

# Brain tumour: Useful contacts and links

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**Being diagnosed with a brain tumour can be life-changing. This leaflet gives some useful contacts that may help you manage some of the challenges. Please speak to your clinical nurse specialist for further information and/or referral.**

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## Charities

- The Brain Tumour Charity <https://www.thebraintumourcharity.org/> and BrainsTrust <https://brainstrust.org.uk/> are the two national brain tumour specific charities in the UK that we often link with at the RBH. Their websites have lots of information on brain tumours and treatment for patients and their families. Both charities do regional meet ups/events as an opportunity to meet others in similar situations and also have online support via facebook groups.
- Macmillan <https://www.macmillan.org.uk/> – The Berkshire Cancer Centre and its staff are supported by Macmillan Cancer Research. There is a vast range of literature available on the Macmillan website; specifically regarding managing symptoms of a brain tumour and side effects of treatment. The website also has advice on issues such as finances and benefits, emotional well-being and employment rights.
- The Macmillan Information Centre located in the Berkshire Cancer Centre is available for advice and information to patients, relatives, visitors and staff. They are open Monday to Thursday 9am-4pm and Friday 9am-2pm (except bank holidays).

## Holistic Needs Assessment

A HNA is a simple questionnaire routinely offered to patients once they have finished treatment to identify any needs or areas of concern. A time is then arranged to privately go through the answers with your clinical nurse specialist and create a care plan on how the team can best support you. The questionnaire can also be completed anytime during your cancer journey, a HNA is often a good starting point if you are struggling or feeling overwhelmed, as the team can work through it to get you feeling better.

## Driving

Drivers diagnosed with a brain tumour **must** notify the DVLA [www.gov.uk/government/organisations/driver-and-vehicle-licensing-agency](http://www.gov.uk/government/organisations/driver-and-vehicle-licensing-agency). This may result in you having to surrender your driving licence.

## Financial support

In the Berkshire Cancer Centre, the Macmillan Information Centre work alongside the Citizens Advice Bureau assisting patients and relatives/carers to fill in benefit applications. Brain tumour patients may be eligible for benefits such as 'Personal Independence Allowance (PIP)' or

'Attendance Allowance'. If you are diagnosed with 'Glioblastoma Multiforme' you are also entitled to a benefit called DS1500. Carers may also be entitled to financial support and some benefits can be provided to help with childcare costs. The Macmillan website has a lot of information on this subject <https://www.macmillan.org.uk/information-and-support/organising/benefits-and-financial-support>.

## Travel

- Patients with certain types of brain tumour are eligible for a disabled person's railcard which entitles you to 1/3 off fares. Apply online by visiting: <https://www.disabledpersons-railcard.co.uk/are-you-eligible/>
- The same applies with bus passes – this may vary depending upon where you live. To find out if you are eligible for a concessionary bus pass, patients who live in Reading please contact 'Reading buses' tel: 0118 959 4000 or email [customerservices@reading-buses.co.uk](mailto:customerservices@reading-buses.co.uk). If you live outside Reading, check with your local bus provider.
- There are also volunteer driver schemes that cover Twyford, Wargrave, Wallingford, Wokingham, Woodley, Kintbury, Lambourn, Maidenhead, Newbury, Thatcham, Sonning Common, Goring, Streatley, Henley, Hungerford, Benson, Bracknell, Bradfield and Bullbrook. They usually ask for a small donation towards this service. Ask at the Macmillan Information Centre for details or visit the Reading Voluntary Action website for more information <http://rva.org.uk/wellbeing/transport/>

## Epilepsy

Many patients diagnosed with a brain tumour develop epileptic seizures so you may require management under the neurologist team alongside the oncologist at the RBH. There is also an epilepsy specialist nurse in the RBH.

Epilepsy Action [www.epilepsy.org.uk](http://www.epilepsy.org.uk) provides practical information on topics such as safety, well-being, memory, sleep, stress and alcohol. There is also advice on benefits, entitlements and employment.

Basic seizure first aid includes: keeping the person safe by moving any harmful objects nearby, not restraining them or putting anything in their mouth, staying with the person and timing how long the seizure lasts. If possible put something soft under their head and loosen any tight clothing and remain with the person and keep calm until they recover. It is advisable to call an ambulance if the seizure doesn't stop after five minutes or if a second seizure follows shortly afterwards.

Sensible precautions when diagnosed with epilepsy include: avoiding swimming, bathing or showering alone and also avoiding power tools and kitchen appliances when alone.

The Hidden Disability (sunflower) lanyards are now recognised in the UK and some patients feel more confident when wearing one out in public places, more information can be found [on hiddendisabilitiesstore.com](http://hiddendisabilitiesstore.com)

## Children and young adults

- Daisy's Dream <https://www.daisysdream.org.uk/> is a professional support service that responds to the needs of children and families affected by life threatening illness and bereavement. It covers Berkshire and surrounding areas and offers services such as telephone support, home or school visits and group events.
- Willow Foundation <https://www.willowfoundation.org.uk/> is a national charity that provides special days out for anyone aged 16-40 who is diagnosed with a serious illness. Application forms can be found on their website.
- SHINE [www.shinecancersupport.org](http://www.shinecancersupport.org) is a UK charity that supports adults in their 20s 30s and 40s who have received a cancer diagnosis. This is done through a range of activities including lunches and drinks evenings, multi-day getaways, workshops, online networking, and mentoring.

## Community Palliative Care

Community Palliative Care Team (CPCT) are specialist nurses that work in the community caring for patients with a terminal illness. At the RBH our patients are supported by either Sue Ryder or Thames Hospice. CPCT are specialised in areas such as pain management and symptom control. They can also assist with psychological/emotional needs. CPCT also have physiotherapists and occupational therapist that can help patients to live safely at home. There are also hospice settings where patients can receive respite and end of life care.

CPCT are a point of contact when the patient is at home as they work seven days a week and their expertise can often avoid an unnecessary hospital admission. Please speak to your clinical nurse specialist if you would like a CPCT referral if you have not yet been offered one.

## Day hospice

This is a service for any patient with a terminal condition. It involves attending the hospice for the day (usually on a weekly basis) and receiving support psychologically, physically and socially. There are specialist palliative care nurses on hand as well as physiotherapists, occupational therapists, dietitians and many other services during your visit. It is an opportunity to meet other people in similar situations and to participate in activities and hobbies. There can be a waiting list for this service so please express interest early.

## Speech and Language Therapy (SALT)

The hospital and the community has a specialist team to help patients with issues such as swallowing difficulties, slurred speech, difficulty connecting words and difficulty comprehending / understanding language / following instructions. Due to the COVID pandemic, this service has been reduced but please speak to your specialist nurse.

## Sight / vision

Patients with visual disturbances as a result of their brain tumour can be booked into the 'Low vision assessment clinic' at the RBH. This team can assess your eye health and provide advice

Compassionate

Aspirational

Resourceful

Excellent

or tools to help you with daily activities. For example, aids can be inserted into glasses lenses to help with visual field loss and double vision.

## Complementary therapies

- MyCancerMyChoices is a charity within the RBH that offers therapies such as massage, reflexology and acupuncture. You can self-refer on the website <https://mycancermychoices.org/>. A small donation is appreciated.
- Mindfulness has proven very effective at managing the emotions and stresses of living with cancer. There are lots of mobile apps available, e.g. Headspace. Brain tumour patients can attend an eight week course run by a specialised psychologist at Oxford. Please let your CNS know if you are interested as there is usually a short waiting list.
- LookGoodFeelBetter <https://www.lookgoodfeelbetter.co.uk/> is an international charity that runs confidence boosting workshops for women, men and young adults to manage the physical side effects of cancer. There are also lots of tips, advice and tutorials available on their website.

## Cancer Rehab Service

Supporting patients to 'Live well with cancer' is a scheme available in the RBH and also in the community. It offers services such as psychological support, physical activity, peer support, self-management and education. There are monthly 'Take control workshops' which are self-management courses for patients and relatives on enhancing recovery. There is also a weekly 'Enhanced supportive care clinic' which is a 1:1 appointment for those preferring a more private discussion or those needing additional support.

## Neuro rehab

Patients with weakness and strength problems as a result of their brain tumour may be entitled to physiotherapy to aid mobility and independence. Services vary depending on where you live and can include rehab at home, or at a local hospital or community centre. This may be discussed with inpatients when planning your discharge from hospital or you can ask your clinical nurse specialist for further details. Please note this service is brain tumour related only and not for any long standing conditions. There are also occupational therapists who work in the community who can assist with aids that make living at home easier if you have limited mobility and/or weakness due to your brain tumour.

## Information for carers

If you have found yourself taking on a 'carer' role since a relative or partner was diagnosed with a brain tumour there are certain entitlements and support available. Please speak to your clinical nurse specialist who can arrange to go through this with you in more detail.

## **Nutrition**

We advise all our patients to eat a healthy varied diet as the nutrients will help you feel better, stronger and have energy. Having a good source of protein is particularly helpful as it aids the body's immune system and ability to heal and repair. There is a really useful E-book available for free download on <https://www.trekstock.com/foodandcancer> that provides a 'no-nonsense, evidence based guide' on cancer and diet.

If you are on a particular chemotherapy treatment called PCV there are certain foods that need to be avoided. Your clinical nurse specialist will discuss this with you.

## **Fatigue and exercise**

Patients with brain tumours, particularly those on treatment, are prone to fatigue. This is more extreme than the usual feeling of 'tiredness' and is very debilitating for the individual. The charities mentioned earlier have a lot of information on ways of combating fatigue. Increasing physical activity often reduces the symptoms of fatigue and increases energy levels – start slow and build up your tolerance. It could be as simple as walking around the garden daily, with the aim of walking round the block when it becomes easier. Any form of physical activity can boost appetite and also improve sleep. This is particularly important when living with fatigue.

## **Clinical trials**

UK Clinical trials for brain tumours do not happen very often, however we have had patients accepted on trials at Oxford University Hospital. If you have found a trial you are interested in please discuss at your next oncology appointment. Cancer Research UK has details of all clinical trials in the UK on their website <https://www.cancerresearchuk.org/about-cancer/find-a-clinical-trial>.

## **Non-NHS prescribed medications**

If you are considering taking medication not prescribed via the NHS, e.g. herbal supplements, please discuss this with your clinical nurse specialist and your consultant. We cannot support medication prescribed outside the NHS but are open to patients trying alternative treatments as long as we are kept informed and patients have thoroughly researched what they are considering taking. Occasionally, non-prescribed medications can interact with chemotherapy drugs, hence the importance of keeping us informed.

## **Surgical care**

All brain tumour surgery is performed at Oxford John Radcliffe Hospital. There is a team of nurses at Oxford equivalent to your RBH clinical nurse specialists who co-ordinate the surgical side of your treatment. The Oxford nursing team can be contacted on 01865 234372. Upon discharge from Oxford the team will give you information on any necessary wound care management such as safe washing and stitch removal.

If your wound becomes more painful, red, swollen or leaking this could be signs of infection. If this happens it is important you contact the Oxford team as soon as possible as they specialise

in this type of wound management.

If you need to contact the Oxford team out of hours regarding your wound please ring 01865 741166 and ask for the neuro-surgery on-call doctor.

## Contacting us

Neuro Oncology Service

Key worker / Clinical Nurse Specialist

**Tel. 0118 322 8542** Monday, Tuesday, Thursday and Friday 8.30am – 4.30pm

To find out more about our Trust visit [www.royalberkshire.nhs.uk](http://www.royalberkshire.nhs.uk)

**Please ask if you need this information in another language or format.**

RBFT Oncology/Neurology, January 2022.

Next review due: January 2024