

Collaborative care

The Neuro Oncology Information Network (NOgIN) provides support for patients with a brain tumour from hospital to home

Westmead Private Hospital in Sydney has been supporting the development of the Neuro Oncology Information Network (NOgIN) for the past seven years. This support group provides a collaborative service for patients diagnosed with a brain tumour. The passion and commitment to providing the best care for neuro-oncology patients and their families, motivated the nurses to implement their own support group.

The diagnosis of a brain tumour can be devastating and the potential neurological deficits and psychosocial effects can have an enormous impact on the patient and family's quality of life.

In Western Sydney, the public and private neurosurgical services are co-located and provided by Westmead Private Hospital and Westmead Hospital. In 2006, Emma Everingham, clinical nurse consultant at Westmead Private Hospital and Diane Lear, clinical nurse consultant at Westmead Hospital, joined forces to launch "NOgIN".

Over the past seven years NOgIN has continued to grow, with the support of the neurosurgeons and extremely positive feedback from the patients and carers who attend the bimonthly information evenings. These sessions provide practical and emotional support from the collaborative team of specialists. Invited speakers include neurosurgical consultants, oncologists, palliative care consultants, psychologists and patients/carers. The evenings consist of two short sessions, due to the wide range of physical, cognitive, emotional and behavioural impairments experienced by patients.

In combination with the information evenings the nurse consultants provide patients with a Brain Tumour Support Pack prior to discharge from hospital. This package includes information about NOgIN, the newsletter and program, along with other Cancer Council resources. During this consultation any concerns about ongoing care are openly discussed,



Emma Everingham and Diane Lear

providing a holistic model of care. The combination of an educational and support model empowers the patient, providing a forum for patients/carers to share information, leading to enhanced coping mechanisms. This was highlighted at the "Carers' Nights" where carers gained support from each other and the opportunity to ask direct questions from the panel of experts.

The ongoing success of NOgIN has also been facilitated by annual fundraising events during International Brain Tumour Awareness Week. This enabled the development of a travel assistance fund for patients to attend meetings and a nursing scholarship fund for neuroscience nursing education. NOgIN also publishes their own newsletter, and is registered with Brain Tumour Alliance Australia and the Cancer Council of NSW. The Westmead Medical Research Foundation also administers a trust fund for NOgIN.

The increasing attendance and expansion of NOgIN over the last seven years proves the service is meeting the needs of patients with a diagnosis of a brain tumour. It also shows how specialist nurses from public and private hospitals can work together to provide a combined

service for all of their patients. These achievements were recently presented at the 11th Quadrennial International Congress of the World Federation of Neuroscience Nurses in Gifu, Japan in September 2013 and the sixth Cooperative Trials Group for Neuro-Oncology (COGNO) Scientific Meeting in Sydney in October 2013. [PH](#)

By Emma Everingham

Patient comments include:

- Thank you for your insight and continual drive with NOgIN, it is truly appreciated.
- The session on palliative care was such a comfort to me and gave me options
- I am glad you are continuing with these evenings, they have made a huge difference to me in my day to day life as a carer
- Meeting with other people in the same situation is comforting, we know we are not alone
- We are reassured we are getting the best treatment
- If only this service was available when my son died of a brain tumour, it is just what we needed