

Working with people affected by a brain tumour, healthcare professionals, policy makers and politicians, we will deliver equal access to the best treatment and care.

Key points

Rehabilitation is the process of assisting individuals with conditions such as brain tumours to maximise their independence and function after injury or illness. Neuro-rehabilitation is likely to be most relevant to people affected by a brain tumour.

- Brain tumours and treatment are likely to have symptoms which affect individuals' cognitive and physical state. Rehabilitation is integral to living with the disease and aiding recovery.
- However, access to rehabilitation services in the UK is varied with long waiting lists and a lack of communication. People with low grade tumours are significantly less likely than those with high grade tumours to have access.
- NHS organisations need to ensure ease of access to appropriate rehabilitation services and a Recovery Package.
- In England, NHS England and Health Education England should support a national review of the cancer rehabilitation workforce as recommended in the cancer strategy.



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Introduction

As a result of a brain tumour, and the adverse effects of treatment those affected may face neurological deficits which can have a negative impact on co-ordination, speech, mobility and the ability to manage personal care.

Rehabilitation can help to manage and alleviate these symptoms, particularly through the application of speech and language therapy, occupational therapy and physiotherapy. Rehabilitation services are delivered in a number of different settings, including hospitals, community health centres, mainstream and special schools for children, assessment units and day centres, as well as the homes of patients.

Referrals to neurorehabilitation units in hospitals are usually made through a healthcare professional such as a GP, but in some centres a patient or carer is able to make an application to access rehabilitation services, subject to bed spaces.

Clinicians should consider referring individuals with a brain tumour for rehabilitation assessment at diagnosis and every stage of follow up. After treatment the primary aim of rehabilitation is for functional improvement and in more advanced stages of the disease there is likely to be greater focus on the individual's quality of life. Clinicians should also offer information on accessing rehabilitation and what it can help address. Sign-posting to post treatment rehabilitation may also be included as part of the Recovery Package.

Once a referral has been made, the rehabilitation unit will carry out an assessment to make sure their service is suitable. Specific details about the referral process, availability of places and funding options will be available from the unit.

The United Kingdom Acquired Brain Injury Forum (UKABIF) website has a **directory** of rehabilitation services which lists care providers, therapists and voluntary organisations that specialise in acquired brain injury.

The issue

It is vital that patients affected by brain tumours are considered for referral for rehabilitation at diagnosis and every stage of follow up. The role of rehabilitation in delivering functional improvement after treatment and improving quality of life has been set out in guidance published by the National Institute for Health and Care Excellence (NICE)¹. NICE also state in the *Quality Standard on Children and young people with cancer* that access to skilled neurorehabilitation can promote autonomy for children and young people and reduce the need for more complex care².

Our report, *Losing Myself: The Reality of Life with a Brain Tumour* has provided a clearer picture of levels of access to neurorehabilitation services across the UK³. Out of 1,004 adults who filled out the questionnaire, 52% had accessed physiotherapy, 50% had accessed occupational therapy, 43% had visited a psychologist, and just 25% had accessed speech and language therapy.

The report also indicated that patients who have access to neurorehabilitation in some form after treatment are generally satisfied with the quality of services they receive. Nearly two-thirds of those who had accessed speech and language therapy, occupational therapy or physiotherapy were satisfied or very satisfied with the experience they received.

However, there was some variation in access to neurorehabilitation, and for patients who were dissatisfied with those services the main difficulties highlighted were around accessing services in the first place, with the most common themes being a long waiting list and poor communication between healthcare professionals and patients. We also found that people with a high grade brain tumour are significantly more likely than those with a low grade brain tumour to have had access to speech and language therapy, occupational therapy and physiotherapy.

We call on NHS organisations to address variations in access to rehabilitation and neurorehabilitation specifically. *Achieving World-Class Cancer Outcomes: A Strategy for England 2016-2020* states that rehabilitation is not yet embedded across the cancer pathway in England and recommends that NHS England and Health Education England should support a national review of the cancer rehabilitation workforce and promote the role of AHPs in multi-disciplinary teams⁴. However, as yet no review has taken place.

In Scotland⁵, Wales⁶ and Northern Ireland⁷, documents from the different administrations highlight the importance of every cancer patient being able to access rehabilitation services.

In Wales, the *National Standards for Rehabilitation of Adult Cancer Patients* were developed and based on NICE service guidelines and calls for a range of measures, including that each Cancer Network Board should agree a single named lead and deputy for cancer rehabilitation, and that every patient should have access to a key worker (usually a clinical nurse specialist). This is important for identifying rehabilitation needs at an early stage of treatment, and for ensuring that there is consistent referral processes across Cancer Networks.

We call on Local Health Boards in Scotland and Wales, and Trusts in Northern Ireland to implement the recommendations around cancer rehabilitation in these documents to ensure consistency of access to neurorehabilitation services, both in acute and community settings.

¹ <https://www.nice.org.uk/guidance/csg4> and www.nice.org.uk/guidance/csgbraincns/evidence/improving-outcomes-for-people-with-brain-and-other-cns-tumours-the-manual2

² <https://www.nice.org.uk/guidance/qs55/resources/guidance-children-and-young-people-with-cancer-pdf>

³ <https://www.thebraintumourcharity.org/about-us/our-publications/losing-myself-reality-life-brain-tumour/>

⁴ <http://www.cancerresearchuk.org/about-us/cancer-strategy-in-england>

⁵ <http://www.gov.scot/Resource/0039/00390510.pdf> and <http://www.gov.scot/Publications/2016/03/9784/downloads#res-1>

⁶ http://www.wales.nhs.uk/sites3/Documents/322/National_Standards_for_Rehabilitation_of_Adult_Cancer_Patients_2010.pdf

⁷ http://www.dhsspsni.gov.uk/service_framework_for_cancer_prevention_treatment_and_care_-_full_document.pdf

Recommendations

The Brain Tumour Charity are not currently actively campaigning on issues related to neuro-rehabilitation. However, we collaborate across several coalitions with an interest in this area and offer our assistance where appropriate.

- NHS England and Health Education England should support a national review of the cancer rehabilitation workforce as recommended in *Achieving World-Class Cancer Outcomes: A Strategy for England 2016-2020*.
- Relevant NHS organisations should ensure that every person affected by a brain tumour has access to a Recovery Package and should distribute the *Patient Guide to Brain Tumour Treatment and Services* to those affected⁸.

⁸ <https://www.thebraintumourcharity.org/understanding-brain-tumours/navigating-the-system/our-patient-guide/>