

SUBMISSION OF THE NEURO-ONCOLOGY GROUP OF NSW

TO



Young people with brain or spinal cord tumours in
nursing homes

Prepared by:

Michael Barton - Conjoint Associate Professor, School of Medicine, UNSW
Radiation Oncologist
Research Director – Collaboration for Cancer Outcomes,
Research and Evaluation
Chair of NSW Neuro-Oncology Group

Dr. Elizabeth Hovey - Staff Specialist - Medical Oncology
Conjoint Lecturer University of New South Wales
Proposed Member of NHMRC Working Party to develop
National Consensus Glioma Guidelines
Secretary of NSW Neuro-Oncology Group

Teresa Simpson - Senior Oncology Social Worker
Member of NSW Neuro-Oncology Group

Correspondence to:

Teresa Simpson
Cancer Therapy Centre – Liverpool Health Service
Locked Bag 7103
Liverpool BC 1871
P: (02) 9828 5180
F: (02) 9828 5188
E-mail: Teresa.Simpson@swhs.nsw.gov.au

INTRODUCTION

The following concerns are raised by the Neuro-Oncology Group of NSW (NOG). NOG is a multi-disciplinary group of physicians and allied health professionals including neurosurgeons, radiation oncologists, medical oncologists, clinical nurse consultants, neuro-oncology social workers and neuropathologists. NOG is a statewide “working group” of health professionals from Sydney, Wollongong, Newcastle and Canberra.

The aim of NOG is to provide a multidisciplinary alliance, promote education about neurological tumours, and also to advocate for the development of statewide infrastructure for patients and their caregivers – such as developing Carer Advocacy Groups, uniform Information Kits / booklets, organising statewide collaboration in patterns of neurological tumour care studies and clinical trials. Ensuring that appropriate high level of care for these patients is available is also a priority.

This submission responds to the third term of reference.

Young people who have a high level of disability as a result of neurological tumours (Brain/Spinal Cord Tumour) are being inappropriately accommodated in high-level residential age care facilities. Young people are defined as people between the ages of 16 - 65 years.

Young people with neurological tumours, who have progressive advanced disease usually present with a range of disabilities including physical, communication, cognitive and behavioural impairments. Mobility can be severely impaired and many of these patients are wheelchair- bound or bed-bound as their disease progresses.

As the course of the tumour progresses, the first line of care and support is typically provided by family caregivers.

These patients are often not able to return to independent community living and require 24 hours care or supervision provided by a highly committed caregiver. Their significant others and caregivers face enormous challenges in trying to:

- provide 24 hour care in the home setting
- cope with the financial burden to pay hire fees for equipment such as a hospital bed, hoist, wheelchair, and incontinence pads and experience further financial loss because they may have to give up work.

The hardship of family caregivers is exacerbated by a lack of appropriate service supports.

PADP programs and/or hospital equipment programs do not supply the necessary equipment for brain tumour patients who are bed bound (eg hospital bed, continence pads).

HACC funded services are extremely difficult to access due to funding shortages. In some cases, services are either refused or only small numbers of hours allocated.

Not surprisingly, anxiety and depression are common reactions as people seek to adapt to multi-layered life changes. These psychological responses are exacerbated by the hardships caused by a lack of suitable service supports. These patients and their significant others are a vulnerable group, have specific needs, and require immense support.

People with advanced stage neurological tumours are, for the most part, incurable. Placement in high-level residential age-care facilities has become a standard practice forced on Oncology teams within NSW Health Hospitals because of the lack of other flexible support options for younger people.

These patients should be eligible for Palliative Care in hospice settings, but.

People with advance neurological tumours usually have a long palliation window period as the severity of their symptoms can fluctuate over several months, in the context of an overall worsening of their condition leading to death.

Due to the long palliation periods and the lack of hospice beds, Palliative Care Services are often reluctant to accept referrals for brain tumour patients because they are likely to require long-term inpatient palliative care. Due to the high levels of demand for the currently limited number of hospice beds, palliative services are unable to provide long-term inpatient hospice services to brain or spinal cord tumour patients, providing instead limited respite hours.

As a result of these aforementioned factors such as the

- lack of HACC-funded home support services,
PADP and equipment services and
Palliative Care hospice beds.

Families becoming overwhelmed and exhausted in seeking to provide for the 24 hour per day complex physical, cognitive, emotional and behavioural support needs to their loved-ones with brain or spinal cord tumours.

Young people with neurological tumours are being inappropriately placed within aged-care residential facilities.

RECOMMENDATIONS

1. To establish care facilities in NSW which specifically target the long-term supported accommodation needs of young people with neurological tumours
2. To improve access to community based home help support programmes
3. To provide a comprehensive financial support scheme for those families who are willing to care for the patient in the home environment (e.g.: hospital bed, incontinence pads)
4. To increase the number of inpatient palliative care beds to cater for young people with high needs who required long-term inpatient palliative care

In conclusion, the current failure of services to provide suitable long-term accommodation services for some of the most vulnerable members of our community is an issue that needs to be addressed with urgency.

Yours sincerely,

Conjoint Associate Professor Michael Barton – Chair NSW NOG

Dr Elizabeth Hovey – Secretary NSW NOG

Teresa Simpson - Member NSW NOG