

# thelittle

# Tees Valley and surrounding areas

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

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# Introduction

We know how lost you can feel when you or your loved one is diagnosed with a brain tumour. But we also know how many invaluable support services there are available locally that can help you at every step of your brain tumour journey.

Here at *brainstrust* we've been working tirelessly with the help of our fantastic volunteers searching high and low for useful, local services for people affected by a brain tumour. This directory, focusing on the charity sector, includes information on some of the best of these services in the Tees Valley. 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
Teeside Social Events	Headway Teeside		WMNT Resource Centre, Stainsby Road, Middlesbrough TS5 4JS	www.headwayteesside.org.uk	This service is about developing community engagement and helping you create new and lasting, therapeutic relationships. The socials, which are held monthly, give you the chance to engage in and experience new things. Past events have included bowling, crazy golf, quizzes, sit-down meals and a day out watching greyhound racing.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Weekly 5km Park Runs	parkrun UK		Various locations	www.parkrun.org.uk/events/events/	These free, weekly, 5km timed runs take place in pleasant parkland surroundings throughout the UK. They are open to people of all abilities, can be completed at your own pace, and can act as great stress relievers. Participants can benefit from the sociable and therapeutic nature of the events and the associated volunteering opportunities can be highly rewarding. All runs start at 9am on Saturday morning. There are currently six parkruns in the Tees Valley region.
North East Shine Network	Shine Cancer Support		Various locations around the North East	northeast@shinecancersupport.org www.shinecancersupport.org/ north-east-shine	This is a relaxed and friendly group for younger adults who have been affected by cancer and want to meet other people with similar experiences. The shine networks meet up on a regular basis for drinks, dinner, beach walks, bowling and more.
Young Carers Social Group	Hartlepool Carers	01429 283 095	Hartlepool Carers, 19A Lowthian Road, Hartlepool, Cleveland TS24 8BH	staff@hartlepoolcarers.org.uk www.hartlepoolcarers.org.uk/sub/ drop-in-services-1	This friendly and inviting weekly group offers fun-filled activities and social events to carers aged under 13. The group meets every Monday between 5pm and 7pm.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Headland Carers Coffee Morning	Hartlepool Carers	01429 283 095	Anchor Court, Durham Street, Headland, Hartlepool TS24 0DA	staff@hartlepoolcarers.org.uk www.hartlepoolcarers.org.uk/sub/ drop-in-services-1	This group is open to all carers in the Headland area and is a great way to seek local advice and meet fellow carers. They meet on the last Tuesday of every month between 10am and 12pm.
Darlington Ramblers Group	Headway Darlington & District	01325 376444	The Northern Echo Arena (Mowden Park), Neasham Rd, Darlington, Durham DL2 1DL	info@headwaydarlington.org.uk www.headwaydarlington.org.uk/ services	The Darlington based rambling club was set up by members of the charity and focuses on organising gentle and accessible walks for anyone who has been affected by a brain injury.
Darlington Specialised Cycle Rides	Gateway Wheelers	0798 6237926	Eastbourne Sports Complex, Bourne Avenue, Off Hundens Lane, Darlington DL1 1LJ	officegatewaywheelers@yahoo.co.uk www.gatewaywheelers.org.uk	This charity provides specialised cycles and equipment to people living with disabilities for use in regular organised rides in Darlington and the North East. The experienced leaders have over 10 years experience in organising suitable rides for people with disabilities. Membership is £4 per year.

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# **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
The Trinity Holistic Centre Counselling Services	The Trinity Holistic Centre	01642 854839	James Cook University Hospital, Marton Rd, Middlesbrough TS4 3BW	www.southtees.nhs.uk/services/ trinity-holistic-centre/emotional- and-psychological-support/	We know occasionally you need some support to regain control. This service offers a clinical psychologist who can provide counselling services for patients and their relatives. The centre can offer you 6 free sessions which last up to 60 minutes each. In addition to this, trained volunteers are always there to lend an ear over a cup of tea or coffee and can also offer emotional and social support

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Open Minds Therapies (Middlesbrough)	Middlesbrough and Stockton Mind	01642 218361	147 Albert Road, Middlesbrough TS1 2PS	hello@middlesbroughandstockton mind.org.uk www.middlesbroughandstockton mind.org.uk/projects-services/open- minds-therapies.aspx	We know the thoughts, feelings and moods associated with a brain tumour diagnosis can often make your day-to-day life more challenging than it needs to be. This service offers a range of psychological therapies from cognitive behavioural therapy to guided self-help in order to help you through these difficult periods Therapy can be delivered either ove the phone or in one-to-one and group sessions from a venue most suitable for you.
Open Minds Therapies (Stockton- on-Tees)	Middlesbrough and Stockton Mind	01642 218631	Catalyst Building, 27 Yarm Road, Stockton-on-Tees TS18 3NJ	hello@middlesbroughandstockton mind.org.uk www.middlesbroughandstockton mind.org.uk/projects-services/open- minds-therapies.aspx	This service, based in Stockton- on-Tees, can offer you numerous psychological therapies from cognitive behavioural therapy to guided self-help either over the phone or in one-to-one and group sessions. This service aims to help you through these difficult periods and can be accessed from a venue most suitable for you.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Move in and Move on' Housing Support	Middlesbrough and Stockton Mind	07972 622657 or 01642 243871	Move in and Move on, 50 Darenth Crescent, Middlesbrough TS3 7JY	mimo@teesvalley.org www.middlesbroughandstockton mind.org.uk/projects-services/move- in-and-move-onaspx	This service can provide you with up to 12 weeks of housing based support to kick-start your journey towards better mental health. The properties have 24-hour access to staff who are always there to offer intensive, recovery focused support. This support can include teaching you new skills to help you live independently in the future, improving your confidence and helping you find suitable accommodation to move on to.
Darlington Family Support Team and Counselling	Darlington & District Hospice Movement	01325 254321	St Teresa's Hospice, The Woodlands, Woodland Road, Darlington DL3 7UA	enquiries@darlingtonhospice.org.uk www.darlingtonhospice.org.uk/ our-care/family.html	This family support team, made up of social workers, counsellors, and volunteer support workers, offer free, confidential advice and support for people who have been diagnosed with a life-limiting illness, and those who care for them. The team works alongside other health and social care service to help and assist with the stresses difficulties and changes that may occur while living with a life- limiting illness. They can help you with emotional issues such as wha to tell your children and practical issues including finances, benefits, housing or accessing appropriate services.

# 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
Headway Teesside Weekly Drop-in	Headway Teesside	01912 834562	The Gateway, Lower East Street, Middlehaven, Middlesbrough TS2 1SW	headwayteesside@aol.com www.headwayteesside.org.uk	This charity aims to provide practical help and support to people who are living with a brain injury in the Teesside area. Support in the past has included drop in sessions, activity sessions to help build confidence and various social outings including ten pin bowling and trips to the seaside. This support can be accessed by patients, families, friends and carers.
Hartlepool Brain Injury Support	Headway Hartlepool	07766 666015	Real Life Options, 107 Innovations Centre, Hub 1, Queens Meadow Business Park, Venture Court, Hartlepool TS25 5TG	alastair.white@headway.org.uk www.headway.org.uk/ supporting-you/in-your-area/ groups-and-branches/north-east/ headway-hartlepool/	This local branch of the national charity aims to support people living with a brain injury in Hartlepool through talks, outings and regular drop in sessions. At the time of writing this service is in its infancy, however, you can get in contact for further information.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Great Aycliffe Cancer Support Group	Great Aycliffe Cancer Support Group	07762 258696	Newton Aycliffe Youth and Community Centre, Burn Ln, Newton Aycliffe DL5 4HT	allisonwhite75@yahoo.co.uk www.greataycliffecancersupport group.co.uk/?page_id=5	This friendly, sociable group welcomes anyone who has been affected by cancer in and around the Great Aycliffe area. They can offer cancer information, regular social activities, day trips and emotional support. They host regular monthly meetings on the first Thursday of every month between 6pm and 7.30pm.
Darlington	Headway	way 01325 376444	The Northern	info@headwaydarlington.org.uk	The charity hosts group sessions
Head Injury Group Sessions	Darlington		Echo Arena (Mowden Park), Neasham Rd, Darlington, Durham DL2 1DL	www.headwaydarlington.org.uk/ services	twice a month which can provide you with support if you have been affected by a brain injury. These sessions give you a chance to meet with other people with similar issues, discuss worries or concerns with a brain injury professional and receive educational and family support on how to cope with cognitive, emotional and behavioural changes. The sessions are currently held on the first and third Monday of the month.

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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
Middlesbrough and Stockton Carers Support	Middlesbrough and Stockton Mind	01642 257020	The Mind Centre, 90–92 Lothian Road, Middlesbrough TS4 2QX	carers@middlesbroughandstockton mind.org.uk www.middlesbroughandstockton mind.org.uk/projects-services/ carers-support.aspx	Caring for someone with a menta health issue is not always easy. This service provides a range of support for carers which can be anything from one on one emotional support to wellbeing workshops. They can meet you anywhere you feel comfortable such as your home, a local café or at their building on Lothian Road. Appointments are usually availab Monday–Thursday 9am–5pm and Friday 9am–4pm however they will try to arrange an appointmen outside these times if needed.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
HartlepoolHartlepoolFamily andand DistrictCarer SupportHospice	01429 855555	Hartlepool	info@hartlepoolhospice.org.uk	This hospice can provide emotional	
	and District		& District Hospice, Alice House, Wells Avenue, Hartlepool TS24 9DA	www.hartlepoolhospice.co.uk/ how-we-help.php?id=196	and practical support for carers alongside their specialist patient care. This support aims to reduce many of the pressures and anxieti on the family, friends and carers of people living with a life limiting illness through respite breaks, organising home care, carer suppo groups, creative therapies and mon They can also provide specialist support to the children whose love ones are living with a life limiting illness.
Stockton Carers Advice and	Sanctuary 0800 917 0204 Various locations Supported Living	5	Various locations	stocktoncarers@sanctuary- housing.co.uk	This service aims to provide practical advice and respite care
Advice and Respite Service			www.sanctuary-supported- living.co.uk/carers	to adult carers in the Stockton borough. They offer a carer respite service which provides up to eight hours per month of free respite for carers, so they have more time for work, training, education or just time to relax and reenergise. Additional hours can be provided at a charge. They also run a range of weekly and monthly support groups, including a lunch club.	

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Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Stockton Carers Group	Sanctuary Supported Living	0800 917 0204	Five Lamps, 32 Dovecot Street, Stockton-on-Tees TS18 1LN	stocktoncarers@sanctuary- housing.co.uk www.sanctuary-supported- living.co.uk/carers	The group can help you meet other carers, get peer support and enjoy a cuppa or lunch in a relaxed and friendly environment. The group meets every Thursday between 1pm and 3pm. There is also a lunch club held every second Tuesday between 12pm and 2.30pm at Brewers Fayre pub on Yarm Road.
Stockton Young Carers Support Service	Eastern Ravens	01642 678454	Eastern Ravens Trust, Community Zone North Shore Academy, Talbot Street, Stockton-on-Tees TS20 2AY	info@easternravenstrust.org www.easternravenstrust.org/ young-carers/	This service offers tailored and flexible support to young carers under the age of 18 who provide regular and ongoing care and emotional support to a family member in the Stockton Borough.
Hartlepool Carers Career and Personal Development Advice	Hartlepool Carers	01429 283 095	Hartlepool Carers, 19A Lowthian Road, Hartlepool, Cleveland TS24 8BH	staff@hartlepoolcarers.org.uk www.hartlepoolcarers.org.uk/sub/ drop-in-services-1	This service offers support to carers who are looking for help getting into work or developing new skills for their CV. These sessions are every Wednesday between 9.30am and 12.30pm and are available to all carers registered with Hartlepool Carers.

# **Support for children**

**500 children a year are diagnosed with a brain tumour, and there are innumerable families living with the disease.** Two thirds of children diagnosed are left with a disability. Families can find communication difficult, and awareness of brain tumours in children is low; this is despite the fact that brain tumours now kill more children than any other illness in the UK. Because of these unique and frustrating challenges, there is help available for you and your child.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Hartlepool Time for You' Support Sessions	Patch Family Support & MIND	01429 862727	Dimensional House, 81 Stranton, Hartlepool TS24 7QT	info@patchfamilysupport.co.uk www.patchfamilysupport.co.uk/ services.asp	These individual therapeutic counselling sessions, for families with children between 0 and 11 years old, work to reduce stress and tension whilst promoting relaxatior The charity also offers one to one individual home support for familie
Hartlepool	Patch Family	01429 862727	Dimensional	info@patchfamilysupport.co.uk	This charity, which focuses on
amily Support Groups	Support		House, 81 Stranton, Hartlepool TS24 7QT	www.patchfamilysupport.co.uk/ services.asp	providing support to families who have children ages 0–11, runs group family sessions at various venues throughout Hartlepool. These sessions consist of a range of activities which will aid your child's development in language, literacy, numeracy and communication, whilst having fun and socialising. The children are offered age appropriate, stimulating activities and are encouraged to participate in the Eat Better, Start Better programme and enjoy a healthy snack and drink with their friends. The sessions cost £1 per child.

# **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
Hartlepool and District Hospice 24 Hour Helpline	Hartlepool and District Hospice	01429 855558		info@hartlepoolhospice.org.uk www.hartlepoolhospice.co.uk/ how-we-help.php?id=199	We know that living or caring for someone with life limiting illness can be a very demanding and often frightening time. This 24-hour helpline is staffed by experienced nurses and doctors who are ready to offer support and advice at any time of the day or night, regardless of whether the person involved is being cared for by the hospice or not. The helpline is also available to health and social care professionals who require assistance and advice
<i>brainstrust</i> 24/7 Helpline	brainstrust	01983 292405	<i>brainstrust,</i> 4 Yvery Court, Castle Road, Cowes, Isle of Wight PO31 7QG	hello@brainstrust.org.uk www.brainstrust.org.uk	With <i>brainstrust</i> 's 24/7, 365 days a year helpline, patients, carers and families can pick up the phone or email and know they will have an immediate, personal response.
Macmillan Support Line	Macmillan Cancer Support	0808 808 0000		www.macmillan.org.uk	If you have questions about cancer, need support or just want someone to talk to, you can call Monday to Friday between 9am and 8pm.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
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 Brain & Spir	Brain & Spine	0808 808 1000		helpline@brainandspine.org.uk	This free and confidential helpline
Helpline	Dline 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.		
North East	Coping With	0191 280 5610	info@copingwithcancer.org.uk	This charity offers an over the	
Telephone Cancer Counselling	phone Cancer North East www.coping	www.copingwithcancer.org.uk	phone talking therapy for people living with cancer in the North East. The service is fully independent, confidential and free for cancer patients and their families, carers and friends. They allow time and space to express your feelings and emotions as well as encourage a range of coping strategies.		

# **Financial support**

Having a brain tumour will, at some point, impact on you financially as well as physically and emotionally. Look this tiger in the eye. The more prepared you are, the more you will be ready if you need additional support. Much better to be proactive, than reactive. The good news is that there is a wealth (pardon the pun) of help out there.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Macmillan Cancer Grants	Macmillan Cancer Support	0808 808 0000	Various	financialguidance@macmilan.org.uk www.macmillan.org.uk	These are one off payments (around 250 pounds) for adults, young people or children with cancer. To apply, ask your local health care professional to supply you with an application form. The grant team will review the application and if approved, payments are generally sent out within 3 working days.
Stockton Warm Homes Healthy People Energy Debt Scheme	Five Lamps	01642 528215	Five Lamps, Eldon Street, Thornaby, Stockton-on-Tees TS17 7DJ	info@fivelamps.org.uk www.fivelamps.org.uk/our-services/ five-lamps-charity/energy-debt/	This service is in place to give support to people whose health makes them vulnerable to cold weather. It can offer emergency heating, energy debt and welfare benefits advice, assistance with minor repairs through a home handyman service, and the installation of smoke alarms/ carbon monoxide detectors/ falls prevention equipment. The project also offers a wider advice and support service to help keep people healthy and more able to cope issues surrounding the cold weather.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
The Teesside Emergency Relief Fund	Tees Valley Community Foundation	01642 260860	Tees Valley Community Foundation, Wallace House, Falcon Court, Preston Farm, Stockton-on-Tees TS18 3TX	info@teesvalleyfoundation.org www.teesvalleyfoundation.org/ apply-for-support/available-grants	This is an emergency grant fund to assist individuals living in Darlington, Hartlepool, Middlesbrough, Stockton on Tees and Redcar & Cleveland who are faced with an emergency or crisis. The fund is operated as a third party grant meaning individuals cannot apply directly, applications must be submitted by a support organisation who have detailed knowledge of the applicant's circumstances. The maximum grant amount is £250.
Individual Respite Grants	County Durham Foundation	0191 378 6340	Victoria House Whitfield Court, St Johns Road, Meadowfield Industrial Estate, Durham DH7 8XL	info@cdcf.org.uk www.cdcf.org.uk/apply-for-a-grant/ grants-for-individuals/respite	This fund provides grants of up to £1,000 to sick or disabled individuals and their carers. Eligible individuals are seen to be in need of respite care or temporary support following hospitalisation, bereavement or because of dependency treatment. To receive this grant, you must be living in either Darlington, Hartlepool, Middleborough, Redcar & Clevelance or Stockton-on-Tees.

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

# **Complementary therapies**

### There are many reasons why people choose to use complementary

**therapies.** Some people find they help them cope with the stresses caused by cancer and its treatments. Many therapies are relaxing, and may lift your spirits when you aren't feeling your best. Complementary therapies may help you:

- feel better and improve your quality of life
- feel less stressed, tense and anxious
- sleep better
- with some of your cancer symptoms
- with some of the side effects of your cancer treatment
- feel more in control

Read on to find out what is available near to you, and please, remember to seek the advice of your doctor before starting any new therapy.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
The Trinity Holistic Centre Complementary Therapies	The Trinity Holistic Centre	01642 854839	James Cook University Hospital, Marton Rd, Middlesbrough TS4 3BW	www.southtees.nhs.uk/ services/trinity-holistic-centre/ complementary-therapies/	This service offers a wide range of treatments including aromatherapy acupuncture, auricular acupuncture reflexology and reiki which will help brighten your day and allow you to relax in a safe, comforting environment. Initially you will be given a personal appointment with a therapist who will help you decide on which treatments will suit your needs.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Hartlepool Complementary Therapies	Hartlepool and District Hospice	01429 855555	Hartlepool & District Hospice, Alice House, Wells Avenue, Hartlepool TS24 9DA	info@hartlepoolhospice.org.uk www.hartlepoolhospice.co.uk/ how-we-help.php?id=198	This hospice has a team of highly trained staff on hand to help you relieve stress and tension, aid your relaxation and promote a sense of wellbeing through the use of reflexology, Indian head massage, reiki and/or massage. These complementary treatments can be carried out at a bedside or in a designated treatment room depending on your individual circumstances.
Darlington Day Therapy	Darlington & District Hospice Movement	01325 254321	St Teresa's Hospice, The Woodlands, Woodland Road, Darlington DL3 7UA	director@darlingtonhospice.org.uk www.darlingtonhospice.org.uk/ our-care/day-therapy	This service is a chance for you to get out of the house and receive treatment whilst meeting and talking to new people in a peaceful setting. The day therapy is situated in a beautiful woodland environment and offers a range of activities and therapies from arts and crafts to Jacuzzi baths, massages and hairdressing. These days also can include medical support if needed.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Darlington Complementary Therapies	Darlington & District Hospice Movement	01325 254321	St Teresa's Hospice, The Woodlands, Woodland Road, Darlington DL3 7UA	enquiries@darlingtonhospice.org.uk www.darlingtonhospice.org.uk/ our-care/complementary.html	This hospice provides complementary therapies, with the emphasis on relieving pain and making the patient feel as comfortable as possible and helping them to live with their illness. The therapies include therapeutic massage, acupuncture, aromatherapy, reflexology, hairdressing, Jacuzzi bath and diversional therapies such as art and crafts, painting and needlework.

# **Holidays and short breaks**

### Going on holiday is a good way to relax and get away from things.

Many people like to plan a holiday for the end of their treatment. Others want to go before or even during treatment. Whether you're travelling for work or play, talk to your doctors and nurses to help you plan. They may be able to suggest a good time to go, as well as help to decide what is realistic for you. Here are some people that could make organising your next holiday that bit easier.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
North Hartlepool Caravan Break	The Chyrelle Addams Cancer Support Trust	07713 577965	Crimdon Dene Holiday Park, Coast Rd, Blackhall Colliery, North Hartlepool TS27 4BN	kay-wigham@live.co.uk www.chyrelleaddams.co.uk/ holiday.html	This charity hires out a holiday caravan to North East cancer patients and their spouse or carer at a discounted rate of £80 per week stay with a £65 deposit. The holiday home has great access to the beaches and sand dunes of Durham's heritage coastline. The price includes bedding hire and a park pass for Crimdon Dene Holiday Park. Any additional persons wishing to stay would be charged £35 each for the week.

# 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
Macmillan Cancer Support	Macmillan Cancer Support	01642 835674		Macmillaninformationcentre@ stees.nhs.uk	We know how confusing it all can be – the initial diagnosis, the
Benefits Advice	••		stees.nhs.uk www.southtees.nhs.uk/ services/cancer/ macmillan-information-centre/ benefits-advice/	treatment and then, on top of this, the legal and monetary issues a brain tumour can bring. This service offers information on the latter – helping you with benefits, tax credits and grants from a friendly benefits advisor. The service also offers ongoing advice and referrals to specialist housing and employment advisers.	
Middlesbrough Free Impartial Advice	Middlesbrough Citizens Advice Bureau	0344 499 4110	9 Linthorpe Road, Middlesbrough TS1 1TH	www.middlesbroughcab.org.uk	This service aims to help people living in Middlesbrough access free, independent information, advice and assistance whenever needed. The service can offer advice on unemployment, debt, benefits and more. They also host a number of outreach advice sessions.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Darlington Confidential Welfare Advice	Citizen's Advice Darlington	01325 256999	Citizens Advice Darlington, Bennet House, 14 Horsemarket, Darlington DL1 5PT	www.darlingtoncab.co.uk	Here you can receive free, confidential and expert advice on a number of issues relating to your rights and responsibilities such as welfare benefits and employment issues.
Hartlepool	Hartlepool	01429 283 095	Hartlepool Carers'	staff@hartlepoolcarers.org.uk	This service offers carers support
Carers Benefits Advice	Carers Centre	www.hartlepoolcarers.org.uk/sub/ drop-in-services-1	and advice to make sure they are receiving their full entitlement of benefits. The session take place every Wednesday between 10am and 12pm. This service is available to all registered carers with Hartlepool Carers.		
Welfare Advice	CLIC Sargent	0800 9154439		welfareadvice@clicsargent.org.uk	This charity, which focuses on providing support for children and young people with cancer, offer an accredited telephone welfare advice service. The advisers can give you information about the benefits you may be entitled and various aspects of welfare rights such as your employment, family, debt, consumer and housing rights. They can also signpost you to other useful organisations if this is appropriate.
Phone Service				www.clicsargent.org.uk/content/ financial-support	

# **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
North East Non-Emergency Patient Transport	North East Ambulance Service (NEAS)	0345 045 0160		www.neas.nhs.uk/our-services/ patient-transport-service.aspx	This service can provide you with pre-planned non-emergency transport to get to tests or treatments at the hospital if you have a medical need which means you cannot use any other form of transport such as help from a friend or relative or public transport. This service can be booked by your GP or by hospital staff. This service covers the Teesside and Darlington areas.

# **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
Teesside Day Hospice	Teesside Hospice	01642 811072	1 Northgate Road, Linthorpe, Middlesbrough TS5 5NW	teessidehospice@hotmail.com www.teessidehospice.org/ what-we-do/day-care	This service focuses on providing patients, families and carers, with day-to-day relief from all the stresses that come hand in hand with a brain tumour diagnosis or other life limiting illness.
Hartlepool Day Hospice	Hartlepool and District Hospice	01429 855555	Hartlepool & District Hospice, Alice House, Wells Avenue, Hartlepool TS24 9DA	info@hartlepoolhospice.org.uk www.hartlepoolhospice.co.uk/ how-we-help.php?id=190	Those living with a life limiting illness in the Hartlepool and East Durham area can access this day hospice service based in the outpatient unit. The hospice provides a relaxed, friendly environment and operates on Wednesdays between 9am and 4pm. This day service can help relieve isolation, give carers a break provide access to rehabilitation, improve wellbeing and help contro symptoms.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Zoë's Place Middlesbrough	Zoë's Place Baby Hospice	01642 457985	Zoë's Place, Crossbeck House, High Street, Normanby, Middlesbrough TS6 9DA	info@zoes-place.org.uk www.zoes-place.org.uk/ middlesbrough	This charity provides palliative, respite and end of life care in a safe home from home environment to babies and infants aged from birth to five years suffering from life-limiting or life-threatening conditions. The experienced staff work alongside healthcare professionals to develop a tailored palliative care plan for each child and family. The 24 hour, one to one support for children can allow parents and carers to recharge thei batteries or to spend time with their other children while knowing their child is in safe hands. The charity also offers a parent support network and sibling support group
St Teresa's	Darlington	01325 254321	St Teresa's Hospice,	enquiries@darlingtonhospice.org.uk	This hospice offers respite care,
Inpatient Service	& District Hospice Movement		The Woodlands, Woodland Road, Darlington DL3 7UA	www.darlingtonhospice.org.uk	pain and symptom management and end of life care in a relaxed and homely atmosphere. They can also admit people for crisis intervention in order to prevent the need for hospital admission. The service gives patients access to their day unit facilities, complementary therapies, the family support team, the medical team at Neasham Road Surgery and a specialist palliative care team. A Hospice at Home service is also available for patients living in Darlington and North Yorkshire.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Butterwick Hospice Stockton	Butterwick Hospice Care	01642 607742	Butterwick Hospice Care, Middlefield Rd, Stockton-on-Tees TS19 8XN	general@butterwick.org.uk www.butterwick.org.uk/ourhospices/ butterwickhospicestockton	This hospice offers a wide range of supportive day services and an inpatient unit for people suffering life limiting illnesses. The support is aimed at people with a progressive life-limiting illness who require symptom management, psychological or social support and are living in Stockton, Billingham, Yarm, Norton and Eaglescliffe and surrounding villages. The hospice also provides care and support to patient's families.
Butterwick House Childrens Hospice	Butterwick Hospice Care	01642 607748	Butterwick Hospice Care, Middlefield Rd, Stockton-on-Tees TS19 8XN	childrens@butterwick.org.uk www.butterwick.org.uk/ourhospices/ butterwickhousehospice	This warm and friendly hospice offers around the clock support for babies, children, teenagers, young adults and their families. This bright and happy environment gives children and young people access to specialist computers, games, arts and crafts, a special hydrotherapy pool, a multi-sensory room, a sensory garden and exciting trips on a specially adapted bus. Stays at the hospice are flexible with some children and young adults coming for the day and others coming for a short break either by themselves or with their family.

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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
Teeside Bereavement Counselling	Teeside Hospice	01642 811063	1 Northgate Road, Linthorpe, Middlesbrough TS5 5NW	teessidehospice@hotmail.com www.teessidehospice.org/ what-we-do/ bereavement- counselling/adults	This service offers you free, confidential support and counselling aimed to help you through the death of a loved one. The service is available even if you are not connected to the Hospice ir any way and is delivered by highly trained staff and volunteers.
Children 'Forget Me Not' Service	Teesside Hospice	01642 811063	1 Northgate Road, Linthorpe, Middlesbrough TS5 5NW	teessidehospice@hotmail.com www.teessidehospice.org/ what-we-do/bereavement- counselling/forget-me-not	We know that coming to terms with the death of a loved one can be especially difficult for children and young adults. This service focuses specifically on people under the age of 18 in the South Tees area. The service offers individual counselling or time limited group work with counsellors who are experienced at working with children who are grieving. Sessions involve the use of a range of creative resources to allow the children to express and understand their grief.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Hartlepool Bereavement Support	Hartlepool and District Hospice	01429 855550	Hartlepool & District Hospice, Alice House, Wells Avenue, Hartlepool TS24 9DA	info@hartlepoolhospice.org.uk www.hartlepoolhospice.co.uk/ how-we-help.php?id=202	We know that coming to terms with the loss of someone you love can be very lonely and confusing. This specialist centre is dedicated to providing caring support to children, young people and adults who have experienced grief and los and are living in the Hartlepool and East Durham area. The centre offer one-to-one counselling, a monthly support group for bereaved parent and Muchloved online service where a family member can set up a memorial page in memory of a loved one.
Hartlepool Bereaved Parents Support Group	Hartlepool and District Hospice	01429 855550	Hartlepool & District Hospice, Alice House, Wells Avenue, Hartlepool TS24 9DA	info@hartlepoolhospice.org.uk www.hartlepoolhospice.co.uk/ how-we-help.php?id=254	The support group is offered to parents living in the Hartlepool and East Durham area who are coping with the loss of an adult child. The group allows parents to meet other parents facing the loss of their child and talk about their experiences and feelings in a warn open and safe environment. The support group meets on the fourth Wednesday of every month from 1pm to 2.30pm at Hartlepool & District Hospice.

Service name	Service provider	Phone contact	Location	Email and web address	Brief description
Children's Bereavement Service	Hartlepool and District Hospice	01429 855550	Hartlepool & District Hospice, Alice House, Wells Avenue, Hartlepool TS24 9DA	info@hartlepoolhospice.org.uk www.hartlepoolhospice.co.uk/ how-we-help.php?id=203	This hospice offers a specialised bereavement service for children and young people. The support is offered by a team of highly trained staff and volunteers who will be there to help before, during and after the loss of a loved one. The service not only offers individual counselling, but also a range of resources for carers, parents and schools such as DVD's, worksheets and specialist literature.
Darlington Bereavement Support Service	Darlington & District Hospice Movement	01325 254321	St Teresa's Hospice, The Woodlands, Woodland Road, Darlington DL3 7UA	director@darlingtonhospice.org.uk www.darlingtonhospice.org.uk/ our-care/bereavement	In order to provide you with a sense of stability and comfort following the death of a loved one this service provides caring and thoughtful support in a number of ways; one to one support, specialist support for children/young people and casual drop-in groups are all available.

# What can *brainstrust* do to help?

### Help available

At times it may feel like it, but you are not alone. Everyone in the *brainstrust* community has experience of what it is like to be diagnosed and to live with a brain tumour. We can help you to feel less isolated – we understand. Below are examples of the help available to you from *brainstrust*. Don't hesitate to get in touch and talk to people who have been where you are now. We'll help you get back on top of things.

### What can brainstrust do to help?

For more information about any of these resources, visit **www.brainstrust.org.uk**, contact **hello@brainstrust.org.uk** or call **01983 292 405**.

### **Resources to keep you informed**

### • Information Standard certified information

on our website **www.brainstrust.org.uk**. Clear, accurate, balanced, evidence-based and up-to-date information, certified by the Information Standard.

### • 24/7 help line

We know that you don't just need to talk to someone 9-5. We've been there. We know the fears and the need to talk to someone who understands at all hours. That's why you can call us anytime. Open 24 hours a day, 7 days a week, the *brainstrust* help line offers brain tumour patients and carers support, information and pragmatic advice over the phone and by email. Call **01983 292405** or email **hello@brainstrust.org.uk** 

• Help you to understand the implications of the diagnosis A brain tumour diagnosis can be very scary, and it is difficult to identify what you need and want to know. We can chat through the impact with you, to help put you back in control.

### Interpretation of medical records

Medical jargon and terminology may be used in the records. If you choose to look at your records (and you are entitled to) you may need help understanding them, so interpretation can be provided. Contact brainstrust on **hello@brainstrust.org.uk** or call **01983 292405**.

### • Help you seek a second opinion

We are mindful that everyone reacts to a serious diagnosis in different ways. It is your right to seek further opinions, and this will empower some people. Some people would prefer not to exercise this right. Some people prefer to know as little as possible about their diagnosis; some people like to relinquish control of their situation to others. All of these are perfectly normal and acceptable ways of coping. And seeking second, even third opinions can cause confusion and stress. But they can inform, and help with decision-making. They can also be reassuring. We can only talk from our experience. We believe that you need to be informed to make decisions. And that might mean gathering information and then deciding not to make a decision. That's a decision too! For more information on second opinions, visit 'Just been told?' on **www.brainstrust.org.uk/advice**symptoms.php

### • Clear signposting

*brainstrust* can point you towards valuable resources to help navigate your journey.

### www.braintumourhub.org.uk

Created for brain tumour patients and carers, the brain tumour hub is an authoritative, easy to navigate database of brain tumour support resources and UK based brain tumour clinical trials. It is intuitive, easy to use, developed with clinicians, patients and carers, and constantly evolving with regular updates.



### Resources to help you feel more in control

### • Coaching

At *brainstrust* we listen, listen some more and then ask questions. We focus on achieving specific immediate goals, which relate to specific areas. For example, weighing up the pros and cons of having a particular treatment, or overcoming a problem with caring. We also know that through coaching, clients can experience a sense of healing, as they make courageous decisions about their lives and work. Coaching focuses on the future and the development of a workable solution. It's about developing strategies and clarity to achieve a better quality of life.

### • Counselling

When there is too much distress and a psychological intervention is needed, counselling can be useful. It is suitable for someone who is struggling to cope or feeling very anxious and depressed and therefore finding it hard to focus on specific immediate goals. Counselling has a broader focus and greater depth than coaching and so is usually a slower-paced intervention. It is concerned with the individual and their relationship to self, as well as with their family and communities. It is less solution focused than coaching (sometimes there is no solution to the problem) and instead aims to help the individual make sense of the situation in which they find themselves in order to make better decisions about what they want and need for the future. In some situations formal counselling may not be appropriate and instead a supportive listening relationship might be more useful.

### • Hypnotherapy

There is plenty of evidence that hypnotherapy helps people with cancer and those who care for them. Hypnotherapy can be used as a complementary therapy alongside conventional medical treatments and for a number of different purposes. Hypnotherapy can help brain tumour patients and carers to: manage anxiety, reduce stress, create a different experience of pain, build confidence and optimism, prepare for surgery and promote post-operative healing, reduce side effects of treatments, e.g. nausea and fatigue, optimise a healthy lifestyle to build resilience.

### Practical resources you can pick up

### • Brain box

### www.brainstrust.org.uk/advice-resources.php#2

The *brainstrust* brain box – the 'must have' support toolkit for people with a brain tumour diagnosis and their carers. We appreciate how difficult things can be once you are diagnosed with a brain tumour; the '4.00am moments', the travelling to and from appointments, the stream of questions that pop into your head, trying to remember the jobs of all the people that you'll meet on your journey, and knowing who to turn to and when. A juggling act that you don't need when you just want to focus your energy on feeling better. So to assist brain tumour patients, we provide this unique invaluable aid.



### • Little White Book

www.brainstrust.org.uk/advice-resources.php#5

A comprehensive, easy to navigate compendium of UK brain tumour support resources.

### Snaggle Tooth Splat

### www.brainstrust.org.uk/advice-resources.php#7

Written for *brainstrust* to help parent carers or patients broach a brain tumour diagnosis with their children. It is a beautifully illustrated book and has featured in the BMA newsletter and Oncology news. The forward has been written by the lovely actress and *brainstrust* supporter, Julie Walters. If you are a parent who has been diagnosed with a brain tumour, or are looking after a poorly little patient, then you can have a copy of this book, for free.



• Who's WHO in YOUR clinical team www.brainstrust.org.uk/advice-resources.php#6 Many patients find that they are left to manage their care pathway for themselves. *brainstrust* has developed this handy resource to help you navigate your journey. It outlines all the healthcare professionals who may be involved in your journey and tells you what it is they do.



### **Resources to help you feel less lonely**

### Meetup

### www.meetup.com/brainstrust



At a *brainstrust* Meetup, members of the brain tumour community get together to have fun. No matter where you are on your journey or what role you have (such as carer, patient, health care professional) you can share

experiences, and seek information from people who know what you're going through. But only if you want to. Feel free to just come along and enjoy. Past Meetups have involved pizza and wine, pub grub, and cream teas.

• facebook brainstrust brain tumour support group www.facebook.com/groups/braintumoursupportbrainstrust/

If you are on facebook, you can join this closed support group where a lot of very friendly patients and carers hang out. It is a really warm and welcoming group who will comfort you, answer questions, make you smile, and importantly are in the same boat as you.

### • facebook UK brain tumour carers group www.facebook.com/groups/ukbraintumourcarers/

This is a group page for carers of people with brain tumours in the UK. It can be very hard and lonely being a carer, so this group is for any carers to ask others questions about care, offer advice, have a general chat, a good laugh or rant/sound off when you need to without offending or upsetting those they look after.

There are over 55,500 people living with a brain tumour in the UK. *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 – Tees Valley, edition 1, published by *brainstrust* November 2016, due for review November 2017.

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