

the little
white
book

North West Children's

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

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Introduction

We know how lost you can feel when a child you care for 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 family's 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 children living with a brain tumour and their families. This directory, focusing on the charity sector, includes information on some of the best of the children's services in the North West. 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, 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 review 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 on **01893 292 405** or email **[hello@ brainstrust.org.uk](mailto:hello@brainstrust.org.uk)**

This guide would not have been possible without the generous support of The Vera Wolstencroft Children and Animal Charitable Trust. The guide forms part of a wider programme of signposting to help people with a brain tumour to feel less isolated, and better resourced. The wider project is supported by The Rank Foundation and the National Lottery's Awards for All scheme, as well as brainstrust's incredible community of people with a brain tumour, their carers and our supporters and volunteers.

We hope you find it useful.

From Claire and all the team at *brainstrust*

Psychological support

It is normal for your child to experience stress and express feelings of worry and concern as a result of their brain tumour diagnosis or treatment.

At times you may need some help dealing with these additional psychological and emotional needs. You can rest assured, there are people out there who you can turn to. These services provide safe and comforting spaces where your family can discuss feelings, needs and concerns in a confidential space with a team experienced in helping patients and those close to them.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Cheshire Children's Emotional Support	The Joshua Tree	01606 331858	The Joshua Tree, 1 Old Hall, Venables Road, Northwich, Cheshire CW9 5RF	office@thejoshuatree.org.uk www.thejoshuatree.org.uk/ our-core-services	This charity understands that every family's experience and needs are unique when facing childhood cancer. They work with numerous families and schools to provide emotional support that is tailored to their needs. Support includes 1–2–1 sessions, play therapy, informal chats and support groups.
Counselling for 5 to 17 year olds	The Counselling & Family Centre	0161 941 7754	The Counselling and Family Centre, 40 Mayors Road, Altrincham WA15 9RP	appointments@thecfc.org.uk www.thecfc.org.uk/ counselling-for-5-17-years-old/	This charity offers a safe place for 5 to 17 year olds to talk and develop an understanding of what is happening and how to get back on track. The initial point of contact with the charity can be made by either the young person, parent or carer. Children under 14 must be accompanied to the centre by an adult, though they don't have to come in to see the counsellor. To use this service you can either book an appointment, drop by the centre or, if it is out of hours, leave a message on the confidential answer service.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Trafford Family Counselling	The Counselling & Family Centre	0161 941 7754	The Counselling and Family Centre, 40 Mayors Road, Altrincham WA15 9RP	appointments@thecfc.org.uk www.thecfc.org.uk/family-support/	Family counselling can be an invaluable source of support following the onset of any number of situations which cause difficulties and disharmony such as illness, death or change in to your normal routines. This service is very flexible as every situation and every family is unique. Your Counsellor will work with you to plan future appointments or to guide you towards another service if that seems more appropriate.
Manchester Palliative Care Counselling for Children	The Gaddum Centre	0161 834 6069	Gaddum Centre, 6 Great Jackson Street, Manchester M15 4AX	info@gaddumcentre.co.uk www.gaddumcentre.btck.co.uk/ Childrensbereavementservice	This service provides specialist counselling for children (aged 4 to 18) and families in Manchester, Salford and Stockport, who feel they need some extra support because a child has a life limiting condition or at any time after the loss of their child from such an illness. Depending on their age, interests and level of understanding they use resources such as play, art, and soft toys to develop a relationship and aid communication. The meetings with workers take place where the youngster chooses, usually at home or school, and contact will usually be either weekly or fortnightly.
Stockport Young Person's Counselling	Beacon Counselling	0161 285 1827	Offices in Bramhall and Stockport	admin@beacon-counselling.org.uk www.beacon-counselling.org.uk/ YoungPeople.php	This charity has been supporting children and young people since 1996, helping them make sense of their emotions and the world around them. They offer 1-to-1 counselling, specially designed group programmes and support to important people in the child's life.

Support groups

Support groups are a place where your child can meet up with other children who are in a similar situation, make friends and gain peer support in a safe and fun environment. They can also be a useful place to gain practical advice, share medical information and exchange possible challenges, solutions and coping strategies with other parents and carers. The groups are usually facilitated by an experienced support worker and are held regularly to foster an inviting, community atmosphere.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
little <i>braintrust</i> Family Meetups	little <i>braintrust</i>	01983 292405	<i>braintrust</i> , 4 Yvery Court, Castle Road, Cowes, Isle of Wight PO31 7QG	hello@braintrust.org.uk www.braintrust.org.uk www.meetup.com/braintrust	These family meet up days are open to all young patients (0–19) and their families. The days are a chance to get to know other families within your area who are going through something similar. They are also an opportunity to create great memories, try something new and make new friends who really understand.
Liverpool Childrens Cancer Support Group	Childrens Cancer Support Group		Ronald McDonald House, Alder Rd, Liverpool, Merseyside L12 2AZ	www.chicsonline.org/liverpool.html	This is an informal and very friendly group for children affected by cancer. Parents and siblings are welcome to attend the meetings which are normally held on the second Tuesday of each month starting at 8pm. There is also a teenage-specific group on the first Thursday of each month and a 10–12 group.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Wirral Childrens Cancer Support Group	Childrens Cancer Support Group	0151 327 4070	Mayer Hall, The Village, Birkenhead, Wirral, Merseyside CH63 7PL	mellor.sharon@yahoo.com www.chicsonline.org/wirral.html	This children-friendly meet up group for those affected by cancer takes place on the second Tuesday each month. They also offer a Wirral-based high school group open to high schoolers affected by cancer and their siblings and friends. The group's aim is to help others make friends, have fun and benefit from peer-support.
Wirral High School Cancer Group	Childrens Cancer Support Group	0151 327 4070	Brightside Centre, Molyneux Drive, New Brighton CH45 1JT	www.chicsonline.org/wirral.html	This High School Group is run by two experienced co-ordinators who have personal experience of a child with a cancer diagnosis. The group is open to all High Schoolers, their siblings and their friends. This is a friendly, inclusive group where High Schoolers can interact, make friends and obtain peer support. The group meet on the last Friday of every month from 7pm to 9pm at the Brightside Centre. Facilities at the centre include a recording studio, a kitchen, a chill out area, a main room with table tennis, TV's, and craft area. The group run lots of activities every month, from football to baking and everything in between. They also have a number of outside events and trips, from Chester Rocks music festival to canal boating.
10–12 Year Old Cancer Support Group	Childrens Cancer Support Group			www.chicsonline.org/liverpool.html	This group, supervised by CRB checked adults, is open to patients and siblings aged between 10 and 12. Here they can get to know each other while having lots of fun at the cinema, bowling alley and many other events.

Support for families and carers

We know caring for a child living with a brain tumour is not a job you apply for and it's also one of the hardest jobs you might have to do.

Sometimes families and carers need extra support dealing with the practicalities of caring for a child with a brain tumour diagnosis and the potentially debilitating effects. There are a lot of services who can help keep you feeling in control and make your life easier with home based assistance, family respite support and plenty of invaluable information and ongoing support tailored to your family's needs.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Manchester Home and Day Care	Francis House Children's Hospice	0161 434 4118	Francis House Children's Hospice, 390 Parrswood Road, Didsbury, Manchester M20 5NA	www.francishouse.org.uk/services/what-we-provide/care/	This hospice has a team who specifically work to provide home based assistance to children and families in need. They can help cover difficult emergency situations such as when a child needs access to specialised medical procedures and aid parents visiting their children in hospital. This hospice also allows children and families to come along during the day to use facilities such as the Jacuzzi, the Snoezelen and Music Therapist. During holiday periods this hospice can provide fun days out as a break for the whole family.
Brain Tumour Family Days	The Brain Tumour Charity	0808 800 0004	Various Venues	emma.percy@thebraintumourcharity.org www.thebraintumourcharity.org/get-support/children-and-families-service/family-days/	These fun, relaxing and supportive family days are aimed at children with a brain tumour, their siblings and parents. The days give families the opportunity to spend time together away from a medical or home setting, meet others experiencing similar difficulties, share stories, and enjoy a day out without the concerns of organising or worries of financial restrictions.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Chorley Hospice Stays for Children	Derian House Children's Hospice	01257 233 300	Derian House Children's Hospice, Chancery Road, Astley Village, Chorley, Lancashire PR7 1DH	info@derianhouse.co.uk derianhouse.net-work.net/ booked-stays	This service can provide your family with a break from the physically and emotionally exhausting around the clock task of caring for your baby or child. The care team here can help share the care of your child by making sure feeds, medicines and care routines are carried out to the routine your child knows at home. Accommodation is available for the whole family to stay if you wish. This service is usually booked for a few days in advance, however, sometimes things happen that cannot be planned such as a family crisis or a sudden deterioration in a child's condition. On these occasions the hospice is able to help for a few nights or longer if things change and end of life care is required.
Chorley Hospice at Home Service	Derian House Children's Hospice	01257 233 300	Derian House Children's Hospice, Chancery Road, Astley Village, Chorley, Lancashire PR7 1DH	info@derianhouse.co.uk derianhouse.net-work.net/ hospice-at-home	The hospice at home team work as part of the Derian House care team and are familiar faces. They link with local children's community nurses and doctors to ensure care and support is co-ordinated and planned. The service understands that some children, due to their condition, are often poorly even though they may not be in the end stages of life. In this instance nurse support at home may be most suitable.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Chorley Family Support	Derian House Children's Hospice	01257 233 300	Derian House Children's Hospice, Chancery Road, Astley Village, Chorley, Lancashire PR7 1DH	info@derianhouse.co.uk derianhouse.net-work.net/ family-support	Once you have joined, this charity aims to provide practical and emotional support and advice in a way that best suits you and your family. Family support includes phone calls, home visits, advocacy support, charity applications and more. They also organise regular family fun days and a range of other activities suitable for the needs of all the family including but not limited to parent support groups, activity weekends, youth club and sibling support groups.
Principal Treatment Centre Support	CLIC Sargent	0300 330 0803	Alder Hey Children's Hospital, Royal Manchester Children's Hospital and various other principal treatment centres	Paul.Gathercole@ clicsargent.org.uk www.clicsargent.org.uk/content/ help-and-support	This charity has social care teams based in the region's oncology principal treatment centres for children (0–15) and teenagers and young adults (16–24). All children diagnosed with a malignant brain tumour will be referred to their teams based in the principal treatment centres. The charity will then usually reach out to you as a family to offer you the opportunity to register with CLIC Sargent, and access to ongoing support and a grant.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Greater Manchester Family Support Worker	Rainbow Trust	0161 628 2194	Chambers Business Centre, Chapel Road, Hollinwood, Oldham OL8 4QQ	wendy.thompson@rainbowtrust.org.uk www.rainbowtrust.org.uk/greater-manchester-team	This charity offers bespoke support to families who have a child aged between 0 and 18 years of age with a life threatening or terminal illness. The support, led by a Family Support Worker from the Greater Manchester team, is varied and diverse. Support includes: 24/7 family support from diagnosis and beyond, sibling support, emotional and practical home-based support, hospital appointment support and bereavement support either face-to-face or over the phone.
North West Practical and Emotional Family Support	Rainbow Trust	0161 633 4684	Chambers Business Centre, Chapel Road, Hollinwood, Oldham OL8 4QQ	wendy.thompson@rainbowtrust.org.uk www.rainbowtrust.org.uk	This charity provides high quality practical and emotional support which is tailored to individual needs and is offered for as long as you need. This support includes short breaks for parents when children are in hospital or isolated in their own home, play stimulation for children who are too poorly to attend school, transport for families to hospital appointments and to assist siblings in accessing school. This support is provided for families in the Greater Manchester, Cumbria and Lancashire areas.

Support for siblings

We know it's not only your child with a diagnosis that is affected by a brain tumour. Sometimes siblings need some guidance and support to help them understand what their brother or sister is going through, how they can make things easier for them and also to talk through their own feelings and emotions. There are a number caring services out there to do just that.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Seasons Sibling Support Group	Francis House Children's Hospice	0161 434 4118	Francis House Children's Hospice, 390 Parrswood Road, Didsbury, Manchester M20 5NA	www.francishouse.org.uk/services/what-we-provide/support/	The Seasons team run a support group aimed at supporting the siblings of sick children. The group uses fun and adventurous activities to allow young people to connect with others who are dealing with similar issues and concerns. The group works to ensure siblings know they are not alone in facing the problems associated with having a sick brother or sister.
Manchester Sibling Project	Rainbow Trust	0161 633 4684	Chambers Business Centre, Chapel Road, Hollinwood, Oldham OL8 4QQ	wendy.thompson@rainbowtrust.org.uk www.rainbowtrust.org.uk	This sibling support project provides support to siblings identified as needing additional support. A Sibling Support Worker can provide 1–1 emotional support, group work and activities specifically designed to support siblings in a variety of different ways. The sibling support work is provided within the Greater Manchester area.

Transitional support

When your child is diagnosed with cancer their life does not stop.

They keep growing and experiencing new things. The transition from childhood to a young adult can often be a difficult time, especially with a brain tumour. Hospitals and other services often struggle to properly fill the gap between support for children and support for adults.

These service work to breach that gap and provide specialised support for this important part of your child's journey.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
SuperJosh Entertainment Packages	The Joshua Wilson Brain Tumour Charity	0161 883 2213	The Joshua Wilson Brain Tumour Charity, Warth Business Centre, Suite 410, Warth Road, Bury, BL9 9TB	hello@joshwilson.org.uk www.joshwilson.org.uk/how-can-josh-help/	This charity provides entertainment packs to teenage children, aged 13 or over, in Hospitals in the North-West. The packs include items such as Xboxes, TVs and iPads. The service hopes to fill the gap between traditional kid's hospital entertainment and the entertainment provided in adult wards..
Cheshire School Support	The Joshua Tree	01606 331858	The Joshua Tree, 1 Old Hall, Venables Road, Northwich, Cheshire CW9 5RF	office@thejoshuatree.org.uk www.thejoshuatree.org.uk/our-core-services	This charity works to support children with a cancer diagnosis and their family in achieving the best academic, social and emotional outcomes both in and out of the school environment. They can help through liaising with schools to ensure that staff receive information on how best to support a child with cancer. They also run regular family activities and events, half-term activities and a monthly Saturday club.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Tameside Counsellors for 13 to 25 Year Olds	Off The Record	0161 355 3553	45 Clarendon Place, Hyde, Cheshire SK14 2ND	office@otr-tameside.org www.otr-tameside.org	The charity runs an independent, free, confidential counselling service that is centrally based for all young people between the ages of 13 and 25 who live in Tameside and Oldham. They are members of the British Association for Counselling meaning they follow a strict code of ethics and practice. The counsellors are trained and will treat young people as individuals; respecting their opinions without judgement.
Manchester Young Person's Individual Support	42nd Street	0161 228 7321	42 nd Street, the SPACE, 87–91 Great Ancoats St, Manchester M4 5AG	theteam@42ndstreet.org.uk www.42ndstreet.org.uk/ individual-support/	This service offers young people the chance to talk one-to-one with a support worker, Counsellor or Therapist to help them to understand the things that are affecting them. Together they can find positive coping strategies that work for them. All of the services at this charity are free and confidential.
Manchester Young People's Counselling	Relate Greater Manchester South	0300 003 2331	Greater Manchester South Relate Centre, 346 Chester Road, Cornbrook, Manchester M16 9EZ	enquiries@relategms.co.uk www.relate.org.uk/ greater-manchester-south/ children-and-young-peoples- counselling	This counselling service can help young people through tough patches by giving them a chance to talk about anything that's on their mind in a confidential, comforting environment. Having someone outside of home or school life can really help them to see problems in a new light and cope with any difficult feelings.

Support lines

Support lines are an invaluable service and it can be a great comfort knowing that a kind, caring and knowledgeable voice is just a phone call away. 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 about your child's diagnosis, treatment and emotional needs.

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	Open 24 hours a day, 7 days a week, the <i>brainstrust</i> helpline offers those caring for a child with a brain tumour and patients over the age of 14 support, information and pragmatic advice over the phone and by email.
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 a brain tumour diagnosis, explain medical jargon and help you make informed decisions. It is open Monday to Thursday between 9am and 2pm and 9am to 1pm on Fridays.

Financial support

We know it is much better to be proactive than reactive when it comes to the financial impact of brain tumour. Having a child with a brain tumour will, at some point, impact on your family 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. Here are some of the grant schemes you may want to consider.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Bury Paediatric Brain Tumour Grants	The Joshua Wilson Brain Tumour Charity	0161 883 2213	The Joshua Wilson Brain Tumour Charity, Bury Business Lodge, Europa House, Barcroft Street, Bury BL9 5BT	hello@joshwilson.org.uk www.joshwilson.org.uk/	This charity aims to provide specific financial support to families of children who have or have had a brain tumour, with special focus on those who also have post-surgery disabilities. This financial support can include help with the purchase of specialist equipment and home adaptations such as ceiling track hoists and through-floor lifts, special treats like post-chemo holidays, assistance in cases of financial hardship where parents have lost income due to being unable to work while caring for their sick child, grants for hospital stay expenses and many other instances. Applications for assistance are considered on a case by case basis by the Trustee panel.
Macmillan Cancer Grants	Macmillan Cancer Support	0808 808 0000	Various	financialguidance@macmillan.org.uk www.macmillan.org.uk	These are one off payments (around 250 pounds) for adults, young people or children with cancer. To apply, ask 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.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Manchester Children's Relief in Need Fund	The Gaddum Centre	0161 834 6069	Gaddum House, 6 Great Jackson St, Manchester M15 4AX	info@gaddumcentre.co.uk www.gaddumcentre.co.uk/ trust-funds-more-info/	This trust fund grant is available to people who live in the cities of Manchester, Salford and Trafford and require financial relief. There are two trust funds one of which focuses on children in need of financial assistance. The Trustees meet during the last week of every month, and applications must be received by the 15 th of every month.

Complementary therapies

There are many reasons why people choose to use complementary therapies. They can be a useful tool for complementing the treatment that your child is already receiving and can improve your child's mental and emotional wellbeing whilst relieving some of the symptoms and side effects of treatment. They can also help your child express their emotions, relax following treatment, and help them to sleep better. Here are therapies that are available near to you, however, please remember to seek the advice of your child's doctor before starting any new therapy or treatment.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Wirral Childrens Alternative and Complementary Therapies	Claire House Hospice	0151 334 4626	Claire House Children's Hospice, Clatterbridge Road, Bebington, Wirral CH63 4JD	www.claire-house.org.uk	This children's care service uses a complete and diverse approach to care offering a wide range of alternative and complementary therapies for children, young people and their families. These therapies range from music therapy and hydrotherapy through to reiki and Indian head massage.
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.
Northenden Sensory Room, Messy Art and Creative Play	Kids Creative	0161 945 9786	438a Palatine Rd, Northenden, Manchester M22 4JT	www.kidscreative.org.uk	This drop-in sensory play space allows your child to develop their creative, motor and communication skills while helping them feel more in control of themselves and their emotions. During these sessions messy play, painting and sensory activities are also available.

Holidays and short breaks

Going away on a holiday or short break can be an excellent way for your family to relax and change focus. Some families choose to plan a holiday for the end of treatment. Others want to go before or even during treatment. Whatever you choose, make sure you talk to your child’s doctors and nurses first 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 your child. The services listed here can help you plan a holiday for your child and even offer funding.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Family Holiday Home Breaks	React	020 8940 2575	Cala Gran Holiday Park, Fleetwood Rd, Fleetwood FY7 8JY	react@reactcharity.org www.reactcharity.org/holidays.php	This charity can offer your family a week-long holiday in one of their three-bedroom holiday homes around the UK. The homes are located in family-friendly parks and can accommodate six people in comfort. The homes are self-catering and site fees are included. The nearest holiday home is located in Cala Gran, Blackpool which is just 2 miles from the seaside with plenty of indoor and outdoor activities including a children’s splash zone, soft play area, farm and a wide range of shops, bars and restaurants. Unfortunately, the mobile homes are not wheelchair adapted however they may be able to contribute towards an equivalent holiday if you send them relevant information and prices.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
The Dr Garrett Memorial Trust Fund	The Gaddum Centre	0161 834 6069	Gaddum House, 6 Great Jackson St, Manchester M15 4AX	info@gaddumcentre.co.uk www.gaddumcentre.co.uk/ trust-funds-more-info/	The grant provides holidays for children and their carers who have not had a funded holiday during the past three years. You must be resident in the City of Manchester and in need of a holiday because of “sickness, disability or poverty” to receive the funds. The grants can also be made to fund group holidays and applications must be received by the end of April each year.
Cumbria Caravan Holidays for Families	Alice’s Escapes	01229 581 665	Alice’s Escapes, P.O. Box 106, Ulverston, Cumbria LA12 2AJ	vicky@alices-escapes.co.uk	This charity offers family caravan holidays for families with seriously-ill children who are living with an active life threatening illness. All holidays include a welcome grocery hamper and, subject to the generosity of supporting attractions, vouchers for days out. The charity currently owns three caravans; Molly’s Place, Mabel’s Place and Lily’s Lodge. Molly’s Place is fully adapted for wheelchair users and can sleep up to five people. Mabel’s Place is luxury lodge style caravan which can sleep up to four people. Lily’s Lodge is a brand new luxury bereavement unit which can sleep up to six people. They are all fitted with central heating, double glazing, TV/DVD player, decking with furniture and BBQ. Cots and highchairs are available on request. The caravan holidays are available from March through to the end of October (end of half term) and sometimes into November, depending on demand and weather. Applications for holidays next year will be taken from January 2017.

Welfare and legal advice

Your family may be entitled to a range of benefits which can make things easier for all of you. However, 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, debt support and other legal issues such as 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 your family are entitled to in a simple and clear way. To help explain legal matters they also have a monthly visit from a qualified solicitor. You can ring the centre to book an appointment.
Merseyside 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.
Manchester Benefits Advice	Maggie's Manchester	0161 641 4849	The Robert Parfett Building, The Christie Hospital NHS Foundation Trust, 15 Kinnaird Road, Manchester M20 4QL	janet.scott@maggiescentres.org www.maggiescentres.org/our-centres/maggies-manchester/	This centre, based at the Christie Hospital, has a dedicated Benefit Advisor who can help you make informed decisions and will make sure your family is receiving the correct benefit allowance with tailored and thoughtful advice.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
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 to you and your family 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.
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 care for a child and feel 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.
Stockport Legal Panel	Beechwood Cancer Care	0161 476 0384	Beechwood Cancer Care Centre, Chelford Grove, Stockport, Cheshire SK3 8LS	enquiries@ beechwoodcancercare.co.uk www.beechwoodcancercare.org.uk/ cancer-care-services/legal-panel/	We know that dealing with legal issues can create further stress and anxiety at a time that is already emotionally exhausting. This charity offers high quality legal services appropriate for you and your family. The legal panel has expertise in employment law, clinical negligence, wills, trusts, probate advice and power of attorney.
Cheetham and Crumpsall Benefits Advice	Cheetham Hill Advice Centre	0161 740 8999	1 Morrowfield Avenue, Cheetham Hill, Manchester M8 1AR	www.cheethamadvice.org.uk	This charity provides confidential help, advice, information and support to local residents of Cheetham and Crumpsall. They can offer advice on welfare benefits, health services, debt and more.

Transport services

If your child has a brain tumour, getting around can be hard. Whether it's for treatment at hospital, getting to school or to carry on living their lives to the full they will need to travel at some point. These services are here to make getting around just that little bit easier.

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 long-lasting or permanent disabilities. Free travel is available on local buses, trains and Mersey Ferries any time, Monday to Sunday.
Greater Manchester National Concessionary Travel Pass	Transport for Greater Manchester	0161 244 1050	Travel Concessions, Customer Services, PO Box 429, Manchester M60 1HX	concessionary.travel@tfgm.com www.tfgm.com/journey_planning/ Tickets/Pages/tickets_low_fares_disabled.aspx	This pass offers free travel to residents of Greater Manchester who have a disability which makes travel more difficult. It allows for free travel on local buses anywhere in England between 9.30am and 11pm Monday to Friday, and all day at weekends and on public holidays. Some disabled people will qualify for a Concession Plus pass which also allows for free travel on buses at all times in Greater Manchester.

Respite and end of life care

When you're caring for your child full-time or for long periods, you need to have breaks otherwise you may start to feel stressed, resentful or even unwell. And your child may benefit from a change of scenery or, believe it or not, a break from you! Here are some organisations that could help you understand children's 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
Manchester Children's Respite Care	Francis House Children's Hospice	0161 434 4118	Francis House Children's Hospice, 390 Parrswood Road, Didsbury, Manchester M20 5NA	www.francishouse.org.uk/services/what-we-provide/care/	This hospice, through close ties with multi-agency teams across the area and consultants at Christie Hospital, provide high quality palliative care for families at a difficult time. Families receive support for as long as they feel the need and medical cover is provided by four dedicated GPs who attend the hospice daily and are on call whenever required. The hospice also offers respite care where children and young people are given the chance to have a break from their normal routine. The diversely talented care team provide tailor-made support which allows children to meet with others in the same situation and get involved in activities which may be new to them. Family and siblings stays at the hospice can also be arranged.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Liverpool Baby Hospice	Zoe's Place	0151 228 0353	Yew Tree Lane, West Derby, Liverpool L12 9HH	admin@zoes-place.org.uk www.zoes-place.org.uk/liverpool/	This hospice is designed to be a 'home away from home' environment in which babies feel comfortable and are able to get the most out of the specialised facilities. They have a soft play area, a variety of sensory toys and specialised equipment which children may need to assist with their care during their stay at the hospice. In addition, they offer a light sensory room which the nursing staff are able to utilise to suit each individual child; for some the room is a place of relaxation whilst for the others it is a source of stimulation and a space for them to express themselves.
Wirral Respite and Palliative Care	Claire House Hospice	0151 334 4626	Claire House Children's Hospice, Clatterbridge Road, Bebington, Wirral CH63 4JD	www.claire-house.org.uk	This service aims to offer a sanctuary for children, young people and their families, allowing them to forget about the daily routine and simply enjoy themselves either on their own or with the expert team of nurses and carers on hand. The care provided allows patients to create memories and experiences that last a lifetime in a caring, comfortable and homely hospice. There is also a "Hospice to Home" service which offers home-based specialist respite, palliative and end of life care.

Bereavement support

Unfortunately not everyone survives having a brain tumour. When you lose a loved one, you may also lose 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 family, carers, 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
Manchester Children's Hospice Bereavement Care	Francis House Children's Hospice	0161 434 4118	Francis House Children's Hospice, 390 Parrswood Road, Didsbury, Manchester M20 5NA	www.franchishouse.org.uk/services/what-we-provide/support/	The care team here will support your family in the days following the passing of your child for as long as it is needed. They can provide practical help and support when dealing with the registrar, coroner and help with arranging funeral services. The team are also available to people who, though not bereaved, might have anxieties about the future care of their child. The care team also offer an informal 24-hour telephone-based listening service.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Chorley Bereavement Support	Derian House Children's Hospice	01257 233 300	Derian House Children's Hospice, Chancery Road, Astley Village, Chorley, Lancashire PR7 1DH	info@derianhouse.co.uk derianhouse.net-work.net/ bereavement-support	This charity service can support your families before, immediately after and in the following months and years after the passing of a child. The service is highly flexible and diverse including a telephone contact service, drop in sessions, group work for parents and siblings to explore the experiences of grief and loss, a memorial book in the quiet room, a pebble pool in their quiet garden for those who wish to have their child's name engraved on a special pebble and an annual remembering service for all bereaved families.
Wirral Bereavement Support and Counselling	Claire House Hospice	0151 334 4626	Claire House Children's Hospice, Clatterbridge Road, Bebington, Wirral CH63 4JD	www.claire-house.org.uk	This charity offers children, young people and their families either individual counselling sessions focusing on grief or group sessions where there is an open discussion of feelings and experiences. The charity knows there is no time limit on grief and loss meaning their counsellors are available to families for as long as is needed. This tailored counselling service can be used by children, parents and extended family through to carers and siblings.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Manchester Children and Families Bereavement Service	The Gaddum Centre	0161 834 6069	Gaddum Centre, 6 Great Jackson Street, Manchester M15 4AX	info@gaddumcentre.co.uk www.gaddumcentre.btck.co.uk/ Childrensbereavementservice	This service has 15 years of experience working with bereaved young people in Manchester and Salford. The service begins with a referral by an adult, however, they prefer to allow a period of time following the passing of a loved one before offering support to make sure this help does not interrupt the normal grieving process.
Oakleaf Childrens Bereavement Support	Liverpool Bereavement Service	0151 236 3932	Liverpool Bereavement Service, 1 st Floor, Granite Buildings, 6 Stanley Street, Liverpool L1 6AF	enquiries@liverpoolbereavement.co.uk www.liverpoolbereavement.com/ ?page_id=32	This service provides bereavement support and counselling for children and young people aged 4 to 18 to help them through the difficult process of grief and loss and would be suitable for children who have lost a sibling. Support includes facilitated loss and grief group work within schools and the provision of coping strategies outside of a school environment.
Bereavement Breaks for Families	Alice's Escapes	01229 581 665	Alice's Escapes, P.O. Box 106, Ulverston, Cumbria LA12 2AJ	vicky@alices-escapes.co.uk	This charity offers bereavement breaks for families who have lost a child. Their bereavement lodge sleeps up to six people. This can be a mix of occupiers; some may wish to keep to an immediate family group and others may bring grand-parents or friends. There is no form required for bereaved parents, however an authorised referral is needed such as an email from a GP or a support charity. The bereavement lodge is open from March through to and including Christmas. Applications are ongoing with no date criteria.

What can little *brainstrust* do to help?

Help available

In our *brainstrust* community, we know what it means for a child to be diagnosed with a brain tumour, and how it can turn your lives upside down. We can help you and your family to feel less alone, because we understand what it's like. Below is some of the help available to you from *brainstrust*. Don't hesitate to get in touch, and talk to people who can help you get the help you need. 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* helpline offers those caring for a child with a brain tumour and patients over the age of 14 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 child's 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

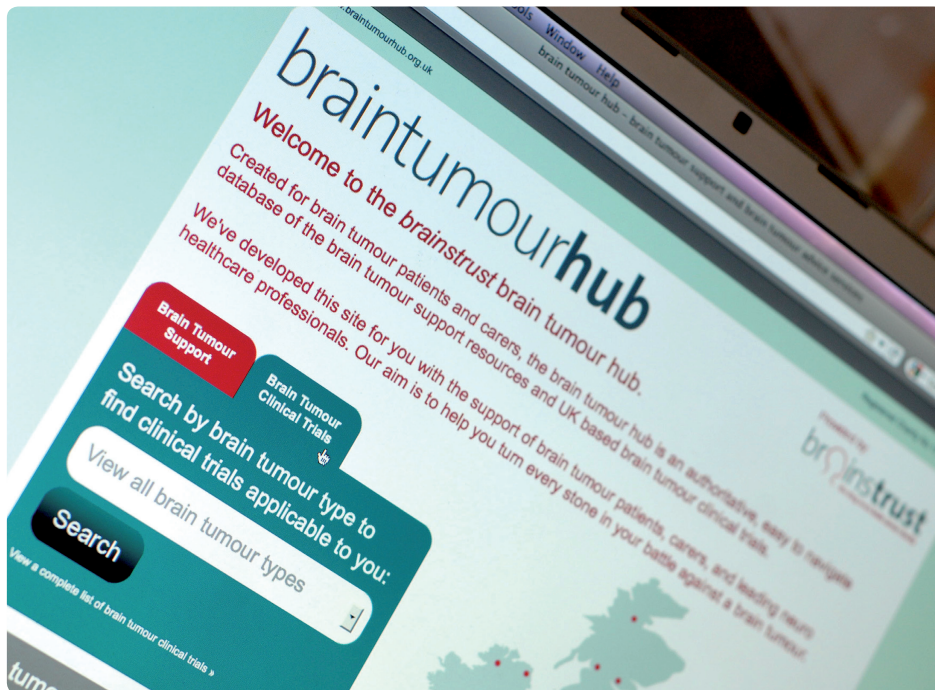
from our experience. We believe that you need to be informed to make decisions. And that might mean gathering information and then deciding not to make a decision. That's a decision too! For more information on second opinions, visit 'Just been told?' on www.brainstrust.org.uk/advice-symptoms.php

- **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, people can experience a sense of healing, as they make courageous decisions about their family's lives. 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 adult caregivers or patients over 18 who are 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 for a number of different purposes. Hypnotherapy can help caregivers to: manage anxiety, reduce stress, build confidence and optimism, prepare for surgery, and 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* little brain box – the ‘must have’ support toolkit for a family living with a brain tumour diagnosis of a child. We appreciate how difficult things can be once you receive the diagnosis; the ‘4am moments’, the travelling to and from appointments, the stream of questions that pop into you ahead, 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 a sick and frightened child. So to help young brain tumour patients and their families, we provide this unique invaluable aid. Every brain box contains resources, toys and tea to comfort, inform and build resilience within a family.



- **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

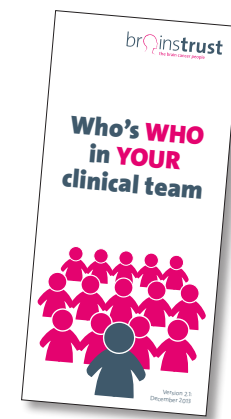
Written for *brainstrust* to help parent caregivers broach a brain tumour diagnosis with their children. It is a beautifully illustrated book and has featured in the BMA newsletter and Oncology news. The forward has been written by the lovely actress and *brainstrust* supporter, Julie Walters. If you are a parent who is 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 families find that they are left to manage their care pathway for themselves. *brainstrust* has developed this handy resource to help you navigate your journey. It outlines all the healthcare professionals who may be involved in your journey and tells you what it is they do.



Resources to help you feel less lonely

- **Meetup**

www.meetup.com/brainstrust



At a *brainstrust* Meetup, members of the brain tumour community get together to have fun. No matter where you are on your journey, caregivers can share experiences, and seek information from other caregivers and patients who know what you're going through. We also run family Meetups, where families can get a chance to meet other families with similar experiences and enjoy a day out doing something new.

- **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.

- **facebook little brainstrust**

www.facebook.com/littlebrainstrust

A smaller support group for carers of young patients provides more specific support, where education, paediatric treatment and caring for children with a brain tumour can all be discussed in a supportive environment.

Notes

Notes

Claire, our new Support Specialist for children and families is on hand to help you get what you need. Whether you would like to attend a family meetup, chat about education or family life, or if you have ideas for how we can make our service better – just email **claire@brainstrust.org.uk** or call **01893 292 405**.

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 – North West Paediatric, edition 1, published by *brainstrust* October 2016, due for review October 2017.

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