

the little white book

Merseyside

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 the Merseyside area. We hope you find it to be an authoritative guide and that it helps you access these resources in your area quickly and when you most need them.

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

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

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

We hope you find it useful.

From all the team at brainstrust

Networking

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

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

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

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Wirral Brain Injury Social Group	Headway Wirral	07506 975261	Potens Building, 20 Park Road, South, Birkenhead CH43 4UX	headway.wirral@gmail.com www.headwaywirral.org.uk	Here you can meet with others affected by brain injuries in a social setting to chat, keep active, enjoy activities and events and even have lunch provided by a talented cook for just £3. The group meets every Thursday between 10am and 2pm. Drop-in sessions are also available at The Fountain Project every Wednesday morning between 10am and 2pm.
Brain Injury Drop-in Sessions	Headway Sefton	07736 774496	Sefton Carers Centre, South Road, Liverpool, Merseyside L22 5RF	headwaysefton@yahoo.co.uk www.headway.org.uk/supporting-you/ in-your-area/groups-and-branches/ north-west/headway-sefton/	These drop-in sessions give you a chance to get information and support on managing an acquired brain injury. The sessions run on the 2nd Wednesday of every month.

Networking Networking Networking

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Service name	Service provider	Phone contact	Location	Email and web address	Brief description
brainstrust Meet Ups	brainstrust	01983 292405	Venues vary. Please get in touch for details.	hello@brainstrust.org.uk www.meetup.com/brainstrust	An opportunity for patients, carers and anyone else affected by a brain tumour
			for details.		to get together socially with others and have fun. You can share experiences and seek information from people who know what you are going through, but only if you want to. Previous get togethers have taken place over pizza, pub grub, and afternoon tea.
Brain Injury	Headway Liverpool	07967 770772	Meetings are held	headwayliverpool@hotmail.co.uk	This service offers regular drop-in
Drop-in Sessions			at Merseyside Youth Association, 65–67 Hanover Street, Liverpool L1 3DY	www.headway.org.uk/supporting-you/in-your-area/groups-and-branches/north-west/headway-liverpool/	sessions for anyone with a brain injury on the 4th Wednesday of every month from 11am to 1pm. The centre offers advice, information, activities, and a listening ear. It's an opportunity to socialise, make new friends and try new activities.
Southport and	Macmillan Cancer	0151 288 6893	Living Well Centre,	sfccg.macmillancic@nhs.net	Anyone affected by cancer is welcome
Formby Walking Group	Support	23–3 ⁵ Scarisbrick Avenue, Southport PR8 1NW		www.southportmacmillancentre.org. uk/southport-and-formby-macmillan- walking-group	to join in with these monthly walks. The group meets on the 1st Friday of each month at 1pm. The walks usually last around an hour, however, shorter routes are also available on the day. More information on the dates, routes and meeting points is available at the drop-in centre or over the phone.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Sunflower Social Groups	Sunflowers	0151 726 8934	21 Aigburth Road,	joan.elmer@liverpoolsunflowers.com	Meeting up with like-minded people
			Liverpool, Merseyside L17 4JR	www.liverpoolsunflowers.com	who are going through similar experiences to you is made easy for you here. They offer a number of drop in sessions from Tuesday to Friday betwee 10am and 4pm. Other networking opportunities include the Wednesday lunch club, monthly family day and a number of art and exercise classes throughout the week.
Liverpool Social	The Brain Charity	0151 298 2999	The Brain Charity,	info@thebraincharity.org.uk	This charity hosts regular social activities for anyone affected by a neurological condition as well as their family and carers. The activities are frequent and varied ranging from art and craft clubs to cook and taste sessions to poetry workshops.
Activities			Norton Street, Liverpool L3 8LR	www.thebraincharity.org.uk/whats- on/events	

Psychological support

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

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

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

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
brainstrust Counselling	brainstrust	01983 292405	Venues vary. Please get in touch for details.	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.
Sunflowers Counselling Service	Sunflowers	0151 726 8934	21 Aigburth Road, Liverpool, Merseyside L17 4JR	joan.elmer@liverpoolsunflowers.com www.liverpoolsunflowers.com	This facility acts as a hub for free counselling and emotional support services for anyone from Merseyside affected by a cancer diagnosis. The informal drop-in service runs daily between 10am and 4pm. To book a one-on-one appointment get in contact via email or phone.

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Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Warrington Counselling and Support	John Holt Cancer Support Foundation	01925 242880 or 01925 240054	15 Palmyra Square South, Warrington WA1 1BL	jhcsf.office@btconnect.com www.jhcancersupport.com/ Counselling_and_Support.html	To help you find direction in a difficult time this service offers free, confidential and professional counselling and support. You may attend as many sessions as it takes for you to feel back in control. One-on-one support is also available as an alternative to ongoing counselling.
Knowsley Emotional Support Sessions for Cancer	Lyndale Knowsley Cancer Support Centre	0151 489 3538	Lyndale Knowsley Cancer Support Centre, 40 Huyton Lane, Huyton, Liverpool L36 7XG	support@lyndalecancersupport.co.uk www.lyndalecancersupport.co.uk	At this centre a group of friendly, dedicated and experienced volunteers run one to one and group emotional support sessions for cancer patients, carers and their families. These are dropin sessions and take place daily between 11am and 3.30pm. Emotional support is also offered over the phone.
Individual Psychologist Sessions	Maggie's Merseyside at Clatterbridge	0151 334 4301	The Clatterbridge Cancer Centre, Wirral CH63 4JD	clatterbridge@maggiescentres.org www.maggiescentres.org/our-centres/ maggies-merseyside/whats-on/	Here you will find a friendly clinical psychologist who can offer you one-on-one talks and family support. There are numerous sessions available throughout the week however these must be pre-booked.

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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
Liverpool Brain Tumour Support Group	The Brain Tumour Charity	01606 45357	The Brain Charity, Norton Street, Liverpool L3 8LR	support@thebraintumourcharity.org www.thebraintumourcharity.org/ get-support/support-your-local-area/ liverpool-support-group/	This group gives you an opportunity to share experiences and meet others also facing similar challenges. The support group is aimed at patients, families and friends of those diagnosed with a brain tumour and meets on the last Monday of each month from 11am to 1pm.
Widnes Cancer Support Groups	Widnes & Runcorn Cancer Support		Widnes & Runcorn Cancer Support	info@widnesandruncorncancer support.org.uk	There are a number of peer support and friendship groups run at this centre.
	Centre		Centre 21–23 Alforde Street, Widnes, Cheshire WA8 7TR	www.widnesandruncorncancer support.org.uk/support-groups/	friendship groups run at this centre. The centre hopes to create a supportive, informal environment filled with warmth and laughter. Support groups include Happy Mondays, Hugs Club and Runcorn Open Arms Club. For further information about the dates and times of each group please get in contact or visit the website.

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Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Liverpool Tea, Coffee & Company Morning	The Brain Charity	0151 298 2999	The Brain Charity, Norton Street, Liverpool L3 8LR	info@thebraincharity.org.uk www.thebraincharity.org.uk/whats-on/ events	This is a chance to meet up with other people who have neurological conditions to share experiences and have a friendly chat. Refreshments are free and there is an opportunity to receive some helpful advice from a member of the team. There are also coffee mornings in Southport held on the first Wednesday of each month between 10am and 12pm and a specific support group for epilepsy which is run monthly. For details on dates please get in contact.
St Helens Cancer Support Group	St Helens Cancer Support Group	01744 21831	93 Corporation St, St Helens, Merseyside WA10 1SX	contact@sthelenscancersupport group.org www.sthelenscancersupport group.org	This friendly and informal group was set up by a small group of cancer patients and their carers. It provides an opportunity to receive social and emotional support outside a hospital setting by talking with people who are going through a similar experience.

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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
Free Caravan Holidays for Carers	The Respite Association	01775 820176	Newton Hall Holiday Park, Staining Road, Staining, Blackpool, Lancashire FY3 OAX	help@respiteassociation.org www.respiteassociation.org/Holidays/ NewtonHallHolidayPark-Staining.aspx	Holidays in a Staining-based caravan are offered to carers of someone diagnosed with cancer. In order to give carers a break from the huge responsibility of looking after someone with cancer, the holidays are offered to carers without the person they normally care for. This allows carers some proper respite and relaxation.
Liverpool Carers Centre	Local Solutions	0151 709 0990	Hall Lane Mount, Vernon Green, Liverpool L7 8TF	info@localsolutions.org.uk www.localsolutions.org.uk/projects/ carers	This centre works to improve the quality of life for carers in Liverpool by delivering a number of carer-specific support services including impartial advice, signposting to specialist organisations and a number of meet-ups and activities.
Sefton Carers Centre	Sefton Carers Centre	0151 288 6060	Sefton Carers Centre, 27–37 South Road, Waterloo, Liverpool, Merseyside L22 5RF	help@carers.sefton.gov.uk www.sefton-carers.org.uk/ index.php/en/	This centre provides numerous support services for carers in the Sefton Borough. The services focus on the provision of useful information and resources as well as counselling and emotional support.

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Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Liverpool Carer Advocacy Drop-in	The Brain Charity	0151 298 2999	The Brain Charity, Norton Street,	info@thebraincharity.org.uk www.thebraincharity.org.uk/	At this drop-in, carer advocates are on hand to offer information and advice
			Liverpool L3 8LR	whats-on/events	on any issues you may be having. The drop-ins are held every Friday afternoon between 1pm and 4pm. Carer advocates are also available during this time via the phone.
St Helens Carer Support Groups	St Helens Carers Centre		31–35 Baldwin Street,	info@sthelenscarers.org.uk	This centre runs several carer-specific
			St Helens, WA10 2RS	www.sthelenscarers.org.uk	support groups which aim to provide you with a feeling of strength and support. They are an opportunity to share information and advice with a group of carers who are in a similar situation to you. For more details on groups please get in contact.
Knowsley Support and Trips	, 0	3	Knowsley Young Carers,	knowsley.youngcarers@knowsley. gov.uk	Here you can meet other young carers, ages 18 and under, in a home from hom
Support and Trips for Young Carers			River Alt Resource Centre, Woolfall Heath Avenue, Huyton L36 3YE	www.knowsleyyoungcarers.co.uk	environment and enjoy trips away to theme parks, cinemas and bowling alleys. This service can also offer you a personal support worker to provide information and advice about caring for someone. The support worker may be able to arrange some assistance at home, giving you more time to yoursel

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Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Liverpool Young Adult Carer Support	Barnardo's	0151 708 7323	Barnardo's Young Adult Carers Service, 24 Colquitt Street, Liverpool, Merseyside L1 4DE	youngcarers.liverpool@barnardos. org.uk www.barnardos.org.uk/ youngcarersnorthwest/young_adult_ carers_liverpool.htm	This service will initially get you in contact with a project worker who can provide you with information on money, benefits, grants and services available for carers. They can also help you develop a better understanding of the medical condition and health needs of the person that you care for. They help develop plans for emergency situations and provide information on how to balance your education, employment and social life with your caring responsibilities.

Support for children

We often get asked for guidance on having that difficult conversation with a child following a brain tumour diagnosis of a parent, sibling or friend.

There are many organisations available which are experienced in providing specialised care for children affected emotionally by cancer. These services can help parents feel better equipped and more confident about providing the support their child needs whilst giving the child a chance to express their thoughts and feelings in a safe environment.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Young People's Counselling	Relate Cheshire & Merseyside	0300 330 5793	151 Dale St, Liverpool L2 2AH	enquires@relatecm.org.uk www.relatecm.org.uk/young-peoples- counselling.aspx	This counselling service can introduce a child, teenager or young person to a friendly, supportive and non-judgmental counsellor who can offer support at either a local Relate centre or at school. The counselling is aimed at any young person aged 10 and over who has been affected by anything from depression to family concerns.
Butterflies Activity-based Therapy	Listening Ear (Merseyside)	0151 487 6558	St Nicholas Centre, 70 Church Road, Halewood, Merseyside L26 6LB	enquiries@listening-ear.co.uk www.listeningearmerseyside.org.uk/ butterflies	The staff here are experienced at delivering activity-based therapy to children aged 4–15 who are experiencing a loss in parental support for whatever reason. The programme uses cognitive behavioural therapy, person-centred and solution focused therapies. Sessions last around 50 minutes and are usually attended weekly.

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Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Lunar Family Service	Listening Ear (Merseyside)	0151 487 6558	St Nicholas Centre, 70 Church Road, Halewood, Merseyside L26 6LB	enquiries@listening-ear.co.uk www.listeningearmerseyside.org.uk/ lunar	The Lunar service is a whole-family therapeutic programme for children and young people aged 4 to 25 who have a parent diagnosed with a life-limiting illness. This service includes sessions based on one-on-one work for children and young people with therapists and sessions involving adult family members. The sessions usually last eighty minutes and are highly flexible in order to allow for periods of illness and treatment.
Liverpool Childrens Creative Therapies	Young Persons Advisory Service	0151 707 1025	Young Person's Advisory Service, 36 Bolton Street, Liverpool L3 5LX	support@ypas.org.uk www.ypas.org.uk/our-services/ counselling-psychotherapy-service/ therapy-for-children-5-10-years/	This creative therapy service aims to improve the mental and emotional wellbeing of children ages 5 to 10. The art and creative therapy sessions allow children to explore and express their feelings which may otherwise be hard to explain.

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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 PO31 7QG	hello@brainstrust.org.uk www.brainstrust.org.uk	With brainstrust's 24/7, 365 days a year support line, patients, carers and families can pick up the phone or email and know that they will have an immediate, personal response.
Cancer Information Nurses	Cancer Research UK	0808 800 4040		www.cancerresearchuk.org	For questions about cancer or further information, you can speak to a cancer information nurse on Monday to Friday, between 9am and 5pm.
Cancer Support Line	Macmillan Cancer Support	0808 808 0000		www.macmillan.org.uk	If you have any questions about cancer, need support, or if you just want someone to talk to, you can call free Monday to Friday, between 9am and 8pm.
Wirral Carers Helpline	Wired	0151 670 0777	Wired Resource Centre, 5 St John Street, Birkenhead, Wirral CH41 6HY	contact@wired.me.uk www.wired.me.uk/Wirral-Carers- website.asp	This helpline is run by friendly staff who are there to listen to your concerns and give you advice on what you may be able to do. The helpline is open Monday to Friday, between 9am and 4pm.

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Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Contact a Nurse	Brain & Spine	0808 808 1000		helpline@brainandspine.org.uk	This free and confidential helpline
Helpline	Foundation			www.brainandspine.org.uk/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.

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 a health care professional to supply you with an application form. The grant team will review the application and if approved, payments are generally sent out within 3 working days.
Wirral Carers Grant	Wired	0151 670 0777	Wired Resource Centre, 5 St John Street, Birkenhead, Wirral CH41 6HY	contact@wired.me.uk www.wirralcarers.co.uk/carersgrant/ grants.html	In order to make your life easier, this service gives you access to funding for health and wellbeing activities to help you in your caring role. This one-off payment also comes with information on local support services which can help you to maintain your independence as a carer.
St Helens Discount Card for Carers	St Helens Carers Centre	01744 675615	31–35 Baldwin Street, St Helens, WA10 2RS	info@sthelenscarers.org.uk www.sthelenscarers.org.uk/ carersdiscountcard.html	This free membership card allows you to benefit from reduced prices in a range of shops, businesses and attractions. It also gives you preferential notice of carerstrust events and mail outs.

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Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Fuel Debt via Health Project	Local Solutions	0151 705 2365	Mount Vernon Green, Hall Lane, Liverpool L7 8TF	BGETproject@localsolutions.org.uk www.localsolutions.org.uk/projects/ fuel_debt_via_health_project	If you have an on-going health condition this free and impartial service can help you deal with your fuel bills regardless of your provider. They can also help check your benefit entitlement, assist with benefit claims, provide budgeting advice and help you deal with other debts. Where appropriate they can also help you apply for grants for energy efficient appliances such as washing machines, cookers, fridges and freezers.

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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
Warrington Beauty Treatments, Relaxation and Therapies	John Holt Cancer Support Foundation	01925 240054	15 Palmyra Square South, Warrington WA1 1BL	jhcsf.office@btconnect.com www.jhcancersupport.com/Holistic_ Therapy.html	Here you can enjoy free relaxing therapy in a peaceful holistic treatment room. The treatment rooms are fully equipped to provide holistic therapies, massage and reflexology, beauty treatments and relaxation classes.
Sunflower Therapies	Liverpool Sunflower Cancer Care Centre	0151 726 8934	Sunflowers, 21 Aigburth Rd, Liverpool, Merseyside L17 4JR	emma@liverpoolsunflowers.com www.liverpoolsunflowers.com	Relaxation can often be vital in aiding your recovery. This therapy room gives you access to a wide range of therapies to improve your wellbeing. They include; aromatherapy, hop ear candles, hot stone therapy, reflexology and reiki. Outside of the therapy room they also offer art therapy, crafts, tai chi and meditation classes.

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Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Knowsley Complementary Therapies	Lyndale Knowsley Cancer Support Centre	0151 489 3538	Lyndale Knowsley Cancer Support, 40 Huyton Lane, Huyton, Liverpool L36 7XG	support@lyndalecancersupport.co.uk www.lyndalecancersupport.co.uk/ ?page_id=821	These complementary therapies are open to people with cancer and their carers. Initially you will be introduced to a friendly therapist who will talk you through the available therapies. The therapies on offer range from auricular acupuncture to aromatherapy to the Bowen technique. Each session lasts roughly one hour.
brainstrust Hypnotherapy Service	brainstrust	01983 292405	Various	hello@brainstrust.org.uk www.brainstrust.org.uk/advice- resources.php#hypnotherapy	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.
Complementary Therapies for Cancer	Sefton Cancer Support Group	01704 879352	Sefton Cancer Support Group, 1 Duke Street, Formby, Merseyside L37 4AL	hello@seftoncancersupport.org.uk www.seftoncancersupport.org.uk	The team at Sefton can offer you a range of complementary therapies. Therapies include aromatherapy, auricular acupuncture, relaxation therapy, chiropody, reflexology and reiki. Please call them for information on session availability.

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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
Knowsley Benefits and Legal Advice	Lyndale Knowsley Cancer Support Centre	0151 489 3538	Lyndale, Knowsley Cancer Support, 40 Huyton Lane, Huyton, Liverpool L36 7XG	support@lyndalecancersupport.co.uk www.lyndalecancersupport.co.uk	This centre has a visit from a qualified benefits advisor on the first Wednesday of each month at 11am. The advisor is available to help explain what you are entitled to in a simple and clear way. To help explain legal matters they also have a monthly visit from a qualified solicitor. Please ring the centre to book an appointment.
Maggie's Benefits Advice	Maggie's Merseyside at Clatterbridge	0151 334 4301	The Clatterbridge Cancer Centre, Wirral CH63 4JD	clatterbridge@maggiescentres.org www.maggiescentres.org/our-centres/ maggies-merseyside/	Meet a friendly, helpful advisor with years of experience in providing welfare benefits advice, financial and debt support to individuals, families and their carers. Advice given is tailor-made to suit your own circumstances.
Liverpool CAB	Citizen's Advice Bureau	0344 848 7700	Liverpool Central CAB, 2nd Floor, 1 Union Court, Cook Street, Liverpool L2 4SJ	bureau@liverpoolcab.org www.liverpoolcab.org	Advisors here can provide help and guidance on debt, housing, benefit entitlements, consumer, and employment issues. The advisors will explain the options available to you and the possible outcomes of different courses of action you could take.

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Service name	Service provider	Phone contact	Location	Email and web address	Brief description
St Helens Carer Benefits Advice	St Helens Carers Centre	01744 675615	31–35 Baldwin Street, St Helens WA10 2RS	info@sthelenscarers.org.uk www.sthelenscarers.org.uk/ benefitsadvice.html	If you are a carer who feels daunted by the benefits system, then this free service is for you. Qualified benefits advisors will help you to work out your entitlement to benefits, financial assistance, council tax discounts, grants and assistance schemes. The team will also be more than happy to complete the forms with you, and support you through the application process.

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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
Merseytravel National Travel Pass	Merseytravel	0151 227 5181	Merseytravel, PO Box 1976, Liverpool L69 3HN	concession@merseytravel.gov.uk www.merseytravel.gov.uk/Tickets/ concessions/Pages/Disabled.aspx	This pass offers free travel in the Merseyside area for people with longlasting or permanent disabilities. Free travel is available on local buses, trains and Mersey Ferries any time, Monday to Sunday.
Merseylink Bus Service	Merseytravel	0151 330 1661	Merseylink Applications, Hubs Support, Merseytravel, PO Box 1976, Liverpool L69 3HN	concession@merseytravel.gov.uk www.merseytravel.gov.uk/travelling- around/transport-accessibility/Pages/ Merseylink.aspx	Merseylink membership gives you access to a free dial-a-ride bus service if you are unable to use ordinary public transport some or all of the time.

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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
Liverpool STARS Service	Carers Trust 4 All	0845 601 1990	Support is based at home	starscare.liverpool@nhs.net www.carerstrust4all.org.uk/palliative- care-services-3.html	This end of life service is specifically designed for those who have chosen their home as their preferred place of care. Support includes psychological aid for patients and advice to families and carers concerning patient care.
Prescot Specialist Palliative Care	Willowbrook Hospice	0151 430 8736	Willowbrook Hospice, Portico Lane, Prescot, Merseyside L34 2QT	general@willowbrookhospice.org.uk www.willowbrook.org.uk/your-care/ specialist-palliative-care/	This hospice is run by a specialist multi-professional team who are highly experienced in caring for patients with life-limiting illnesses. Each patient is treated individually with a holistic approach making sure their physical, spiritual, psychological, social and emotional needs are all tended to. Support is also offered to the patient's carers and family.
Liverpool Respite Day Service	Marie Curie	0151 801 1400	Marie Curie Hospice, Speke Road, Woolton, Liverpool L25 8QA	merseyside.fundraising@mariecurie. org.uk www.mariecurie.org.uk/help/hospice- care/hospices/liverpool/services/day- services	Individual appointments, group activities and complementary therapies are all available at this specialist day service. Care is tailored to your individual needs and can be delivered at the hospice, in a local community venue or at home. Services are free for patients and families.

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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
Maggie's Bereavement Support	Maggie's Merseyside at Clatterbridge	0151 334 4301	The Clatterbridge Cancer Centre, Wirral CH63 4JD	clatterbridge@maggiescentres.org www.maggiescentres.org/our-centres/ maggies-merseyside/	This centre can support you when a loved one has passed away from cancer. You can speak to others going through a similar experience and find advice, support and strategies for coping. One-to-one bereavement support is also available.
Liverpool Bereavement Service	Liverpool Bereavement Service	0151 236 3932	Liverpool Bereavement Service, 1st Floor, Granite Buildings, 6 Stanley Street, Liverpool L1 6AF	enquiries@liverpoolbereavement.co.uk www.liverpoolbereavement.com	With years of experience in supporting people through bereavement, this is the ideal place to turn to for free, sensitive help and advice on how to cope with your loss.
St Helens Bereavement Service	St Helens Bereavement Service	01744 451793	St Helens Bereavement Service, Tontine House, (Fourth Floor), 24 Church Street, St Helens, Merseyside WA10 1BD	sthelensbs@fsmail.net www.sthelensgateway.info/ organisations/st-helens-bereavement- service	This voluntary organisation provides a confidential befriending service to help you deal with the loss of a loved one. They will help you develop an understanding of your loss through emotional and social support.

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Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Oakleaf Childrens Bereavement Support	Liverpool Bereavement Service	0151 236 3932	Liverpool Bereavement Service, 1st Floor, Granite Buildings, 6 Stanley Street, Liverpool L1 6AF	enquiries@liverpoolbereavement.co.uk ww.liverpoolbereavement.com/? page_id=32	The Oakleaf service provides bereavement support and counselling for children and young people aged 4 to 18 years of age to help them through the difficult process of grief and loss. Support includes facilitated loss and grief group work within schools and the provision of coping strategies outside of a school environment.
Wirral Bereavement Care	Cruse Bereavement Care	0151 645 6604	Royal Standard House, 334 New Chester Road, Birkenhead, Wirral CH42 1LE	wirral@cruse.org.uk www.cruse.org.uk/wirral-area-map	This bereavement service offers one- to-one personal support and various welcoming bereavement support groups to adults aged 18 and over living in the Borough of Wirral.

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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 – Merseyside, edition 1, published by brainstrust April 2016, due for review April 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)