Supporting patients with brain tumours

Alison Corbett
Macmillan Clinical Nurse Specialist
Neuro-Oncology
Key contributions that CNSs make to cancer care

- Innovation, project management and change management
- Acting as a key worker across the whole care pathway
- Advanced clinical/diagnostic skills
- Leadership within the MDT and wider cancer team
- In-depth knowledge of a tumour area
- Excellent decision-making abilities
- Ability to assess patients' holistic needs
- Empathy for patients and their families
- Advanced communication and advocacy skills

Clinical Nurse Specialist
Tumour types & treatment pathways

**Low grade tumours**
- Low grade astrocytoma
- Low grade oligodendroglioma
- Meningioma
- Ependymoma
- Haemangioblastoma
- Acoustic neuroma
- Pituitary tumours

**Treatment**
- Surgery
- Surveillance
- Radiotherapy
- Radio surgery

**High Grade Tumours**
- High grade astrocytomas
- Medulloblastomas (PNETs)
- Glioblastomas

**Treatment**
- Surgery - biopsy/debulk
- Radiotherapy 60Gy in 30#
- with concomitant & adjuvant temozolomide
- 2nd line chemotherapy
- Best supportive care
Pathway 1. Treatment Plan

Mould Room

CT Scan Appointments

Dexamethasone
If required, your dose will be changed as necessary during your treatment
Steroid Information Sheet

Radiotherapy
Every Day
Monday to Friday
For 30 days
(8 weeks)

Temozolomide Chemotherapy (Concomitant)
Every Day
1. Fast 1 hour before and 1 hour after
2. Co-trimoxazole 1 tablet twice a day
   Monday, Wednesday and Friday
3. Anti-sickness medication as prescribed
4. Weekly Blood Tests

MRI Scan
3 – 4 weeks after radiotherapy ends

Outpatient Appointment
4 weeks after radiotherapy ends to decide if require adjuvant chemotherapy

Outpatient Appointments and Blood Tests
Every 4 weeks prior to the start of each cycle of chemotherapy

Mould Room Appointment
Mould made for your face
Information Sheet 1

Radiology Department Appointment
Planning CT Scan for radiotherapy treatment
Information Sheet 2

Radiotherapy Department Appointment
Start Radiotherapy Treatment
For 30 days (6 weeks)
Information Sheet 3

Pharmacy Department Appointment
Collect and start your chemotherapy prescription
(6 weeks)
Information Sheet 4

Radiotherapy Department Appointment
Weekly Review by Specialist Nurse when on Treatment
Information Sheet 5

Brain (MRI) Scan
Radiology Department
3 – 4 weeks after radiotherapy ends

Outpatient Appointment
To discuss:
- to decide whether appropriate to re-start adjuvant chemotherapy
Information Sheet 6
# Specific management requirements

<table>
<thead>
<tr>
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<tbody>
<tr>
<td>Seizures/Anti epileptic medication management (AEDs)</td>
<td>Fear of seizures in public places, managing medication, side effects of medication, drowsiness, aggression, visits to neurologist &amp; living with epilepsy</td>
</tr>
<tr>
<td>Cognitive deficits</td>
<td>Short term memory loss, personality changes, speech problems, lack of concentration, loss of control, changes in role, incontinence, loss of sight/hearing, worsened mobility, loss of independence, safety/vulnerable adult.</td>
</tr>
<tr>
<td>Haematology/biochemistry</td>
<td>Regular blood monitoring, risk of low platelets /neutropenia whilst on treatment. Effect of steroid therapy on blood results ie, blood sugars.</td>
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<tr>
<td>Risk of raised intracranial pressure</td>
<td>Awareness of symptoms and what course of action to take. Nausea, dizziness, am headaches, stiff neck, visual problems – linking symptoms.</td>
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# Pathway 2. Practical Issues and Referrals

<table>
<thead>
<tr>
<th>Issue</th>
<th>Referral</th>
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<tbody>
<tr>
<td>Inability to drive/ change of roles</td>
<td>DVLA, counsellor</td>
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<tr>
<td>Difficulty working &amp; financial issues</td>
<td>Welfare Officer DLA / AA/DS1500</td>
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<td>Loss of job</td>
<td>Prescription exemption</td>
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<td>Travel costs</td>
<td>Blue badge</td>
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<td></td>
<td>Macmillan grants</td>
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<tr>
<td>Fertility issues due to treatments</td>
<td>Sperm banking/egg retrieval</td>
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<tr>
<td>Libido/sexual problems</td>
<td>Couples counselling</td>
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<tr>
<td>Seizures</td>
<td>Epilepsy first aid information</td>
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<tr>
<td>Living with Epilepsy</td>
<td>Referral to Neurologist</td>
</tr>
<tr>
<td>Mobility problems</td>
<td>Referral to Physiotherapist</td>
</tr>
<tr>
<td>Co-ordination, balance</td>
<td>Occupational Therapist - Home visit/relaxation</td>
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<tr>
<td>Anxiety</td>
<td>Massage Therapist, counsellor, local centres</td>
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<tr>
<td>Language deficits, short term memory loss</td>
<td>SALT (Speech and Language Therapist)</td>
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<tr>
<td>Difficulties meeting ADLs</td>
<td>Social worker - care package</td>
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<tr>
<td>Hair loss / body image</td>
<td>Hairdresser/make over charities</td>
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<tr>
<td>Nutritional/weight issues/diabetes</td>
<td>Dietician</td>
</tr>
<tr>
<td>Holidays</td>
<td>Travel advice and information/ Macmillan</td>
</tr>
</tbody>
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Pathway 3. Psychological Care

1st OPA Week 1
Build trusting relationship
Post Traumatic Stress Debriefing
Montreal Cognitive Assessment (MoCA)
Holistic Needs Assessment (HNA)

2nd OPA Week 2
Expectation Adjustment Interventions
Introduce ‘ongoingness’
‘Special Consultation’ Invitation

On treat Weeks 3-8
Repeat HNA & MoCA as required
Grief & loss therapy
Couples counselling/ relationship changes
Anger management / relaxation techniques
Patient paced increased awareness
Quality of Life assessment

Weeks 7-8 specific
Detachment Counselling
Psychological Needs Assessment-refer
Palliative care referral
Case study

- Female in mid 20s
- Previously fit and well
- PS1
- Presented to GP with symptoms of raised intracranial pressure
- Referred/imaging/referral to Neuro-surgeons.
- Debulking operation November 2011
- WHO Grade III Anaplastic Astrocytoma
- November 2011 fractionated radiotherapy, 60Gy in 30#
- May 2012 new onset seizures - confirmed progressive disease
- Commenced PCV chemotherapy
- Repeated delays due to pancytopenia (over 3 months) stopped October 2012
- Application for Bevacizumab approved - now completed 12 cycles. Remains off steroids.
Imaging June 2013 and January 2014
Team Work!

- Declined community palliative care and social service input.
- Medical, practical, emotional and psychological needs met by Neuro-oncology team at The Royal Marsden, GP and CLIC Sargent working in collaboration.
- Special needs met included expediting rehousing, grants for wig and clothes to assist with body image difficulties, constant monitoring and communication with regards to bloods, steroid and anti epilepsy management, all of which increased quality of life and reduced social stigma.
Conclusion

I hope that this presentation has;

Highlighted the complex & individual needs of patients with brain tumours

Shown the importance of working in collaboration in order to identify and meet each patient’s individual needs in order to achieve maximum quality of life.
Room for improvement?

- We are very appreciative when we can communicate with GPs in a timely fashion and are very much open to suggestions as to how this could be improved.

- If you think that a ‘GP information pack’ would be helpful - to be given to all GPs when we have a new brain tumour patient- then please put this on your feedback form.

- Any other suggestions as to how communication could be improved would also be welcomed.

Thank you for listening
Contact details

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