Operational policy

The operational policy was agreed by the Neuro-oncology MDT on 24th June 2011
Kings health partners Cancer Centre
Operational Policy for the Care of patients with suspected neurological malignancy

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1.0 Introduction

Specialist Neuro-oncology surgery has been a key service provided by the department of neurosurgery at Kings College Hospital (KCH) ever since its establishment in 1995 following the merger of the neurosciences units at the Brook and Maudsley Hospitals. Prior to the merger, high quality Neuro-oncology service was a well-recognised feature of both the latter hospitals. Kings College Hospital is part of kings heath partners in partnership with Guy’s and St Thomas’s Hospital (GSTT).

The implementation of Improving Outcomes Guidance for People with brain tumours and other CNS tumours is progressing in line with the local network agreed action plan (standards to be issued).

Consultant neurosurgeons work in partnership with a comprehensive multi-disciplinary team (as defined by Improving Outcomes Guidance). The infrastructure within which the Neuro-oncology service is provided includes 62 neurosurgical adult and 10 paediatric ward beds, an 11-beded neurosurgical high dependency unit and four operating theatres equipped with Neuro-navigational, image guidance and stereotactic equipments necessary for optimal neuro-oncological surgery. Extensive neuroradiology services and expertise are available on site including two 1.5 Tesla MRI scanners and dedicated CT scanner for neurosurgery. The oncology services are located at the closely linked Guys and St. Thomas’s and Maidstone Hospitals. The Trust’s commitment to the ongoing growth and development of Neuro-oncology services has been demonstrated by the employment of further neurosurgeons with subspecialty interest in Neuro-oncology; set up of the teleconferencing facilities allowing four way live discussion of the MDT’s patients between Kings, St. Thomas’, Maidstone and Kent and Canterbury Hospitals and investment in stereotactic and surgical equipments.

Our vision is to work with local clinical teams to support local diagnosis and care, through providing ready access to the very highest level of clinical expertise and quality. We believe that patient care should be delivered locally wherever possible and we are working with our partners in South East London Cancer Network, Kent and Medway Cancer Network to further establish the communication, technology and outreach services that will enable us to minimise journeys to the centre and maximise use of local resources.

King’s is committed to improving patients’ experiences of care and providing the highest quality, personalised support to patients and their families (3.9 million catchment area). Experienced Clinical Nurse Specialists are central to the MDT and the holistic care of our patients. There is a separate MDT for Paediatric and Teenage and young adults, supported by Oncologists from the Royal Marsden Hospital with dedicated sessions. Kings maintains close links with the Royal Marsden Hospital. We have an ongoing service development strategy that includes gathering feedback from patients on all aspects of their journeys through our care. For outpatient attendances and inpatient admission, King’s is compliant with all cancer waiting time targets.

Children and Young Persons will be managed according to the South London and Kent and Medway Children and Young Persons pathway.

The Children and Young Persons neurosurgery and in-patient care is compliant with the South London and Kent and Medway age appropriate pathway. There is a
dedicated teenage and young adult clinic run on a monthly basis. Our principal treatment centre for children, teenagers and young adults is the Royal Marsden Hospital.
### 2.0 Neuro-oncology Catchments Population and Activity

King’s College Hospital serves a large geographical area for its Neuro-oncology services, including the natural catchment area of south London and Kent. A significant volume of work is also received from the rest of London and across the country.

For Neuro-oncology in particular, the service currently receives referrals from:

**South East London Cancer Network:**
- Guy’s and St Thomas’ NHS Foundation Trust – local MDM
- South London Health Care trust.
- University Hospital Lewisham
- Royal Marsden Hospital (paediatric and young adults)

**Kent and Medway Cancer Network:**
- Medway Foundation NHS Trust, Medway Maritime Hospital
- Dartford and Gravesham NHS Trust, Darenth Valley Hospital
  - East Kent University Hospitals NHS Trust:
  - Queen Elizabeth the Queen Mother Hospital
  - William Harvey Hospital
- Kent and Canterbury Hospital – local MDT to be established
- Maidstone & Tunbridge Wells NHS Trust
- Kent and Sussex Hospital
- Pembury Hospital
- Maidstone Hospital – local MDT to be established

Surgery rates for Neuro-oncology vary, although the national figure is suggested as being in the region of 10-15%. The King’s Neuro-oncology team expects to carry out over 500 surgical procedures this year and these numbers are growing. The number of patients that are not operated on has increased year on year as has the outpatient activity figures explaining the plateau in operations between 2005 and 2008. However the growth in surgical procedures in 2011 can be attributed to the employment of an additional Neuro surgeon, with a specialist interest in skull based surgery and the expansion of the skull based service.

*Fig 1: Neuro-oncology surgical procedures undertaken by the King’s team in the last 9 years.*

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<th>Year</th>
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<td>2009/10</td>
<td>493</td>
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<tr>
<td>2010/11</td>
<td>571</td>
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The amount of discussion that is carried out in the Neuro-oncology MDT is also continuing to grow, as a result of this the MDT is now 1.5 hours in duration to facilitate
appropriate discussion for the increased numbers referred to the service.

Fig. 2 numbers of MDT discussion per month.

<table>
<thead>
<tr>
<th>Month</th>
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<td>Apr-10</td>
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<tr>
<td>May-10</td>
<td>103</td>
<td>4 Weeks</td>
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<tr>
<td>Jun-10</td>
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<td>4 weeks</td>
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<tr>
<td>Jul-10</td>
<td>136</td>
<td>5 Weeks</td>
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<tr>
<td>Aug-10</td>
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<td>25.5</td>
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<tr>
<td>Sep-10</td>
<td>92</td>
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<td>Oct-10</td>
<td>127</td>
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<tr>
<td>Nov-10</td>
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<tr>
<td>Dec-10</td>
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<tr>
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</tr>
<tr>
<td>Mar-11</td>
<td>128</td>
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**Catchments Population** King’s is the referral centre for Neuro-oncology for the South East London Cancer Network (SELCN) (population of 1.6 million 2010) and the Kent and Medway Cancer Network (KMCN: population 1.8 million 2010). We also take a proportion of patients from South West London as well as other parts of London and Surrey.
### 3.0 MDT Structure

Core team members or their cover attend the meeting on a weekly basis. Weekly MDT attendance is recorded. The MDM has identified representation at the Tumour Working Group (TWG). In addition, the specialist MDT welcomes attendance from the unit hospitals although it is recognized that it is not possible for them to attend every week. However, video-conferencing is available to enable this to happen.

### 3.1 Core Team Members

<table>
<thead>
<tr>
<th>Surgical Team Lead and Cover arrangements</th>
</tr>
</thead>
<tbody>
<tr>
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</tr>
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**NOTE: Neuro-surgical SpR on Call contact number 0203 2994207**

<table>
<thead>
<tr>
<th>Radiologists – Lead and Cover arrangements</th>
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<tbody>
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<td>COVER – Dr N Sibtain (Consultant Neuro-radiologist)</td>
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<tr>
<th>Oncologist Lead and Cover arrangements</th>
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<tbody>
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<td>COVER – Dr Hall</td>
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<td>Dr L Brazil</td>
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<td>0207 1881456</td>
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<tr>
<td>Responsibility for recruitment into clinic trials.</td>
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<tr>
<td>COVER – Dr Ron Beaney</td>
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<tr>
<td>----------------------</td>
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<tr>
<td>Dr Julia Hall</td>
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**Cover: Dr Sadler**

**Neuro-pathologists Lead and Cover arrangements**

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**Cover: Dr Al-Sarraj, Dr Bodi or Dr Tibor**

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<th>Dr H. Tibor</th>
<th>Consultant Neuro-Pathologist</th>
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**Cover: Dr Al-Sarraj, Dr Bodi or Dr King**

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<th>Mrs. V Hurwitz</th>
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**Cover: Jamie Logan**

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</table>

**Cover: Vicky Hurwitz**

<table>
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<tr>
<th>Additional CNS Post</th>
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**Palliative Care**

<table>
<thead>
<tr>
<th>Dr R Burman</th>
<th>Consultant, Palliative Care, KCH</th>
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</tr>
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</table>

**COVER – SPR Palliative care**

<table>
<thead>
<tr>
<th>Therapies</th>
<th>Rotational to MDT attendance</th>
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<tbody>
<tr>
<td>Occupational Therapy – Lesley Hughes Lead</td>
<td>020 3299 2338</td>
</tr>
<tr>
<td>Physiotherapy</td>
<td>020 3299 2724</td>
</tr>
</tbody>
</table>
### Speech and Language Therapy - Sue Toller lead

<table>
<thead>
<tr>
<th>Therapy Radiographer</th>
<th>020 3299 4665/1809</th>
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</thead>
</table>

<table>
<thead>
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<th>Clinical Neuro-psychologist</th>
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</thead>
<tbody>
<tr>
<td>Neurologist</td>
<td>0203 299 5408</td>
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</table>

### MDT Coordinator

<table>
<thead>
<tr>
<th>Ms Donna Moore</th>
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<th><a href="mailto:kch-tr.neuro-oncology@nhs.net">kch-tr.neuro-oncology@nhs.net</a></th>
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</thead>
<tbody>
<tr>
<td>Neuro-Oncology Co-ordinator – Kings College Hospital</td>
<td></td>
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</table>

### Cover: Neuro oncology CNS

#### 3.2 Extended Team Members

<table>
<thead>
<tr>
<th>Surgical Team</th>
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</thead>
<tbody>
<tr>
<td>Mr. N Thomas <a href="mailto:Nick.thomas1@nhs.net">Nick.thomas1@nhs.net</a></td>
<td>Lead Consultant neurosurgeon for base of skull tumours also subspecialty interest in pituitary tumours</td>
</tr>
<tr>
<td>Mr. Sinan Barazi <a href="mailto:sbarazi@nhs.net">sbarazi@nhs.net</a></td>
<td>Consultant Neurosurgeon with subspecialty base of skull and pituitary tumours</td>
</tr>
<tr>
<td>Mr. R Selway <a href="mailto:Richard.selway@nhs.net">Richard.selway@nhs.net</a></td>
<td>Consultant neurosurgeon with subspecialty epilepsy surgery</td>
</tr>
<tr>
<td>Mr. D Walsh <a href="mailto:danielwalsh@nhs.net">danielwalsh@nhs.net</a></td>
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</tr>
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<td>Consultant neurosurgeon with subspecialty in Paediatric neurosurgery</td>
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<tr>
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<td>Consultant neurosurgeon</td>
</tr>
<tr>
<td>Mr. David Bell <a href="mailto:david.bell9@nhs.net">david.bell9@nhs.net</a></td>
<td>Consultant neurosurgeon with subspecialty in spinal surgery and MSCC.</td>
</tr>
<tr>
<td>Clinical Psychiatrist</td>
<td>Margaret Evison</td>
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<tr>
<td>Dietician</td>
<td>Alan Rio</td>
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<tr>
<td>Epilepsy Nurse Specialist</td>
<td>Sara Lailey <a href="mailto:Sara.lailey@nhs.net">Sara.lailey@nhs.net</a></td>
</tr>
</tbody>
</table>
4.0 The MDT Meeting

4.1 Weekly Specialist Neuro-oncology MDT meeting
The Neuro-oncology MDT meets weekly to ensure all patients are discussed contemporaneously and is held on Friday afternoons at 1 pm in Belgrave MDM Room, Ground Floor, Hambledon Wing at King’s College Hospital. The room is equipped with teleconferencing facilities to allow live discussion of patients between Kings, Guys and St Thomas’s, Maidstone and Kent and Canterbury Hospitals. All core members or their cover, attend each meeting and their attendance is recorded.

4.2 Role of the MDT meeting
- To identify and review all patients with neurological tumours within the supra-regional network, ensuring rapid and equal access
- To confirm diagnosis and stage of the disease
- To decide on the appropriateness of further investigations and staging
- Assess suitability and surgical approach to the tumours
- Plan treatment
- Referral for palliative care in advanced disease
- To ensure proper documentation of all patients in notes and database
- To ensure that all of the decisions made are communicated to General Practitioners and referring consultants
- Discuss post operative patients to correlate radiology and histology and to decide on further management including radiotherapy, chemotherapy or further surgery
- To discuss management of patients with recurrent disease
- To ensure feedback to referrers regarding the appropriateness of referral in line with agreed guidelines
- To assess therapy needs of patients

4.3 Access to the MDT meeting
All patients with suspected neurological tumours should be referred to and discussed at the specialist Neuro-oncology MDT meeting. The referral proforma can be accessed via the website www.kch.nhs.uk (Appendix 1) and returned via email from an NHS.net email account or faxed to the MDT co-ordinator. Emails and contact details of the Clinical Nurse Specialist/MDT co-ordinator are made available to the all referring teams (SE London and Kent and Medway Cancer Network). All referral details are documented and later filed in the case notes. They are up-loaded on to the electronic patient record within three hours of the meeting. It is acknowledged that there may not be King's case notes at this stage of referral however they will have an electronic patient record. These patients are discussed in the next MDT meeting to formulate a management plan.

For some patients it may not be appropriate to travel to the specialist centre as there may be clear contraindications to surgery due to co-morbidity or widespread metastatic disease (See to referral guidelines). The details of such patients and the proposed MDT treatment plan (palliative care, chemotherapy) will still be collected and entered in the data base for audit purposes. The referrers are welcome to attend meetings. Video-conferencing is used.

All patients to be discussed must be referred to the MDT co-ordinator by 1pm on Thursday for the complete list to be circulated to the Core MDT on Thursday afternoon for the Friday meeting. Scans must be sent via image link to Kings college hospital. It is the responsibility of the referring consultant to ensure that the relevant
radiology is available. The patient’s imaging must have reached the MDT co-coordinator in accordance with the 1pm Thursday deadline. Imaging and referrals received after this time will be discussed the following week; however in the instance where action is required prior to the next scheduled meeting this will be recorded and discussed retrospectively.

The agreed management plan for each patient is documented using the standard proforma (Appendix 1) during the meeting, on the Neuro-oncology database and minuted by the MDT co-ordinator.

Recorded outcomes are circulated to each member of the team, with a copy of each individual patient’s outcome placed in their notes and on the electronic patient record. The referring consultant and GP will be notified within one working day of the MDT discussion.

4.3.1 Intra-hospital Referrals:
All patients admitted to King’s College Hospital with a suspected or confirmed diagnosis of neurological tumours should have already been discussed in the previous MDT meeting. It is recognised that there will be times when a patient may be admitted and/or operated without previous discussion in the MDT meeting, primarily because of the clinical urgency of the case. In all such situations, the patients should still be discussed in the following MDT meeting in order to formulate further management plan. A member of the admitting neurosurgical team should be present at the MDT meeting to present the clinical details and feed back the recommendations.

4.3.2 Patient Booking
Once the Neuro-oncology MDT has decided that neurosurgical input is required for management of a patient, depending on urgency of the case, patient may either require admission/ transfer to the Kings College Hospital site or may be booked into the Neuro-oncology clinic held bi-monthly which includes the following core members

- Neuro-surgeon
- Oncologist responsible for radiotherapy
- Oncologist responsible for chemotherapy
- Specialist nurse

For those patients requiring admission, the Neuro-oncology CNS will liaise with the surgical team regarding a suitable date. Patients with less acute needs are seen in the next Neuro-oncology clinic which is held on the Kings College Hospital site and runs on the 2nd and 4th Monday afternoon of each month. All information/ arrangements are fed back to the referring team by the Neuro-oncology CNS and Neuro-oncology co-coordinator. All patients for admission must have MRSA screen results for nose, throat and groin/perineum faxed to the Neuro-oncology co-coordinator following the outcome.

It is the responsibility of the referrer to feedback the MDT outcome to the patient—unless the patient is due to be admitted for surgery within a week, the Neuro oncology CNS will then call the patient following the MDT meeting and talk through any clinical questions with them. The patient may be offered an appointment in the Neuro-oncology pre-assessment clinic where the role of surgery will be discussed and an admission date confirmed. The pre-assessment clinic is held on a weekly basis and is attended by Consultant Neurosurgeon and a Neuro-oncology CNS.

Where a patient is reviewed a second or subsequent time by the MDT a new form will be generated and treated as above.
See Appendix for contact details
Radiology must be electronically transferred. These can then be viewed and discussed at the MDT meeting for specialist opinion. Local hospital PACS systems cannot be shown in the MDT meeting room.

For urgent transfer/admission requests:

Complete Neuro-Oncology Referral Proforma online and contact Neurosurgical Registrar at Kings College hospital on 0207 2994207 to arrange physical transfer/admission.

As part of the Neuro-oncology Cancer Centre developments we have an established referral proforma and guidelines which sets out required referral information. We ask always to be advised of existing diagnostic tests and staging so patients are not subject to repeat tests unless clinically indicated.

All patients with a suspected or confirmed neurological malignancy (Brain or CNS tumours) should be notified to the specialist team. The team will agree the treatment options for each patient. The team may also discuss patients diagnosed outside of the Cancer Centre where the agreed management plan may be for the unit to continue the care. All patients will have a referral form filled in by the referring local team and a record of the MDT discussion will be kept. These forms will be subject to audit on an annual basis.

*In urgent circumstances, clinical decisions may need to be made outside of the MDT meetings. In such cases, the consultant in charge of the patient will initiate or refer for treatment without delay and the management plan will be presented at the next MDT.*

4.4 Structure of the MDT Meeting
The Lead Clinician is the chairperson of the MDT meeting who has responsibility for making sure that the meeting runs efficiently and that the appropriate conclusions of each case are summarised so that they can be recorded by the MDT co-coordinator.

All cases are presented and must include name, age, presenting symptoms, co morbidities, base line level of daily activities and quality of life, current medications, findings on examination (general and neurological) and all pre-operative/ staging investigations. Radiology and pathology is presented by appropriate members of the team

4.5 Responsibilities of Neuro-oncology Lead Clinician
The principal responsibility of this role is to ensure high quality services and clinical management for all patients suspected of having a neurological malignancy, in line with the objectives as laid out in the Manual of Cancer Service Standards and as documented in the Trust MDT role description and confirmed in the letter from the Trust Lead Cancer Clinician to the Neuro-oncology MDT lead

That is:
- To ensure that designated specialists work effectively together in teams such that decisions regarding all aspects of diagnosis, treatment and care of individual patients and decisions regarding the team’s operational policies are multidisciplinary decisions.
- To ensure that care is given according to recognised guidelines (including
guidelines for onward referrals) with appropriate information being collected to inform clinical decision-making and to support clinical governance/audit.

- To ensure that mechanisms are in place to support entry of eligible patients into clinical trials, subject to patients giving fully informed consent.
- To ensure that the MDT coordinator will ensure that minimum data is collected as per the national cancer dataset.
- Chairs quarterly tumour working group which annually reviews and updates operational policies.

4.6 Attendance at MDT meetings:
Core members must attend 66% of all MDT meetings each year. Attendance at the meetings is recorded electronically by the MDT coordinator and is reviewed by the lead clinician on an annual basis.

4.7 Relationship of the Specialist MDT to the Diagnostic MDTs

4.7.1 Kings College Hospital
Neurosurgery for patients with neurological tumours and the immediate post-operative care is performed at King’s College Hospital site. These patients are all discussed at the specialist KCH MDT meeting. However, the MDT also performs the important function of dealing with Neuro-oncology cases that are inoperable for reasons such as multiple metastases, severe co morbidity, and those referred for palliation.

Local Network MDT meetings are being developed.

4.7.2 Other Network Relationships
The MDT will work with its partners (Guys and St Thomas’, Maidstone and Kent and Canterbury Hospitals) as well as the local hospitals in the catchment area.

Patients requiring chemotherapy and radiotherapy will be given treatment as close to home as possible at the nearest local unit. The treatment will be given under the guidance of local chemotherapy and radiotherapy protocols.

4.7.3 Annual Review
The Neuro-oncology specialist team will meet at least annually with all referring teams to discuss the operational policy (including referral and treatment guidelines), radiotherapy, chemotherapy and to perform a collaborative audit of all patients referred.

The specialist team is continuously working to improve communication with all referring hospitals.

4.8 Attendance at South East London Cancer Network Meetings
There will be representation from the key stakeholders and the network management teams from the South East London Cancer Network and Kent and Medway Cancer Network.

There is a Senior Lead, Medic and Nurse Manager who attend the Network forum. The Chief Executive attends the Network Board Meetings.

4.9 Operational Policy Annual Review Meeting
The MDT will meet at least once each year with all key stakeholders to review the operational policy. Changes will be disseminated to all key stakeholders by the Neuro-
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4.10 The role and responsibilities of the Clinical Nurse Specialist

The Neuro-oncology Clinical Nurse specialist role includes:

- To be the first point of contact for patients accepted under the care of the MDT.
- Act as key-worker or responsible for nominating the key worker for the patient.
- To educate support and counsel patients providing relevant written information as appropriate.
- To lead on patient and carer’s communication issues for the MDT.
- To co-ordinate the pathway of the patients referred to the Neuro-oncology MDT meeting, ensuring where clinically appropriate that delays are avoided.
- To contribute to the MDT discussion, patient assessment and care planning decisions of the team.
- To ensure the results of patients holistic needs assessments are taken into account in the decision making process.
- To ensure that patients are able to access members of the MDT for support and advice as appropriate.
- Develop the nurse led services as agreed by the MDT.
- Contribute to the Trust wide development of cancer services as requested and work as a member of the Cancer Nurses Forum.
- To provide teaching and educational input to relevant courses and provide expert nursing advice and support to other health professionals in the area of neurological cancer.
- Ensure effective written communication and verbal communication between the MDT, referring Trusts, GPs and specialist centers.
- To work with the Trust Cancer Data Team supporting the collection of Neuro cancer data and involve in clinical audit.
- To be involved in research/clinical audit in the area of neurological cancer.
- Utilising research providing evidenced based care in the specialist area.

Additional responsibilities of Vicky Hurwitz:

- Lead Clinical Nurse Specialist
- Responsible for users and carers issues and information
- Responsibility for recruitment
- Responsible for managing the MDT in conjunction with Mr. Ashkan.

4.11 The Role of the MDT Co-ordinator

The MDT Co-ordinator supports each MDT meeting. This co-ordinator ensures that all patients requiring discussion are added to the meeting agenda, that all necessary diagnostic information (scans, reports etc) is available, that the management plan agreed at the meeting is recorded and that cancer waiting time data is collected. The MDT co-ordinator works closely with the CNS, supporting the exchange of information between the specialist team and referring units. Referring units are able to access the MDT co-ordinator directly via email/fax/phone to ensure that patients are discussed at the specialist MDT without delay. Requests and organisation of diagnostic information are co-coordinated through this role.

4.12 Service Improvement
The Lead Clinician for service improvement is Mr K Ashkan who is the person responsible for ensuring that service improvement is integrated into the functioning of the MDT.

4.12.1 Key worker
All patients accepted to the MDT will be allocated a Key Worker who co-ordinate’s the care through the pathway. This will be the most appropriate person at each stage of their treatment journey. The named key worker will be recorded on the MDT Proforma at the time of their discussion. All patients being given histopathology results will have their key worker or nominated cover present at this meeting; they will also be informed of their key workers name and given a flyer with their contact details on. This is documented in the patient’s electronic patient notes.

4.12.2 Key worker clinic
Patients will be offered a clinic appointment with the clinician in charge of their care and/or designated key worker to receive the results of their histology and to formulate a management plan for further treatment if required. This is facilitated in the Cicely Saunders information centre away from the main hospital building. Clinic slots are 30 minutes in duration.
5.0 Organisation of Care

5.1 Surgical Services
All surgery for neurological tumours within the catchment networks is carried out on the Kings College Hospital site by members of the core team.

Following discussion at the MDT meeting and completion of recommended investigations at the local hospital, patients accepted for surgical intervention are admitted to the KCH site, usually a day before the planned surgery. Depending on clinical and technical issues, patients may undergo biopsy, debulking or complete resection of tumours. The theatres at KCH are equipped with state of the art stereotactic and image guidance systems to allow localisation and accurate approach to the tumours. Expertise is available for functional mapping and awake surgery if needed. Following surgery, patients are cared for on the neurosurgical high dependency and then ward beds. The patients are then discussed in the subsequent MDT meeting to correlate the histology, radiology and clinical findings and formulate further management and referral-on aspects.

There are also regular clinics preceded by an MDT meeting for discussion of all patients to be seen in the clinic.

It should be noted that all consultant neurosurgeons at KCH, along with their team, take part in the emergency on call rota. Advice and expertise are therefore always available should a patient require urgent transfer/intervention.

See Appendix for contact details

5.2 Radiological Services
Cross-sectional diagnostic imaging (Computerised Tomography and Magnetic Resonance Imaging) from both King’s College Hospital and the regional district general hospitals is reviewed at the Neuro-oncology MDT by a consultant Neuro-radiologist both pre-operatively and post-operatively. With some difficult cases we have the option of using Magnetic Resonance spectroscopy or functional MRI.

Expertise for CT guided biopsy of spinal and Para-spinal tumours is available. When a conclusive MDT decision is not possible we have the option of following-up patients in the dedicated Neuro-oncology clinic with further interval cross-sectional imaging reported by the Neuro-radiologist.

See Appendix for attached Neuro-Radiology Guidelines

5.3 Pathology services
The biopsies are reported in the Department of Clinical Neuropathology within 24-48 hours depending on need for immunohistochemistry. Intra-operative (frozen and smear) diagnoses are available on a 24-hour basis. The reports can be reviewed on the EPR system immediately after authorisation of the report. The Neuropathologists undertake a rigorous audit system to review all cases. Neuro-pathology participates in the national and European QAs for both the neuropathologists and laboratory techniques. Molecular techniques are available. FISH analysis of 1p19q status which is an indicator or prognosis has been carried out on all relevant samples back to 2007.

Neuro-Pathology will be reported in line with the Royal college of Physicians guidelines and protocols.
5.4 In-Patient ward facilities
The unit accepts both emergency and elective admissions from this area. Neurosciences provides a challenging but exciting working environment and the unit is committed to providing high quality nursing care, using Essence of Care as a benchmark for best practice. Two Modern Matrons, Two Practice Development Nurse and a team of clinical nurse specialists support the unit, providing day-to-day support for the ward staff and patients and acting as clinical resources.

The unit comprises:

Murray Falconer ward – a thirty one bedded neurosurgical ward, caring for the complete spectrum of elective neurosurgical conditions. This is a ‘clean’ ward which accepts patients who have been pre-screened for MRSA.

Kinnier Wilson ward – a twenty bedded acute neurosurgical ward, which cares for the complete spectrum of emergency neurosurgical admissions.

David Marsden ward – a twenty three bedded neuromedical ward, which, in addition to caring for elective and emergency neuromedical patients, has a five bedded telemetry unit.

Kinnier Wilson High Dependency Unit – an eleven bedded neurosurgical and neuromedical unit, that provides care for acutely unwell patients that require a higher level of nursing care and medical intervention than that which can be provided in the ward environment. Six level three beds are available on the Surgical Critical Care Unit.

In-patient areas for Young Persons are based on Kinnier Wilson Ward. Children and Young Persons are managed according to the South London and Kent and Medway Children and Young Persons pathway.

The Children neurosurgery and in-patient care is based on Lion Ward. The service is compliant with the South London and Kent and Medway age appropriate pathway.

Staff development is actively encouraged within the unit, with Band Five and Band Six staff rotating between the wards, in order to develop clinical skills in the varied environment of neurosciences nursing. All new staffs have a five day organisational induction and are also offered a five day local induction. Education is provided either in-house by the Practice Development team or courses run by the Education Department. Staffs are encouraged to actively explore opportunities to undertake relevant postgraduate studies. Staffs are also able to gain valuable mentoring experience as pre-registration students undertake placements on the unit throughout their training.

5.5 Oncology Services

Patients requiring adjuvant therapy are treated under the oncology guidelines. See Appendix 4.

If a patient is not well enough to withstand a full course of treatment, palliative radiotherapy may be discussed with them. We offer a varied range of palliative regimes. The aim is to control symptoms and enhance the patient’s quality of life. Upon a diagnosis of a high grade brain tumour referral to palliative care is offered and recommended. This is done either through the multi-disciplinary meeting if the patient
is an inpatient, or it can be done by the clinical nurse specialist at any time during the patients care. As patients conditions progress the clinical nurse specialist can then make referrals to community palliative care as agreed by them and the patient/carer. Palliative care referrals can also be made by the GP.

5.5.1 Post radiotherapy telephone clinic
Following on from radiotherapy, patients who have been treated at GSTFT will be booked an appointment with their key worker for a telephone consultation two weeks post treatment. During this consultation the key worker aims to bridge the gap between concomitant and adjuvant treatment as we realize that this is an emotional time for patients and their carer’s, as well as review steroid doses and begin addressing survivorship issues.

5.6 Palliative and Supportive Care
There is a well established Palliative Care Service at King's. Out of hours nursing care is provided by a number of local providers throughout the networks including

- St Christopher’s hospice
- Trinity Hospice
- Greenwich and Bexley community hospice
- EllenorLions Hospice
- Pilgrims Hospice
- Heart of Kent hospice
- Hospice in the weald
- Demeza Hospice for children and young adults

Early referrals for patients on active treatment, given with palliative intent, are encouraged in the local area. In such patients, the prognosis will usually be limited and focus of treatment will have changed from curative to palliative. A demonstrable need for specialist palliative care services must be established. Appropriate reasons for referral include: pain control, control of other symptoms, e.g. vomiting. Psychological distress of patient/family or carer, terminal care/dying (prognosis usually less than two weeks) and complex social needs. The patient and/or their family/carer must be informed and agree to the referral.

All senior staff delivering significant news will be or have undertaken the Advanced Communication Course.

5.7 Other Clinical Support Services

5.7.1 Neuropsychology
The neuropsychology service is essentially a diagnostic assessment. A detailed neuropsychological assessment is carried out to determine the nature and extent of intellectual and cognitive impairments in these patients. The assessment covers a range of functions including intellectual functions, memory, language, perception and executive functioning.

Referrals come via the neurosurgeons and the Neuro-oncology clinical nurse specialists. Referrals are also received from the oncologists at St Thomas’ Hospital and Maidstone Hospital who are part of the Joint Neuro-Oncology Clinic at Kings College Hospital. Referrals also come from neurologists.

Patients may be referred for a number of reasons including:
- patient or relative or one of the MDT members is concerned about changes in
the patients intellectual or cognitive functioning
  ▪ provide a baseline before surgery
  ▪ provide baseline prior to radiotherapy treatment
  ▪ work related issues
  ▪ Post radiotherapy and long term follow-up as appropriate

### 5.7.2 Neuro-rehabilitation

The Neuro-rehabilitation policy has been produced by the Neuro specialist therapy leads. It details the service provision at Kings College Hospital and the referral processes. Please see attached document in Appendices 9.

<table>
<thead>
<tr>
<th>Service</th>
<th>Phone Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Occupational Therapy</td>
<td>020 3299 2338</td>
</tr>
<tr>
<td>Physiotherapy</td>
<td>020 3299 2724</td>
</tr>
<tr>
<td>Speech and Language Therapy</td>
<td>020 3299 4665</td>
</tr>
</tbody>
</table>

### 5.7.3 Counselling

Counseling is offered as required to relatives, and patients at Guys and St Thomas’ hospital.

### 5.7.6 Interpretation Service

King’s College Hospital provides an interpretation service as listed below
  ▪ Onsite Spanish and Italian Interpreting and Translation
  ▪ Interpreters for pre-booked face to face consultations
  ▪ Telephone interpreting for urgent situations when it isn't possible to pre-book an interpreter to come on site (24 hours a day)
  ▪ Translators for the deaf and hard of hearing RNID/RAD interpreters
  ▪ Pre-booking is required

### 5.8 Macmillan Southwark Citizen Advice Bureau (CABx)

Kings College Hospital has recently established a cancer information service based at the Cicely Saunders institute which provides information, benefits advice and a CAB trained volunteer. Neuro-oncology patients at St Thomas’ Hospital have access to on site Citizen Advice Bureau clinics provided fortnightly. Many of the local cab offices now contain Macmillan attachments allowing for patients to gain specialist advice locally.

#### 5.8.1 Macmillan information centre at Cicely Saunders institute

On the Kings college hospital site there is the Macmillan information and support centre, which is open Mon-Friday 10-4pm, to support patients and their carers in a relaxed environment, away from the main hospital building, where there is a range of information available for cancer and long term illness, staffed by a manager a trained volunteers.

#### 5.8.2. Dimbleby cancer care centre

Patients who go on to have adjuvant treatment at GSTFT have the opportunity to access many services at the Dimbleby cancer centre. A range of holistic treatments, including, massage, aromatherapy, reflexology, counselling and bereavement support are available free to any patient with a diagnosis of cancer.

#### 5.8.3. Macmillan information centre

Patients and their carers who attend Maidstone hospital for follow up treatment have access to a Macmillan information centre on the Maidstone site that is staffed by Macmillan volunteers who are available to offer support and access to range of
5.8.4 Site specific support group
A site specific support group is available to all patients and their carers, facilitated by a clinical nurse specialist and a counsellor from the Dimbleby cancer centre, both of whom are trained in facilitating support groups. The support group runs monthly (1st Monday of the month 1.30-3pm) and offers psychological support to patients in a relaxed informal setting.

5.8.5 New diagnosis group
Kings are currently offering patients the opportunity to attend a new diagnosis group, facilitated by a team of therapists. The group has been funding by a Macmillan development grant and currently has funding for 4 intakes (currently on intake 2). The intervention aims to offer psychological and emotional support to patients with a newly diagnosed brain tumour.

5.8.6 Long term follow up / survivorship
The lead clinician for survivorship issues attends the SELCN survivorship meeting and is currently looking at how to address survivorship issues for patients with a confirmed brain and CNS tumour.
6.0 Clinical Guidelines:

Increased awareness and a low threshold of suspicion are probably the most important means of decreasing the delay in diagnosis of brain tumours. Patients with brain tumours usually present with symptoms of raised intracranial pressure such as headaches, nausea and vomiting; focal neurological deficits such as hemiparesis and cranial nerve palsy or epilepsy.

Agreed referral criteria and treatment protocols will determine which patients the specialist team will treat, or refer back to the local unit. The patient pathway for access to the specialist MDT is attached (Appendix). The pathway will be subject to network ratification and annual review. This ensures that all patients are discussed by a member of the relevant specialist team prior to commencement of treatment.

6.1.1 GP consultation

Once a brain tumour is suspected, GP’s can refer patients via the two-week wait office to the local hospital for review and investigations by the specialist, which will predominantly be the local neurologists. These require the two week wait referral forms to be completed.

The following should sound alarm bells with General Practitioners:

SELCN GUIDELINES FOR REFERRAL TO CNS CLINICS

- Sub acute progressive neurological deficit developing over days to weeks (e.g. weakness, sensory loss, dysphasia, ataxia)
- New onset seizures characterised by one or more of the following:
  - Focal seizures
  - Prolonged post-ictal focal deficit (longer than one hour)
  - Status epilepticus
  - Associated inter-ictal focal deficit
- Patients with headache, vomiting and papilloedema
- Cranial nerve palsy (e.g. diplopia, visual failure including optician defined visual field loss, unilateral sensorineural deafness).

Consider urgent referral for:

- Patients with non-migrainous headaches of recent onset, present for at least one month, when accompanied by features suggestive of raised intracranial pressure (e.g. woken by headache, vomiting, and drowsiness).

NB: This last guideline is intended to provide the primary care physician with the discretion to decline urgent referral if there are other known features (e.g. depression, somatisation disorder) making a diagnosis of brain tumour very unlikely.

Patients should be aware of and understand the reason for referral to the Neuro-Oncology service.

Initial investigations such as CT scan of the brain may be organised by the general
practitioners while waiting for the clinic appointment in the local hospital. However, the above investigations should not delay referral. If the radiological investigations suggest or confirm a neurological malignancy, the patient should then be referred to the Neuro-oncology centre for discussion in the MDT meeting. It is expected that these patients will be discussed in the Unit MDT meeting prior to referral. The unit may be requested to further investigate and stage the tumour by the Neuro-oncology MDT.

6.1.2 Appropriateness and timeliness of urgent and suspected neurological tumours GP referrals

**Appropriateness** - All the urgent GP referral under the two week wait rule are audited. Those referrals that do not meet the Two Week Wait guidelines in terms of appropriateness are fed back. The data is then forwarded to the PCTs and SELCN Primary Care Service Improvement Lead on a monthly basis.

**Timeliness** – the two week wait database produces reports on this which, as above, are sent to PCTs and SELCN Primary Care Service Improvement Lead on a monthly basis.

6.2 Referral Guidelines – South East London Cancer Network and Kent and Medway Cancer Network referring diagnostic teams

All patients with radiological suspicion of a neurological malignancy should be referred to the Neuro-oncology MDM for discussion on further management within two working days of the date of imaging report.

Neurosurgical Registrar at Kings College hospital on 0203 2994207 (diverted to a mobile if required) acts as a contact for Neurosurgical emergency advice.

6.2 Investigations prior to referral

Patients with a scan showing a possible abscess, tumour with associated hydrocephalus, spinal cord compression, posterior fossa or midline or 3rd ventricular tumour, or GCS 13/15 or less warrant emergency referral and must have the following investigations undertaken:

- Brain contrast CT scan or preferably a contrast MRI scan.
- Chest x-ray
- Full blood count/U+E/Clotting screen
- If patient is on Aspirin, Warfarin, Clopidogrel or Dipyridamole, they must be stopped until discussed with neurosurgeons
- Commence patient on Dexamethasone 8mgs bd at 08.00am and 14.00 pm (unless abscess suspected)

All other patients must have the following investigations done prior to referral
• Brain MRI with Gadolinium scan (contrast CT if patient cannot tolerate MRI)
• Chest x-ray
• If metastatic disease suspected: Chest/Abdomen/Pelvis CT scan and tumour markers (directed by results of CT Chest/abdo/pelvis)
• If spinal tumour suspected: whole neural-axis MRI scan
• Full neurological examination
• Full blood count/electrolytes/Clotting screen
• If patient is on Aspirin, Clopidogrel or Dypiridamole they must be stopped
• Stop anticoagulants e.g. warfarin unless high risk such as metallic heart valve, intra-cardiac thrombus or pulmonary embolus in the previous 6 months. In these cases may switch over warfarin to intravenous heparin infusion.
• Commence patient on Dexamethasone 8mgs bd (unless abscess suspected)

The Neuro-oncology MDT may require the local hospital/ referring team to perform further investigations before a definitive management plan can be formulated or patient transferred to the neurosciences centre. Specialist imaging maybe organized after MDT discussion

Please refer to the Network Imaging Guidelines for further detailed information

6.3 Surgical Guidelines
Preoperative Investigations:
• Patients undergoing neurosurgery need to fulfill general fitness and anaesthetic criteria.
• Any metabolic, hematological (particularly platelet) and clotting abnormalities should be corrected.
• Non steroidal anti inflammatory drugs e.g. Aspirin, Clopidogrel and Dypiridamole should be stopped at time of referral and at least 10 days before surgery.
• Anticoagulants such as warfarin should be stopped except in high risk patients such as those with intra-cardiac thrombus, metallic heart valve or a pulmonary thrombus in the previous six months.
• In such high risk patients warfarin should be switched over to intravenous heparin (if in doubt discuss with the local Haematologist).
• In all patients being transferred under the emergency protocol, anticoagulants should be stopped in preparation for imminent surgery upon admission to KCH.
• Almost all patients with brain tumours undergoing surgery will need to be on Dexamethasone to cover the peri-operative period. The neurosurgical team can be contacted for advice with regard to this.
• Patients with epilepsy will need to be on anti-epileptic medications.

It is essential that patients are spoken to by the local team responsible for their care regarding the reason for referral to Kings College Hospital and documentation of the discussion must be done in the patients local notes. An open and honest discussion will be must be undertaken by a person trained in the connected advanced communication skills course.

6.3.1 Surgical Procedures:
Following on from a first consultation with a MDT member, a pathway will be decided upon depending on the clinical condition of the patient, the location and size of the lesion, and the nature of the tumour (based on the macroscopic appearance of the lesion at operation as well as the intra-operative histology assessed by frozen section and smear), one of the following pathways may be selected:
1. Biopsy: Usually for deep seated lesions or for tumours located in the critical areas of the brain. Stereotactic techniques allow accurate localisation of the target, reducing the risk of surgery whilst increasing the diagnostic yield.

2. Partial excision/ debulking: usually for larger more superficially located intrinsic brain tumours. Modern neuronavigational systems combined with techniques such as awake surgery allow more extensive resection whilst reducing the risks.

3. Complete resection: usually for “benign” tumours such as Meningioma’s or some low grade gliomas

6.4 Pathology guidelines
The biopsies will be reported by a qualified Consultant Neuropathologist in the Department of Clinical Neuropathology within 5 days. Intra-operative (smear) diagnoses are available on a 24-hour basis. A fully integrated pathology report should be available within 5 days. This includes histology and special techniques.

Molecular analysis, such as FISH technique (fluorescence in situ hybridization) for chromosome 1p and 19q rearrangements in gliomas is now available in house.
### 7.0 Data Collection

#### 7.1 Neuro-oncology Database and Minimum dataset

**Neuro-oncology Database and Minimum dataset**

The Brain/CNS MDT has agreed to collect and maintain Cancer waiting Times (including Going Further on Cancer Waits) and Cancer Registration Dataset. The Cancer waiting Times data is collected and uploaded by the MDT co-ordinator for Brain/CNS to the local database used by Kings College Hospital within one week of NSMDT image report. This information is then uploaded on to the national database Open Exeter on a monthly basis. The same data is then sent to Thames Cancer Registry, along with Neuro pathology data.

Kings College Hospital is amongst the first centres to provide data centrally for a national database.
8.0 COMMUNICATION AND PATIENT SUPPORT FRAMEWORK

8.1 Communication with Patients and Families

• Patient/carer informed of NSMDT outcome within 1 working day for inpatients or 5 working days for outpatients.
• Referrals to palliative care or rehabilitation services will happen within 1 working day of decision of NSMDT
• All patients will be allocated a Key Worker- see appendix for key worker contact details.
• Information Prescriptions will be given at key times
• All patients will be given information by members of staff trained in Advanced Communications
• No information will be given by junior doctors
• All patients will be offered a copy of clinic letters and hand held records

Further information for patients can be gained from
1. SELCN patient information web site at www.patientinfo.selcn.nhs.uk
2. Richard Dimbleby Information at St Thomas’
3. Cicely Saunders Institute at Kings College Hospital
4. Kent Information Centre

Relevant information is available to all patients at each point in their care pathway. Written and verbal information is available from the nurse specialist. The documents available are:

Copying letters to patients
All patients will be asked during their first clinic attendance if they would like to receive copies of their clinic letters and discharge summaries. The decision is recorded in the notes and copies of all communications if requested are sent to patients routinely. Patients are also offered written materials on local provision of services related to brain and CNS malignancies.

8.2 Communication with General Practitioners and referring Consultants

8.2.1 Notification of General Practitioner/referrer:

General Practitioners will be informed at the following points:
• Within 24 hours post discussion of referral
• Within 24 hours of discussion of diagnosis with patient
• On discharge
• MDT update outcomes
• At any other key points in the patient pathway

As standard practice, clinic letters are sent out within 2-3 days of the appointment. All patients who are registered with a GP in Southwark/ Lambeth clinic letters are now emailed immediately after each patient visit.

Discharge Summaries are sent to general practitioners and referring consultants within
one week of discharge.

The Neuro-oncology database is an important tool for communication with general practitioners and referring consultants. The database has easy printable summary sheets for communication between clinicians and to place within patient case notes. The database summary sheet is used as the basis for the fax back information sheet sent to all referring clinicians after discussion of the patient at the MDT meeting. Additional communication to referrers includes outpatient clinic letters and discharge letters.

Information is provided to the PCT’s on a monthly basis from the Two Week Wait office on the appropriateness and timeliness of the urgent suspected cancer referrals.

8.3 Patient Access – Travel and Accommodation

Patients will be given travel and accommodation details on request (see appendix 7) or via http://www.kch.nhs.uk/patientsvisitors/visiting/temporary-accommodation
| 9.0 Audit |  
| --- | --- |
| **9.1 Cancer Waiting Times** |  
In accordance with national requirements, Kings College Hospitals monitors cancer waiting times. This must be done for patients who are referred directly from primary care but also for tertiary patients where Kings must work with referring hospitals to ensure that patients do not breach waiting times.  
An audit programme is an essential component of the cancer centre. |
| **9.2 Patient Satisfaction Survey** |  
The National patient satisfaction survey is to be repeated in August 2011 and will be subjected to peer review. The MDT core group have reviewed the results of the May 2011 survey and peer review actions arising have been identified, agreed and an implementation action plan formulated ensuring changes are made in a timely fashion. Progress on changes will be reported on at the next annual meeting. Monitoring of action points will be the responsibility of the Clinical Nurse Specialist with responsibility for user involvement. |
| **9.3 Clinical Outcomes Audit and Action Planning** |  
These will be undertaken annually and reviewed |
### 10.0 Participation in Approved Trials – September 2011

<table>
<thead>
<tr>
<th>Acronym</th>
<th>10.1.1 Title</th>
<th>PIs</th>
<th>Status</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>NBT and Gliogene Study</strong></td>
<td>National Brain Tumour Study</td>
<td>NCRN Lucy Brazil</td>
<td><strong>Open</strong> GSTT and KCH RECRUITED 52</td>
</tr>
<tr>
<td></td>
<td>Identification of low penetrance alleles for GLIOMAS through genome-wide association analyses using SNPs (Single Nucleotide Polymorphisms) Also meningiomas</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>EORTC 22042-26042</strong></td>
<td>Adjuvant postoperative high-dose radiotherapy for atypical and malignant meningioma: a phase I-11 and observational study</td>
<td>EORTC/NCRN Lucy Brazil</td>
<td><strong>Open</strong> UK Site Open GSTT 1 recruited but withdrawn</td>
</tr>
<tr>
<td><strong>TATA/BR14</strong></td>
<td>A randomised controlled trial of temozolomide as adjuvant and or concurrent treatment in anaplastic (WHO grade III glioma)</td>
<td>NCRN EORTC Lucy Brazil</td>
<td><strong>Open</strong> UK GSTT ready to open waiting for research nurse input</td>
</tr>
<tr>
<td><strong>09/H0808/103</strong></td>
<td>Relatives and patients perspective of social cognition dysfunction following brain tumour</td>
<td>Angela Costello</td>
<td>Closed KCH Recruited 26</td>
</tr>
<tr>
<td><strong>BIBW Phase 1 Trial</strong></td>
<td>Phase 1 Trial • Oral EGFR/HER2 inhibitor in pts with tumours known to over express EGFR/HER-2 and relapsed Glioma or pts with stable secondary brain mets</td>
<td>James Spicer</td>
<td>Closed GSTT Recruited 1</td>
</tr>
<tr>
<td><strong>Micro-nutrient Trial</strong></td>
<td>Observational Trial of micronutrients in GBM</td>
<td>Richard Gullan Bali Ruprai</td>
<td>Closed KCH and GSTT Recruited 26</td>
</tr>
<tr>
<td><strong>RECENTIN</strong></td>
<td>Phase 111, Randomised, Multicentred Study in Recurrent GBM Compare the Efficacy of AZD2171 (RECENTIN) Monotherapy and the Combination of AZD2171 with Lomustine to the Efficacy of Lomustine Alone</td>
<td>Ron Beaney</td>
<td>Closed GSTT Recruited 1</td>
</tr>
</tbody>
</table>

**STUDIES UNDER DEVELOPMENT Sept 2011**

<table>
<thead>
<tr>
<th>Study</th>
<th>PI/CI</th>
<th>Design/status</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>EORTC 26081 CODEL STUDY</strong></td>
<td>EORTC Lucy Brazil</td>
<td>In set-up in UK CTAAC ENDORSED REC APPROVED accepted for GSTT site approval NCRN badged</td>
</tr>
</tbody>
</table>

Phase 3 Intergroup Study of Radiotherapy versus Temozolomide versus Radiotherapy with Concomitant and Adjuvant Temozolomide for patients with Newly Diagnosed Anaplastic Oligodendrogliaoma or
<table>
<thead>
<tr>
<th>Study Description</th>
<th>Principal Investigator</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anaplastic Mixed Glioma with Chromosomal co-deletions of 1p and 19q</td>
<td></td>
<td></td>
</tr>
<tr>
<td>GALA 5 NEUROSURGICAL TRIAL</td>
<td>K.ASH KAN</td>
<td>A multi centre UK trial looking at the safety and efficacy of gliolan and gliadel used in combination in patients with high grade glioma</td>
</tr>
<tr>
<td>EORTC elderly Trial</td>
<td>Ron Beaney</td>
<td>Applying for CTAAC ENDORSEMENT NCRN BADGED Applied GSTT</td>
</tr>
<tr>
<td>DORIC Recentin/Aressa Multi-centre randomised, double-blind phase 2 study comparing cediranib plus gerfitanib with cediranib plus placebo in subjects with recurrent/progressive glioblastoma multiforme</td>
<td>Lucy Brazil</td>
<td>UCL/CRUK sponsored NCRN BADGED undergoing R and D at GSTT</td>
</tr>
</tbody>
</table>

**Recruitment to Brain Studies by Year**

[Bar chart showing recruitment by year with data for 2004 to 2011]
11.0 Appendices

Appendix 1  MDT Proforma 11-2k-227 11-2k-233
Appendix 2  Patient pathway 11-2k-233
Appendix 3  Referral Proforma and guidelines
Appendix 4  Chemotherapy protocols: temozolamide and radiotherapy and PCV.
Appendix 5  Follow-up pathway 11-1c-108K 11-2k-236
Appendix 6  Neuro-rehabilitation Policy
Appendix 7  Patient access
Appendix 8  Key worker contact details flyer- 11-2k-226
Appendix 9  CNS business card- 11-2k-226
Appendix 10  Support group flyer- 11-2k-226
Appendix 11  Cicely Saunders information center flyer- 11-2k-226
# King's College Hospital – Neuro-oncology MDT Proforma

**PLEASE ANSWER ALL QUESTIONS ON BOTH PAGES.**

Please complete electronically and email to kch-tr.neuro-oncology@nhs.net

For further information please call Donna – Neuro-oncology Coordinator on 020 3299 4151

<table>
<thead>
<tr>
<th>Date of Referral:</th>
<th>Hospital and Ward:</th>
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<table>
<thead>
<tr>
<th>Patient's Name</th>
<th>Consultant:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of Birth</td>
<td>Referring Doctor:</td>
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<tr>
<td>NHS Number</td>
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<thead>
<tr>
<th>Patient's telephone no.</th>
<th>Referrer Contacts</th>
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<tr>
<td></td>
<td>E-mail Address:</td>
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<tr>
<td></td>
<td>Fax Number:</td>
</tr>
<tr>
<td></td>
<td>Bleep:</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Patient's Address</th>
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<table>
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<tr>
<th>Next of Kin Name and Tel. Number</th>
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<table>
<thead>
<tr>
<th>GP name and address + Tel Number</th>
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</table>

**HISTORY OF PRESENTING COMPLAINT** *(Date of admission / clinic etc):* 

**SPECIFIC QUESTION FOR MDT:**

**CLINICAL FINDINGS:** *(Please include a brief report below or email reports with proforma)*

<table>
<thead>
<tr>
<th>MRI Head/Spine</th>
<th>Yes ☐ No ☐</th>
<th>Date: Report:</th>
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<tr>
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</table>

<table>
<thead>
<tr>
<th>CT Head/Spine</th>
<th>Yes ☐ No ☐</th>
<th>Date: Report:</th>
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<tbody>
<tr>
<td></td>
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</table>

<table>
<thead>
<tr>
<th>CT CAP</th>
<th>Yes ☐ No ☐</th>
<th>Date: Report:</th>
</tr>
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<tbody>
<tr>
<td></td>
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<td></td>
</tr>
</tbody>
</table>
Other: (Lumbar Puncture, Bloods, Chest x-ray etc)

<table>
<thead>
<tr>
<th>PATIENT WEIGHT:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>SURGICAL PROCEDURE (if any):</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>PAST MEDICAL HISTORY:</th>
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</table>

<table>
<thead>
<tr>
<th>PREVIOUS DIAGNOSIS OF CANCER:</th>
</tr>
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<table>
<thead>
<tr>
<th>TREATMENT GIVEN:</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>CURRENT MEDICATIONS: <em>(Including information on anti-coagulant medication, if stopped when?)</em></th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>CURRENT PERFORMANCE STATUS:</th>
</tr>
</thead>
</table>

Use table below for descriptions:

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Asymptomatic (Fully active, able to carry on all pre-disease activities without restriction)</td>
</tr>
<tr>
<td>1</td>
<td>Symptomatic but completely ambulatory (Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature. For example, light housework, office work)</td>
</tr>
<tr>
<td>2</td>
<td>Symptomatic, &lt;50% in bed during the day (Ambulatory and capable of all self care but unable to carry out any work activities. Up and about more than 50% of waking hours)</td>
</tr>
<tr>
<td>3</td>
<td>Symptomatic, &gt;50% in bed, but not bed bound (Capable of only limited self-care, confined to bed or chair 50% or more of waking hours)</td>
</tr>
<tr>
<td>4</td>
<td>Bed bound (Completely disabled. Cannot carry on any self-care. Totally confined to bed or chair)</td>
</tr>
<tr>
<td>5</td>
<td>Death</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>PATIENT FIT FOR GENERAL ANAESTHETIC?</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>CURRENT NEUROLOGICAL STATUS <em>(GCS/Pupils/Focal Neurology):</em></th>
</tr>
</thead>
</table>
Appendix 2

Kent and Medway and SE London and Kings
PROTOCOL FOR REFERRAL OF NON-EMERGENCY NEUROSURGICAL PATIENTS TO KINGS COLLEGE HOSPITAL

All patients with suspected intracranial space occupying lesion must have:
- Brain MRI with Gadolinium scan (contrast CT if patient cannot tolerate MRI)
- Chest x-ray
- If metastatic disease suspected: Chest/Abdomen/Pelvis CT scan and tumour markers
- If spinal tumour suspected: whole neural-axis MRI scan
- Full neurological examination
- Full blood count/U+E/Clotting screen
- If patient is on Aspirin, Clopidogrel or Dipyridamole they must be stopped
- Stop anticoagulants e.g. warfarin unless high risk such as metallic heart valve, intra-cardiac thrombus or pulmonary embolus in the previous 6 months. In these cases may switch over warfarin to intravenous heparin infusion.
- Commence patient on Dexamethasone 8mgs BD (8am and 2pm) (unless abscess suspected)

Note: If scan shows possible abscess, tumour with associated hydrocephalus, spinal cord compression, posterior fossa or midline or 3rd ventricular tumour, or GCS 13/15 or less: Follow the Emergency referral protocol.

Complete the Neuro-Oncology Referral Proforma (accessed via www.kch.nhs.uk under GP’s/refers, then access referral forms) and refer/arrange for the local Neurologist to review the patient.

Local Neurologist must arrange for patient to be discussed in the Neuro-Oncology Multidisciplinary Team meeting at Kings College Hospital. Contact MDT Co-coordinator via email kch-tr.neuro-oncology@nhs.net or call 020 3299 4151 (direct line)

Organise for scans to be imaged linked to Kings by Thursday at 1pm for discussion on Friday.
All films sent will have a foreign film report done by a Neuro-Radiologist. These reports will also be sent to the reporting radiologist following the meeting.
If surgically accessible patient will be transferred to Kings for consultation then biopsy, debulking or excision of tumour

If surgically inaccessible patient to stay in local hospital
All post operative patients will be discussed in the Neuro-Oncology Multidisciplinary Team Meeting on Friday at Kings College Hospital and referred to appropriate Oncologist, Neuro-Oncology Clinic or Palliative care.

If patient safe for discharge will be discharged home from Kings. If patient unsafe for discharge will be transferred back to local hospital for care package to be organised.

Appendix 3  NON-EMERGENCY REFERRAL TO KINGS COLLEGE HOSPITAL NEUROSURGERY

Patient presents with symptoms suggestive of space occupying lesion

CT/MRI scan confirms space occupying lesion
If patient on Aspirin, Clopidogrel or Dypiridamole then stop. Change warfarin to IV heparin if anticoagulation is absolutely indicated (see text above) AND unless abscess suspected commence patient on Dexamethasone 8mgs bd

Undertake neurological examination and further investigations – FBC/U+E/Clotting Screen, MRI+Gadolinium and chest x-ray for all patients.
If metastatic disease suspected perform Chest/Abdo/Pelvis CT and tumour markers
If spinal tumour perform whole neural axis MRI scan

Complete Neuro-Oncology Proforma and refer to local neurologist for opinion

Neurologist organises for patient to be discussed in the Neuro-Oncology MDM meeting at Kings College Hospital

Send films by image link to Kings Contact neuro oncology co-ordinator on 020 3299 4151

Scan shows possible abscess, tumour with associated hydrocephalus, Spinal Cord Compression, posterior fossa, midline or 3rd ventricular tumour, or GCS 13/15 or less

Follow emergency protocol

Patient discussed in the Neuro-Oncology MDM

Operable

Patient transferred to Kings for biopsy, debulking or excision

Inoperable

Referred by local team to Oncologist or Palliative care

Patient discussed post operatively in Neuro-Oncology MDM and referred to appropriate Oncologist or clinic
PROTOCOL FOR REFERRAL OF EMERGENCY NEUROSURGICAL PATIENTS TO KINGS COLLEGE HOSPITAL

All patients admitted with suspected space occupying lesion must have:

- Brain contrast CT scan, preferably a contrast MRI scan
- Chest x-ray
- If patient is on Aspirin, Warfarin, Clopidogrel or Dipyridamole, these must be stopped
- Commence patient on Dexamethasone 8mgs bd (unless abscess suspected)
- FBC/U+E/Clotting screen

If scan shows possible abscess, tumour with associated hydrocephalus, spinal cord compression, posterior fossa or midline or 3rd ventricular tumour, or GCS 13/15 or less:
(Note: All other cases follow the Non-Emergency referral protocol)

- Complete Neuro-Oncology Referral Proforma and contact Neurosurgical Registrar at Kings College Hospital on 0203 2994207 – Diverted to a mobile when not in hospital.
- Organise for films to be imaged linked to Kings College Hospital.

If surgically accessible patient will be transferred to Kings for biopsy, debulking or excision of tumour.

If surgically inaccessible patient to stay in local hospital

All patients will be discussed in the Neuro-Oncology Multidisciplinary Team Meeting on Friday at Kings College Hospital and referred to appropriate Oncologist, Neuro-Oncology Clinic or Palliative care

If patient safe for discharge will be discharged home from Kings

If patient unsafe for discharge will be transferred back to local hospital for care package to be organised

The Nominated Neuro-Oncology Trust Lead Clinicians will ensure that all the protocols are adhered to and referral forms are fully completed

NB: if family/ patient wishes to discuss decision of best supportive care then can discuss with them at Kings College Neuro-Oncology Clinic. This will not be offer as routine.
EMERGENCY REFERRAL TO KINGS COLLEGE HOSPITAL NEUROSURGERY

Patient presents with symptoms suggestive of space occupying lesion

CT/MRI scan confirms space occupying lesion
If patient on Aspirin, Warfarin, Clopidogrel, Dipyridamole then stop it AND unless abscess suspected commence patient on Dexamethasone 8mgs bd

Scan shows possible abscess, tumour with associated hydrocephalus, Spinal Cord Compression, posterior fossa, midline or 3rd ventricular tumour, or GCS 13/15 or less

Scan shows non-emergency tumour

Follow non-emergency protocol

Complete Neuro-Oncology Referral Proforma and contact Neurosurgical Registrar at Kings College hospital on 0203 2994207

Image link scans to Kings College Hospital

Operable

Patient transferred to Kings and surgery undertaken – biopsy, debulking or excision

Inoperable – stay in local hospital

Patient discussed in Neuro-Oncology MDM on Friday at Kings and local team refer to appropriate Oncologist, Neuro-Oncology Clinic or Palliative Care

Patient discussed in Neuro-Oncology MDM on Friday at Kings and referred to appropriate Oncologist, Neuro-Oncology Clinic or Palliative Care. Contact details for MDT Co-ordinator 020 3299 4151 kch-tr.neuro-oncology@nhs.net

Patient safe for discharge Patient not safe for discharge or needs care
Follow-up Pathway 11-2k-236 11-1c-108k

Contact details
Patients for MDT discussion at King’s College Hospital can be made directly, as agreed with both networks, using the network agreed proforma (Appendix 1) emailed directly to the Neuro-Oncology MDT Co-ordinator.

All relevant histology and radiology must be sent concurrently, to prevent delay to

Email: kch-tr.neuro-oncology@nhs.net
Fax 0203 299 1665
Telephone: 020 3299 4151

Palliative Care
The team provides a Monday - Friday 9:00am to 5:00pm service. At weekends a SpR is available across Guy’s, King’s and St Thomas’ (GKT) to see patients in King’s. A consultant is also available after 5pm and before 9am to offer telephone advice for healthcare professionals with palliative care problems.

Neuro-Psychology 020 3299 8330
### PATIENT AGREEMENT TO SYSTEMIC THERAPY: CONSENT FORM TEMOZOLAMIDE / RADIOThERAPY

<table>
<thead>
<tr>
<th>Hospital Name:</th>
<th>Patient’s surname/family name</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guy’s Hospital</td>
<td></td>
</tr>
<tr>
<td>St. Thomas’ Hospital King’s College Hospital</td>
<td></td>
</tr>
<tr>
<td>Lewisham Hospital</td>
<td></td>
</tr>
<tr>
<td>South London Healthcare NHS Trust:</td>
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<tr>
<td>Princess Royal University Hospital Queen Elizabeth Hospital Queen Mary’s Hospital</td>
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<table>
<thead>
<tr>
<th>Patient’s first names</th>
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<table>
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<tr>
<th>NHS number (or other identifier)</th>
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<tr>
<th>Male Female</th>
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<table>
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<tr>
<th>Special requirements (e.g. other language/other communication method)</th>
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### 11.1 Chemotherapy for Brain/Central Nervous System Cancer

**Oral Temozolamide / Radiotherapy**

<table>
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<tr>
<th>Responsible health professional</th>
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<table>
<thead>
<tr>
<th>Job title</th>
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</tbody>
</table>
Name of proposed procedure or course of treatment (include brief explanation if medical term not clear)

A separate consent form exists and must be completed for Radiotherapy
Oral Temozolamide (7 days per week) daily concomitantly with Radiotherapy (5 days per week) for 6 weeks (up to 49 days), followed by 4 weeks resting period, then Oral Temozolamide alone daily on days 1 to 5, every 28 days for up to 6 cycles

11.2 Statement of health professional (to be filled in by health professional with appropriate knowledge of proposed procedure, as specified in consent policy)

To be retained in patient’s notes

Reason for Update: Review date: Jan 2013 Version: 1 Approved by Consultant: Lucy Brazil Supersedes: All other versions Date: 19/01/11 Prepared by: Manuel Rahman Checked by: Lucy Brazil Approved by SELCN DTAC Chair: Janine Mansi Date: 19/01/11

Patient identifier/label: Page 2 of 6
I have explained the procedure to the patient. In particular, I have explained:

**The intended benefits**

Improved survival Control of symptoms

**Significant, unavoidable or frequently occurring risks:**

Common side-effects include bruising or bleeding, anaemia (low number of red blood cells), feeling sick (nausea) and being sick (vomiting), diarrhoea, constipation, loss of appetite and temporary taste changes, rashes, headache, tiredness and feeling weak.

A less common but potentially life threatening side-effect is reduced resistance to infection which can lead to a blood infection. Contact your doctor or the hospital straight away if:

- your temperature goes above 38ºC (100.4ºF)
- you suddenly feel unwell (even with a normal temperature).

Other less common side-effects include hair loss, dizziness and drowsiness

Cancer can increase your risk of developing a blood clot (thrombosis), and having chemotherapy may increase this risk further. A blood clot may cause pain, redness and swelling in a leg, or breathlessness and chest pain - you must tell your doctor straight away if you have any of these symptoms.

Some chemotherapy drugs can damage women’s ovaries and men’s sperm, with risk of infertility and early menopause in women. I have warned the patient about the likelihood of:

- Early menopause in women
- Infertility (in men and in women)

Some chemotherapy drugs may damage the development of a baby in the womb (foetus), leading to the many risks associated with an abnormal pregnancy. Therefore, I have discussed the issues of protected sex. This is an issue for both men and women. The patient has been advised not to become pregnant / not to get a partner pregnant during the period of treatment.

What the treatment is likely to involve (including inpatient / outpatient treatment, timing of the treatment, follow-up appointments etc) and location

Antibiotics will be given 3 days per week whilst you are having both chemotherapy and radiotherapy to reduce the risk of infection

Any other risks:

………………………………………………………………………………………………………

………………………………………………………………………………………………………

………………………………………………………………………………………………………

… Patient identifier/label: Page 3 of 6 to be retained in patient’s notes Reason for Update: Review date: Jan 2013 Version: 1 Approved by Consultant: Lucy Brazil Supersedes: All other versions Date: 19/01/11 Prepared by: Manuel Rahman Checked by: Lucy Brazil Approved by SELCN DTAC Chair: Janine Mansi Date: 19/01/11
I have also discussed what the procedure is likely to involve, the benefits and risks of any available alternative treatments (including no treatment) and any particular concerns of this patient.

The following leaflet/tape has been provided:

Macmillan/Cancerbackup leaflet for Temozolamide Oral Chemotherapy
South East London Cancer Network Temozolamide Patient Treatment Plan
24 hour chemotherapy service contact details

…………………………………………………………………………………………………………………………

…………………………………………………………………………………………………………………………

Signed:........................................ Date ........................................
Name (PRINT) ........................................... Job title ........................................
Contact details (if patient wishes to discuss options later) .................................................................

…………………………………………………………………………………………………………………………

…………………………………………………………………………………………………………………………

......

Statement of interpreter (where appropriate)
Language Line ref:.........................................................................................................................
I have interpreted the information above to the patient to the best of my ability and in a way in which I believe s/he can understand.
Signed ........................................................ Date ........................................
Name (PRINT) ...............................................................................................................................

Copy accepted by patient: yes/no (please ring) Patient identifier/label:

Page 4 of 6 To be retained in patient's notes Reason for Update: Review date: Jan 2013 Version: 1
Approved by Consultant: Lucy Brazil Supersedes: All other versions Date: 19/01/11 Prepared by: Manuel Rahman Checked by:
Lucy Brazil Approved by SELCN DTAC Chair: Janine Mansi Date: 19/01/11
Statement of patient

Please read this form carefully. If your treatment has been planned in advance, you should already have your own copy of page 2 which describes the benefits and risks of the proposed treatment. If not, you will be offered a copy now. If you have any further questions, do ask – we are here to help you. You have the right to change your mind at any time, including after you have signed this form.

I agree to the procedure and course of treatment described on this form.

I understand that you cannot give me a guarantee that a particular person will perform the procedure. The person will, however, have appropriate training and experience.

I understand that any procedure in addition to those described on this form will only be carried out if it is necessary to save my life or to prevent serious harm to my health.

I have been told about additional procedures which may become necessary during my treatment. I have listed below any procedures which I do not wish to be carried out without further discussion.

11.2.1 ………………………………………………………………………………………………

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………………………………………………………………………………………………

A witness should sign below if the patient is unable to sign but has indicated his or her consent. Young people/children may also like a parent to sign here (see notes).

Signature ……………………………………… Date ………………………………………

Name ………………………………………………………………………………………………

Confirmation of consent (to be completed by a health professional when the patient is admitted for the procedure, if the patient has signed the form in advance)

On behalf of the team treating the patient, I have confirmed with the patient that s/he has no further questions and wishes the procedure to go ahead.

Signed: ……………………………………… Date ………………………………………

Name (PRINT) ……………………………………………………………………………………

Job title …………………………………………………

Important notes: (tick if applicable)

☐ See also advance decision (eg Jehovah’s Witness form)

☐ Patient has withdrawn consent (ask patient to sign /date here) ……………………………...

Patient identifier/label: Page 5 of 6 To be retained in patient’s notes

Reason for Update: Review
date: Jan 2013 Version: 1 Approved by Consultant: Lucy Brazil Supersedes: All other versions Date: 19/01/11 Prepared by: Manuel Rahman Checked by: Lucy Brazil Approved by SELCN DTAC Chair: Janine Mansi Date: 19/01/11
Guidance to health professionals  (to be read in conjunction with consent policy)

What a consent form is for
This form documents the patient’s agreement to go ahead with the investigation or treatment you have proposed. It is not a legal waiver – if patients, for example, do not receive enough information on which to base their decision, then the consent may not be valid, even though the form has been signed. Patients are also entitled to change their mind after signing the form, if they retain capacity to do so. The form should act as an aide-memoire to health professionals and patients, by providing a check-list of the kind of information patients should be offered, and by enabling the patient to have a written record of the main points discussed. In no way, however, should the written information provided for the patient be regarded as a substitute for face-to-face discussions with the patient.
The law on consent

See the Department of Health’s *Reference guide to consent for examination or treatment* for a comprehensive summary of the law on consent (also available at www.doh.gov.uk/consent).

12.1.1 Who can give consent

Everyone aged 16 or more is presumed to have the capacity to give consent for themselves, unless the opposite is demonstrated. If a child under the age of 16 has “sufficient understanding and intelligence to enable him or her to understand fully what is proposed”, then he or she will have the capacity to give consent for himself or herself. Young people aged 16 and 17, and legally ‘competent’ younger children, may therefore sign this form for themselves, but may like a parent to countersign as well. If the child is not able to give consent for himself or herself, some-one with parental responsibility may do so on their behalf and a separate form is available for this purpose. Even where a child is able to give consent for himself or herself, you should always involve those with parental responsibility in the child’s care, unless the child specifically asks you not to do so. If a patient has the mental capacity to give consent but is physically unable to sign a form, you should complete this form as usual, and ask an independent witness to confirm that the patient has given consent orally or non-verbally.

12.1.2 When NOT to use this form

If the patient is 18 or over and lacks the capacity to give consent, you should use form 4 (form for adults who lack the capacity to consent to investigation or treatment) instead of this form. A patient lacks capacity if they have an impairment of the mind or brain or disturbance affecting the way their mind or brain works and they cannot:

• understand information about the decision to be made
• retain that information in their mind
• use or weigh that information as part of the decision-making process, or
• communicate their decision (by talking, using sign language or any other means).

You should always take all reasonable steps (for example involving more specialist colleagues) to support a patient in making their own decision, before concluding that they are unable to do so.

Relatives cannot be asked to sign a form on behalf of an adult who lacks capacity to consent for themselves, unless they have been given the authority to do so under a Lasting Power of Attorney or as a court appointed deputy.

12.1.3 Information

Information about what the treatment will involve, its benefits and risks (including side-effects and complications) and the alternatives to the particular procedure proposed, is crucial for patients...
making up their minds. The courts have stated that patients should be told about ‘significant risks which would affect the judgement of a reasonable patient’. ‘Significant’ has not been legally defined, but the GMC requires doctors to tell patients about ‘serious or frequently occurring’ risks. In addition if patients make clear they have particular concerns about certain kinds of risk, you should make sure they are informed about these risks, even if they are very small or rare. You should always answer questions honestly. Sometimes, patients may make it clear that they do not want to have any information about the options, but want you to decide on their behalf. In such circumstances, you should do your best to ensure that the patient receives at least very basic information about what is proposed. Where information is refused, you should document this on page 2 of the form or in the patient’s notes.

References:
1- South East London Cancer Network, Agreed lists of Chemotherapy Regimens
   http://www.selcn.nhs.uk/portal/index.asp
2- Macmillan Cancer Support, Cancer Information
3- Royal Marsden NHS Foundation Trust, Consent Forms
Chemotherapy protocol and consent for PCV.

### PATIENT AGREEMENT TO SYSTEMIC THERAPY: CONSENT FORM PCV

<table>
<thead>
<tr>
<th>Hospital Name:</th>
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<tbody>
<tr>
<td>Guy’s Hospital</td>
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<tr>
<td>St. Thomas’ Hospital King’s College Hospital</td>
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<tr>
<td>Lewisham Hospital</td>
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<td>South London Healthcare NHS Trust:</td>
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<tr>
<td>Princess Royal University Hospital Queen Elizabeth Hospital Queen Mary’s Hospital</td>
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<table>
<thead>
<tr>
<th>Patient’s surname/family name</th>
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<table>
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<th>Patient’s first names</th>
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<table>
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<th>NHS number (or other identifier)</th>
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<th>Male Female</th>
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<th>Special requirements (e.g. other language/other communication method)</th>
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Chemotherapy for Brain/Central Nervous System Cancer

PCV Oral Procarbazine and Lomustine + Intravenous Vincristine

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<tr>
<th>Responsible health professional</th>
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<table>
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<tr>
<th>Job title</th>
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**Name of proposed procedure or course of treatment** (include brief explanation if medical term not clear)

- Oral Procarbazine daily on days 1 to 10
- Oral Lomustine on day 1
- Intravenous Vincristine on day 1
- Every 6 weeks for 4 to 6 cycles

**Statement of health professional** (to be filled in by health professional with appropriate knowledge of proposed procedure, as specified in consent policy)

I have explained the procedure to the patient. In particular, I have explained:

**The intended benefits**

**To be retained in patient’s notes** Reason for Update: Review date: Jan 2013 Version: 1 Approved by Consultant: Lucy Brazil Supersedes: All other versions Date: 19/01/11 Prepared by: Manuel Rahman Checked by: Lucy Brazil Approved by SELCN DTAC Chair: Janine Mansi Date: 19/01/11 Patient identifier/label: Page 2 of 6 **To be retained in patient’s notes** Reason for Update: Review date: Jan 2013 Version: 1 Approved by Consultant: Lucy Brazil Supersedes: All other versions Date: 19/01/11 Prepared by: Manuel Rahman Checked by: Lucy Brazil Approved by SELCN DTAC Chair: Janine Mansi Date: 19/01/11
Improved survival Control of symptoms

Curative – to give you the best possible chance of being cured

Palliative – the aim is not to cure but to control or shrink the disease. The aim is to improve both quality of life and survival

Adjuvant – therapy given after surgery to reduce the risk of recurrence of cancer

Neo-adjuvant – therapy given before surgery to shrink the cancer and reduce the risk of recurrence of cancer

**Significant, unavoidable or frequently occurring risks:**

Common side-effects include bruising or bleeding, anaemia (low number of red blood cells), feeling sick (nausea) and being sick (vomiting), numbness or tingling in hands or feet (due to Vincristine), tiredness and feeling weak and flu-like symptoms (headaches, aching joints or muscles, a temperature, weakness and chills)

A less common but potentially life threatening side-effect is reduced resistance to infection which can lead to a blood infection. Contact your doctor or the hospital straight away if:

- your temperature goes above 38°C (100.4°F)
- you suddenly feel unwell (even with a normal temperature)

Other less common side-effects include hair thinning, skin change and changes to the lungs (due to Lomustine). Vincristine may leak in the tissue around the vein while it is being given causing stinging and burning around the vein.

Potential side-effects with the anti-sickness medication may include constipation, headaches, indigestion, difficulty sleeping and agitation.

Cancer can increase your risk of developing a blood clot (thrombosis), and having chemotherapy may increase this risk further. A blood clot may cause pain, redness and swelling in a leg, or breathlessness and chest pain - you must tell your doctor straight away if you have any of these symptoms.

Some chemotherapy drugs can damage women’s ovaries and men’s sperm, with risk of infertility and early menopause in women. I have warned the patient about the likelihood of:

- early menopause in women
- infertility (in men and in women)

Some chemotherapy drugs may damage the development of a baby in the womb (foetus), leading to the many risks associated with an abnormal pregnancy. Therefore, I have discussed the issues of protected sex. This is an issue for both men and women. The patient has been advised not to become pregnant / not to get a partner pregnant during the period of treatment. Patient identifier/label: Page 3 of 6 **To be retained in patient’s notes**
What the treatment is likely to involve (including inpatient / outpatient treatment, timing of
the treatment, follow-up appointments etc) and location.
Any other risks:
………………………………………………………………………………………………………
………………………………………………………………………………………………………
I have also discussed what the procedure is likely to involve, the benefits and risks of any
available alternative treatments (including no treatment) and any particular concerns of
this patient.
The following leaflet/tape has been provided:
Macmillan/Cancerbackup leaflet for PCV chemotherapy
South East London Cancer Network PCV Patient Treatment Plan
24 hour chemotherapy service contact details
………………………………………………………………………………………………………
………………………………………………………………………………………………………
Signed:…………………………….. Date ………………………
Name (PRINT) ………………………. ……… Job title …….. ……………………. …
Contact details (if patient wishes to discuss options later) ………………………………
………………………………………………………………………………………………………
……

Statement of interpreter (where appropriate)
Language Line ref:…………………………………………………………………………………
I have interpreted the information above to the patient to the best of my ability and in a
way in which I believe s/he can understand.
Signed ………………………………………………… Date ………………………
Name (PRINT) ……………………………………………………………………

Copy accepted by patient: yes/no (please ring) Patient identifier/label:
Page 4 of 6 To be retained in patient's notes Reason for Update: Review date: Jan 2013 Version: 1
Approved by Consultant: Lucy Brazil Supersedes: All other versions Date: 19/01/11 Prepared by: Manuel Rahman Checked by:
Lucy Brazil Approved by SELCN DTAC Chair: Janine Mansi Date: 19/01/11
Statement of patient
Please read this form carefully. If your treatment has been planned in advance, you should already have your own copy of page 2 which describes the benefits and risks of the proposed treatment. If not, you will be offered a copy now. If you have any further questions, do ask – we are here to help you. You have the right to change your mind at any time, including after you have signed this form.

I agree to the procedure and course of treatment described on this form.

I understand that you cannot give me a guarantee that a particular person will perform the procedure. The person will, however, have appropriate training and experience.

I understand that any procedure in addition to those described on this form will only be carried out if it is necessary to save my life or to prevent serious harm to my health.

I have been told about additional procedures which may become necessary during my treatment. I have listed below any procedures which I do not wish to be carried out without further discussion.

…………………………………………………………………………

12.1.4 ……………………………………………………………………………………………

………………………………………………………………………………………………

……………………

Patient’s signature ........................................... Date.............................
Name ............................................................... (PRINT)

A witness should sign below if the patient is unable to sign but has indicated his or her consent. Young people/children may also like a parent to sign here (see notes).

Signature .......................................................... Date ..................................
Name (PRINT) ........................................................................................................

Confirmation of consent (to be completed by a health professional when the patient is admitted for the procedure, if the patient has signed the form in advance)

On behalf of the team treating the patient, I have confirmed with the patient that s/he has no further questions and wishes the procedure to go ahead.

Signed:.............................................................. Date . ............................
Name (PRINT) ................................. ......... Job title ........ ..............

Important notes: (tick if applicable)
□ See also advance decision (eg Jehovah’s Witness form)
□ Patient has withdrawn consent (ask patient to sign /date here) ....................

Patient identifier/label: Page 5 of 6 To be retained in patient’s notes Reason for Update: Review date: Jan 2013 Version: 1 Approved by Consultant: Lucy Brazil Supersedes: All other versions Date: 19/01/11 Prepared by: Manuel Rahman Checked by: Lucy Brazil Approved by SELCN DTAC Chair: Janine Mansi Date: 19/01/11
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13.1.1 Who can give consent
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2- Macmillan Cancer Support, Cancer Information
3- Royal Marsden NHS Foundation Trust, Consent Forms
South East London Cancer Network

and

Kent and Medway Cancer Network

Operational Policy for Neuro-rehabilitation Facilities

Brain and Cancer CNS

Kings Health Partners Cancer Centre, King’s College Hospital NHS Foundation Trust

Bexley, Bromley, Greenwich, Lambeth, Lewisham, Southwark

Kent and Medway

Agreed By:

Date: 15/07/11

To be reviewed annually. Date of next Review: July 2012
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Note: Kent and Medway Network List of Neurorehabilitation Facilities to follow- please contact Bryony Neame Kent and Medway Cancer Network for details.
1.0 Introduction

Adult neuro-oncology patients are admitted to healthcare settings- acute trusts and inpatient or outpatient services- at various stages along their cancer journey- diagnosis, active treatment, post treatment, palliative and end of life. Patients at each of these stages present with differing physical, cognitive and psychosocial needs depending on the particular difficulties they are facing at that time. Therefore rehabilitation services must aim to tailor intervention to the presenting needs of the individual patient.

The patient’s treatment pathway often necessitates transitional care between King’s College Hospital, Guy’s and St. Thomas’ Hospital and their local cancer services within the South East London Cancer Network. On the emergence of symptoms and/or treatment side effects that impact on functional independence and quality of life, patients will have timely access to rehabilitation services when required, regardless of which stage they are at on the neuro-oncology pathway (see appendix 1).

An Allied Health Professional (AHP) is one of sixteen professions distinct from Medicine and Nursing. AHPs are autonomous and carry individual case loads. For the purpose of cancer rehabilitation and this document, AHP refers to Dietetics, Occupational Therapy, Physiotherapy and Speech and Language Therapy. This reflects the scope of the NCAT (National Cancer Action Team) cancer rehabilitation pathways (2010) and the NICE Improving Supportive and Palliative Care rehabilitation chapter (2004).

2.0 Objectives

- Patients should have access to AHP assessment and intervention whenever required, at any stage in their cancer pathway
- Patients should have access to comprehensive assessment to identify their health and social care needs, regardless of what stage they are at on their cancer journey
- Each patient’s potential to derive a benefit from rehabilitation and therapeutic intervention should be assessed, and referral to rehabilitation services made without delay
- Patients should receive an active and planned approach to rehabilitation including assessment, diagnosis, goal setting, care planning (and evaluation through formal outcome measures when possible)
- Patients should play a central role in setting goals, and should be involved in every stage of care- from referral and assessment through to discharge from rehabilitation services
- Services provided should be culturally appropriate, designed to suit individual, cultural and language requirements
- Links should be built between healthcare teams and other agencies in order to develop collaborative working and ensure a seamless transfer of care across the rehabilitation pathway
- AHPs should be members of site- specific multidisciplinary teams (MDTs) if such MDTs exist in their place of work
3.0 Overview of Service Provided

- AHPs provide patient assessment, diagnosis, treatment, support, advice and staff training, specialising in the management of cognitive, perceptual, physical and psychosocial impairments resulting from brain and CNS cancer. AHPs specialise in the provision of neuro-rehabilitation. Clinical interventions include:

  - Assessment of cognitive, physical and neurological function with identification and prioritisation of risks
  - Intervention to restore and maintain patient to optimum cognitive and physical function, minimise risk and prevent unnecessary deterioration in cognitive and physical health
  - Monitoring and re-assessment of physical and cognitive/communicative function of patients who may have progressively deteriorating physical and cognitive presentation
  - Provision without delay of and/or referral for therapeutic equipment including splints and orthoses, adaptive equipment, environmental adaptations, wheelchairs, walking aids and communication aids as indicated
  - Provision of manual handling risk assessment, training and advice for patients and their carers
  - Onward referral to a home enteral nutrition team if indicated
  - Advice and support regarding management of symptoms related to cancer such as communication impairment, dysphagia, fatigue, pain, anxiety, reduced motivation.
  - Discharge planning from the acute setting and appropriate identification of ongoing clinical risks and rehabilitation needs
  - Provision of generic and neuro-specialist rehabilitation programmes in a setting that best meets the patient’s needs e.g. inpatient or community based.

4.0 Patient pathway across SELCN

4.1 ASSESSMENT:

All patients with brain and CNS tumours will have access to AHP assessment to identify their impairments and needs. The following areas should be discussed with the patient/carer:

- History of presenting condition
- Social support available
- Details of home and/or work environments
- Premorbid function
The following areas will be assessed (assessment of specific areas may be completed by a specific AHP discipline- some areas may be assessed jointly).

Physical presentation- muscle power, tone, range of motion, balance, coordination, dexterity, energy levels, fitness and respiratory status.

Motor function- transfers, mobility, posture, wheelchair requirements, upper limb function.

Swallowing function- ability to take normal range of food and drink consistencies or modified consistency textures in quantities to meet nutritional and hydrational requirements.

Communication skills-ability to communicate functionally within a specific context, at various levels of complexity.

Risk assessment- falls risks, environmental risks in home or work environment, manual handling risks.

Cognitive assessment- screening for cognitive impairment and in-depth assessment of problems areas including attention, orientation, information processing, sensory processing, perception, memory, executive function.

Assessment of functional vision and hearing.

Assessment of Activities of Daily Living (ADLs) that are relevant to the patient including the areas of self care, productivity and leisure (including work, child care, study, volunteer work, driving etc), taking into consideration the environment in which the patient lives/ works.

The patient will be supported to identify and discuss problematic symptoms related to cancer such as fatigue, pain, anxiety, stress and reduced motivation

Patient will be given an opportunity to discuss impact of cancer on physical and emotional relationships.

4.2 GOAL-SETTING

Following completion of initial assessment SMART goals will be set with the patient and their family/ carer if appropriate. Goals may be risk reduction and prevention, rehabilitation, maintenance and management orientated.

Goals will be appropriately graded to the changing, fluctuating and/or deteriorating needs if the patient.

Goals will be reviewed on a regular basis and short and long term goals communicated between acute and rehabilitation facilities to ensure a seamless transfer of care.

4.3 INTERVENTION:

The specific intervention that is provided to the patient will be a direct result of the assessment findings, taking into consideration the patient’s/carer’s wishes and point in the care pathway.

Intervention will be evidence-based where possible. Therapists will provide treatment as indicated
including opportunities for the patient to communicate functionally and engage in activities of daily living including personal care, productivity and leisure activities. Therapists will recognise & respond to highly complex physical, emotional & psychological needs and offer specialist treatment and refer for specialist support as necessary.

The aim of rehabilitation for patients with brain and CNS tumours is to reduce risk, optimise function, and maximise quality of life. Therapists will be involved throughout the patient’s pathway and are instrumental in achieving their rehabilitation goals. The specific treatments and interventions will be individual to each patient and will be based on comprehensive assessment, taking into consideration the patient’s own goals.

**Cognition**

Where appropriate patients will receive targeted cognitive rehabilitation to address identified cognitive impairments e.g. cognitive-communication work or training on internal memory strategies. Compensatory approaches will be considered for those patients who are unable to benefit from strategy training. Education about cognitive impairments and specific strategies will be given to the patient and their carers/ employer etc.

**Communication Skills**

As appropriate patients will receive disorder- specific communication rehabilitation focusing on identified impairments and social interactions, aimed at restoring meaningful interactive communication with those in his/her environment. Work will focus on maximising comprehension and expression of speech and language, through verbal and non-verbal channels, as possible. Augmentative and assistive communication will be integrated if required.

**Mental Capacity**

Therapists are skilled in contributing to and fulfilling the assessment of a patient’s mental capacity to make specific decisions. These contributions will be in facilitating and optimising the patient’s physical, cognitive and communicative functions in the decision-making process.

**Psychological**

Therapists will identify and facilitate the patient and carer’s adjustment to loss and disability which may be associated with brain and CNS cancer related to independence, control of environment, self esteem and quality of life. Advice on anxiety and anger management will also be provided where indicated. Therapists will be considerate of the patient’s and carer’s emotional and social wellbeing and make appropriate referrals to specialist agencies where possible.

**Equipment**

Patients should have access to assessment and provision of equipment for adaptive, supportive or rehabilitative purposes. Therapists must ensure that if equipment is identified as a requirement to facilitate independence in daily living then it arranged without delay. Risk assessment will be carried out for provision of such equipment and, if required, training offered to the patient and their carers for complex items. Wheelchair and appropriate pressure relieving cushions will be considered for those with mobility and/or breathing difficulties and mobility aids reviewed for appropriateness throughout the
rehabilitation process. Following specialist assessment, if communication aids are required to augment or assist communication skills, appropriate recommendations will be made.

**Exercise and Wellbeing**

Therapists will be considerate of reducing and preventing secondary complications of brain and CNS tumour such as physical skin breakdown, loss of soft tissue range of movement, through advice on medication, postural management and provision of splints where required. Patients will be advised on the benefits of exercise and assisted to increase their levels of activity through exercise prescription. This may be through strengthening exercises and cardiovascular training. The patient will be advised about effective exercise and activity and provided with written support material where required.

Mobility and function should be progressed as able with gait re-education and ongoing re-assessment for mobility aids provided.

**Fatigue and Anxiety Management**

Fatigue management will be considered in those patients whom find daily activities including communication difficult to complete due to tiredness. Various management techniques such as relaxation, healthy sleep patterns, energy conservation, environmental adaptations, pacing & compensatory techniques should be considered. Levels of nutrition and hydration will be considered and referral made to the local Dietetics service made if necessary. Patients will be encouraged to undertake exercise programmes aimed at improving strength and stamina. Anxiety & stress management will be considered and onward referral for more specialist services made as required.

**Information and Support**

Therapists will provide advice and education to the patient and their carer throughout the patient’s pathway but also facilitate self-management through enabling patients to make informed choices about their rehabilitation and by providing information and support on all aspects of their cancer care. Therapists can provide specific training for carers e.g. manual handling in the home environment

**Continence**

Therapists will recognise difficulties that patients may experience with continence and be able to signpost to the specialist services available in their area. They will also offer advice on exercises aimed at muscle strengthening of the pelvic floor and work to improve mobility and transfers to assist with toileting needs. They can also offer advice on adaptive clothing and assessment for equipment provision.

**Nutrition**

During rehabilitation the patient’s levels of nutrition and hydration should be considered. Appropriate therapists will address the patient’s functional ability to swallow and maintain adequate levels of stamina throughout a meal. Specialist clinical evaluation of a patient’s swallowing ability will be carried out, with resultant provision of specific advice for instrumental swallow assessment if required and advice to reduce risks of aspiration and malnutrition. If reduced nutritional or hydrational intake is suspected, early contact will be made by therapists with the patient’s General Practitioner and onward referral to the patient’s local Dietetic service as required. The advice will include addressing other issues around meal preparation from the buying of food through to equipment provision to assist during preparation and feeding. Therapists will consider the impact of nutrition on patient’s ability to
engage in rehab.

Referral and Liaison
Therapists will act as a signpost for further specialist services and support groups. They will have access or know how to access the wider MDT and make early referrals to such services. There will be identification of care needs and provision of information to both formal and informal care providers.

Respiratory Function
Patients with respiratory symptoms will be encouraged through training to develop self-management techniques for breathlessness and secretion clearance. Therapists will provide advice and support including information provision and education for patients and carers around breathlessness. Where appropriate, aerobic and strengthening exercise prescription will be considered including Pulmonary Rehabilitation. Therapists can also provide advice on pharmacological interventions such as Oxygen and Opiates, including inhaler technique. Patients with spinal cord compression may need closer monitoring of their respiratory status and provision of assistive technology for secretion clearance.

Activities of Daily Living
Goal-orientated rehabilitation will be implemented to enable maximum functioning in activities of daily living. Therapists will educate carers on the importance of facilitating the patient’s participation in activities of daily living in order to maintain existing function, quality of life and independence. Assessment of the home environment will be completed either through interview, home visit or community services and provide appropriate equipment or adaptations to facilitate access and independence.

Therapists will provide advice and information on accessing/maintaining social and leisure activities including providing information on accessing benefits advice, blue badge and shop mobility schemes.

Work/Education
Those patients who wish to return to work or education or become involved in voluntary or unpaid work will have access to assessment of their ability to engage in such activities and support and advice regarding returning to these activities. Where such facilities are available referrals will be made to vocational rehabilitation programmes.

Complementary/Alternative medicine
AHPs who have training in complementary and alternative medicine e.g. acupuncture, mindfulness based stress reduction, will offer these services to appropriate patients.

4.4 DISCHARGE

Acute settings
Discharge from acute settings will be planned in partnership with the patient and their carers, ensuring discharge takes place at the appropriate point when acute therapeutic intervention is no longer required.

The need for referral to rehabilitation services will be identified and completed without delay.

Discharge planning will take into consideration the need to refer to other therapy services and statutory and voluntary services as required and referrals to these agencies should be activated without delay.

Where there is a transfer of care to another therapy team high quality verbal and/or written handovers will be provided to the accepting team without delay to ensure a seamless transfer of care.

If it is anticipated that a patient being discharged from the acute setting will wait for a significant period for initial contact from community services the patient/carer will be provided with contact details of the acute trust therapists and advised to make contact for advice.

Equipment will be provided without delay- adaptive equipment, splints and orthotics, wheelchair referrals, liaison with nursing team regarding hospital beds, pressure care.

For those patients at a palliative or end of life stage, equipment provision will be completed urgently to facilitate the patient --- maintaining safety and dignity in their preferred environment.

Training will be given to family/carers if required regarding manual handling, positioning, feeding and communication strategies.

Rehabilitation settings

For those patients in rehabilitation settings, discharge will occur once goals are achieved and recommendations implemented. The patient will be informed of any decisions made regarding their discharge from the service.

When patients have been discharged from a service, they will be given advice on how to re-access services should their needs change in the future.

5.0 Neuro-Oncology MDMs

Where possible brain and CNS Cancer MDMs will be attended by AHP representatives in order to facilitate MDT decision making regarding appropriateness of onward rehabilitation referrals.
References

London Cancer Services- proposed model of care.


NHS National Cancer Action Team (2009). Rehabilitation Care Pathway Brain CNS.

Appendices

Appendix 1: SELCN Neuro-oncology patient pathway

Appendix 2: List of Neuro-rehabilitation facilities across SELCN
Appendix 2: List of Neuro-rehab facilities

- Borough by borough
- Inpatient rehab (Neuro and generic if no Neuro exists)
• Inpatient ICT
• Community ICT
• Community Neuro rehab (or generic rehab if no Neuro exists)
• Supported discharge teams
• London Consortium rehabilitation units
• SCI Units
• Outpatient therapy services

**Bexley**

<table>
<thead>
<tr>
<th>Team</th>
<th>Brief Outline</th>
<th>Geographical area covered</th>
<th>Contact Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Health Rehabilitation Team</td>
<td>Not Neuro specific Physio/ OT/ Rehab Assistants Accept end of life care patients</td>
<td>Physio allocated by GP address (Bexley Only) OT- allocated by Council Tax/Home address</td>
<td>Community Health Rehabilitation Bostall House Goldie Leigh Lodge Hill London SE2 0AY Tel: 02083197070 Fax: 02083197106</td>
</tr>
<tr>
<td>Community SLT</td>
<td>Adults with physical disabilities</td>
<td>Bexley GP</td>
<td>Enith Health Centre 50 Pier Road Erith DA8 1RQ Tel: 01322 356100 x2258 07889302331 Fax: 01322 521330</td>
</tr>
<tr>
<td>Elmstead Unit, Queen Mary's Hospital</td>
<td>Adults with physical disabilities - mainly of neurological origin. Mainly MS unit but accept other diagnosis 20 beds, 6 for medical, 14 for MS</td>
<td>Bexley, Bromley and Greenwich</td>
<td>Tel: 0208302 2678 x 4328</td>
</tr>
<tr>
<td>Care and Re-enablement Team</td>
<td>Case by Case assessment by therapist Re-enablement/care provided by rehab assistants Do not accept Terminal Stage Patients- need clear rehab goals</td>
<td>Bexley Council residents</td>
<td>02030454801</td>
</tr>
<tr>
<td>Step Up Step Down Unit</td>
<td>10 day max stay policy Step up from home to prevent admission Step down from hospital post discharge</td>
<td>Bexley GP</td>
<td>02083085423</td>
</tr>
<tr>
<td>Social Services- single point of access</td>
<td>Rapid response Care package inquiries Available community services i.e. ICT</td>
<td>Bexley Council residents</td>
<td>Tel: 02083037777 Ext: 6363</td>
</tr>
<tr>
<td>Queen Mary's Hospital, Sidcup</td>
<td>Outpatient Physio (not neuro specific)</td>
<td>Bexley GP</td>
<td>Frognal Avenue Sidcup Kent DA14 6LT</td>
</tr>
<tr>
<td>Team</td>
<td>Brief outline</td>
<td>Geographical area covered</td>
<td>Contact details</td>
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</tr>
<tr>
<td>SCRehN  Specialist Community Rehabilitation Neurological Service</td>
<td>OT/ Physio/ SLT/Nursing/Psychology/Dietitian Community based rehabilitation.</td>
<td>Must have Bromley GP</td>
<td>37 Marvels Lane Grove Park SE12 9PN email to: <a href="mailto:LH.SCRehN@nhs.net">LH.SCRehN@nhs.net</a> Tel: 0203 049 2651 Fax: 0203 049 2631</td>
</tr>
<tr>
<td>Community Physiotherapy Bromley and Beckenham</td>
<td>Community physio- mainly for those who are housebound and cannot access outpatient services. Will accept people with a cancer diagnosis.</td>
<td>Bromley and Beckenham Based on GP's address.</td>
<td>1st Floor Room 167 Beckenham Beacon Hospital 379 Croydon Road Beckenham BR3 3QL Tel: 01689 866655 Fax: 020 82893242</td>
</tr>
<tr>
<td>Community Physiotherapy Orpington</td>
<td>Community physio- mainly for those who are housebound and cannot access outpatient services. Will accept people with a cancer diagnosis.</td>
<td>Chislehurst, Bromley, Biggin Hill, Orpington. Based on GP's address.</td>
<td>St Paul’s Cray Tel: 0208 3004226 Fax: 02083001553</td>
</tr>
<tr>
<td>Outpatient Physiotherapy</td>
<td>Princess Royal University Hospital</td>
<td>Bromley</td>
<td>Princess Royal University Site Farnborough Common Orpington Kent BR6 8ND Tel: 01689 863000 (main switchboard)</td>
</tr>
<tr>
<td>Bromley Healthcare Community Occupational Therapy</td>
<td>Community OT Rehabilitation team- will see all diagnoses as long as there is a rehab need. Will also provide aids and minor adaptations.</td>
<td>East team and West team based on GP's address.</td>
<td>East team Tel: 0208 4617424 West team Tel:0208 4617106</td>
</tr>
<tr>
<td>Bromley Intermediate Care Services</td>
<td>Bed- based Intermediate Care : Elmwood Unit- over 65s Orpington Hospital Unit- over 18s Community Assessment and Rehabilitation Team (CART) see people in their own home. CART east and CART West depending on GP address. Accept all diagnosis as long as there is a rehab need. Goals should be achievable in a 6 week timeframe. Patient must require at least two disciplines (OT/ Physio/</td>
<td>Single Point of Access for all referrals</td>
<td>Tel: 01689 858495 Fax: 01689 855351</td>
</tr>
<tr>
<td>Team</td>
<td>Brief outline</td>
<td>Geographical area covered</td>
<td>Contact details</td>
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<tr>
<td>Neuro rehabilitation Team (Part of the Community Rehabilitation Service)</td>
<td>OT/ PT /SLT/Dieticians/Neurology Matron/Therapy Assistants. Over 18 years of age. Have an acquired Neurological condition. Will accept people with a cancer diagnosis. For people who are able to participate in rehabilitation. Goals set will be time-limited.</td>
<td>Registered with Greenwich GP</td>
<td>Community Assessment and Rehab. Service Memorial Hospital Shooters Hill SE18 3RZ. Tel: 020 89212304 Fax: 020 89213392 Referrals: self-referral, by hospital, GP, other agency</td>
</tr>
<tr>
<td>Greenwich and Bexley Community Hospice</td>
<td>Accept people with approx. 2 week life prognosis. Also can carry out symptom control then discharge patient home.</td>
<td>Greenwich and Bexley residents.</td>
<td>185 Bostall Hill Abbey Wood SE2 OGB. Tel:0208 8312 2244 Fax:020 8312 4344 Referrals via South London Referral for palliative care form. Referrals from: GP, Hospital consultant, Specialist Nurse</td>
</tr>
<tr>
<td>Lambeth Neuro-Rehab and Complex Teams (GSTFT)</td>
<td>OT, PT, SLT Operate dynamic waiting lists and prioritisation systems</td>
<td>Lambeth with Lambeth GP</td>
<td>SPA (Single Point of Access), Pulross Centre, 47a Pulross Road, SW9 8AE, Tel: 020 3049 4004 Fax: 020 3049 4014</td>
</tr>
<tr>
<td>Guy’s and St Thomas’ Foundation</td>
<td>- Neuro PT (1:1 / Balance rehab)</td>
<td>Any patient under the GSST consultant</td>
<td>General Tel No: 0207 188 7188</td>
</tr>
</tbody>
</table>
Trust.
Out-patients services
- OT and PT Upper limb Clinic
- SLT (1:1)
- Oncology DT (1:1 / Group sessions)
Other contacts:
- Specialist Oncology PT
- Specialist Oncology OT

Neuro PT Ext.: 85088
Oncology PT Ext: 85110
Hand OT Ext: 84174
Oncology OT Ext: 84185
DT Ext: 84129
SLT: Ext: 86233

Lewisham

<table>
<thead>
<tr>
<th>Team</th>
<th>Brief outline</th>
<th>Geographical area covered</th>
<th>Contact details</th>
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<tbody>
<tr>
<td>Lewisham Community Adult Neuro-rehabilitation Team</td>
<td>Has PT, OT, SLT and access to Social Work and Dietician</td>
<td>Lewisham</td>
<td>Tel: 0208 613 9222</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Fax: 0208 613 9219</td>
</tr>
<tr>
<td>Lewisham Intermediate Care (Home based and bed based services)</td>
<td>Has OT, PT, Rehab assistants, Nurses and Doctors. Assesses/treats individuals for up to 6 weeks rehabilitation</td>
<td>Lewisham</td>
<td>Tel: 0208 333 3000</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Ext 8155 / 8181</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Fax: 0207 333 3224</td>
</tr>
<tr>
<td>Lewisham Adult Therapy Team</td>
<td>Has OT, PT and SLT</td>
<td>Lewisham</td>
<td>Tel: 0208 613 9222</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Fax: 0208 613 9219</td>
</tr>
<tr>
<td>Lewisham university Hospital Out-patient services</td>
<td>Has OT, PT, SLT</td>
<td>Lewisham</td>
<td>Hospital General No: 0208 333 3000</td>
</tr>
<tr>
<td>Lewisham Day Hospital</td>
<td>Has OT and PT for falls and balance Intervention.</td>
<td>Lewisham</td>
<td>Tel: 0208333 3030</td>
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<td></td>
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<td>Ext: 8057</td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>Fax: 02086139219</td>
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Southwark

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<th>Team</th>
<th>Brief outline</th>
<th>Geographical area covered</th>
<th>Contact details</th>
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</thead>
<tbody>
<tr>
<td>Southwark Neuro Rehab Team (GSTfT)</td>
<td>Physio, OT, SLT &amp; Rehab Assistant Tend to be episodes of care with ability to self-refer back to team. Neuro specialty</td>
<td>Southwark residents</td>
<td>Tel: 0207 525 3597</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Fax: 0208 693 3165</td>
</tr>
<tr>
<td>Southwark Adult Therapies Team</td>
<td>Physio only, tend to see more people with secondary brain tumours</td>
<td>Southwark residents</td>
<td>Tel: 0207 525 3843</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Fax: 0208 693 6760</td>
</tr>
</tbody>
</table>

London Consortium Specialist Neuro-rehabilitation Facilities

Blackheath Brain Injury Rehabilitation Centre
Thames Brain Injury Rehabilitation Unit
Heathside Neurodisability Unit
- 80-82 Blackheath Hill
  London
  SE10 8AD
  Tel: 020 8692 4007
  Email: blackheath@fshc.co.uk

Royal Hospital for Neuro-disability Putney
- West Hill
  Putney
  London
  SW15 3SW
  Tel: 020 8780 4500
  Fax: 020 8780 4501
  Safehaven: fax: 020 8780 4511
  Email: info@rhn.org.uk

Regional Neurorehabilitation Northwick Park Hospital
- Northwick Park Hospital,
  North West London Trust, Watford Road, Harrow, HA1 3 US
  Tel No: 0208 869 2800 / 2811
  Fax: 0208 869 3215

Neurorehabilitation & Therapy Services - National Hospital for Neurology & Neurosurgery
- Queen Square, London, WC1N 3BG
  Tel No: 020 7837 3611

National Hospital for Neurosurgery and Neurology Molly Lane Fox Unit
- Based at Queen Square
  Queen Square, London, WC1N 3BG
  Tel: 0203 448366

Frank Cooksey Rehabilitation Unit
- Lewisham University Hospital,
  High Street,
  London SE13 6LH
  Tel: 0208 3333462

Lishman Unit
- Douglas Bennett House
  Maudsley Hospital
  SE5 8AZ
  Inpatient referrals: Tel: 020 3228 2137
  Fax: 020 3228 2023
  Outpatient referrals: Tel: 020 3228 2092
  Fax: 020 3228 2087

Regional Neurological Rehabilitation Unit Homerton Hospital
- RNRU
  Homerton University Hospital NHS Foundation Trust
  Homerton Row
  London
  E9 6SR
  Tel: 020 8510 7970
  Fax: 020 8510 7318.
**Wolfson Neuro-rehabilitation Centre**
- Wolfson Neurorehabilitation Centre, Copse Hill, Wimbledon, SW20 0NQ
  - Tel: 0208 2666544
  - Fax: 0208 2666523

**Spinal Cord Injury Units (referral must come from Medical team)**

<table>
<thead>
<tr>
<th>Location</th>
<th>Hospital/Unit</th>
<th>Telephone</th>
<th>Unit</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Stanmore</strong></td>
<td>The Royal National Orthopaedic Hospital</td>
<td>020 8954 2300</td>
<td>2300</td>
</tr>
<tr>
<td><strong>Stoke</strong></td>
<td>National Spinal Injuries Centre</td>
<td>01296 315000</td>
<td>315000</td>
</tr>
</tbody>
</table>

Note: Kent and Medway Network List of Neurorehabilitation Facilities to follow—please contact Bryony Neame Kent and Medway Cancer Network for details.
Appendix 7

Patient Access - Travel and Accommodation

Road travel:
The King’s site has changed over the past four years with the opening of a new building (the Golden Jubilee Wing) and improved management of traffic circulation around the site. There are new, larger parking facilities on the hospital campus sited adjacent to clinical areas. King’s is outside the Congestion Charging zone.

Both Guys and St Thomas and Maidstone have limited parking for patients and relatives. There is a large NCP car park adjacent to Guys hospital.

Hospital transport:
In certain, clinically indicated, circumstances, hospital transport may be provided to enable patients to attend the Outpatient Clinics – this can usually be arranged via the patient’s GP by contacting 0207 1883888.

Rail travel:
Denmark Hill Station is 5 minutes walk from King’s. Denmark Hill has regular direct rail links to:
- Central London - Black friars, London Bridge and Victoria
- South East England and Kent - Orpington, Sevenoaks, Dartford, etc.

Loughborough Junction Station (Thames link services to London Blackfriars via Elephant and Castle) is approximately 12 minutes walk away.

Both Guy’s and St Thomas Hospitals are within easy reach of the main line underground stations. Guy’s Hospital has a dedicated walkway from the hospital building into London Bridge mainline and underground stations. St Thomas Hospital is a seven minute walk from Waterloo/Waterloo East main line stations and Waterloo and Lambeth North underground stations.

Bus Travel:
All three sites of the Joint Cancer Centre have excellent access from a number of bus routes

Accommodation:
An up-to date-list of local bed and Breakfast accommodation can be supplied to patients by contacting the key worker.
Appendix 8

Neuro-oncology
Clinical Nurse Specialists

Who are we?
Jamie Logan, Gillian Blackler and Vicky Hurwitz

What we do?
- We meet patients pre and post surgery
- Provide you with an opportunity to talk through information
given to you by the Doctors
- Support you and go through results of your surgery and
provide you with written information
- Act as a link with other health professionals as needed
- Offer nursing advice on symptom and medication managemnt
- Act as your keyworker, easing your journey through the service
- Support and give advice to you and your family/carers

Where are we based?
Based here at Kings College hospital but we will be present during your clinic
appointments if you go onto have further treatment at Guys and St Thomas Hospital.

Contact details:
Telephone: 0203 2998691
Fax: 0203 2991865
Email: kch-tr-neuro-oncology@nhs.net
Pager: via KCH switchboard KH 3851

The service can be accessed from
9.00 - 5.00 Monday - Friday.
However, an answer phone is always
available should we be out of the office.

Other members of the Neuro Oncology team involved in your care.
- Mr. Bhangu: Consultant Neurosurgeon
- Mr. Ashkan: Consultant Neurosurgeon
- Mr. Gullan: Consultant Neurosurgeon
- Mr. Bell: Consultant Neurosurgeon
- Mr. Thomas: Consultant Neurosurgeon
- Dr. Beany: Consultant Clinical Oncologist & Radiotherapist
- Dr. Brazil: Consultant Clinical Oncologist & Radiotherapist

Useful contacts:
Donna Moore
Neuro-oncology co-ordinator Kings College Hospital
Tel: 02032994151

Appointments at Guys and St Thomas hospital:
0207 1889793

National Information Sources:
www.macmillan.org.uk for all kinds of support and information
www.dvla.gov.uk for information regarding driving and surrendering your drivers license.
Brain Tumour Support Group
For patients and carers

Whether you are just diagnosed or are already having treatment, this group will give you the opportunity to meet others going through similar experiences.

We meet on the first Monday of each month
1.30 – 3.00pm
At Dimbleby Cancer Care
2nd Floor, Gassiot House
St Thomas’ Hospital

Dates for 2011
10 January, 7 February, 7 March,
4 April, 9 May, 6 June, 4 July,
1 August, 5 September, 3 October,
7 November, 5 December

For more information contact: Jamie Logan 020 3299 4151
Or Dimbleby Cancer Care 020 7188 5918
How to find us

You can talk to us on
0203 299 5229

or visit
Macmillan Information and Support Centre
Cicely Saunders Institute
King’s College Hospital
Denmark Hill
London SE5 9RS

Located at King’s College Hospital between the Beasenher Wing and the Weston Education Centre

Open Monday to Friday 10am to 4pm (except Bank Holidays)

Questions about living with cancer?
Call Macmillan free on 0800 000 000 (Mon-Fri 9am - 8pm)
 Alternatively, visit macmillan.org.uk

Hard of hearing? Use textphone 0808 808 0121, or Text Relay.

Non English speaker? Interpreters available.

We are here for you

Macmillan Information and Support Service

We are Macmillan. Cancer Support

© Macmillan Cancer Support, March 2011. MACS11519

Macmillan Cancer Support, registered charity in England and Wales (264017); Scotland (SC039907); and Isle of Man (604).
Who we are

When you’re affected by cancer or a long term condition, having the right kind of information and support, at the right time, is essential. The Macmillan Information and Support Centre at King’s College Hospital provides a welcoming, confidential, drop-in service for anyone affected by cancer or long term conditions. This includes people who:

- require information
- are living with the consequences of a difficult diagnosis
- are looking to reduce the risk of developing cancer or long term conditions
- are a carer, relative, or friend looking for support
- are healthcare professionals looking for advice

How we can help

Staffed by a Macmillan information and support manager and trained volunteers, we are able to provide:

- literature on all aspects of living with cancer and long term conditions.
- internet access to guide people to appropriate information resources.
- the opportunity to discuss treatments, side effects and other disease related issues.
- the opportunity to talk to someone in a private, comfortable, quiet room.
- over the phone information and support for those not able to access the service in person.
- tailored NHS Information Prescriptions

We also offer

- links to local and national support services
- signposting people to self help and support groups
- referral to our local complementary therapy service
- liaison with other voluntary and statutory agencies
- access to benefits advice

‘Having someone to talk to and find the information I needed was so helpful’

Information centre visitor