Rehabilitation Services within Essex Cancer Network for people with Brain & CNS tumours

The NICE IOG for people with Brain & other CNS tumours (2006) states that patients with such tumours should have rapid access to AHP assessment & rehabilitation, including specialist neurorehabilitation where appropriate, as their condition changes. This includes the immediate access to, or provision of, specialist equipment as necessary, and access to neurorehabilitation services should not be based on diagnosis or prognosis, but on the needs of the patient, rehabilitation potential and patient goals.

Tumours of the brain and CNS can be complex due to poor prognosis, extent of disability, and experiences of long-term progressive, physical, cognitive and emotional problems. This requires an AHP workforce that is skilled in both physical and emotional issues to deal sensitively and competently with patients and their families/carers.

Rehabilitation in oncology should be offered from pre-diagnosis through to end of life and at all key stages in-between, as determined by the functional problems encountered by the patient and/or carer/family. Rehabilitation in oncology and palliative care aims to be:

- Preventative – reducing the impact of expected disabilities and assistance in learning to cope with any disabilities
- Restorative – returning the patient to pre-illness level without disability
- Supportive – in the presence of persistent disease and the continual need for treatment, the goal is to limit functional loss and provide support
- Palliative – further loss of function, put in place measures which eliminate or reduce complications and to provide support (symptom management)

Cancer rehabilitation attempts to maximise patients’ ability to function, to promote their independence and to help them adapt to their condition. It offers a major route to improving their quality of life, no matter how long or short the timescale. It aims to maximise dignity and reduce the extent to which cancer interferes with an individuals physical, psychosocial and economic functioning.
This report looks at the AHP service provision (Physiotherapy, Occupational Therapy, Dietetics, Speech and Language Therapy and Lymphoedema Therapists) across the Essex Cancer Network (ECN) with recommendations for service development, referring to the local rehabilitation pathway produced in conjunction with the NCAT Brain & CNS tumour rehabilitation guidelines (appendix 1 and 2). The NICE Supportive and Palliative Care IOG describes a recommended model of rehabilitation assessment and support, with 4 levels of training and expertise for AHP groups. Level 2 would describe generalist or rotational staff, Level 3 are experienced AHPs with a basic level of cancer training, and Level 4 are advanced practitioners working solely or predominantly within cancer or palliative care with higher level training in the rehabilitation needs of people with cancer. The Brain & CNS IOG recommends that patients with brain and CNS tumours should be seen by Level 3 or 4 practitioners due to the complexity of the disease.

The current Essex Cancer Network Rehabilitation Pathway for patients with brain and CNS tumours can be found in appendix 3.

North East Essex

North East Essex has a good structure for patients with brain and CNS tumours between the acute trust and the voluntary sector (St Helena Hospice). There are no staff in post specifically for such patient groups as the patient numbers are not sufficient. The majority of in-patients are transferred to Essex County Hospital where there is a rehabilitation team consisting of a senior OT (full time), senior physiotherapist (0.5 WTE) and a senior dietician (0.5 WTE). Unfortunately the OT and dietetic posts are rotational which means that they do not fulfil the NICE Supportive & Palliative Care Level 3 or 4 practitioner guidelines. The SaLT input is not oncology specific and is provided as required by generalist (Level 2) staff. The physiotherapy post is level 3 as this is currently a static post. There is also an Oncology Rehabilitation Assistant working across Occupational Therapy and Physiotherapy at Essex County.

Patients can be referred to all AHP services via radiotherapy, and work is in progress to improve referral processes from the chemotherapy suite to PT/OT.
There has historically been a lack of holistic nursing assessment available to patients due to the lack of a CNS. There has been a recent appointment to this post (split between CHUFT and MEHT) which will have a positive impact on holistic assessment and appropriate referral to rehabilitation services. There has recently been developments regarding the network MDT and AHP representation has been determined by means of a rota between the Occupational Therapist and Physiotherapist at Essex County.

There is a well established neurological rehabilitation team consisting of specialist physiotherapists and occupational therapists trained in neurological conditions, with access to speech and language therapy services. The team (with the exception of speech and language therapy services) have not historically taken patients with brain tumours with a poor prognosis. However, as the Brain & CNS IOG states that people should have access to services based on clinical need not prognosis the referral criteria has recently been amended. It is generally agreed in North East Essex that the neurorehabilitation team accept low grade tumours with the hospice accepting patients with high grade tumours or advanced disease. Patients who have complex neurological problems from their condition are now able to be referred to the team for intervention and support, with St Helena Hospice dealing with clients with complex psycho-social issues, or minor physical disorders that do not require specialist neurorehabilitation. The neurorehabilitation team does have a large waiting list in comparison to the hospice but urgent referrals may be expedited if the patient’s condition dictates. However, it must be noted that patients with complex physical and psychosocial issues may be under the care of the hospice if this is deemed appropriate by the patient, their family and the rehabilitation teams; this will be determined on an individual basis. There is also access to hydrotherapy either via musculoskeletal out-patients or with neurorehabilitation team.

There is an exercise group available for people who are suffering from the effects of treatment (fatigue, weight gain and deconditioning), and a one-to-one advisory service is available with a specialist oncology physiotherapist if people wish to improve their symptoms outside of a group environment. In-patient rehabilitation occurs on the acute oncology wards. There are rehabilitation facilities available at Kate Grant ward in Clacton, though patients are not necessarily accepted dependent on prognosis.

Patients with lymphoedema can be referred to the North Essex Lymphoedema Service (NELS) which has 0.8WTE lumphoedema therapist supported by 0.6WTE of physiotherapy input (awaiting formal MLD training).

Key Points NEE

- Good neurorehabilitation, acute and specialist palliative care services available though not all Level 3
- In-patient, out-patient and domiciliary services available
- Hydrotherapy available if appropriate
- New Brain CNS will improve patient referrals to rehabilitation
Mid Essex

In Mid Essex the services are currently in a state of change due to the opening of a new hospital building and a re-shaping of services. The oncology patients at Broomfield Hospital are situated on a general surgical and medical wards so the AHP team is both rotational and generalist as they are dealing mainly with non-cancer patients within their caseload. There is a neurological rehabilitation service for half a day, 5 days a week for PT which is consultant referral or referral for OT/PT following an in-patient stay. There are no Brain and CNS tumour specific posts as in other areas due to the low number of patients involved. Speech and Language Therapy and Dietetic input is from generalist (Level 2) staff for in-patients and out-patients.

Patients being repatriated from Queens Hospital following surgery are often placed on the Stroke Unit where they receive in-patient neurorehabilitation. Patients may be sent to general medical wards where they will be seen by the generalist ward staff.

There is good support from Farleigh Hospice for specialist palliative care occupational therapy and physiotherapy services, and the majority of domiciliary work is carried out by this team, with occasional referrals to St Peter’s (Maldon) and Braintree Community Hospital for input. Farleigh Hospice have also set up a Multi Professional Team Meeting for neurology patients (including people with Brain and CNS tumours) in Mid Essex to formulate care plans and ensure access to on-going rehabilitation is available. There is currently no exercise group to combat treatment effects. There are no radiotherapy services at MEHT so patients would be referred to the rehab team at CHUFT and patients would be offered rehab in Colchester for physiotherapy and occupational therapy assessment and dietetic input. Equipment cannot be provided by the NEE team for Mid Essex patients by OT but the two teams can liaise regarding the needs of patients across boundaries.

A member of the hospice team attends the network MDT meeting though these are subject to repeated technology failure (the Essex Cancer Network has commissioned a review of these services).

St Peter’s hospital in Maldon has a small number of in-patient beds that can be accessed for rehabilitation, and patients are occasionally repatriated from ECH to St Peters. Braintree Hospital has a small number of beds for end of life care which can be accessed if required.

As with North East Essex, there has not been a CNS in post. The new appointment of a shared CNS will hopefully improve referrals to rehabilitation services.
Lymphoedema services are available from the Helen Rollason Centre in Chelmsford (1WTE) and St Peter’s hospital in Maldon.

Key Points Mid Essex
- Good support for OT & PT via Farleigh Hospice for patients and carers with identified palliative care needs (although there is no service level agreement)
- Network MDT attendance
- No level 3 or 4 staff within acute trust
- Neurorehabilitation available from the acute Trust (physiotherapy only)

South East Essex

South East Essex has a rehabilitation ward (Paglesham Ward) to which patients can be transferred dependent upon rehabilitation potential. This unit has neurologically trained Physiotherapists, Occupational Therapists and Speech and Language Therapists who can also follow up patients in the community. Patients who are not deemed to have rehabilitation potential are transferred to the oncology ward (Elizabeth Loury Ward) where they have static senior occupational therapy (1WTE) and rotational physiotherapy, dietetic and speech and language therapy input.

Members of the rehabilitation team attend a weekly MDT meeting with Dr Madhavan, as well as attending the Network MDT. Community Physiotherapy is available from senior PTs for patients with rehabilitation potential. Referrals are accepted from the ward, Haven Hospice, GPs, DNs, OT’s and Macmillan Nurses. This service is intended to provide input to achieve short term goals and not for long term maintenance.

There are currently no formal links with radiotherapy or chemotherapy for out-patient AHP services.

Haven hospice does not directly employ any AHP services. Palliative services are provided for the Hospice via the PCT duty OT Team, and acute community services for PT, dietetics and SaLT. Lymphoedema services are supplied from the South Essex Lymphoedema Service.

There are no specific posts to cover patients Brain and CNS cancer, as with other areas there are not sufficient patient numbers. There are 2 Brain CNS’s and a Palliative Care Nurse who can refer to AHP services following holistic assessment.

The Southend Hospital palliative care team/Haven Hospice run a comprehensive Cancer and Palliative Care Education Course which is attended by AHP’s working in this field.
Key Points South East Essex

- Good neurological rehabilitation facilities available as in-patient with community follow up available
- Well established links with CNS and palliative care nurses
- Community and acute teams cover hospice patients
- Network MDT attendance
- Level 4 OT in acute and community
- Good training program available
- No Brain & CNS specific posts

South West Essex

Patients with palliative needs are transferred to Orsett Ward which has static specialist occupational therapy (1WTE) and Physiotherapy (0.6WTE Mon - Wed) with input from generalist dietician and Speech and Language Therapists. It must be noted that the Physiotherapist also covers the medical respiratory patients across the hospital which take priority in times of staff absence, bed pressures etc. There is support available for patients with Brain and CNS tumours via the neurorehabilitation physiotherapy team who are available to treat in-patients. Some primary tumours would be placed on general medical wards and have input from the neurorehabilitation physiotherapy team with general/rotational staff covering all other AHP roles. There are no specific roles covering Brain & CNS tumours due to the relatively low number of cases.

There is very limited physiotherapy input into St. Luke’s hospice, with just 4 hours per week funded for in-patients and out-patients. Occupational therapy services are provided via the community Macmillan team which has 2 WTE senior OTs in post. Patients requiring speech and language therapy and dietetic input are referred to the acute services.

Hydrotherapy services are available dependent on the patient’s condition. Rehabilitation beds are available in the community but are difficult to access and have a limited time scale (1-2 weeks). There is community Physiotherapy available but not cancer specific – the Neurorehabilitation team are able to see Brain & CNS patients as out-patients with consultant referral. There is representation for the Network MDT from the community Macmillan occupational therapy Team.

Radiotherapy and chemotherapy services are provided at Southend hospital. It has been noted that there are no formal lines of communication between AHPs at present between Southend and Basildon which can cause delays in patient care.

CNS input is via the Southend Team; there are good links with the community Macmillan OT Team who frequently refer patients receiving chemotherapy or radiotherapy at Southend.
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There is currently no specific training other than a basic introduction to cancer course.

Key points South West Essex

- Very little physio input at St Luke's Hospice
- Good in-patient and community Level 4 OT services available
- Neurorehab available as in-patient and out-patient (physio only)
- Need to improve lines of communication between SWE and cancer centre
- Hydro available if appropriate

Links with Queen’s Hospital

As the neurosurgical centre for the Essex Cancer Network, all patients with Brain & CNS tumours are discussed by the neurosurgical team and local hospitals in a weekly videolink SMDT meeting. Surgical patients are transferred to Queen’s hospital either for elective or emergency surgery following discussion with the neurosurgical team. Rehabilitation is provided on the ward by the neurosurgical OT and PT team and discharge home may be facilitated by this team. More complex patients requiring further rehabilitation are transferred back to local hospitals for input. It has been noted that lines of communication between Queen’s Hospital and local hospitals could be improved and contact lists have been compiled for all rehabilitation staff in Essex and Queen’s to facilitate this. This will be helpful in ensuring continuation of care along the pathway for patients returning to the community, or for patients requiring complex in-patient rehabilitation.

Summary

There are variations across the network in the provision of services for patients with Brain & CNS tumours. There are no specific posts for this client group across the network due to the small caseload in each locality. Neurorehabilitation is available in all areas but in Mid and South West Essex this involves physiotherapy only. There is, however, good support in these areas from the hospice and community teams.

With the exception of Southend there is little or no formal training for AHPs in this area. This will be addressed in the Essex Cancer Network AHP Training and Education Strategy document, as brain tumours is an area consistently cited as an area that AHPs would like more training in.
### Organisational Workforce Template

#### Essex Cancer Network

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**Level 4 in place**

**Level 3 in place, no level 4 therapist**

**Neuro specialist**

**Generic staff**

**No therapist/permanent staff**
Brain & CNS Cancer Rehabilitation Pathway

Initial presentation at local GP or hospital, local imaging and SMDT discussion. Treated on acute ward.

Yes → Surgery

No → Transfer to local hospital

Transfer to local hospital → Radiotherapy

Radiotherapy

Yes → Chemotherapy

No → Transfer home

Chemotherapy

In-patient

Out-patient

Hospital in-patient team

Rehabilitation Co-ordinated by AHP Neuro-oncology Lead

Hospice team (appropriate for palliative patients with complex psychosocial needs or patients without rehabilitation potential)

Specialist neurorehabilitation (appropriate for patients with complex physical needs. Must have rehabilitation potential)

General Rehabilitation
(Teams such as general community teams, musculoskeletal or intermediate care, appropriate for patients without complex needs)

Hospice Team/Palliative Care Team

End of life care

Post-treatment/monitoring

Local Teams

Queens Hospital team

CHUFT/SUHFT

Local Teams

Local Hospital

Diagnosis

Treatment

Essex Cancer Network