

the little white book

Greater London

**A directory of resources to help people
affected by a brain tumour**

Edition 1: May 2016

Contents

Networking	2
Psychological support	4
Support groups	8
Support for carers	14
Support for children	18
Support lines	20
Financial support	22
Complementary therapies	24
Holidays and short breaks	28
Welfare and legal advice	30
Transport services	38
Respite and end of life care	40
Bereavement support	46
What can <i>braintrust</i> do to help?	48

Introduction

We know how lost you can feel when you or your loved one is diagnosed with a brain tumour. But we also know how many invaluable support services there are available locally that can help you at every step of your brain tumour journey.

Here at *brainstrust* we've been working tirelessly with the help of our fantastic volunteers searching high and low for useful, local services for people affected by a brain tumour. This directory, focusing on the charity sector, includes information on some of the best of these services in Greater London. We hope you find it to be an authoritative guide and that it helps you access these resources in your area quickly and when you most need them.

We may not have included everything here just yet, but we have been able to bring together many sources of help that we're comfortable with and that we regularly recommend to our community. You can find the most up to date version of this information, and more online at **www.braintumourhub.org.uk**

Things change. New services will pop up, and some may stop operating or change their focus, but we will be reviewing the information within this directory every year. If there are any additional services that you would like to see in here, please get in touch with us on **01983 292 405** or email **hello@brainstrust.org.uk**

This guide would not have been possible without the support of The Rank Foundation, The Vera Wolstencroft Children and Animal Charitable Trust and the National Lottery through the Big Lottery Fund.

We hope you find it useful.

From all the team at *brainstrust*

Networking

The essence of networking is to share experiential sympathy and understanding which can be beyond the scope of health care professionals.

Networking also allows you to meet others from the wider community – not just those who typically attend support groups. These people can include researchers, fundraisers, charity workers and other interested parties.

It is important to be aware that whilst networking events can be a source of excellent information, they are much more ‘free-flowing’ than facilitated support groups. The discussion is not controlled, opinions can be subjective, and they may not constitute medical advice.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
brainstrust Meet Ups	brainstrust	07969 702201	Venues vary – please get in touch for details.	hello@brainstrust.org.uk www.meetup.com/brainstrust/	An opportunity for patients, carers and anyone affected by a brain tumour to get together socially with others and have fun. You can share experiences and seek information from people who know what you’re going through, but only if you want to. Previous get-togethers have taken place over pizza, tapas and afternoon tea.
Younger Adult Cancer Networking	Shine Cancer Support		Somerset House, Strand, London WC2R 1LA	london@shinecancersupport.org www.shinecancersupport.co.uk	Shine Cancer Support is a network for younger adults in their 20s, 30s and 40s living with and beyond cancer.
Nordic Walking Group	Maggie’s West London	020 7386 1750	Maggie’s West London, Charing Cross Hospital, Fulham Palace Road, London W6 8RF	london@maggiescentres.org www.maggiescentres.org/our-centres/maggies-west-london/whats-on/	Nordic Walking is a great way for people to get active, improve their fitness and meet other people. Walkers have found the classes, which last around an hour, a really enjoyable experience, not only for improving health and wellbeing, but also for invaluable peer support.

Psychological support

Alongside the care you receive from doctors, nurses and other health professionals you may wish to seek psychological and emotional support.

It is quite usual to experience stress, worry and concerns as a result of a brain tumour diagnosis or treatment. It may lead you to experience one or more of the following: anxiety, uncertainty about the future, anger, adjustment difficulties, distress, family communication problems, changes in body image, depression, decision-making difficulties, challenges balancing illness and treatment alongside the demands of life.

Some people can find it helpful to discuss their feelings, needs and concerns in a confidential space with a team experienced in helping patients and those close to them. Here we have some options for you.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Professional Post-Diagnosis Support	Dimbleby Cancer Care	020 7188 5918	St Thomas' Hospital, Westminster Bridge Road, London SE1 7EH	richarddimblebycentre@gstt.nhs.uk www.dimblebycancercare.org/services	This team of counsellors, psychologists and psychotherapists are experienced in helping people with the problems that follow a cancer diagnosis, and can be accessed by patients directly or by clinical teams. Access to a psychiatrist is also available.
London Personal Support and Group Activities	Paul's Cancer Support Centre	020 7924 3924	20 – 22 York Road, London SW11 3QA	support@paulscancersupport.org.uk www.paulscancersupportcentre.org.uk	This support centre provides a range of services for people affected by cancer such as one-to-one counselling, hypnotherapy, life coaching and "GetActive" classes. Their services can be used by anyone who can reach the centre, which is less than 10 minutes walk from Clapham Junction station, and at any stage – from diagnosis, through treatment and afterwards.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Cancer Support and Counselling Centres	Helen Rollason Cancer Support Centres	01245 380 719	Helen Rollason Cancer Support Centre, Radiotherapy Department, Ground Floor – Podium Building, North Middlesex University Hospital, Sterling Way, Edmonton, London N18 1QX	enquiries@helenrollason.org.uk www.helenrollason.org.uk	Three friendly, relaxing places where cancer patients can go – with their families, friends and carers – for support and counselling. Patients can also have therapies that work together with their medical treatment and reduce stress including massage and reflexology. Centres are available in Middlesex, Essex and Hertfordshire.
Emotional Support and Expert Advice	Maggie's West London	020 7386 1750	Maggie's West London, Charing Cross Hospital, Fulham Palace Road, London W6 8RF	london@maggiescentres.org www.maggiescentres.org/our-centres/maggies-west-london/	Drop into Maggie's for practical, emotional and social support from their professional staff at any time from 9am to 5pm, Monday to Friday. Maggie's also run groups, classes and workshops, free of charge.
The Jewish Community's Cancer Care and Support	Chai Cancer Care	0808 808 4567	Nightingale, 105 Nightingale Lane, London SW12 8NB and 142–146 Great North Way, London NW4 1EH	www.chaicancercare.org	This charity provides comprehensive, professional and expert services to any member of the Jewish community affected by cancer – patients, their families and friends.
brainstrust Counselling	brainstrust	01983 292405	Various	hello@brainstrust.org.uk www.brainstrust.org.uk	A programme of counselling uniquely designed for patients and carers affected by a brain tumour diagnosis. Sessions can either be face to face or over the telephone depending on the circumstances.

Support groups

Support groups are a place for people to give and receive both emotional and practical support as well as to exchange information. People with a brain tumour, as well as their friends and families, find support groups to be a valuable resource where people can share medical information, get confirmation that their feelings are “normal,” educate others, or just let off steam. When someone is searching for a support group, the single most important thing to remember may be: if the group doesn’t feel right to you or doesn’t match your needs, try a different group. There are many options available.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Hillingdon Brain Tumour Support Group	Hillingdon Brain Tumour Group	07769 323142	Hillingdon Park Baptist Church, Hercies Road, Hillingdon UB10 9LS	support@hbtg.org.uk www.hbtg.org.uk	Anyone is welcome to join the brain tumour support group in Hillingdon. The group is held at the Hillingdon Park Baptist Church and is aimed at patients, families and friends of those diagnosed with a brain tumour.
London Brain Tumour Support Group	Maggie’s West London	020 7386 1750	Maggie’s West London, Charing Cross Hospital, Fulham Palace Road, London W6 8RF	london@maggiescentres.org www.maggiescentres.org/our-centres/maggies-west-london/whats-on/	This group is open to adults affected by a brain tumour, including friends and relatives of those living with a diagnosis. It offers a chance to share experiences and issues related to living with or caring for someone with a brain tumour, facilitated by a clinical psychologist. Some meetings include a guest speaker. The group meets on a monthly basis, on the second Tuesday of each month between 1pm and 3pm.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Meningioma UK North London Support Group	Meningioma UK	01787 374 084	Community Room, Enfield Town Library, 22 Church Street, Enfield EN2 6AX	sue@meningioma.uk.org www.meningioma.uk.org/news/	This group is for those who have had or have a meningioma, their carers or family. The group offers the opportunity for people to discuss and share ideas and experiences and gain peer support. The group meets three times a year on a Saturday. There are groups in Essex, Kent, Cambridge and Enfield.
West Kent Brain Tumour Support Group	Maidstone and Tunbridge Wells NHS Trust	01622 228743	The Robert Hardwick Room, Academic Centre, Maidstone Hospital, Kent ME16 9QQ	e.kennaird@nhs.net www.mtw.nhs.uk	An informal way for patients to meet one another and maybe discuss their experiences over a cuppa and a biscuit. All patients and their families are welcome. The group meets on the last Thursday of the month between 7pm and 9pm.
Medway Brain Tumour Support Group	Medway Community Healthcare	07565 881564	St Mary's Island Community Centre, Island Way West, St Mary's Island, Chatham, Kent ME4 3EP	medch.mbtsg@nhs.net www.medwaycommunityhealthcare.nhs.uk/our-services/brain-tumour-support/	This support group offers the opportunity to meet other people who have been through similar experiences. Anyone is welcome to attend any of the meetings but it may be advisable to let them know you are coming, so they can tell you if the meeting is cancelled suddenly or the venue changed. Meetings are held at 11am until 1pm on the first Tuesday of every month.
Mid-Essex Brain Tumour Support Group	Macmillan Cancer Support and Mid Essex Hospital	07919 304 034	Farleigh Hospice, The Lantern Suite, North Court Road, Chelmsford CM1 7FH	Gillian.Read@meht.nhs.uk	This nurse-led support group meets on the first Thursday of the month between 5pm and 7pm. All brain tumour patients are welcome.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
London (St Thomas' Hospital) Support Group	The Brain Tumour Charity	020 7188 5918	Dimbleby Cancer Centre, 2nd Floor, Gassiot's House, St Thomas' Hospital, London SE1 7EH	dimblebycancercare@gstt.nhs.uk www.thebraintumourcharity.org/ support-information/Support/ Support-in-your-area/Support-groups	Everyone is welcome to join this brain tumour support group in London which is held at the Dimbleby Cancer Centre in St Thomas' Hospital and aimed at patients, families and friends of those diagnosed with a brain tumour. The group meets on the first Monday of the month between 2.30pm and 4pm. The group will be relocating to the new Cancer Centre at Guys Hospital in October 2016.
Romford Support Group	The Brain Tumour Charity	07944 680914	The Salvation Army Centre, High Street, Romford RM1 1JJ	tilly.attreed@ thebraintumourcharity.org www.thebraintumourcharity.org/ support-information/Support/ Support-in-your-area/Support-groups	This is a nurse-led support group in Romford which is aimed at patients, families and friends of those diagnosed with a brain tumour. This group meets on the first Wednesday of every month throughout the year and anyone is welcome. This group meets on the first Wednesday of every month between 1pm and 3pm.
Little Grey Cells Southend Brain Tumour Support Group	The Brain Tumour Charity and Macmillan Cancer Support	01702 385113	Macmillan Information Centre, Southend, Prittlewell Chase, Westcliff-on-Sea, Essex SS0 0RY	support@thebraintumourcharity.org www.thebraintumourcharity.org/ get-support/support-your-local-area/ little-grey-cells-brain-tumour- support-group/	This welcoming brain tumour support group alternates each meeting between Macmillan Information Centre, Southend University Hospital and a social venue. The group meets 6 times per year.

Support for carers

Being a carer is not a job you apply for. We know. It's also one of the hardest jobs you might have to do. You could be facing looking after someone with both a cancer diagnosis and the prospect of a significantly debilitating neurological disease. Because of this it's important that you get the help you need too. There is a lot out there for you.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Cancer Carer Support Centres	Helen Rollason Cancer Support Centres	01245 380 719	Helen Rollason Cancer Support Centre, Radiotherapy Department, Ground Floor – Podium Building, North Middlesex University Hospital, Sterling Way, Edmonton, London N18 1QX	enquiries@helenrollason.org.uk www.helenrollason.org.uk	These support centres offer various services for carers including drop-in support, counselling and complementary therapies. They also run a number of monthly support groups which carers are welcome to attend. The centres are located in Edmonton, Chelmsford and Sawbridgeworth.
London Carer Support Drop-in	Maggie's West London	020 7386 1750	Maggie's West London, Charing Cross Hospital, Fulham Palace Road, London W6 8RF	london@maggiescentres.org www.maggiescentres.org/our-centres/maggies-west-london/	If you are a carer of someone affected by a brain tumour you can make use of this drop-in service. Here you will find practical, emotional and social support from their professional staff at any time from 9am to 5pm, Monday to Friday. Also available are a number of groups, classes and workshops all offered free of charge.
Friends and Family Support Course	Maggie's West London	020 7386 1750	Maggie's West London, Charing Cross Hospital, Fulham Palace Road, London W6 8RF	london@maggiescentres.org www.maggiescentres.org/our-centres/maggies-west-london/	This six-week course is for anyone caring for a person who has cancer. The Friends and Family course helps you learn more about cancer, cancer treatments and the likely side effects. You can also learn about your role as a carer, and the impact cancer might have on your life.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
London Jewish Community's Cancer Carer Support	Chai Cancer Care	0808 808 4567	Nightingale 105 Nightingale Lane, London SW12 8NB and 142–146 Great North Way, London NW4 1EH	www.chaicancercare.org	These centres provide comprehensive, professional and expert support services to any member of the Jewish community affected by cancer from patients to carers to families and friends. These services include counselling, advocacy and various group activities. Centres are available in North-West London, South London, Redbridge, Hackney and Southend.
London Cancer Carer Counselling	Cancer Counselling London	020 7249 0595	They operate from three separate locations: Clerkenwell, Islington and Stoke Newington	jane@cancercounsellinglondon.org.uk www.cancercounsellinglondon.org.uk	If you are looking for emotional support because you or someone close to you has been diagnosed with cancer, this team of qualified specialist therapists are here to help you at all stages of the disease.
Experienced Carer Support and Coaching	<i>brainstrust</i>	01983 292405	4 Yvery Court, Castle Road, Cowes, Isle of Wight PO31 7QG	hello@brainstrust.org.uk www.brainstrust.org.uk	Our coaching based relationship with brain tumour patients and carers enable you as a carer to develop your own resilience and to use brain tumour support resources from all providers to their full potential.
Medway Carer Support	Crossroads Care Medway	01634 868885	Crossroads Care Medway, 8 Chestnut Avenue, Walderslade, Chatham, Kent ME5 9AJ	www.medwaycrossroads.org	This specialist voluntary organisation provides support to carers in their own homes, giving carers time to be themselves. This support includes short breaks and respite, information, advice and guidance. This charity serves all of the Medway towns, including Strood, Rochester, Chatham, Gillingham, Rainham, and the more rural areas such as the Hoo Peninsula.

Support for children

500 children a year are diagnosed with a brain tumour, and there are innumerable families living with the disease. Two thirds of children diagnosed are left with a disability. Families can find communication difficult, and awareness of brain tumours in children is low; this is despite the fact that brain tumours now kill more children than any other illness in the UK. Because of these unique and frustrating challenges, there is help available for you and your child.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Drop-in Cancer Support Sessions for Children	Don't Forget the Kids	07506 307173	BroadWaters Children Centre, Adams Road, Tottenham, London N17 6HE	dontforgetthekidsuk@gmail.com www.dontforgetthekids.co.uk	A voluntary organisation which aims to provide self-help support groups for children (up to the age of 17) who have parents/carers living with cancer. Drop-in sessions run every Monday between 3.30pm and 6.00pm.
Surrey Family and Child Support	Momentum	020 8974 5931	139 King's Road Kingston upon Thames, Surrey KT2 5JE	bianca@moment-um.org www.moment-um.org	This charity aims to provide support for children (up to the age of 17) and the families of children, undergoing treatment for cancer in Surrey and South West London. They offer family support, special character visits to the hospital, outings, support groups, free family photos and more.
Childhood Cancer Family Support	little <i>brainstrust</i>	01983 229405	<i>brainstrust</i> , 4 Yvery Court, Castle Road, Cowes, Isle of Wight PO31 7QG	hello@brainstrust.org.uk www.brainstrust.org.uk/ little-brainstrust	Our service aims to help families with children who are battling a brain tumour, wherever they are in the UK. We offer a number of resources, meet ups and emotional support to help you stay in control.

Support lines

Support lines are an invaluable service available to brain tumour patients and their carers. They are often available when a clinician isn't, and the advice can be objective. Some of the helplines are driven by patient and carer experience, meaning the person on the end of the phone may know exactly what you are going through. The phone support you receive may not constitute medical advice, but it will complement it and help you to answer questions you may have.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
brainstrust 24/7 helpline	brainstrust	01983 292405	brainstrust, 4 Yvery Court, Castle Road, Cowes, Isle of Wight PO31 7QG	hello@brainstrust.org.uk www.brainstrust.org.uk	With brainstrust 24/7, 365 days a year helpline, patients, carers, and families can pick up the phone or email and know they will get an immediate, personal response.
Cancer Information Nurses	Cancer Research UK	0808 800 4040		www.cancerresearchuk.org	For questions about cancer or further information, you can speak to a cancer information nurse on Monday to Friday, between 9am and 5pm.
Cancer Support Line	Macmillan Cancer Support	0808 808 0000		www.macmillan.org.uk	If you have any questions about cancer, need support, or if you just want someone to talk to, you can call free Monday to Friday, between 9am and 8pm.
Contact a Nurse Helpline	Brain & Spine Foundation	0808 808 1000		helpline@brainandspine.org.uk www.brainandspine.org.uk/helpline	This free and confidential helpline allows you to contact a nurse to discuss your brain tumour diagnosis and any queries you may have. It is open Monday to Thursday between 9am and 2pm and 9am to 1pm on Fridays.

Financial support

Having a brain tumour will, at some point, impact on you financially as well as physically and emotionally. Look this tiger in the eye. The more prepared you are, the more you will be ready if you need additional support. Much better to be proactive, than reactive. The good news is that there is a wealth (pardon the pun) of help out there.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Macmillan Grants	Macmillan Cancer Support	0808 808 0000	Various	financialguidance@macmillan.org.uk www.macmillan.org.uk	These are one-off payments (around 250 pounds) for adults, young people or children with cancer. To apply, ask a health care professional to supply you with an application form. The grant team will review the application and if approved, payments are generally sent out within 3 working days.
CRF Fund Grant	Cancer Recovery Foundation	0207 470 8755	Cancer Recovery Foundation UK, Garden Studios, 71–75 Shelton Street, London WC2H 9JQ	enquiries@cancerrecovery.org.uk www.cancerrecovery.org.uk/adult-programmes/crf-fund-grant/	This fund was created to help cancer patients with money towards overdue utility bills, council tax, telephone bills, travel (for the patient only) and rent. The maximum amount of funding is £300 per applicant per calendar year. You will hear back about the outcome of your application within one week.

Complementary therapies

There are many reasons why people choose to use complementary therapies. Some people find they help them cope with the stresses caused by cancer and its treatments. Many therapies are relaxing, and may lift your spirits when you aren't feeling your best. Complementary therapies may help you:

- feel better and improve your quality of life
- feel less stressed, tense and anxious
- sleep better
- with some of your cancer symptoms
- with some of the side effects of your cancer treatment
- feel more in control

Read on to find out what is available near to you, and please, remember to seek the advice of your doctor before starting any new therapy.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
London Cancer Complementary Therapies	Paul's Cancer Support Centre	020 7924 3924	20–22 York Road, London SW11 3QA	support@paulscancersupport.org.uk www.paulscancersupportcentre.org.uk	This support centre provides a range of services for people affected by cancer, including family and friends. One-to-one services include adapted Thai massage, counselling, craniosacral therapy, healing, hypnotherapy, life coaching, massage, meditation, reflexology, relaxation and visualisation and shiatsu.
Hypnotherapy Service	brainstrust	01983 292405	brainstrust, 4 Yvery Court, Castle Road, Cowes, Isle of Wight PO31 7QG	hello@brainstrust.org.uk www.brainstrust.org.uk	brainstrust provide hypnotherapy for brain tumour patients and their carers. Hypnotherapy can help with anxiety and stress, diet and lifestyle, resilience, self-esteem and confidence, pre and post-operative care and pain management. We have a network of qualified hypnotherapists across the UK.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Edmonton Complementary Therapies and Workshops	Helen Rollason Cancer Support Centres	01245 380 719	Helen Rollason Cancer Support Centre, Radiotherapy Department, Ground Floor – Podium Building, North Middlesex University Hospital, Sterling Way, Edmonton, London N18 1QX	enquiries@helenrollason.org.uk www.helenrollason.org.uk	These centres offer free services for patients, including; massage, reflexology, aromatherapy, bach flower remedies and “Look Good... Feel Better workshops”. Centres are also available in Essex and Hertfordshire.
Relaxation Sessions and Art Therapy Group	Maggie’s West London	020 7386 1750	Maggie’s West London, Charing Cross Hospital, Fulham Palace Road, London W6 8RF	london@maggiescentres.org www.maggiescentres.org/our-centres/ maggies-west-london/whats-on/	At this centre, you can join in with drop-in sessions of guided relaxation which aim to help you manage stress and anxiety. The centre also runs an expressive art group as a way to help explore your difficult to express feelings and build your confidence. No prior experience or skill in art is required.
Relaxing Therapies and Nutrition Advice	Dimbleby Cancer Care	020 7188 5918	St Thomas’ Hospital, Westminster Bridge Road, London SE1 7EH	richarddimblebycentre@gstt.nhs.uk www.dimblebycancercare.org	Many people use complementary therapies to help them to adjust to having cancer. They are frequently used to relax patients before they undergo treatment, both on the hospital wards and in the centres. The treatments that are available here include aromatherapy, massage, reflexology, relaxation and stress management, and nutrition and healthy eating.

Holidays and short breaks

Going on holiday is a good way to relax and get away from things.

Many people like to plan a holiday for the end of their treatment. Others want to go before or even during treatment. Whether you're travelling for work or play, talk to your doctors and nurses to help you plan. They may be able to suggest a good time to go, as well as help to decide what is realistic for you. Here are some people that could make organising your next holiday that bit easier.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Respite Holiday Homes for Families	Momentum	020 8974 5931	Momentum, 139 King's Road, Kingston upon Thames, Surrey KT2 5JE	bianca@moment-um.org www.moment-um.org/holiday-home	This charity supports families who have a child diagnosed with cancer. They offer holidays at the charity's log cabin where families can go for much-needed respite breaks. Currently, they own two Holiday Homes in the New Forest at Shorefield Country Park.
Shepperton Family Canal Boat Break	Momentum	020 8974 5931	Shepperton Marina, Felix Lane, Shepperton TW17 8NS	ellen@moment-um.org www.moment-um.org/how-we-help/boating-breaks/	This children's charity owns a 40ft canal boat named 'Moments on the River' which is docked at Shepperton Marina. This new service has not yet launched at the time of writing (launches in June 2016) however you can enquire about pre-booking. Families may book the boat for a week at a time.

Welfare and legal advice

You may be entitled to a range of benefits which can make things easier for you. But navigating the welfare system can be a huge challenge, and sometimes you need someone who can guide you through the maze of help that is available. These services may also be able to advise on things like getting a blue badge, your rights at work and other legal issues such as wills and power of attorney.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Experienced Benefits Advisers	Maggie's West London	020 7386 1750	Maggie's West London, Charing Cross Hospital, Fulham Palace Road, London W6 8RF	london@maggiescentres.org www.maggiescentres.org/our-centres/maggies-west-london/	We know that living with cancer can have a major impact on your expenses, through lost income and increased costs such as heating and travel. Here you will find experienced benefits advisers who can help you understand which benefits you are entitled to, talk you through the application process and assist you with form filling.
Camden Welfare Benefits Service	Citizens Advice Bureau and Macmillan	0207 794 0500 ext 37698	Royal Free Hospital, Pond Street, London NW3 2QG	rf.camdencab@nhs.net www.camdencabservice.org.uk	This service provides free, confidential and impartial advice on welfare benefits, debt, employment and housing. It is for any patient who is being treated for cancer at the Royal Free Hospital or their carer.
Toynbee Hall Welfare Rights Service	Macmillan	020 7392 2958	Toynbee Hall, (administration address only), 28 Commercial Street, London E1 6LS	info@toynbeehall.org.uk www.toynbeehall.org.uk/macmillan-benefits-advice	This service provides advice, advocacy and information on welfare benefits and entitlements to people affected by cancer living in the London boroughs of Hackney, Newham, Tower Hamlets and the City of London.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Peckham Welfare Benefits Service	Citizens Advice Bureau and Macmillan	020 7732 5386	Southwark Citizens Advice Bureau, Peckham CAB, 97 Peckham High Street, London SE15 5RS	macmillan@southwarkcabservice.org.uk www.southwarkcabservice.org.uk/Specialist/macmillan.htm	This service currently provides weekly outreach advice sessions by appointment for cancer patients attending King's College Hospital, Guy's and St Thomas' Hospitals, University Hospital Lewisham, and Queen Elizabeth Hospital. They can give help and advice with applying for entitlement to benefits, appealing against benefit decisions, applying for tax credits, health costs such as prescriptions and travel to hospital, transport concessions such as disabled parking badge, accessing charitable grants and housing costs.
Hammersmith and Charing Cross Hospitals Benefits Advice Service	Macmillan	Please speak to your health care professional for a referral	6th Floor East Wing, Lab Block, Charing Cross Hospital, Fulham Palace Road, London W6 8RF	financialguidance@macmillan.org.uk www.macmillan.org.uk/in-your-area/choose-location.html	Free and confidential benefits advice to people who are currently being treated for cancer as either outpatients or inpatients at the Hammersmith or Charing Cross hospitals. They can advise you on a range of issues including what benefits you are eligible for, how to maximise your income, tax credits, grants, housing costs and transport concessions.
Wandsworth Welfare Benefits Service	Citizens Advice Bureau and Macmillan	0207 042 0333	Wandsworth CAB, Mission House, 14 York Road, London SW11 3QA	rodrigo.fenick@wandsworthcabx.org.uk or donatus.anyanwu@wandsworthcabx.org.uk www.wandsworthcabx.org.uk/macmillan/	This service supports people with cancer and the carers of people affected by cancer. The advice offered covers welfare benefits, housing, employment and debt. This advice and support involves assisting clients to apply for grants from Macmillan or the Social Fund, negotiating with creditors and appealing benefit decisions.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Redbridge Macmillan Advice Project	Macmillan	020 8514 1359	Broadway Chambers, 1 Cranbrook Road, Ilford IG1 4DU	financialguidance@macmillan.org.uk www.macmillan.org.uk/in-your-area/choose-location.html	They provide free and confidential benefits advice to people living with cancer and their families. They can advise you on a range of issues including what benefits you're eligible for, how to maximise your income, appeals, tax credits, grants, housing costs and transport concessions.
Barnet Benefits Project	Citizens Advice Bureau and Macmillan	0208 4404227	Citizens Advice Barnet, 30 Station Rd, Barnet EN5 1PL	infomacmillan@barnetcab.org.uk www.barnetcab.org.uk	A confidential, impartial and independent welfare benefits service for people living with cancer, their families and carers living in the Barnet area.
Hertfordshire Welfare Benefits and Money Advice Service	Citizens Advice Bureau and Macmillan	030 3313 1313	The Vanstone Suite, Community Centre, The Vanstone Suite, Allum Lane, Elstree, Hertfordshire WD6 3PJ	macmillanproject@hertsmerecab.org.uk www.hertsmerecab.org.uk	This service provides advice on a range of welfare benefits, tax credits and debt. The service also helps with health costs such as travel to hospital, transport concessions such as a disabled parking badge, appealing against benefit decisions and access to Macmillan and other charitable grants.
Croydon Citizens Advice Bureau	Citizens Advice Bureau and Macmillan	01689 808135	1a Overbury Crescent, New Addington, Croydon, Surrey CR0 0LR	macmillan.cab@croydoncab.org.uk www.citizensadvicecroydon.org	A welfare benefits service for people living with cancer, their families and carers. This service is for individuals being treated for cancer at Mayday Hospital and Croydon residents who are affected by cancer.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Mid and South Essex Welfare Benefits Service	Macmillan	0800 019 6003	There is no office for this service – they arrange visits SS16 5NL	macmillanteam@colchester.gov.uk www.macmillan.org.uk/in-your-area/choose-location.html	A free, confidential and impartial specialist Welfare Rights service for people living with cancer and their families in South Essex. They can advise on a range of issues. Their aim is to strive to ensure that people affected by cancer receive the support and help needed. Referrals can be made either by telephone or email directly by you or on your behalf by a friend, relative, representative or a professional.
Guilford Welfare Rights Adviser	Macmillan	01483 230849	Guildford Citizens Advice Bureau, 15–21 Haydon Place, Guildford, Surrey GU1 4LL	macmillan@guildfordcab.org.uk www.guildfordcab.org.uk	Help with applying for benefits, the cost of travel for treatment, blue badges, appealing against decisions, accessing charity grants and other problems such as employment and housing. Help is given over the phone or via email. A home visit or visit to the place of treatment can arranged when necessary.
Bromley Benefits Advisers	Bromley by Bow Centre	020 8709 9700	Bromley by Bow Centre, St Leonard's St, Bromley by Bow, London E3 3BT	connect@bbbc.org.uk www.bbbc.org.uk	This experienced team of qualified advisors will work with you to make sure that you are receiving the benefits you are entitled to and help you to put things right if they have gone wrong.
St Thomas' Hospital Benefits Advice Service	Dimbleby Cancer Care	020 7188 5918	St Thomas' Hospital, Westminster Bridge Road, London SE1 7EH	richarddimblebycentre@gstt.nhs.uk www.dimblebycancercare.org	The benefits system can be confusing and there are still many people who are not aware of what benefits they can claim. This service offers a Citizen's Advice Bureau benefits expert who can help cancer patients claim their full entitlements.

Transport services

Getting around if you have a brain tumour can be hard. But it's something you need to do. Whether it's for treatment at hospital, or to carry on living your life to the full you will need to travel. But many affected by a brain tumour are unable to drive, and taxis and public transport can be expensive and confusing. Don't worry – you are not alone here, and there's quite a lot out there to get you on your way.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Hospital and Appointment Community Transport	Royal Voluntary Service	0845 600 5885	Royal Voluntary Service, Crown Meadow Court, Brosse Way, Bromley, Kent BR2 8FE	londonhub@ royalvoluntaryservice.org.uk www.royalvoluntaryservice.org.uk	Every year, Royal Voluntary Service volunteers undertake some 90,000 journeys on behalf of older people. These may be trips to and from the hospital or to a GP appointment.
Congestion Charge Refund	Transport for London	0343 222 2222	Congestion Charge, PO Box 4782, Worthing BN11 9PS	www.tfl.gov.uk/modes/driving/ congestion-charge/ discounts-and- exemptions?intcmp=2133	If you hold a valid Blue Badge in the European Economic Area, you're eligible to register for a 100% discount, even if you don't own a vehicle or drive. You can register up to two vehicles that you would normally use to travel within the Congestion Charge zone. This could be your own vehicle or one you travel in. Download the registration form online.
London Dial-a-Ride	Transport for London	0343 222 7777	Dial-a-Ride Passenger Services, PO Box 68799, London SE1P 4RD	DAR@tfl.gov.uk www.tfl.gov.uk/modes/dial-a-ride/	A free door-to-door service for those with a permanent or long-term disability which makes using public transport difficult some or all of the time. Visit the website or call to apply for membership.

Respite and end of life care

When you're caring for someone full-time or for long periods, you need to have breaks otherwise you may start to feel stressed, resentful or even unwell. And believe it or not, the person you are looking after may want a break from you! Here are some organisations that could help you understand respite care, and they can also help you with planning for care towards the end of life, should you need to do this.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Greater London Palliative Care	St Christopher's Hospice	020 8768 4500	St Christopher's Hospice, 51–59 Lawrie Park Road, London SE26 6DZ	info@stchristophers.org.uk www.stchristophers.org.uk	This Hospice exists to promote and provide skilled and compassionate palliative care of the highest quality. They serve a diverse population of 1.5 million people in the London boroughs of Bromley, Croydon, Lambeth, Lewisham and Southwark, reaching some of England's most deprived areas. All their care is provided free of charge. St Christopher's is an adult hospice caring for patients from the age of 18 upwards.
London Support for Life-limiting Conditions	Richard House Children's Hospice	020 7511 0222	Richard House Children's Hospice, Richard House Drive, Beckton, London E16 3RG	info@richardhouse.org.uk www.richardhouse.org.uk	This hospice supports families whose children and young adults are living with a life-limiting health condition. Their purpose-built hospice is located in Beckton, East London and the majority of the families that they support live in East and North London.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
South-East London Children's Hospice Care	Demelza Hospice Care for Children	020 8859 9800	5 Wensley Close, Eltham, SE9 5AB	info@demelza.org.uk www.demelza.org.uk	Demelza South East London is a 6-bedded hospice providing a large range of hospice and care services to children, young people and their families. Life-limited or life threatened children or young people and their families benefit from a wide range of facilities that include the use of multi-sensory and soft play equipment.
Kent Children's Hospice Care	Demelza Hospice Care for Children	01795 845 200	Demelza House, Rook Lane, Bobbing, Sittingbourne, Kent ME9 8DZ	info@demelza.org.uk www.demelza.org.uk	Demelza Kent is a 10-bedded hospice providing a large range of hospice and care services to children, young people and their families. Life-limited or life threatened children or young people and their families benefit from a wide range of facilities that include a Multi-Sensory room, Soft Play, a Hydrotherapy Pool, and The Inclusion Zone (TIZ) for young people.
Community Support Team for Children	Demelza Hospice Care for Children	01323 446 461	Langtye Farm, Langtye Lane, Ripe, Lewes, East Sussex BN8 6BA	info@demelza.org.uk www.demelza.org.uk	This community support team provides a hospice at home service for children in East Sussex and parts of South West Kent.
Essex Children's Hospice	Haven House Children's Hospice	020 8506 5513	The White House, High Road, Woodford Green, Essex IG8 9LB	enquiries@havenhouse.org.uk www.havenhouse.org.uk	This children's hospice supports families and cares for children and young people with life-limiting and life-threatening conditions across North and East London, West Essex and East Hertfordshire.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Hertfordshire Children's Hospice	Noah's Ark Children's Hospice	020 8449 8877	Noah's Ark Children's Hospice, 3 Beauchamp Court, 10 Victors Way, Barnet, Hertfordshire EN5 5TZ	info@noahsarkhospice.org.uk www.noahsarkhospice.org.uk	This children's hospice is an expanding support service, seeking to serve an estimated 900 life-limited or life-threatened children or young people, and their families, living within the communities of Barnet, Camden, Enfield, Haringey and Islington.
North London Respite Care	North London Hospice	020 8343 8841	North London Hospice Finchley, 47 Woodside Avenue, London N12 8TT (For SatNav use the postcode N12 8TF)	nlh@northlondonhospice.co.uk www.northlondonhospice.org	This service believes providing the highest quality palliative and end of life care is paramount. They support patients and families living with a life limiting illness through an inpatient unit, care in the community, outpatient services, therapies, and spiritual care. They have three hospices which work across the communities of Enfield, Barnet and Haringey.

Bereavement support

Unfortunately not everyone survives having a brain tumour. When a person you look after dies, you may be not only losing a loved one, but as a carer you may be losing your sense of purpose when your caring role ends. It may not feel like it, but there are many people who you can turn to for help and support, including health and social services professionals who are becoming more aware of this impact.

Bereavement care and support is available to carers, family and close friends from a variety of organisations. Family members and friends can also provide emotional support.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Bereavement Counselling and Psychological Support	Dimbleby Cancer Care	020 7188 5918	St Thomas' Hospital, Westminster Bridge Road, London SE1 7EH	richarddimblebycentre@gstt.nhs.uk www.dimblebycancercare.org	This team of counsellors, psychologists and psychotherapists are experienced in helping with problems that people often have to deal with following a cancer diagnosis or bereavement, and can be accessed by patients, partners, carers or family members directly or by clinical teams. Access to a psychiatrist is also available.
Bereavement Support Groups, Events and Advice	The Loss Foundation	07732 070972	Stockwell Community Centre, 1 Studley Road, London SW4 6RA	erin@thelossfoundation.org www.thelossfoundation.org	A registered charity providing support to people who have lost loved ones to cancer; spouses, family members, friends. The charity operates support groups, within London and Oxford, and other supportive events. They provide an array of bereavement information on their website to support those that fall out of the support group catchment area. They also run loss and bereavement retreats for people who have lost loved ones to cancer.

What can *brainstrust* do to help?

Help available

At times it may feel like it, but you are not alone. Everyone in the *brainstrust* community has experience of what it is like to be diagnosed and to live with a brain tumour. We can help you to feel less isolated – we understand. Below are examples of the help available to you from *brainstrust*. Don't hesitate to get in touch and talk to people who have been where you are now. We'll help you get back on top of things.

What can *brainstrust* do to help?

For more information about any of these resources, visit www.brainstrust.org.uk, contact hello@brainstrust.org.uk or call 01983 292 405.

Resources to keep you informed

- **Information Standard certified information**
on our website www.brainstrust.org.uk. Clear, accurate, balanced, evidence-based and up-to-date information, certified by the Information Standard.
- **24/7 help line**
We know that you don't just need to talk to someone 9-5. We've been there. We know the fears and the need to talk to someone who understands at all hours. That's why you can call us anytime. Open 24 hours a day, 7 days a week, the *brainstrust* help line offers brain tumour patients and carers support, information and pragmatic advice over the phone and by email. Call **01983 292405** or email hello@brainstrust.org.uk
- **Help you to understand the implications of the diagnosis**
A brain tumour diagnosis can be very scary, and it is difficult to identify what you need and want to know. We can chat through the impact with you, to help put you back in control.
- **Interpretation of medical records**
Medical jargon and terminology may be used in the records. If you choose to look at your records (and you are entitled to) you may need help understanding them, so interpretation can be provided. Contact brainstrust on hello@brainstrust.org.uk or call **01983 292405**.
- **Help you seek a second opinion**
We are mindful that everyone reacts to a serious diagnosis in different ways. It is your right to seek further opinions, and this will empower some people. Some people would prefer not to exercise this right. Some people prefer to know as little as possible about their diagnosis; some people like to relinquish control of their situation to others. All of these are perfectly normal and acceptable ways of coping. And seeking second, even third opinions can cause confusion and stress. But they can inform, and help with decision-making. They can also be reassuring. We can only talk

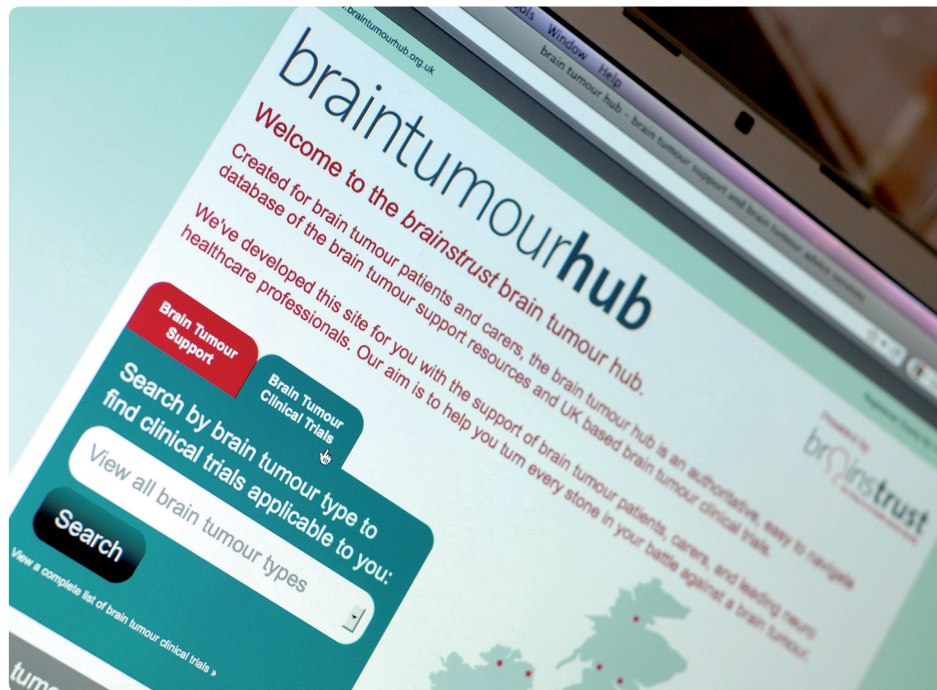
from our experience. We believe that you need to be informed to make decisions. And that might mean gathering information and then deciding not to make a decision. That's a decision too! For more information on second opinions, visit 'Just been told?' on www.brainstrust.org.uk/advice-symptoms.php

- **Clear signposting**

brainstrust can point you towards valuable resources to help navigate your journey.

- **www.braintumourhub.org.uk**

Created for brain tumour patients and carers, the brain tumour hub is an authoritative, easy to navigate database of brain tumour support resources and UK based brain tumour clinical trials. It is intuitive, easy to use, developed with clinicians, patients and carers, and constantly evolving with regular updates.



Resources to help you feel more in control

- **Coaching**

At *brainstrust* we listen, listen some more and then ask questions. We focus on achieving specific immediate goals, which relate to specific areas. For example, weighing up the pros and cons of having a particular treatment, or overcoming a problem with caring. We also know that through coaching, clients can experience a sense of healing, as they make courageous decisions about their lives and work. Coaching focuses on the future and the development of a workable solution. It's about developing strategies and clarity to achieve a better quality of life.

- **Counselling**

When there is too much distress and a psychological intervention is needed, counselling can be useful. It is suitable for someone who is struggling to cope or feeling very anxious and depressed and therefore finding it hard to focus on specific immediate goals. Counselling has a broader focus and greater depth than coaching and so is usually a slower-paced intervention. It is concerned with the individual and their relationship to self, as well as with their family and communities. It is less solution focused than coaching (sometimes there is no solution to the problem) and instead aims to help the individual make sense of the situation in which they find themselves in order to make better decisions about what they want and need for the future. In some situations formal counselling may not be appropriate and instead a supportive listening relationship might be more useful.

- **Hypnotherapy**

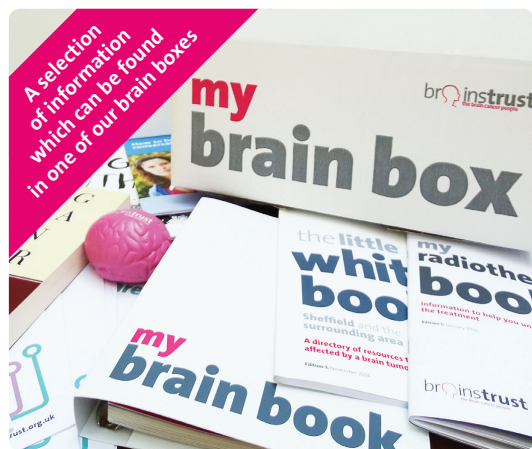
There is plenty of evidence that hypnotherapy helps people with cancer and those who care for them. Hypnotherapy can be used as a complementary therapy alongside conventional medical treatments and for a number of different purposes. Hypnotherapy can help brain tumour patients and carers to: manage anxiety, reduce stress, create a different experience of pain, build confidence and optimism, prepare for surgery and promote post-operative healing, reduce side effects of treatments, e.g. nausea and fatigue, optimise a healthy lifestyle to build resilience.

Practical resources you can pick up

- **Brain box**

www.brainstrust.org.uk/advice-resources.php#2

The *brainstrust* brain box – the ‘must have’ support toolkit for people with a brain tumour diagnosis and their carers. We appreciate how difficult things can be once you are diagnosed with a brain tumour; the ‘4.00am moments’, the travelling to and from appointments, the stream of questions that pop into your head, trying to remember the jobs of all the people that you’ll meet on your journey, and knowing who to turn to and when. A juggling act that you don’t need when you just want to focus your energy on feeling better. So to assist brain tumour patients, we provide this unique invaluable aid.



- **Little White Book**

www.brainstrust.org.uk/advice-resources.php#5

A comprehensive, easy to navigate compendium of UK brain tumour support resources.



- **Snaggle Tooth Splat**

www.brainstrust.org.uk/advice-resources.php#7

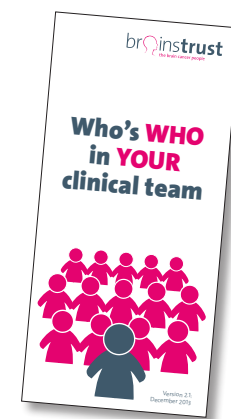
Written for *brainstrust* to help parent carers or patients broach a brain tumour diagnosis with their children. It is a beautifully illustrated book and has featured in the BMA newsletter and Oncology news. The forward has been written by the lovely actress and *brainstrust* supporter, Julie Walters. If you are a parent who has been diagnosed with a brain tumour, or are looking after a poorly little patient, then you can have a copy of this book, for free.



- **Who's WHO in YOUR clinical team**

www.brainstrust.org.uk/advice-resources.php#6

Many patients find that they are left to manage their care pathway for themselves. *brainstrust* has developed this handy resource to help you navigate your journey. It outlines all the healthcare professionals who may be involved in your journey and tells you what it is they do.



Resources to help you feel less lonely

- **Meetup**

www.meetup.com/brainstrust



At a *brainstrust* Meetup, members of the brain tumour community get together to have fun. No matter where you are on your journey or what role you have (such as carer, patient, health care professional) you can share experiences, and seek information from people who know what you're going through. But only if you want to. Feel free to just come along and enjoy. Past Meetups have involved pizza and wine, pub grub, and cream teas.

- **facebook brainstrust brain tumour support group**

www.facebook.com/groups/braintumoursupportbrainstrust/

If you are on facebook, you can join this closed support group where a lot of very friendly patients and carers hang out. It is a really warm and welcoming group who will comfort you, answer questions, make you smile, and importantly are in the same boat as you.

- **facebook UK brain tumour carers group**

www.facebook.com/groups/ukbraintumourcarers/

This is a group page for carers of people with brain tumours in the UK. It can be very hard and lonely being a carer, so this group is for any carers to ask others questions about care, offer advice, have a general chat, a good laugh or rant/sound off when you need to without offending or upsetting those they look after.

Notes

Notes

There are over 55,500 people living with a brain tumour in the UK. brainstrust is the charity and the community that's here to help these people and those who look after them, whoever they are and no matter where they are on their journey.

We know we don't have all the answers, but chances are we know someone who does. Get in touch today, for 24/7 help on 01983 292 405 or email hello@brainstrust.org.uk

www.brainstrust.org.uk

**The little white book – Greater London,
edition 1, published by *brainstrust* May 2016,
due for review May 2017.**

© *brainstrust* 2016.

Registered charitable trust, *brainstrust* is a registered charity in England and Wales (1114634), and Scotland (SC044642)

