

the little white book

Glasgow and **surrounding areas**

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 Glasgow. 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.

From 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	brainstrust	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 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.
Glasgow Support Group	The Brain Tumour Charity	07827 595855	Maggie's Cancer Caring Centre, Gartnavel Hospital, 1053 Great Western Road, Glasgow G12 0YN	gus.ironside@thebraintumour charity.org www.thebraintumourcharity.org	Held on the first Tuesday of every month, these meetings take place at the Maggie's Centre within the grounds of Gartnavel Hospital. The meetings start at 1.30pm and finish at around 3pm and are aimed at patients, families and friends of anyone diagnosed with a brain tumour.

Networking Networking

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
The Monday and Wednesday Groups	Headway Glasgow	0141 332 8878	The Renfield Centre, 260 Bath Street, Glasgow G2 4JP	headwayglasgow@btconnect.com www.headwayglasgow.org	These weekly groups are for people with a brain injury. The groups give you a chance to have a tea and a chat and take part in various activities to stimulate
					memory, number and word use. The groups run between 1.30pm and 4pm and often provide information on other outings and external activities. They also have regular speakers on a variety of topics such as benefits and local organisations.
The Walking Group	Headway Glasgow	0141 332 8878	The Renfield Centre, 260 Bath Street, Glasgow G2 4JP	headwayglasgow@btconnect.com www.headwayglasgow.org	This group, open to people with a brain injury, meets monthly for short walks around the Glasgow area. Longer walks will be available based on demand. Previous walks have been to the Glasgow Necropolis, Hogganfield Loch and Pollok Park.
Thursday Art	Headway Glasgow	0141 332 8878	The Renfield Centre,	headwayglasgow@btconnect.com	These two-hour art groups for people with a brain injury offer a chance to unleash your imagination in a group of people who understand what you are going through. The activities in these classes include drawing, painting, clay work, collage and papier mache. The groups take place every Thursday between 2 and 4pm.
Thursday Art Group			260 Bath Street, Glasgow G2 4JP	www.headwayglasgow.org	

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Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Epilepsy Befriending Service	Epilepsy Connections	0141 248 4125	100 Wellington Street, Glasgow G2 6DH	info@epilepsyconnections.org.uk www.epilepsyconnections.org.uk/our- services/befriending-service/	This befriending service will match you with a like-minded, friendly and approachable volunteer who will meet with you fortnightly and help you take part in a range of social activities including sports, eating out and shopping. A good way of improving you well-being and quality of life.
Epilepsy	Epilepsy	0141 248 4125	100 Wellington	info@epilepsyconnections.org.uk	An allotment open to adults who wish
Allotment Connections Group	Connections		Street, Glasgow G2 6DH	www.epilepsyconnections.org.uk/ forthcoming-events/	to gain some healthy exercise and meet up with other people with epilepsy whilst gaining some useful gardening skills and experience. There is also an opportunity to grow your own healthy produce to take home. The group meets at the allotment every Friday between 10.30am and 1pm.
Move More	Macmillan Cancer	0141 287 0241	Various	movemore@glasgowlife.org.uk	This charity has a number of active
Glasgow	Support			www.glasgowlife.org.uk/communities/goodmove/movemore/pages/default.aspx	classes in the Glasgow area for people living with and beyond cancer. Gentle exercise classes can help reduce fatiguaid the recovery of your confidence an improve your mood. Classes include walking groups, gentle movement, gardening and a circuit class.

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 &	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 may take place either face-to- face or over the telephone depending on circumstances.
The Beatson Counselling Services	Beatson West of Scotland Cancer	0141 301 7000	The Beatson West of Scotland	Contact by telephone or ask a member of staff for details.	This service aims to help you clarify any worrying thoughts, feelings or
	Care Centre		Cancer Centre, 1053 Great Western Road, Glasgow G12 0YN	www.beatson.scot.nhs.uk	difficulties you may be having with your diagnosis. Your counsellor will listen to you, help you make sense of your feelings, and offer you emotional support. The service is offered to both in-patients and out patients as well as their immediate family before, during and after treatment. Get in touch to arrange an appointment.

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Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Talking Therapy and Counselling	Cancer Support Scotland	0141 337 8199 or Freephone 0800 652 4531	The Calman Centre, 75 Shelley Road, Glasgow G12 OZE	info@cancersupportscotland.org www.cancersupportscotland.org	Here you can access one-to-one talking therapies in a safe confidential environment from counsellors experienced in working with people touched by cancer. This service is available to anyone affected, including those who have lost a loved one.
Managing Stress Workshops	Maggie's Glasgow	0141 357 2269	Gartnavel General Hospital, 1053 Great Western Road, Glasgow G12 OYN	glasgow@maggiescentres.org www.maggiescentres.org/our-centres/ maggies-glasgow/whats-on/	These 6-week long workshops, run by a Cancer Support Specialist, are specifically designed for those affected by cancer. The course introduces different methods of relaxation including: controlling anxious thoughts, meditation, visualisation and 'quick' or emergency relaxation.
Where Now? Post-Treatment Course	Maggie's Glasgow	0141 357 2269	Gartnavel General Hospital, 1053 Great Western Road, Glasgow G12 OYN	glasgow@maggiescentres.org www.maggiescentres.org/our-centres/ maggies-glasgow/whats-on/	This is a seven-week course for anyone who has finished their cancer treatment, as well as their friends and family. It offers skills and techniques to support you through this transition period and beyond. Sessions last around three hours and are led by a cancer support specialist and a clinical psychologist.
Glasgow Libraries Drop-in Support	Macmillan Cancer Support and Cancer Support Scotland	0141 287 2999	Macmillan @ Glasgow Libraries, The Mitchell, North Street, Glasgow G3 7DN	macmillan@glasgowlife.org.uk www.glasgowlife.org.uk/libraries/ macmillan-at-glasgow-libraries/your- local-library/Pages/default.aspx	Libraries throughout the city of Glasgow are host to a free and confidential dropin service for anyone affected by cancer. Here you can get emotional support and high quality information to help you through your cancer journey.

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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
Glasgow Support Group	The Brain Tumour Charity	07827 595855	Maggie's Centre, Gartnavel Hospital, 1053 Great Western Road, Glasgow G12 0YN	gus.ironside@thebraintumour charity.org www.thebraintumourcharity.org	Everyone is welcome to join this warm and inviting group aimed at patients, families and friends of anyone diagnosed with a brain tumour. Meetings take place on the first Tuesday of every month from 1.30pm to 3pm.
Glasgow Carer Cafés	Carers Link	0800 975 2131 or 0141 955 2131	Milngavie Enterprise Centre, Ellangowan Road, Milngavie, Glasgow G62 8PH	www.carerslink.org.uk/courses/ groups/	The Carer Cafes meet on a monthly basis and are open to any carer who would welcome the opportunity to socialise, share information, offer mutual support, drink coffee, eat biscuits and have a 'richt guid blether.' Feel free to come along whenever you can. The group meets on the second Friday of each month between 10.30am and 12.30pm. Groups are currently running in Milngavie, Kirkintilloch, Bishopbriggs and Bearsden.

Support groups Support groups

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Brain Tumour Support Group	Maggie's Glasgow	0141 357 2269	Gartnavel General Hospital, 1053 Great Western Road, Glasgow G12 0YN	glasgow@maggiescentres.org www.maggiescentres.org/our-centres/ maggies-glasgow/whats-on/	This monthly group provides an opportunity to talk to other people who are in a similar situation to you. Groups offer a safe space to express emotions you might not want to share with your friends and family. You might learn from those a little way ahead of you on their journey and develop your own strategies for coping.
North Lanarkshire Brain Tumour Support Group	Maggie's Lanarkshire	07827 595855	Maggie's Lanarkshire, Monklands Hospital, The Elizabeth Montgomerie Building, Airdrie, Lanarkshire ML6 OJS	lanarkshire@maggiescentres.org www.thebraintumourcharity.org/get- support/ support-your-local-area/ lanarkshire-brain-tumour-support- group/	Ths is open to people diagnosed with a brain tumour as well as their friends and family. Here you can talk and share experiences with other people in a similar situation. They meet on the first Wednesday of the month, between 2pm and 3.30pm.
Young Person's Peer Support Group	CLIC Sargent and Maggie's Glasgow	0141 301 7680	Maggie's Glasgow, Gartnavel General Hospital, 1053 Great Western Road, Glasgow G12 0YN	Siobhan.McKay@clicsargent.org.uk www.clicsargent.org.uk	This supportive group allows young people with a diagnosis of cancer or leukaemia to access peer support whilst gaining confidence and reducing stress. The group, run by a young person's social worker, community worker and psychologist, is for people aged between 16 and 24 who are registered with CLIC Sargent. The group meet monthly on a Wednesday between 6pm and 7.30pm. The team also runs a number of group outings with Maggie's for afternoon tea, ten-pin bowling and meals out. Young people are notified of the groups via the CLIC Sargent private Facebook page and must give prior notice to the CLIC Sargent team if they would like to dropin to a session.

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
Confident Caring Group	Marie Curie	0141 557 7515	Marie Curie Hospice, Balornock Road, Glasgow G21 3US	confidentcaring@mariecurie.org.uk www.mariecurie.org.uk	For carers who would like information and advice to help with their caring role. At each session you meet others in a similar situation to yourself in a relaxed environment. Two clinical nurses lead the sessions covering a wide range of topics.
East Renfrewshire Carers Centre	East Renfrewshire Carers	0141 638 4888	They have various centres in the area. Contact them to find the one nearest to you.	enquiries@eastrenfrewshirecarers.co.uk www.eastrenfrewshirecarers.co.uk	They offer a full programme to support adult and young carers. Services include information, advice, emotional support and a short break service.
Talking Therapy for Carers	Cancer Support Scotland	0141 337 8199 or Freephone 0800 652 4531	The Calman Centre, 75 Shelley Road, Glasgow G12 OZE	info@cancersupportscotland.org www.cancersupportscotland.org	Offers one to one confidential counselling with fully qualified counsellors for those affected by cancer. The sessions can be tailored to your individual needs and can cover a wide range of issues such as anxiety, relationship concerns and facing change.
West Glasgow Carers Centre	Carers Trust	0141 959 9871	1561 Great Western Road, Glasgow G13 1HN	westcarers@volunteerglasgow.org www.carers.org	Provides not just written resources but also advice and emotional support, as well as a young persons peer support group and help for older carers.

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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 Butterfly Project	The Prince and Princess of Wales Hospice	0141 429 5599	Prince and Princess of Wales Hospice, 71 Carlton Place, Glasgow G5 9TD	carol.graham@ppwh.org.uk www.ppwh.org.uk/family-carers/how- we-can-help-you	This pre and post child bereavement service offers individual support to young people and children (2 to 18 years) as well as their parents through one-to-one counselling and therapy. They also run bereavement groups on a regular basis which provide a safe, friendly place for children and young people to express and explore how they think and feel about the loss of a loved one.
Kids' Days	Maggie's Glasgow	0141 357 2269	Gartnavel General Hospital, 1053 Great Western Road, Glasgow G12 0YN	glasgow@maggiescentres.org www.maggiescentres.org/our-centres/ maggies-glasgow/whats-on/	These regular kids' days aim to give children who are affected by an adult's cancer diagnosis the opportunity to access useful support and information in an engaging way. They get the chance to discuss thoughts and fears, visit a local hospital, put a toy through the CT scanner and take part in expressive art therapy classes. The days run from 10am to 2pm and must be pre booked.

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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 PO317QG	hello@brainstrust.org.uk www.brainstrust.org.uk	With <i>brainstrust's</i> 24/7, 365 days a year helpline, patients, carers and families can pick up the phone or email and know they will have an immediate, personal response.
Macmillan Support Line	Macmillan Cancer Support	0808 808 0000		www.macmillan.org.uk	If you have questions about cancer, need support or just want someone to talk to, you can call Monday to Friday between 9am and 8pm.
Cancer Information Nurses	Cancer Research UK	0808 800 4040		www.cancerresearchuk.org	If you have any questions about cancer or need more information you can speak with a cancer information nurse from Monday to Friday between 9am and 5pm.

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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@macmilan.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 your local 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.
One-off and Recurrent Grants	The Andrew and Mary Elizabeth Little Charitable Trust	0141 221 8931	Low Beaton Richmond Solicitors, Sterling House, 20 Renfield Street, Glasgow G2 5AP	gabrielle@lbr-law.co.uk grants-search.turn2us.org.uk/grant/ the-andrew-mary-elizabeth-little- charitable-trust-13654?iframe=False	The grants are offered to people in need of income support, disability benefits or pensions who live in the Glasgow area.

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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
Exercise and Relaxation Classes	Maggie's Glasgow	0141 357 2269	Maggie's Glasgow, Gartnavel Hospital, 1053 Great Western Road, Glasgow G12 0YN	glasgow@maggiescentres.org www.maggiescentres.org	There are a range of exercise options available at this centre such as yoga and tai chi. The classes are tailored to people with cancer and flexible to suit your needs.
brainstrust Hypnotherapy Service	brainstrust	01983 292405	Various	hello@brainstrust.org.uk www.brainstrust.org.uk	A programme of hypnotherapy uniquely designed for patients and carers affected by a brain tumour diagnosis. Sessions may take place either face to face or over the telephone depending on circumstances.

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Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Complementary Therapies for Cancer	Cancer Support Scotland	0141 337 8199 or Freephone 0800 652 4531	The Calman Centre, 75 Shelley Road, Glasgow G12 OZE	info@cancersupportscotland.org www.cancersupportscotland.org	This service offers a range of complementary therapies to those affected by cancer. Therapies include reflexology, massage, reiki, and aromatherapy. Get in touch to find out which days these therapies are available on.
Glasgow Therapy Sessions	Marie Curie	0141 557 7400	Marie Curie Hospice, Balornock Road, Glasgow G21 3US	glasgow.hospice@mariecurie.org.uk www.mariecurie.org.uk/help/hospice- care/hospices/glasgow/services/day- services#Complementarytherapies	There are a wide range of safe, natural and relaxing therapies available here to supplement traditional care. Therapies include: acupressure, acupuncture, aromatherapy, hypnotherapy, Indian head massage, massage, reflexology, reiki, relaxation and shiatsu. The session are available for both patients and carer from Monday to Friday between 10am and 4pm.

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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
Malcolm Sargent House	CLIC Sargent	01292 671233	Malcolm Sargent House, 24 Links Road, Prestwick, Ayrshire KA9 1QG	MSH@clicsargent.org.uk www.clicsargent.org.uk	Located on Ayrshire's stunning coastline, Malcolm Sargent House offers holidays for young people affected by cancer and their families during and after treatment. They also provide shorter breaks during the weekends and in low season.
Calum's Cabin in Rothesay	Calum's Cabin	07544 979538	Calum's Cabin, "Calenna", Mountstuart Road, Rothesay 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 stay. The charity also helps with travel costs to the island.
The Kieran Mess Luxury Holiday Home	The Kieran Mess Foundation		The Kieran Mess Foundation, 4 Swinton Place, The Ferns Lawthorn, Irvine, Ayrshire KA11 2EG	enquiries@thekieranmessfoundation. org.uk www.thekieranmessfoundation.org/ holiday-home.html	They offer a luxury holiday home at Thurston Manor which provides a relaxing and comfortable environment for children with cancer and their families.

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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
Benefits Advisor and Welfare Rights Service	Maggie's Glasgow	0141 357 2269	Maggie's Glasgow, Gartnavel Hospital, 1053 Great Western Road, Glasgow G12 0YN	glasgow@maggiescentres.org www.maggiescentres.org/our- centres/maggies-glasgow/	A drop-in service where you can get help on welfare rights from Maggie's own experienced and approachable benefits adviser. The centre is open Monday to Friday between 9am and 5pm.
Glasgow Benefits Service	Glasgow Central Citizens Advice Bureau	0141 552 5556	1st Floor, 88 Bell Street, Glasgow G1 1LQ	Submit email enquiries through the following weblink: www.glasgowcentralcab.org.uk/email.html www.glasgowcentralcab.org.uk/benefits.html	At this drop-in you will find experienced advisors who are there to help you with a range of benefits issues, whether you are working, unemployed or disabled. They can talk you through the benefits you are currently entitled to and can explain how changes in the benefits system will affect you.
Macmillan Benefits and Rights Service	Macmillan Cancer Support	0141 301 7374	Beatson West of Scotland Cancer Care Centre, 1053 Great Western Road, Glasgow G12 0YN	www.beatson.scot.nhs.uk/content/ default.asp?page=s21_7	The benefits system can be complex and confusing. What you are entitled to depends on factors such as age, income and whereabouts in the UK you live. Here you can find out about your benefits rights and who can help you to claim.

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Service name	Service provider	Phone contact	Location	Email and web address	Brief description
North Lanarkshire Benefits Advice	Maggie's Lanarkshire	01236 771199	Maggie's Lanarkshire, Monklands Hospital, The Elizabeth Montgomerie Building, Airdrie, Lanarkshire ML6 OJS	lanarkshire@maggiescentres.org www.maggiescentres.org/our- centres/maggies-lanarkshire/ whats-on/	Here you can talk to a trained benefits advisor about financial and practical assistance that you may be entitled to. Assistance includes help with filling out forms to appealing decisions on benefit claims.

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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
Beatson Patient Transport	Beatson West of Scotland CancerCentre	0141 531 3737	Beatson West of Scotland Cancer Care Centre, 1053 Great Western Road, Glasgow G12 OYN	www.beatson.scot.nhs.uk/content/ default.asp?page=s22_8_10	This helpful service organises transport to the Beatson West of Scotland Cancer Centre for patients receiving treatment.
Disabled Persons Bus Pass	Transport Scotland	0141 333 3211	Transport Scotland, Buchanan House, 58 Port Dundas Road, Glasgow G4 0HF	www.transport.gov.scot/public- transport/concessionary-travel-people- aged-60-or-disability	This pass entitles people with a disability to free or subsidised bus travel so they can get around Scotland or their local area.
Volunteer Drivers	Accord Hospice	0141 581 2000	Accord Hospice, 7 Morton Avenue, Paisley PA2 7BW	kenneth.mathie@accord.org.uk www.accordhospice.org.uk	If you are under the care of the hospice they provide a volunteer driver service where a volunteer will transport you to hospital treatments.

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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
Specialist Respite Support	Prince and Princess of Wales Hospice	0141 429 5599	Prince and Princess of Wales Hospice, 71 Carlton Place, Glasgow G5 9TD	info@ppwh.org.uk www.ppwh.org.uk	This hospice has an in-patient ward which offers a comfortable environment for those patients that may benefit from receiving more specialist support. The hospice offers short stays to control pain and manage symptoms and a service which focuses on care in the final days of life.
Paisley Specialist Palliative Care	Accord Hospice	0141 581 2000	Accord Hospice, 7 Morton Avenue, Paisley PA2 7BW	kenneth.mathie@accord.org.uk www.accordhospice.org.uk	Services here include an in-patient unit, day therapy, patient and family support and complementary therapies. The services are available to both patients and their families.
Renfrewshire Palliative and End of Life Care	St Vincent's Hospice	01505 705635	St Vincent's Hospice, Midton Road, Howwood, Johnstone, Renfrewshire PA9 1AF	info@svh.co.uk www.stvincentshospice.co.uk	This hospice offers a specialised end of life in-patient unit, a day hospice focusing on palliative care, community nurse specialists focusing on supportive care, a consultant-led palliative medicine outpatient clinic, an outpatient pain clinic and patient family support.

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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
Glasgow Bereavement Support	Cruse Bereavement Care Scotland	0845 600 2227	Cruse Bereavement Care, Centre Chamber, 11 Bothwell Street, Glasgow G2 6LY	info@crusescotland.org.uk www.crusescotland.org.uk	This service offers regionalised support to the local community in Glasgow. Support includes telephone support, face to face support, informative local leaflets and bereavement support groups.
Bereavement Talking Therapy	Cancer Support Scotland	0141 337 8199 or Freephone 0800 652 4531	Cancer Support Scotland, The Calman Centre, 75 Shelley Road, Glasgow G12 0ZE	info@cancersupportscotland.org www.cancersupportscotland.org	These comforting one-to-one talking therapies, run by trained counsellors, can be specifically tailored for those who have experienced the loss of a loved one due to cancer.
Overnight Telephone Counselling	Breathing Space Scotland	0800 838587	Various contact centres in Clydebank, Cardonald and South Queensferry	info@breathingspacescotland.co.uk www.breathingspace.scot	This service offers telephone counselling with specialist advisors who will listen and assist you with your concerns about your mood, thoughts and feelings. The telephone counselling service is open Monday to Thursday from 6pm to 2am and right throughout the weekend from 6pm on to 6am on Monday.

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Service name	Service provider	Phone contact	Location	Email and web address	Brief description
North Lanarkshire Bereavement Support Group	Maggie's Lanarkshire	01236 771199	Maggie's Lanarkshire, Monklands Hospital, The Elizabeth Montgomerie Building, Airdrie, Lanarkshire ML6 0JS	lanarkshire@maggiescentres.org www.maggiescentres.org/our- centres/maggies-lanarkshire/ whats-on/	This group is led by a psychologist and is aimed at people who have experienced bereavement due to cancer. It provides an opportunity to talk, express emotions and share experiences in a safe environment. It also provides a chance to meet with other people in a similar situation who may help you develop new coping strategies.

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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

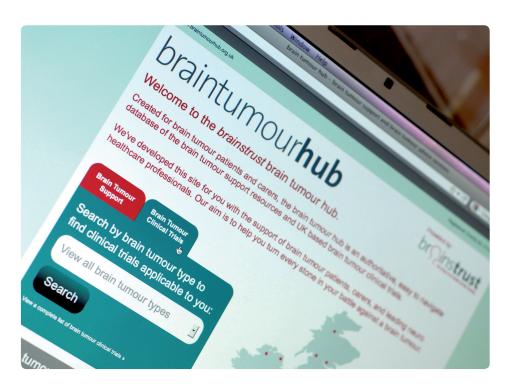
from our experience. We believe that you need to be informed to make decisions. And that might mean gathering information and then deciding not to make a decision. That's a decision too! For more information on second opinions, visit 'Just been told?' on www.brainstrust.org.uk/advice-symptoms.php

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.



What can brainstrust do to help? What can brainstrust do to help?

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. *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 – Glasgow, edition 1, published by *brainstrust* May 2016, due for review May 2017.

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Health & care information you can trust

The Information Standard

Certified Member

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