

# Supportive Care For Patients With High-Grade Glioma (primary brain tumours)

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# SHORE-C



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brighton and sussex  
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# Primary brain tumours are graded

- grade 1:  
low grade
- grade 2:

pilocytic astrocytoma  
children only, curable

very slow growing astrocytoma  
(survival up to 20 years)

- grade 3:  
high grade
- grade 4:

anaplastic astrocytoma  
anaplastic oligodendroglioma  
survival 1 - 5 years

glioblastoma multiforme  
survival 3 months - 2 years

# How common are primary brain tumours?

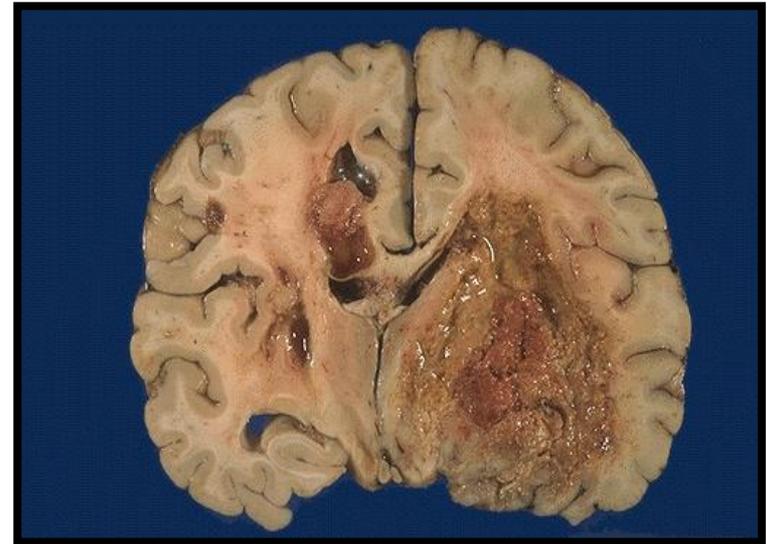
- 2% of adult cancers = 4,500 per year in UK
- 70-80% are High-Grade Glioma (HGG)
  - incurable with low life expectancy
- most common between 45-65 years
- seen more in men than women

# Effects of the tumour

Depends on location, grade and size

Destroys normal brain tissue

- visual or speech problems
- limb weakness
- personality changes
- memory loss
- poor concentration



Raises the pressure inside the skull

- headache, nausea, vomiting, fits, confusion, drowsiness, loss of consciousness

# Diagnosis & treatment

## Diagnosis

- brain scan

## Immediate treatment

- reduce raised intracranial pressure
  - steroids
- control seizures
  - anti-epileptic drugs



# Neurosurgery

- require tissue for diagnosis (biopsy)
- maximum removal of tumour whilst preserving the healthy brain
- surgical options
  - biopsy only
  - craniotomy / “awake craniotomy”



# Radiotherapy

Radiotherapy doubles life expectancy

- only administered once due to toxicity
- a short, palliative course of radiotherapy is given to those who are less fit or older
  - can improve or control symptoms
  - allows the steroid dose to be reduced/stopped

# Chemotherapy

- effectiveness is limited by blood-brain barrier
- doses needed often cause toxic side-effects
- wafers containing chemotherapy sometimes inserted into the cavity after tumour removal

## Temozolomide (2006)

- tablet, taken during radiotherapy and after too
- small survival gain

# Unwanted side-effects

## Steroids

- physical - fluid retention, weight gain, bruising, immunosuppression
- psychological - irritability, insomnia, increased appetite, psychosis



## Surgery

- removal/damage of healthy brain tissue

# Unwanted side-effects

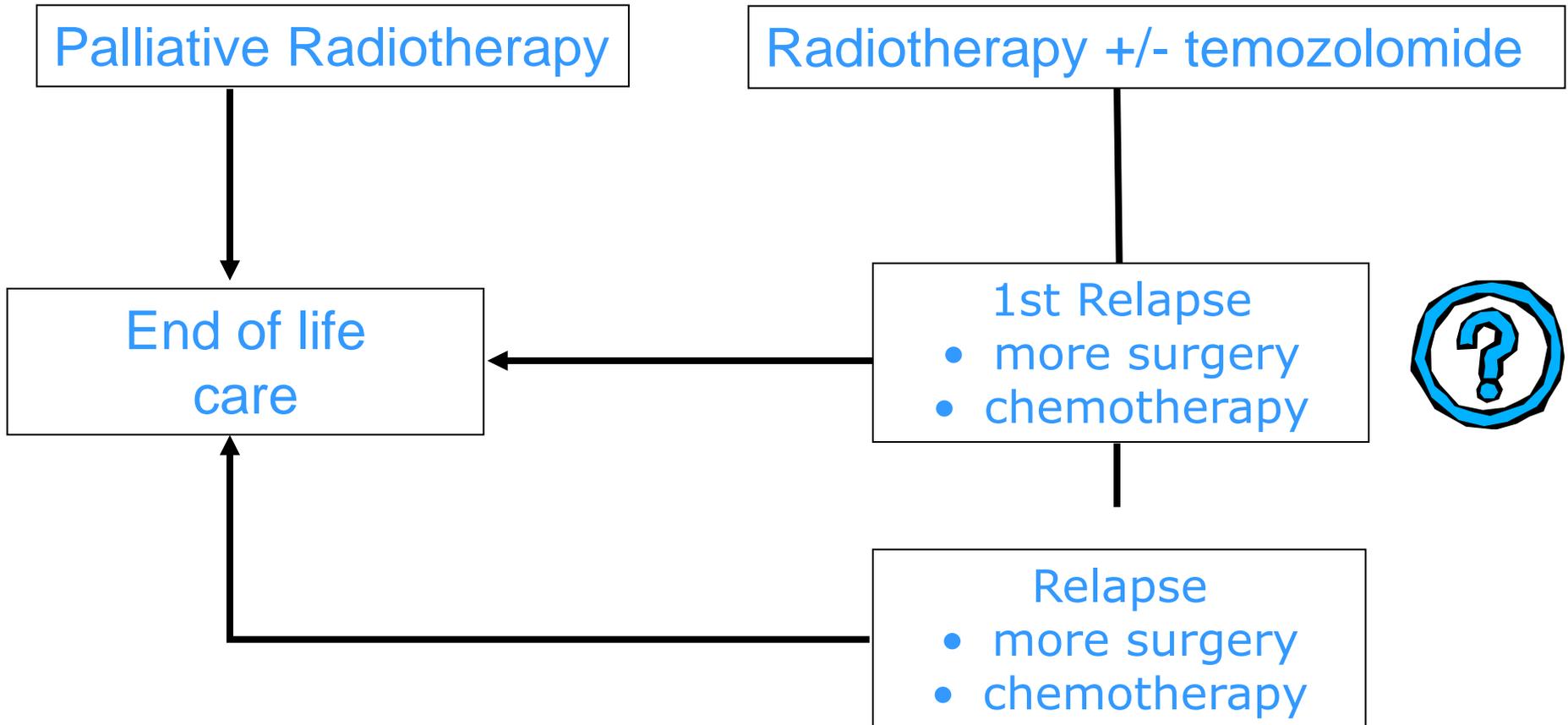
## Radiotherapy

- damage to healthy tissue, permanent hair loss, fatigue, sleep disturbance, sore scalp
- late effects – tissue atrophy, necrosis, memory and concentration problems, personality changes

## Chemotherapy

- nausea, fatigue, myelosuppression, rash

# After initial treatment



# Some questions posed locally

- from the perspective of patients & families what is the purpose of follow-up (FU)
- how useful is it
- how frequently should FU be done
- who should be consulting with these patients
- should patients see deteriorating brain scans
- how much does practise differ between centres

# Literature review

- **The Lancet Oncology** vol.9, Sept 2008, 884-891  
Psychosocial & supportive-care needs in high-grade glioma
- **Neuro-Oncology** vol.14, April 2012, 392-404  
Systematic review of supportive care needs in patients with primary malignant brain tumours

# What is known

- group with a wide variety of needs and very shortened life expectancy
- fatigue, anxiety, depression, personality changes and cognitive deficits prominent problems
- preservation of QoL, realistic hope, normality in everyday living, and existential issues paramount

# What is known

- some research suggests routine FU & information does not meet the needs of patients & relatives
- limited evidence about best FU practice between completion of 1<sup>st</sup> treatment and management by palliative team
- no studies comparing different FU practices

# UK Guidance

- 1<sup>st</sup> published guidelines (Davies & Hopkins 1997) were limited and subsequently criticised (Davies & Higginson 2003)
- current NICE (2006) Improving Outcomes Guidance is detailed on clinical management, but lacks good evidence and practice guidance on the supportive aspects of care

# Programme of work

Phase 1  
Pilot study  
April – September 2006  
Psychology, Health & Medicine 2011, Vol.16, 357-65



Phase 2  
National Clinician Survey  
June – October 2008  
Journal of Evaluation in Clinical Practice 2011, Vol.17, 1-6



Phase 3  
Comparative Observational Study  
January 2009 – January 2011  
CNS Oncology 2012, Vol.1, 39-48

# Pilot work

## Hurstwood Park Neurological Centre

### Objectives

develop tools for:-

- services survey tool
- patient interview schedule
- carer questionnaire

### Methods

- qualitative exploratory interviews with patients and healthcare professionals

# National Clinician Survey

## Objectives

- UK-wide survey of current FU practice

## Methods

- all UK Cancer Networks asked to identify doctors responsible for care of patients with HGG
- electronic/postal services survey

# Survey Results

- 68/102 (84%) doctors responded
- 3-monthly clinic visits to see an oncologist with *ad hoc* specialist nurse support was the norm
- a few centres conducted joint consultation clinics
- nurse-led telephone FU instead of visits was rare
- regular brain scanning was usual practice
- access to allied supportive services was considered useful, but actual levels of need and achievement of delivery was unknown

# Comparative Study of Follow-Up Care

## Objectives

- to evaluate and compare from the perspective of patients and caregivers oncologist-led FU with a joint consultation FU method

## Services compared

- oncologist-led FU, a 2-step process, first visit for a brain scan, then return a week or so later for the results
- joint FU is a single visit with the scan done on arrival followed by a consultation with the team for results

# Methods

- longitudinal observational study
- recruitment from 2 UK centres providing oncologist-led FU and 1 using joint consultations
- assessments at baseline, 3- and 6-months
- patients: 40, 32, 26
- caregivers: 32, 25, 19

# Methods

## Face-to-face interviews with patients

- recording services accessed
- ratings of experiences of care
- quality of life (FACTBr) measurement
- identification of unmet care needs (POS)

## Caregivers completed questionnaires

- wellbeing assessed (GHQ-12)
- questions parallel to the patient interview about services accessed & experiences of care

# Experiences of care

Table 1. Summary of experiences of follow-up care.

Statements	Strongly agreeing or agreeing (%)			
	Patients		Caregivers	
	Oncologist FU	Group FU	Oncologist FU	Group FU
Staff treat patients respectfully	96.2	95.6	100	96.4
Staff treat patients as individuals	98.1	91.1	100	100
Staff tell patients the truth about their illness	92.5	95.6	100	96.3
<b>Patients generally get to see the same staff</b>	<b>77.4*</b>	<b>95.6*</b>	<b>85.7*</b>	<b>100*</b>
Care is well coordinated	81.1	82.2	93.8	85.7
Sufficient information is always provided	79.2	77.8	87.4	78.6
Bad news is always managed sensitively	85.1	78.9	87.5	88.5
There is always an opportunity to ask questions	88.7	95.6	93.8	85.7
<b>Staff check information is understandable to patients</b>	<b>81.1*</b>	<b>97.7*</b>	<b>95.8</b>	<b>96.4</b>
There is always enough consultation time	86.8	88.9	89.8	78.6
Staff accommodate patient decision-making preferences	85.7	75.0	81.3	85.7
Follow-up is an intrusive reminder of the illness	24.5	15.9	10.4	14.3
Follow-up is inclusive of family/caregivers	96.2	95.6	89.8	100
Follow-up is burdensome	1.9	0	4.3	0
Written information is always of high quality	80.8	77.1	73.3	63.0
I would prefer fewer staff at the follow-up consultation	15.1	20.0	23.4	25.0
Follow-up ensures changes can be addressed early	90.4	95.6	93.6	89.3
Follow-up provides support	81.1	88.9	95.5	89.3
Staff always maintain patient privacy in consultations	92.5	95.6	98.0	96.4
The time taken by follow-up visits is wasted time	0	0	0	0
<b>Test results/scans are always available when required</b>	<b>79.2*</b>	<b>100*</b>	<b>93.2</b>	<b>96.4</b>
Travel to follow-up clinic is burdensome	34.0	24.4	25.0	10.7

\*denotes significant effect of FU method  $p < 0.05$  (Pearson chi-square).

# Patients quality of life (QoL) and caregivers wellbeing

- QoL either improved or was stable during the 6 months of the study, no effect of FU method
- similar QoL to other samples with HGG or other metastatic cancer (lung, breast, gynae)
- results showed 56% of caregivers suffered probable psychiatric morbidity (general population = 12%), no effect of FU method

# Unmet care needs

No effect of FU method, but

Patients most frequent practical problems:

- fatigue
- anxiety
- reduced independence

Desired service improvements:

- better emotional support
- proactive nurse telephone FU
- better information about course of their illness

# Conclusions

- as treatment is palliative more efforts are need to ensure good continuity of care best managed through a well functioning team approach
- FU is failing to meet the psychological needs of patients and caregivers
- innovative, integrated, interventions that effectively support caregivers need to be developed

# Acknowledgements

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THANK YOU