

**5TH SATELLITE SYMPOSIUM ON
NEUROPSYCHOLOGICAL REHABILITATION
7TH - 8TH JULY 2008**

ABSTRACT SUBMISSION

TOPIC: FAMILY AND CARER ISSUES

TITLE: 'THE COURAGE TO CARE'

Author: Cheryl Koenig

Position: Carer; Author of 3 books relating to Brain Injury; Consumer Representative on the following committees:

- Consumer Participant for NSW Health GMCT Brain Injury Rehabilitation Directorate
- Consumer Representative to Medical Services Advisory Committee (MSAC) Review Panel – MSAC 1109 - Deep Brain Stimulation for Essential Tremor and Dystonia
- Carer Representative for Carers NSW
- Community Representative for the Speech Pathology of Australia's Ethics Committee
- Advisory Panel Member for NSW Brain Injury Association's Mentoring Project
- Fundraising committee for Liverpool Brain Injury Hospital
- Ambassador for 'The Friendship Foundation' – a not-for-profit organisation designed to assist carers and people who are socially disadvantaged due to chronic illness or injury.

AIM: TO PROVIDE CLINICIANS WITH A GREATER UNDERSTANDING OF THE NEEDS OF A CARER, AND SHED SOME INSIGHT INTO THEIR PERSPECTIVE WHILST THEY NAVIGATE THE HEALTH SYSTEM AND THE TRAUMATIC JOURNEY OF 'BRAIN INJURY'.

BACKGROUND:

My son sustained an extremely-severe-traumatic-brain-injury 10 years ago when he was hit by a car. He was a '3' on the Glasgow Coma Score, in a coma for 6 weeks, in PTA for over 10 months and was given a very poor prognosis. However with the combination of good therapy, sheer determination and family support, he now not only walks well, but can run, snow-ski, play the piano, tennis, swim laps and is learning to drive – all this whilst working in 4 part-time jobs, 5 days a week.

I became a consumer representative over 3 years ago for the GMCT with the intent of being involved in the development of policy and improvement of health care services in the area of brain injury. During this time I have written 2 booklets for NSW HEALTH which involved interviewing a diversified range of people with a brain injury and also their carers. From my personal experience in the extensive rehabilitation of my own son, along with gaining a wealth of insight through meeting and interviewing many other consumers, I am able to contribute a wide reflection of consumer perspectives that would be beneficial and constructive in any discussion relevant to improving the lives of those afflicted with brain injury. I intend to discuss what carers feel are the most helpful aspects of inpatient care, as well as the critical issue that arose in almost every interview for my booklets; 'The Transition Period' – i.e. transition from the safe environment of the hospital to discharge into the often intimidating community environment.