

# the little white book

### Aberdeen, The Highlands 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 Aberdeen and The Highlands. 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
Aberdeen Cancer Support Drop-in	Maggie's Aberdeen	01224 645928	Maggie's Aberdeen, Aberdeen Royal Infirmary, Elizabeth Montgomerie Building, Westburn Road, Foresterhill, Aberdeen AB25 2UZ	aberdeen@maggiescentres.org www.maggiescentres.org/our-centres/ maggies-aberdeen/whats-on/	This drop-in service offers you a chance to have a chat with a Cancer Support Specialist for any questions or worries you may have about cancer. The experienced team will listen and to guide you to the information you need. The service is available 9am to 5pm on weekdays. Also on offer are kid's days, talking heads workshops, relaxation sessions, an expressive writing group and a qigong exercise class.
Inverness Cancer Support Drop-in	Maggie's Highlands	01463 706306	Raigmore Hospital, Old Perth Road, Inverness IV2 3FL	highlands@maggiescentres.org www.maggiescentres.org/our-centres/ maggies-highlands/whats-on/	This drop-in service offers you a chance to chat to a Cancer Support Specialist fo any questions or worries you may have about cancer. The experienced team will listen and guide you to the information you need. The service is available 9am to 5pm on weekdays. Also available are a number of exercise sessions tailored for cancer including Ta Chi, Qi Gong, yoga and a weekly walking group.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Move More Aberdeen	Macmillan Cancer Support	01224 047925	Gordons Centre, Corunna Rd, Bridge of Don, Aberdeen AB23 8DU	MoveMore@sportaberdeen.co.uk www.macmillan.org.uk/in-your-area/ local-dashboard/detail/Practical%20 help%20and%20support%20groups/ 8845/Move-More-Aberdeen?proximity =2.13%20miles%20from%20you	We know taking part in physical activity during and after treatment can play a huge role in enabling you to take back control. Exercise can help you prevent and manage some of the effects of treatment, such as fatigue, depression, muscle wasting and risks to your heart health. This scheme aims to help you to get active by organising various activities from gardening and walking groups to gentle movement and circuit classes. All the activities are free of charge and you'll be with others who know what you are going through.
Inverness	Look Good Feel	Look Good Feel 01463 706306 Raigmore Hospital, Better and Old Perth Road, Maggie's Highlands Inverness IV2 3FL	6	highlands@maggiescentres.org	This one-off monthly course teaches
Inverness Look Good Feel Better			Inverness	www.maggiescentres.org/our-centres/ maggies-highlands/whats-on/	women with cancer how to manage some of the visible side-effects of treatment. The course, which is run by beauty professionals, introduces some simple techniques that can help you feel more confident about your changed appearance. You will also receive a free goody bag of premium beauty products.

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Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Aberdeen and	CLAN Cancer	01224 647000	CLAN House,	enquiries@clanhouse.org	These welcoming coffee mornings
Highlands Coffee Mornings and Networking Groups	Support		120 Westburn Road, Aberdeen AB25 2QA Coffee-mornings-aberdeen	offer an opportunity to meet others who know what you are going through. The coffee mornings are held on the first Saturday of the month from 10am – 12noon and no booking is required. The mornings cost £2 which includes unlimited tea/coffee, home bakes and often a sale of good quality books. This charity also offers art and craft workshops, health walks, and knitting/ crochet groups. Other coffee mornings and networking groups are also available at various centres throughout the highlands.	
Weekly 5km Park Runs	parkrun UK		Various locations	www.parkrun.org.uk/events/events/	These free, weekly, 5km timed runs take place in pleasant parkland surroundings throughout the UK. They are open to people of all abilities, can be completed at your own pace, and can act as great stress relievers. Participants can benefit from the sociable and therapeutic nature of the events and the associated volunteering opportunities can be highly rewarding. All runs start at 9am on Saturday morning. There are currently six park runs in the Aberdeen and Highlands area.

## **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
Aberdeen Counselling Support	The Rosemount Centre for Complementary Therapies	01224 636378	The Rosemount Centre, 1C Mount Street, Aberdeen AB25 2RA	www.rosemountcentre.com/ a-variety-of-therapies/counselling/	We know that a brain tumour can sometimes leave you feeling powerless This service can help you through times of stress, anxiety and depression through counselling. The service gives you the opportunity to explore your situation and feelings, in a safe and confidential environment, which can help energise you and perhaps enable you to find a way forward.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Aberdeen	CLAN Cancer	01224 647000	CLAN House,	enquiries@clanhouse.org	Here you will find information about
and Highlands Emotional Support and Counselling	Support		120 Westburn Road, Aberdeen AB25 2QA	d, clanhouse.org/local/services/ emotional-support-counselling- aberdeen 9am-4.30pm with a l until 7pm on Thursday session on the first Sa month from 9.30am- depth support is offer professional counsello support face-to-face of when booked in advan is also available at var	cancer-related issues as well as one-to- one emotional support. The service is run as a drop-in from Monday to Friday, 9am–4.30pm with a late opening until 7pm on Thursdays and a monthly session on the first Saturday of the month from 9.30am–1pm. More in- depth support is offered by a team of professional counsellors who can offer support face-to-face or by telephone when booked in advance. This service is also available at various centres throughout the highlands.
Online Video	Cancer Support (	0800 652 4531		info@cancersupportscotland.org	This charity understands that visiting
Talking Therapy	Scotland			www.cancersupportscotland.org/ services/online-video-talking-therapy/	their centre at Gartnavel for support is not always an option. Therefore, they now offer an online Video Talking Therapy (OVTT) service. This allows people to book appointments and access support from the comfort of their own home, at a suitable time during the day using Skype. The sessions have the same structure and continuity of face-to-face therapy and are conducted in a private room, maintaining the same standards of privacy and confidentiality.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Aberdeen Young Persons Counselling		01224 573892	1 Alford Place, Aberdeen AB10 1YD	acisyouth.office@mhaberdeen.org.uk www.mha.uk.net/services/youth/ index.php	This counselling and information service is aimed at young people between the ages of 12 and 18 living in Aberdeen City. The service provides confidential therapeutic counselling in a safe space to help young people to come to terms with conflict, distress, loss or a change in their life.

## 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
Grampian Brain Tumour Support Group	The Brain Tumour Charity and CLAN Cancer Support	07827 595855	CLAN Cancer Support, 120 Westburn Road, Aberdeen AB25 2QA	gus.ironside@ thebraintumourcharity.org www.thebraintumourcharity.org/ get-support/support-your-local-area/ grampian-support-group/	These monthly meetings, held at CLAN house, are open to anyone affected by a brain tumour. They are a chance for patients, families and friends to gain peer support in a safe and welcoming environment.
Inverness Brain Tumour Network Group	Maggie's Highlands	01463 706306	Raigmore Hospital, Old Perth Road, Inverness IV2 3FL	highlands@maggiescentres.org www.maggiescentres.org/our-centres/ maggies-highlands/whats-on/	This group is for men and women with brain tumours and their carers. The group provides an opportunity to talk to other people who are in a simila situation to you, share experiences and express emotions you might not want to share with your friends and family. It is also a great opportunity to learn from those a little way ahead of you in their journey and develop your own coping strategies. The group is run as a drop-in and takes place on the second Monday of every month, between 1.30pm and 2.30pm. The centre also runs other cancer support groups such as the friends and family group and th living with advanced cancer group.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Highlands Brain Injury Support Groups	Headway Highland	07767 416006	Various locations in the Highlands	leeheadway@yahoo.com www.headwayhighland.org.uk	These friendly support groups focus on social activities such as arts and crafts, board games, table tennis, bowling, quiz's or just having a chat over a tea/ coffee. From time to time, there are guest speakers to deliver a talk/presentation on a topic that is of interest to the group and some sessions have an educational element where the group discuss a topic related to brain injury, for example, fatigue. Support groups are available in Caithness, Inverness, Fort William, Nairn and Dingwall.
Aberdeenshire Brain Injury Support Groups	Headway Grampian	07917787826	23 North Silver Street, Aberdeen AB10 1RJ	www.headway.org.uk/supporting-you/ in-your-area/groups-and-branches/ scotland/brain-injury-grampian/	This charity hosts monthly meeting for people affected by brain injuries. These meetings usually have a speaker on a diverse set of subjects which is followed by time to chat and socialise and have a coffee or tea. The support groups are also available in Inverurie and Elgin.
PINK Cancer Support Group	CLAN Cancer Support	01224 647000	CLAN Cancer Support 120 Westburn Road, Aberdeen AB25 2QA	enquiries@clanhouse.org clanhouse.org/services/ support-services/support-groups/	This group offers friendship and support to women affected by cancer. The Group meets on the second Tuesday of the month at 7.30 pm.
Ballater Support Group	CLAN Cancer Support	01339 756318	Victoria Rd, Ballater AB35 5QX	enquiries@clanhouse.org clanhouse.org/local/services/ support-groups-ballater	This support groups offer a social, friendly environment to gain peer support. The group meets at 4pm on the last Wednesday of the month at Ballater Golf Club.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
'Peedie Blether' Orkney Support Group	CLAN Cancer Support	01856 873393	CLAN Cancer Support, 30 Victoria Street, Kirkwall KW15 1DN	orkney@clanhouse.org clanhouse.org/local/services/ peedie-blether-sessions-orkney	The 'Peedie Blether' support group offers friendship and peer support in a social environment. There is no booking required and everyone is welcome to come along for a coffee and a chat. The group meets on the last Saturday of the month from 10.30am–12.30pm at the charity's support and wellbeing centre in Kirkwall.
Elgin Men's and	CLAN Cancer (	01343 544132	CLAN Cancer	elgin@clanhouse.org	These two informal groups offer peer
Ladies Cancer Support Group	Support		Support, 227 High Street, Elgin IV30 1DJ	clanhouse.org/local/elgin/	support and friendship to men and women affected by cancer. The men's group meets on the first Thursday of the month at 10am and weekly on a Tuesday from 5.30pm whilst the ladies group meets on the fourth Friday of the month from 2–4pm.

## **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
Aberdeen Parent	VSA	01224 358550	Elaine Dukes,	elaine.dukes@vsa.org.uk	Here you can a find dedicated
Carer Support			38 Castle Street, Aberdeen AB11 5YU	www.vsa.org.uk/children-and-families/ parent-carer-support/	information worker for parent carers who can signpost you to relevant support services and resources. We know each family has different supp and assistance needs and this servic aims to provide a flexible and adapt approach, ensuring each family achi the best possible outcomes for every involved.
Orkney Young Carer Support	Orkney Young Carers Service	01856 870500	Orkney Young Carers Service, Orkney Carers Centre, Kirkwall Travel Centre West Castle Street, Kirkwall KW15 1GU	youngcarers@crossroadsorkney.co.uk www.orkneyyoungcarers.org/ whattheoycsoffers.html#top	This centre hosts free monthly activity sessions for Young Carers to meet new people, relax, have fun and take a break from their caring responsivities. The centre offers one to one or group support sessions, a befriending service, counselling and an assessment of a Young Carers responsibilities and needs
Highland Carer	Connecting Carers	01463 723560	Glen Orrin House,	carers@connectingcarers.org.uk	This charity hosts lots of support groups
Support Groups			0	connectingcarers.org.uk/carers-services/ support-activity-groups.aspx	all over the Highlands for carers. They give you the chance to meet others in similar situations, learn new skills or just have a chat over a coffee. The charity also offers a book group, craft group and respite breaks for Highland carers.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Highland Connecting Young Carers	Connecting Carers	01463 723562	Glen Orrin House, High Street, Dingwall IV15 9TF	carers@connectingcarers.org.uk connectingcarers.org.uk/ carers-services/connecting-young- carers.aspx	This charity works with young carers between the ages of 5 and 24 to help them be better informed, better supported and better connected to other young carers in Highland. The charity provides thoughtful support and days out which may include theatre trips, art projects and activity days. Also on offer is advice about grants and various skill building activities.
Orkney Carer Centre	Crossroads Orkney	01856 87 0500	Crossroads Orkney, Orkney Carers Centre, Kirkwall Travel Centre, West Castle Street, Kirkwall, Orkney KW15 1GU	carers@crossroadsorkney.co.uk www.crossroadsorkney.co.uk/pg/ centre.html	This drop-in centre can provide you with information and advice about issues affecting carers such as benefits to both the carer and the dependent, support services such as daycare, homecare, befriending service, respite breaks, aids and adaptions, power of attorney and transport. They also offer emotional support, carer training and advocacy.

## **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
Aberdeen Children and Teens Group	CLAN Cancer Support	01224 647000	CLAN Cancer Support, 120 Westburn Road, Aberdeen AB25 2QA	lisa.maxwell@clanhouse.org clanhouse.org/local/services/children- teens-groups	These groups provide social and fun activities for children and young people affected by cancer. They are usually held monthly on Saturdays and more regularly during school holidays. The charity has published two books for children dealing with a cancer diagnosis and can offer a dedicated space at CLAN House for children, young people and their families equipped with toys, games and books. Children and family support is also available in Elgin, Inverurie and Shetland.
Aberdeen	red ChildrenEdinburghFamilyEH9 1ATwww.children	0131 446 2300	83 Whitehouse Loan,	cfs@children1st.org.uk	This hands-on charity gives support
Tailored Children and Family Support		www.children1st.org.uk	to families under stress in many of Scotland's communities including Aberdeen, Moray and Inverness. They offer a tailored approach to suit each family's needs including direct support for children, tailored to their age, circumstances and wishes.		

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Aberdeen Kids' Days	Maggie's Aberdeen	01224 645928	Maggie's Aberdeen, Aberdeen Royal Infirmary, Elizabeth Montgomerie Building, Westburn Road, Foresterhill, Aberdeen	aberdeen@maggiescentres.org www.maggiescentres.org/our-centres/ maggies-aberdeen/whats-on/	Kid's days are relaxed and fun organised days aimed at children who have a parent or other caregiver with a diagnosis of cancer. Here you will learn how to talk more confidently about cancer and share feelings as a family. The days will also help children to become more knowledgeable about cancer, the hospital and cancer
			AB25 2UZ		treatment.

## **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
<i>brainstrust</i> 24/7 Helpline	brainstrust	01983 292405	<i>brainstrust</i> , 4 Yvery Court, Castle Road, Cowes, Isle of Wight PO31 7QG	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.
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. The helpline is open every weekday morning between 9am and 2pm from Monday to Thursday and 9am to 1pm on Fridays.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Brain Tumour Action Telephone Helpline	Brain Tumour Action	0131 466 3116	Brain Tumour Action, 25 Ann Street, Edinburgh EH4 1PL	administrator@braintumouraction. org.uk braintumouraction.org.uk/index.php/ how-can-we-help/	This helpline offers support, information and counselling over the phone. The service works as a 24-hour answer phone. Simply leave your details after the tone and they will get back to you, nearly always within the same day. Support can also be offered by email.

## **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 Cancer Grants	Macmillan Cancer Support	0808 808 0000		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.
CLIC Sargent	CLIC Sargent	CLIC Sargent 0300 330 0803		welfareadvice@clicsargent.org.uk	These are one-off grants that are
Grant for Young People				www.clicsargent.org.uk/content/ financial-support	These are one-off grants that are offered to children and young people with cancer, and their families, as soon as they come into contact with CLIC Sargent Social Worker. They can help ease the sudden financial demands that a cancer diagnosis can bring by covering costs of food, travel and other day-to- day expenses. The grant is available at any time within the first 12 months of diagnosis.

## **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
Inverness Relaxation, Yoga and Creative Therapies	Maggie's Highlands	01463 706306	Raigmore Hospital, Old Perth Road, Inverness IV2 3FL	highlands@maggiescentres.org www.maggiescentres.org/our-centres/ maggies-highlands/whats-on/	This centre offers a variety of therapies and classes which are specifically designed for people living with cancer. This includes an expressive art class, creative writing session, a relaxation and visualisation group and a yoga class for beginners.
Aberdeen and Highlands Complementary Therapies	CLAN Cancer Support	01224 647000	CLAN Cancer Support, 120 Westburn Road, Aberdeen AB25 2QA	enquiries@clanhouse.org clanhouse.org/local/services/ complementary-therapies-aberdeen	This charity can offer various therapies tailored to cancer which include massage, aromatherapy, reflexology, energy healing, homoeopathy, reiki, shiatsu, aqua detox and mistletoe therapy. They also run relaxation and visualisation classes and a gentle yoga group. These therapies are also available at various centres throughout the highlands.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Aberdeen Salon and Nutrition Workshops	CLAN Cancer Support	01224 647000	CLAN Cancer Support, 120 Westburn Road, Aberdeen AB25 2QA	enquiries@clanhouse.org clanhouse.org/local/services/ the-salon-aberdeen	These workshops are specifically designed with cancer patients in mind. There is a wig styling and hair cutting workshop available weekly on Mondays from 9.30am–2.30pm and a monthly session on Tuesdays from 10am–1pm which also offers one-to-one skin consultations. One-to-one consultations with an experienced nutritionist are available on Wednesday afternoons with a pre-booking. These nutrition sessions also include a selection of complimentary lunchtime tasters available every Wednesday from 12 noon–1pm.
Aberdeen Relaxing Holistic Therapies	The Rosemount Centre for Complementary Therapies	01224 636378	The Rosemount Centre, 1C Mount Street, Aberdeen AB25 2RA	clanhouse.org/local/services/ the-salon-aberdeen	This centre offers a wide range of therapies which can be used to aid general well-being and relaxation, as well as supporting you in dealing with medical conditions. Some therapies will focus more on the physical aspects whilst others address mental and emotional well-being as well.

## **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
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 in Irvine which provides a relaxing and comfortable environment for children with cancer and their families.

## 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
Banff & Buchan Citizens Advice Bureau	Macmillan Cancer Support and Aberdeen Citizens Advice Bureau	01779 481 881	48 Marischall Street, Top Floor, Peterhead AB42 1HS	macmillanproject@aberdeenshirecab. casonline.org.uk www.macmillan.org.uk/in-your- area/local-dashboard/detail/ Benefit%20advice%20services/8274/ BanffBuchan-Citizens-Advice- Bureau?proximity=27.23%20miles %20from%20you	This information and advice service is available to anyone receiving treatment for cancer at Aberdeen Royal Infirmary as well as their family. They can offer advice on a wide range of issues such as benefits, grants, housing, debt and employment.
Free Confidential Welfare Advice	Aberdeen Citizens Advice Bureau	01224 569750		www.aberdeencab.org.uk	This service has been providing advice and information to the people of Aberdeen for over 70 years. All clients ar offered free, impartial and confidential advice on issues such as benefits, debt, work-related problems, relationships and housing.
Aberdeen Cash n Your Pocket Referrals	Cash In Your Pocket Partnership	01224 686077	RTLG-ZRAX-CXCU, C/o ACVO, 38 Castle Street, Aberdeen AB11 5YU	www.ciyp.co.uk	This service coordinates an online directory of information on services which offer help to people struggling financially in Aberdeenshire. The directory also allows for an immediate referral to the Cash In Your Pocket Partnership in order to put you in touch with the most relevant organisations and get the help you need.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Inverness Specialist Benefits Advisor	Maggie's Highlands	01463 706306	Raigmore Hospital, Old Perth Road, Inverness IV2 3FL	highlands@maggiescentres.org www.maggiescentres.org/our-centres/ maggies-highlands/whats-on/	We know that living with a brain tumour can impact your finances, through lost income and increased costs such as heating and travel. If you, or someone you care for, is living with cancer, the specialist Benefits Advisor at this centre can help you complete forms and also access any additional support that you might be eligible for, such as parking permits.

## **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
CLAN Haven	CLAN Cancer	01224 647000	120 Westburn Rd,	haven@clanhouse.org	This B&B is available to anyone
Aberdeen	Support		00 120 Westburn Rd, Aberdeen AB25 2QA	haven@clanhouse.org clanhouse.org/services/ support-services/clan-haven/	affected by cancer who is attending, or accompanying a friend or relative to, Aberdeen hospitals. The facility, situated just 20 minutes walk from Aberdeen Royal Infirmary, has been designed to promote a calm, relaxed atmosphere with dedicated staff on hand to provide practical and emotional support during your stay. To help cover some of the cost there is a minimum donation of £30 per person per night for bed, a simple breakfast and transport to the hospital if available. For those attending the Balfour Hospital, or travelling from the islands via Kirkwall to hospitals on the Scottish mainland, CLAN Haven Orkney is available.
Volunteer Drivers for Cancer Care Treatment	Cancer Cars Scotland			www.cancercars.co.uk	This database lists numerous volunteer driving schemes for cancer treatment in Scotland. This website is designed to assist health professionals, people with cancer, their relatives and friends to find voluntary organisations in Scotland which provide a personal transport service to hospital appointments.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Elgin Hospital Volunteer Transport	CLAN Cancer Support	01343 544132	CLAN Cancer Support, 227 High Street, Elgin IV30 1DJ	elgin@clanhouse.org clanhouse.org/local/services/ transport-elgin	This charity aims to provide transport via a team of volunteer drivers to those travelling to and from Aberdeen hospitals, CLAN House in Aberdeen, Dr Gray's hospital in Elgin and Raigmore hospital in Inverness. Please call to find out if they can help you.

## **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
Inverness Inpatient unit	Highland Hospice	01463 243132	Highland Hospice, Ness House, 1 Bishops Road, Inverness IV3 55B	generalenquiries@highlandhospice. org.uk highlandhospice.org/care-services/ in-patient-unit	This inpatient unit, located at Invergordon Community Hospital in the Fyrish ward, provides care for people who are affected by cancer and non- cancer life-limiting illnesses and those close to them. The service aims to treat patients and their families as individuals and help with everyone's unique physical, psychological, spiritual and social needs.
Inverness Day Therapy	Highland Hospice	01463 243132	Highland Hospice, Ness House, 1 Bishops Road, Inverness IV3 5SB	generalenquiries@highlandhospice. org.uk highlandhospice.org/care-services/ day-therapy-services	This day therapy service provides increased support to patients being cared for at home, and to their carers. A team of specialist staff offer a wide range of activities which include one-to-one support, group support, exercise, arts & crafts, foot care, beauty services, trips and life story work. The day therapy services are available Tuesday, Wednesday and Friday each week between 10.30am and 3pm and volunteer driver transport if available.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Inverness Family Support	Highland Hospice	01463 243132	Highland Hospice, Ness House, 1 Bishops Road, Inverness IV3 5SB	generalenquiries@highlandhospice. org.uk highlandhospice.org/care-services/ family-support-services	This family support service has a focus on supporting patients and their families during illness and into bereavement. They can respond to a variety of patient and family needs through involvement in care or planning for a patient's discharge, form filling, emotional support to all family members, spiritual or religious support, and outreach bereavement support even for the more remote areas of the highlands.

## **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.

ervice name	Service provider	Phone contact	Location	Email and web address	Brief description
Aberdeen Cancer Bereavement Group	Maggie's Aberdeen	01224 645928	Maggie's Aberdeen, Aberdeen Royal Infirmary, Elizabeth Montgomerie Building, Westburn Road, Foresterhill, Aberdeen AB25 2UZ	aberdeen@maggiescentres.org www.maggiescentres.org/our-centres/ maggies-aberdeen/whats-on/	If someone close to you has died from cancer this centre can help you. This bereavement support group is a place to speak to others going through a similar experience and find advice, support and strategies for coping. It covers both emotional and practical concerns, from the day-to- day impact of bereavement to dealing with anniversaries and rebuilding your life. If you would prefer one-to- one bereavement support that is also available here.
riendship fter ereavement roup	CLAN Cancer Support	01224 647000	CLAN Cancer Support, 120 Westburn Road, Aberdeen AB25 2QA	enquiries@clanhouse.org clanhouse.org/services/ support-services/support-groups/	This group offers friendship and support to anyone who has been bereaved. New members are welcom but are asked to contact CLAN before coming along for the first time. The group meets at CLAN House every Monday evening from 7.30 pm.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
The Faces of Loss Inverness Group	Maggie's Highlands	01463 706306	Raigmore Hospital, Old Perth Road, Inverness IV2 3FL	highlands@maggiescentres.org www.maggiescentres.org/our-centres/ maggies-highlands/whats-on/	This drop-in group session, run by a Psychologist and a Cancer Support Specialist, is for people who are living with bereavement due to cancer. The session is held on the second Wednesday of every month between 5.30pm and 7pm.
Grampian Support for Bereaved Children and Young People	Grampian Child Bereavement Network	01224 594099	The Co-ordinator, Grampian Child Bereavement Network, c/o MHA, 1 Alford Place, Aberdeen AB10 1YD	coordinator@gcbn.org.uk www.gcbn.org.uk	This organisation is a central point of referral for children who have been bereaved. The service can refer on to national and local resources such as referrals to numerous bereavement counselling services.

## 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

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.



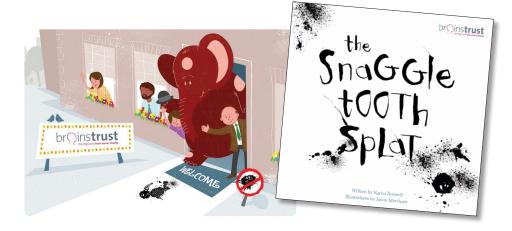
 Little White Book www.brainstrust.org.uk/advice-resources.php#5 A comprehensive, easy to navigate compendium of UK brain tumour support resources.



#### • 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**

## **Notes**

#### • 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* January 2017, due for review January 2018.

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