

**Medb Bradley; Neuro-Oncology Clinical Nurse**

Managing Your Care: Information Evening, Wednesday 10th September 2014

Brainwaves NI in partnership with NICaN Brain & CNS Group



**Medb Bradley**  
Regional Neuro-Oncology Macmillan CNS

# Providing a Network of Care

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### From impending diagnosis

The possibility of a CNS tumour is devastating for the patient and their family and often filled with fear and dread



## Examples of Patient Concerns

- ▶ **Emotional Concerns**
- ▶ Fear/anger/ disbelief/ denial
- ▶ Concerns and fear of impending treatment, fear of the future
- ▶ Fear of loss of dignity and control
- ▶ Fear of loss of role and causing financial concerns
- ▶ Fear of not having enough time
- ▶ Fear of not having sorted everything out
- ▶ **Physical**
- ▶ Loss of function/disability /loss of independence/loss of control/ fear of seizures/memory problems/speech problems incontinence, fear of being a burden on loved ones

## Family concerns



## Examples of Family Concerns

- ▶ Fear/anger/disbelief regarding diagnosis and treatment
- ▶ Fear he/she will not or is not receiving best care
- ▶ Fear about managing disability/ symptoms and coping/ knowing what to do
- ▶ Fear for taking on new roles and responsibilities
- ▶ Fear of not being able to cope and letting loved one down
- ▶ Fear of asking for help and support and not knowing who to ask
- ▶ Children's own individual fears and concerns about what is happening

## Studies regarding supportive care needs of patients and carers

- ▶ Janda et al ( 2008 ) investigating the unmet supportive needs and interests in services among patients with a brain tumour and their carers found -
- ▶ Carers wanted help dealing with fears about the patients mental health or physical deterioration
- ▶ The impact caring had on their own life and reducing stress in the patients life
- ▶ The study found greater higher emotional distress predicted higher supportive needs for patients and their carers

## Journal of the Multinational Association of Supportive care in Cancer ( Toronto )

- ▶ Patients supportive care needs are temporally dependant on disease course and treatment
- ▶ In this particular study patients with benign tumours lacked but needed many supportive resources currently available to cancer patients
- ▶ One potential solution to this current gap in supportive care involve extending support services already available for cancer patients to patients with benign brain tumours

## Up hill struggle for patients and their families



- ▶ Given the complex and multifaceted nature of problems faced by the neuro-oncology patient, few would dispute the needs of such patients and their families are likely to be best met by a team approach to care

## Challenges Faced in providing a network of care

- ▶ Identifying resources to support the provision of a network of care for patients
- ▶ Education regarding diagnosis/treatment available, managing symptoms for patients and their families and across care settings both within the hospital and community setting
- ▶ Improving Communication across care settings from hospital to community from the point of diagnosis
- ▶ Improving knowledge and access about community services for rehabilitation and supportive care such as palliative care in the local community

- ▶ Identifying sources of psychological support and counselling for patients and carers in their local areas.
- ▶ Identifying financial assistance for patients and their carers
- ▶ Looking towards the future with improved service developments
- ▶ Continuing to integrate research into our practice and install confidence in our services
- ▶ Raise the profile of brain tumours both benign and malignant tumours for patients and their carers

## Assessing and addressing Patient and Family concerns



## Providing a Network of care from diagnosis across both the hospital and community setting

