information guide (46 pages), and a Temodal treatment diary.

1. The DVD provides health care professionals explaining what to expect from surgery, radiotherapy and chemotherapy and how to manage some of the common side effects and challenges of the condition.

2. The booklet 'The Way Ahead - a guide for those diagnosed with a brain tumour includes easy-to-understand information on the type of brain tumour you have, its symptoms, the treatment options and links to further support and help.
3. The Temodal Treatment Diary (a tool to help you track and understand your treatment schedules) is a practical diary that you and your doctor can use to record correct dosages, start/finish treatment dates, medical appointments and other information you need on a daily basis. It is for use when you have finished your radiotherapy treatment.

The MSD package production involved a review by the following health professionals: Dr Lawrence Cher (MBBS, FRACP, MD); Laraine Cross (BA Grad Dip Ed BSW); Rochelle Firth (RN, NP, BN, Grad Dip Clin Pract, Neuro Certificate), Dr Elizabeth Hovey (MBBS, FRACP, MSc), Grant Ovens (B Pharm, MPS) and Mark Tudehope (B Pharm).

The June meeting of the NSW Neuro Oncology Group had a discussion about the patient forums to identify what resources are most appropriate for the CALD community.

Existing Australian CALD resources for brain tumour patients/carers

An examination of existing Australian brain tumour information in languages other than English indicates that a range of Fact Sheets in different languages are available through the state cancer councils. Also, most cancer councils provide some assistance for multinational groups to obtain a translator to assist them. A list of existing material available in languages other than English will be considered at the August Steering Committee.

Research on care and support for brain tumour patients

Considerable research has been undertaken in the past 15 years in Australia on the availability and quality of support for brain tumour patients and carers. Dr Danette Langbecker has been involved in most of that research and the 2008 32-page booklet published by Queensland University of Technology 'It's Ok to Ask' was produced as an outcome of some of this research. A synopsis of Australian research into brain tumour care and support will be considered by the August Steering Committee meeting.

Existing research will also assist the Steering Committee to determine how it will identify the most appropriate brain tumour material for translation and production of other resources such as videos for CALD patients. The methodology used to identify what patients/carers want in terms of CALD resources will be an important consideration for the Steering Committee as it will produce an evidence base for action in the second stage of the project – namely translation and production of materials. The methodology may, for example, involve face to face forums with patients, written questionnaires, telephone interviews, and/or a combination of these. Information to identify patients and carers who can take part in the forums/questionnaires is also critical. The BTAA database may be one of a number of sources of such information.

Translation services

Analysis of available translational services is being undertaken so that the Steering Committee can identify probable costings and options. This background will be considered by the August Steering Committee meeting.

Volunteers and promotion

The project will require assistance from associated organisations and individuals. It is an opportunity for BTAA to work collaboratively on how to get information resources to all brain tumour patients and their carers in a timely fashion. This aligns closely with BTAA's mission.

Information on the BTAA CA Project will be put onto the website so that interested parties can contribute. Through the materials that the project produces, the BTAA website will be an important source of support information for CALD patients.