

the little white book

South East Scotland

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

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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 South East Scotland. 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**

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We hope you find it useful.

Carol and 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	<i>brainstrust</i>	07969 702201	Venues vary – please get in touch for details.	carol@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.
Edinburgh Brain Tumour Networking Group	Maggie’s Edinburgh	0131 537 3131	Maggie’s Edinburgh, Western General Hospital, The Stables, Crewe Road, Edinburgh EH4 2XU	edinburgh@maggiescentres.org www.maggiescentres.org/our-centres/maggies-edinburgh/	This group is for men and woman living with a brain tumour and their carers. The group provides an opportunity to talk to others in a similar situation. Meet ups are run on a drop-in basis on the first Tuesday of the month between 7pm and 9pm.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Dumfries Brain Injury Activity Centre	Headway Dumfries & Galloway	01387 261166	Headway House (Dumfries & Galloway) Association Ltd, Afton Drive, Dumfries DG2 9ES	general@headwaydg.org www.headwaydg.org/services/adult_services/day_service	A team of project workers have developed a diverse day-service open to people affected by a brain injury. The morning sessions focus on physical and mental rehabilitation through memory groups, cognitive exercises, and daily living & literacy skills. In the afternoon, sessions focus on the therapeutic nature of socialising. Activities include gardening, rambling, fishing, film clubs, drama clubs, camera clubs, art classes, and quizzes. The service is open Monday to Thursday.
East Lothian Brain Injury Support Group	Headway East Lothian	07895 193974	Headway – the brain injury association, The Bleachingfield Centre, Countess Crescent, Dunbar EH42 1DX	headwayeastlothian@live.co.uk www.headway-eastlothian.org.uk/in-your-area/	This active charity holds three regular meet up groups in Musselburgh, Haddington and Dunbar. The group activities range from a quiet chat over a coffee and a game of dominos to organised workshops which can help you to build new skills in a social environment. They also have monthly outings to places such as The Falkirk Wheel and The Alnwick Gardens which usually take place on the last Friday of each month.
Fife Brain Injury Networking Activities	Headway Fife	01592 370034	Fife Headway, 23 Whyte Causeway, Kirkcaldy KY1 1XF	fifeheadway20@btinternet.com www.fifeheadway.co.uk	This charity offers a variety of fun and engaging networking activities for adults who have been affected by a brain injury. The activities include tai chi, ten pin bowling, crafts and monthly meetings led by guest speakers. The meetings usually take place on last Tuesday of the month between 7pm and 9pm in Linton Lane Centre. Transport may be available depending on location.

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
brainstrust Counselling	<i>brainstrust</i>	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.
Cancer Support Specialist Drop-in	Maggie's Fife	01592 647997	Maggie's Fife, Victoria Hospital, Hayfield Road, Kirkcaldy, Fife KY2 5AH	fife@maggiescentre.org www.maggiescentres.org/our-centres/maggies-fife/	Here you have access to a professional, qualified Cancer Support Specialist at any time. They can offer a listening ear for your concerns, provide emotional support and guide you to the information you need.
Edinburgh Family Support	Marie Curie	0131 470 2201	Marie Curie Hospice Edinburgh, Frogson Road West, Edinburgh EH10 7DR	edinburgh.hospice@mariecurie.org.uk www.mariecurie.org.uk/help/hospice-care/hospices/edinburgh	A team of friendly social workers are here to offer practical, emotional and spiritual support to family members of people currently receiving care from the Marie Curie hospice.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Edinburgh Professional Cancer Support	Maggie's Edinburgh	0131 537 3131	Maggie's Edinburgh, Western General Hospital, The Stables, Crewe Road, Edinburgh EH4 2XU	edinburgh@maggiescentres.org www.maggiescentres.org/our-centres/maggies-edinburgh/	We know that sometimes you need some extra help coping with your diagnosis. At this centre there are three cancer support specialists, a psychotherapist and a clinical psychologist all available to give you that helping hand you need. The centre also runs a number of workshops to help you manage stress, achieve relaxation and attain post-treatment support.

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
Dumfries Cancer Support Group	MacMillan Cancer Support	01387 241978	The MacMillan Centre, Dumfries and Galloway Royal Infirmary, Bankend Road, Dumfries DG1 4AP	claire.drummond@nhs.net www.nhsdg.scot.nhs	This supportive and inviting group is for people who have experienced cancer either as a patient, carer, family member or friend. The group runs on the first Tuesday of the month between 7pm and 8.30pm.
Fife Brain Tumour Support Group	The Brain Tumour Charity	07827 595855	Maggie’s Fife, Victoria Hospital, Hayfield Road, Kirkcaldy, Fife KY2 5AH	gus.ironside@thebraintumourcharity.org www.thebraintumourcharity.org/get-support/support-your-local-area/fife-support-group/	A monthly support group for people affected by a brain tumour within the Fife region. Light refreshments are provided and any reasonable travel expenses will be reimbursed. The group meet on the last Thursday of alternate months between 6pm and 8pm.
Edinburgh Brain Tumour Support Group	Brain Tumour Action	0131 334 3609	Maggie’s, Western General Hospital, Crewe Road South, Edinburgh EH4 2XU	administrator@braintumouraction.org.uk www.braintumouraction.org.uk/index.php/support/	This caring and understanding group is for anyone affected by a brain tumour diagnosis including patients, carers, relatives and friends. They meet on the first Tuesday of every month at 7pm.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Kelso Brain Injury Support Group	Headway Borders Kelso	07826 519567	Abbey Row Community Centre, The Knowes, Kelso, Roxburghshire TD5 7BJ	jan.lee.56@hotmail.co.uk www.headway.org.uk/supporting-you/in-your-area/groups-and-branches/scotland/headway-borders/	This relatively new yet well-respected group offer support, skill development and companionship to those in the Borders area with an acquired brain injury. Family members and carers are also welcome to come along. Some group members prefer to sit and chat over a cuppa whilst others occupy themselves with various activities such as arts and crafts, quizzes, and baking. The group meets on the 2nd Thursday of each month between 2pm and 4pm

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
Princess Royal Trust Borders Carer Centre	Carers trust	01896 752431	The Princess Royal Trust Borders Carer Centre, Brewerybrig, Low Buckholmside, Galashiels TD1 1RT	enquiries@scotborders.gov.uk www.borderscarerscentre.co.uk	This Borders support centre is available to help you as a carer to care safely and maintain your own physical and mental wellbeing. It can also provide you with information, support, respect and recognition on aspects such as respite and personal care. The centre is open between 10am and 2pm from Monday to Friday.
VOCAL Carers Centre	CarersNet	0131 622 6666	VOCAL Carers Centre, 8-13 Johnston Terrace, Edinburgh EH1 2PW	centre@vocal.org.uk www.vocal.org.uk	This organisation focuses on providing support to carers in all family and relationship settings. They deliver practical advice on community care, assessments, financial information and receiving support as a carer. Their emotional support covers aspects of caring such as changing relationships and dealing with guilt. The centre is open Monday to Friday between 9am and 5pm.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Family and Friends Support Group	Maggie's Edinburgh	0131 537 3131	Maggie's Edinburgh, Western General Hospital, The Stables, Crewe Road, Edinburgh EH4 2XU	edinburgh@maggiescentres.org www.maggiescentres.org/our-centres/maggies-edinburgh/	We know caring for someone with cancer can be a challenging time both physically and mentally. Here you have access to a group space for you and other carers to meet up, relax and enjoy some well-earned 'me' time. This support group is also available at Maggie's Fife.
Edinburgh Support for Minority Ethnic Carers	MECOPP Carers Centre	0131 467 2994	MECOPP Carers Centre, 172 Leith Walk, Edinburgh EH6 5EA	info@mecopp.org.uk www.mecopp.org.uk	This organisation provides numerous support services for minority ethnic carers in Edinburgh. This includes multi-lingual advice and information, advocacy support, education and training opportunities, healthy living programmes, and domestic care support. They also run a number of recreational, social and therapeutic activities.
Carer Breaks Information and Advice	Wee Break Midlothian	0131 271 3707	VOCAL carer's centre, 30/1 Hardengreen Estate, Dalhousie Road, Dalkeith EH22 3NX	centre@vocal.org.uk www.weebreak.org	Whether it is a few hours or a few weeks long, a break from caring can help you relax, recoup and regain your energy. If you are looking after someone in the Midlothian area this charity can help you take a well-earned break from your caring role. They can provide you with information and advice on planning the break, help you find funding and share useful tips from others carers.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Wester Hailes Health Agency Carer's Group	Westernhaven Information and Support Centre	0131 453 9400	MacMillan Cancer Information and Support Centre, Westernhaven, 30 Harvester Way, Edinburgh EH1 43JF	clare.d.westerhaven@gmail.com westerhaven.wix.com/support	We know your tasks as a carer can sometimes prove to be stressful and isolating. This carer's group can offer practical and emotional advice and mutual support from other carers. Their warm and welcoming atmosphere can take your mind off your caring responsibilities allowing you to enjoy the fun and relaxing activities on offer. The group runs every Friday between 10.15am and 12.15pm.

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
The Royal Hospital Teenage Cancer Trust Unit	Teenage Cancer Trust	0131 536 0000	The Royal Hospital for Sick Children, 9 Sciennes Road, Edinburgh EH9 1LF	hello@teenagecancertrust.org www.teenagecancertrust.org/get-help/how-we-can-help/our-units/royal-hospital-sick-children	The Teenage Cancer Trust Unit is situated in the Royal Hospital for Sick children. The unit, aimed at 13 to 16 year olds, has two beds and the rooms are equipped with soft furnishings, bespoke furniture, DVD and gaming facilities with wifi and laptops provided.
Child Cancer Family Support Service	Children with Cancer and Leukaemia, Advice and Support for Parents (CCLASP)	0131 467 7420	Unit 24 and 7, North Leith Sands EH6 4ER	info@cclasp.net www.cclasp.net	This children's charity is run by parents whose children (aged from birth to 19 years) have been affected by various types of cancer. They offer a wide range of services from the provision of transport for clinic appointments to summer picnics and family outings.
The Sick Kids Drop-in Centre	The Sick Kids Friends Foundation	0131 536 0887	20 Millerfield Place, Edinburgh EH9 1LW	helen.taylor@nhslothian.scot.nhs.uk www.edinburghsickkids.org/what-we-do/drop-in-centre/	This drop-in centre provides an informal, homely atmosphere away from busy wards for children affected by long-term, life-impacting conditions and their families. There are three main rooms; a comfortable lounge to relax and have a cuppa, a quiet room used for complementary therapies and emotional counselling and a bright, stimulating activity room for children.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Art Therapy for Children	The Teapot Trust	01875 812012	The Teapot Trust, Cockenzie Business Centre, Cockenzie, East Lothian EH32 0XL	info@teapot-trust.org www.teapot-trust.org/about-us/ our-services/	This innovative service allows any child attending a clinic to engage with an art therapist by joining the art table and participating in painting, drawing, collages, and clay modelling. The group helps to reduce anxiety before medical procedures as well as providing a safe space for children to show difficult to express feelings about their illness.

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
National Entitlement Card (NEC)	City of Edinburgh Council	0131 200 2351	One Edinburgh, Level C.3, Waverley Court, 4 East Market Street, Edinburgh EH8 8BG	oneedinburgh@edinburgh.gov.uk www.edinburgh.gov.uk/info/20088/public_transport/1091/nec_card_travel_discounts	This card can provide cheaper travel for young people, older people and people with a disability. If the card is issued by the City of Edinburgh council due to disability the card also includes free bus and tram travel across Scotland.
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.

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
brainstrust Hypnotherapy Service	<i>brainstrust</i>	01983 292405	<i>brainstrust</i> , 4 Yvery Court, Castle Road, Cowes, Isle of Wight PO31 7QG	hello@brainstrust.org.uk www.brainstrust.org.uk	<i>brainstrust</i> 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.
Borders Holistic Care for Cancer	Lavender Touch	01896 208255	The Lavender Touch, Unit 1, Craft Centre, Tweedbank, Galashiels, Scottish Borders TG1 3RU	www.lavendertouch.co.uk	A Borders charity which provides complementary therapies for people who have cancer. Treatments can help people at any stage of their condition and can be given at the centre, your local health centre, community hospital or your own home.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Edinburgh Therapies for Cancer	Marie Curie Hospice	0131 470 2201	Marie Curie Hospice Edinburgh, 45 Frogston Road West, Edinburgh EH10 7DR	edinburgh.hospice@mariecurie.org.uk www.mariecurie.org.uk	This Edinburgh based hospice offers complimentary therapies to be used alongside conventional medical treatment. These therapies include acupuncture, aromatherapy, Indian head massage, reflexology and reiki.
Managing Stress, Learning Relaxation and Visualisation Course	Maggie's Edinburgh	0131 537 3131	Maggie's Edinburgh, Western General Hospital, The Stables, Crewe Road, Edinburgh EH4 2XU	edinburgh@maggiescentres.org www.maggiescentres.org/our-centres/ maggies-edinburgh/	A six week course for anyone who has or has ever had cancer as well as their family and friends. The course covers a variety of methods of relaxation and resources including informative handouts and a relaxation CD.

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
Isle of Bute Cabin Retreat	Calum's Cabin	07544 979538	Calum's Cabin, "Calenna" Mountstuart Road, Rothesay, Bute PA20 9LD	booking@calumscabin.com www.calumscabin.com	A countryside retreat on the Island of Bute where families with a child with cancer can come and relax, spend quality time together and make irreplaceable memories. The charity also helps with travel costs to the island.
CLIC Villa Home From Home	CLIC Sargent	0131 662 1457	CLIC Villa, 15 Hatton Place, Edinburgh EH9 1UD	www.clicsargent.org.uk/in-my-area/ clic-sargent-homes-from-home/ clic-villa	CLIC Villa is a beautifully kept, listed Victorian property situated near Edinburgh's Royal Hospital for Sick Children. The villa hopes to deliver a home from home atmosphere whilst ensuring travel to the hospital is as convenient as can be.

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
Midlothian Benefits Service	MacMillan Cancer Support and Midlothian Council	0131 271 3910	The service is linked with cancer advice services in both the Western General Hospital and the Royal Infirmary in Edinburgh.	tracey.ross@midlothian.gov.uk www.midlothian.gov.uk/info/592/benefits/438/the_welfare_rights_service/5	This service provides benefits advice for people affected by cancer and their families. The service offers help through home visits, telephone advice, form filling and advocacy.
Borders Benefit Advice Service	The Borders MacMillan Welfare Benefits Partnership	01896 661394	Borders Macmillan Welfare Benefits Partnership Welfare Benefits Service, Scottish Borders Council, Paton Street, Galashiels TD1 3AS	wbs@scotborders.gsx.gov.uk www.scotborders.gov.uk/info/603/benefits_advice_and_assessment/1467/borders_macmillan_welfare_benefits_partnership	This service can make sure you are receiving all the benefits that you are entitled to. Just phone the number provided to arrange a meeting. You can see the advisor at the Macmillan Centre, Borders General Hospital or at home.
Dumfries and Galloway Citizens Advice Service	Citizens Advice Bureau	01387 268286	Cancer Information Support Centre, Dumfries and Galloway Royal Infirmary, Bankend Road, Dumfries DG1 4AP	support4life@dagcas.org www.dagcas.org	This service provides benefits advice and a walk-in clinic in the Cancer Information and Support Centre in Dumfries and Galloway. The clinic is open on both Wednesday and Friday from 10am to 12pm.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Fife Benefits Advice	MacMillan Cancer Support	01592 647997	Maggies Fife, Victoria Hospital, Hayfield Road, Kirkcaldy, Fife KY2 5AH	fife@maggiescentre.org www.maggiescentres.org/our-centres/maggies-fife/	This service, located at the Victoria Hospital, provides benefits advice to anyone affected by cancer. There are drop-in sessions on Thursday between 10.30am and 12.30pm or you can make an appointment to see an advisor on Thursday afternoons or on Friday mornings or afternoons. The specialist benefits advisor will help you complete benefit claims forms and also make sure you have access to any additional support that you might be eligible for, such as parking permits.
Benefits Advice Appointments	Maggie's Edinburgh	0131 537 3131	Maggie's Edinburgh, Western General Hospital, The Stables, Crewe Road, Edinburgh EH4 2XU	edinburgh@maggiescentres.org www.maggiescentres.org/our-centres/maggies-edinburgh/	These pre-booked appointments can give you access to the centre's specialist benefits advisor who has experience in the benefits claims process and benefit entitlements. They can help you fill out claims forms and make sure you are receiving everything you are entitled to, meaning there is one less thing to worry about in your cancer journey.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
West Lothian Benefits Advice Service	Macmillian Cancer Support	01506 283000	Macmillan Information Point (South Corridor), Western General Hospital, Crewe Road, Edinburgh EH4 2XU	macmillan@westlothian.gov.uk www.macmillan.org.uk/in-your-area/chooselocation.html	This service is for anyone either living in West Lothian or attending the Western General Hospital who have been affected by cancer including family and carers. They have a holistic approach to advice and will not only look to maximise your income through available benefits, but will assist in accessing other services available in West Lothian, including occupational therapy, a home safety service, travel concessions, and money, energy and housing advice. They offer regular advice sessions at the Western General Hospital, St John's Hospital and Carmondean Library. Home visits are also available. Please get in contact for further details.
Edinburgh Welfare Rights Service	City of Edinburgh Macmillan Welfare Rights Partnership	0131 529 5000	The Advice Service, 249 High Street, Edinburgh EH1 1YJ	Macmillan@edinburgh.gov.uk www.macmillan.org.uk/in-your-area/chooselocation.html	This service offers a free and confidential benefits advice service for people living with or affected by cancer. The service is also open to the families and carers of those affected by cancer. It is open Monday to Thursday between 9am and 4pm and Friday between 9am and 3.40pm.

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
Volunteer Drivers for Cancer Treatment	Cancer Cars Scotland		Various locations	www.cancercars.co.uk	This online service provides a database of volunteer driver schemes for cancer care treatment across Scotland. There are currently 7 volunteer driver schemes listed in the Edinburgh and Lothian region.
Edinburgh Taxicard	Edinburgh City Council	0131 469 3891	Travel concessions, Freepost 242, Edinburgh EH1 0AH	travelconcessions@edinburgh.gov.uk www.edinburgh.gov.uk/info/20088/public_transport/359/taxicard	If your disability makes using ordinary buses difficult you can apply for a Taxicard to help you make cheap taxi journeys around the city. There are a number of taxi companies participating in the scheme but pre-booking the cab and stating any special requirements is essential. The card also allows you to travel on trains within the Lothian area for free.

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
Edinburgh Palliative Care	St Columba's Hospice	0131 551 1381	St Columba's Hospice, 15 Boswell Road, Edinburgh EH5 3RW	info@stcolumbashospice.org.uk www.stcolumbashospice.org.uk	This hospice provides a range of services for patients and their loved ones. These services include complementary therapy, counselling, inpatient care and a day hospice.
Edinburgh Hospice Care	Marie Curie	0131 470 2201	Marie Curie Hospice Edinburgh, Frogson Road West, Edinburgh EH10 7DR	edinburgh.hospice@mariecurie.org.uk www.mariecurie.org.uk/help/hospice-care/hospices/edinburgh	Here you will find attentive inpatient, day and home care services for people with cancer. The hospice also provides specialist palliative medicine to local hospitals.
West Lothian Palliative Care Service	Marie Curie	0150 652 3531	West Lothian Palliative Care Service, Macmillan Centre, St Johns Hospital, Howden Street Road, Livingston, West Lothian EH54 6PP	gail.allan@mariecurie.org.uk www.mariecurie.org.uk/help/hospice-care/hospices/edinburgh/services/west-lothian-palliative-care	If you are a resident in West Lothian and are living with an advanced, progressive and incurable illness this service can help you and your family stay in control. The team can offer information and advice to guide and support your decisions, emotional and spiritual support, assessment of pain and other symptoms, and can help you develop a well thought out plan for the type of care you wish to receive in the future.

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
Facilitated Bereavement Support Sessions	NHS Lothian	07769 110243	Carmondean Community Centre – The South Barn, Fells Rigg, Livingston, West Lothian EH54 8AX	bereavement.service@nhslothian.scot.nhs.uk www.westlothian.gov.uk/article/5059/Bereavement-Support	This group is for anyone who has recently experienced the death of someone close. They offer space and time for you to learn how to support yourself during difficult times. The group is facilitated by 2 qualified counsellors who are experienced in working with bereaved people. It meets on the third Sunday of each month between 10.30am and 12.30pm
Edinburgh Community Bereavement Care	CRUSE	0845 600 2227	Cruse Bereavement Care Scotland, CBCS Headquarters, Riverview House, Friarton Road, Perth PH2 8DF	info@crusescotland.org.uk www.crusescotland.org.uk/support.html	A charity offering bereavement information and support provided by a number of local community-based teams. The services offered by the Edinburgh team includes face to face counselling, telephone counselling, helpful leaflets and support groups.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Group-based Bereavement Support Programme	ACORN	0131 208 1882	Various locations	acorns.info@gmail.com. www.homeinstead.co.uk/edinburgh/1314.do/acorns-bereavement-support-programme	A local bereavement service offering a six-week bereavement programme at various locations in Edinburgh. The support programme is open to all and covers topics including feelings, cooking for one, money, health, socialising and the future. Discussions take place over a series of 90 minute sessions.
Connections Bereavement Support Group	Maggie's Fife	01592 647997	Maggie's Fife, Victoria Hospital, Hayfield Road, Kirkcaldy, Fife KY2 5AH	fife@maggiescentre.org www.maggiescentres.org/our-centres/maggies-fife/	This bereavement support group provides a place for you to share your thoughts and feelings with others going through a similar experience. This group will help you find advice, support and develop important coping strategies.
Rachel House Children's Hospice Rainbow Rooms and Support	Children's Hospice Association Scotland	01577 865777	Rachel House Children's Hospice, Avenue Rd, Kinross, Kinross-Shire KY13 8FX	info@chas.org.uk www.chas.org.uk/how_we_help_families/bereavement_support	The Rachel House Hospice in Kinross can offer you thoughtful support following the loss of your much-loved child. If you wish, the hospice gives you the opportunity to spend time with your child after his or her death in one of their private, calm and restful Rainbow Rooms. Here you can spend time together as a family, saying your final goodbyes. Ongoing bereavement support is available for the whole family through telephone befriending, group support, spiritual care, and remembering days.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Therapeutic Play for Bereaved Children	Richmond's Hope	0131 661 6818	Richmond's Hope, 227 Niddrie Mains Road, Edinburgh EH16 4PA	info@richmondshope.org.uk www.richmondshope.org.uk	This charity specifically aims to help children explore their feelings and find ways of coping with loss. Usually, children will take part in one-to-one therapeutic play sessions which can help them express their thoughts and preserve invaluable memories of their loved one. These sessions last for roughly 40 minutes and are usually attended once a week on weekdays between 9am and 5pm.

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

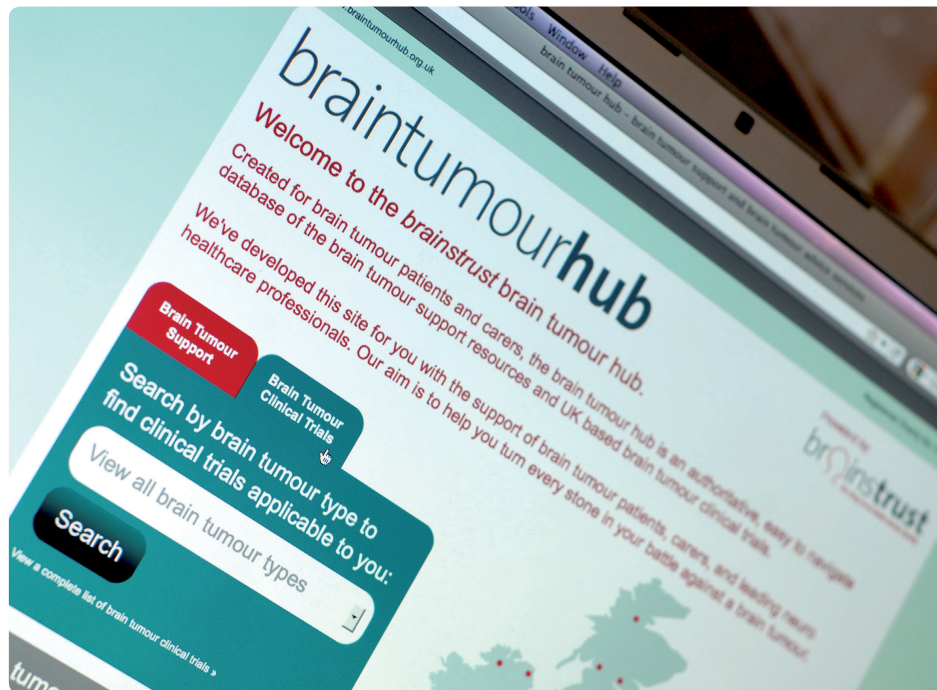
from our experience. We believe that you need to be informed to make decisions. And that might mean gathering information and then deciding not to make a decision. That's a decision too! For more information on second opinions, visit 'Just been told?' on www.brainstrust.org.uk/advice-symptoms.php

- **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

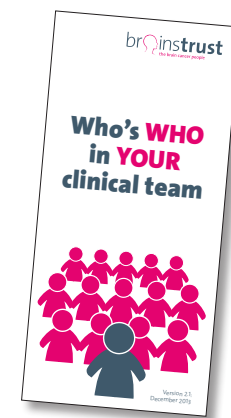
Written for *brainstrust* to help parent carers or patients broach a brain tumour diagnosis with their children. It is a beautifully illustrated book and has featured in the BMA newsletter and Oncology news. The forward has been written by the lovely actress and *brainstrust* supporter, Julie Walters. 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.

There are over 55,500 people living with a brain tumour in the UK. *braintrust* 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@braintrust.org.uk

www.braintrust.org.uk

**The little white book – South East Scotland,
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