

Being a carer

Looking after yourself



While it's important you're in good health (mental and physical) so you can care for your loved one, it's also important you remember to take care of yourself for you.

Being a carer is a selfless and difficult thing to do, and likely not something you expected or wished to be doing.

So remember to be kind to yourself and that you're worth a short break, a day away or to share with a loved one.



If you'd like to talk to someone about how you're feeling, or would like to find out where you can get further support (including details of support groups), you can contact The Brain Tumour Charity's Information and Support Team:

Phone: 0808 800 0004

(free from landlines and most mobiles) Email: support@thebraintumourcharity.org Live chat: thebraintumourcharity.org/live-chat Website: thebraintumourcharity.org/getsupport Closed Facebook groups: thebraintumourcharity.org/facebook-support

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Who is a carer?

A carer is anybody who, usually unpaid, looks after a family member, partner or friend that needs help because of illness, frailty or disability. Carers come from all walks of life, all cultures and can be of any age.

It may be that you don't consider yourself to be a 'carer' - what you're doing is just part of your relationship with the person you're looking after and 'only what anyone else would do in that situation'.

However, if you're involved in looking after someone with a brain tumour, you are classed as a carer and all carers share some basic needs.

How can carers look after themselves?

Of course, each carer's experience is unique to their own circumstances. Below are some practical suggestions that have been shared with us by carers, as things that have most helped them to cope:

- breaks in caring
- practical support
- carer's assessment
- financial support
- emotional support
- information about where to get the above support.

Breaks in caring

This can mean anything from daily breaks of an hour or two to a short weekend break or respite breaks/holidays of one week or more. Or it could be a combination of these - whatever works best for you.

Daily breaks and making time for yourself

Many carers feel guilty if they take time out for themselves, but you're important too and need to be cared for as well. It's important to have some time for yourself, even if only for an hour or two each day. Having some time out can actually make you a more effective carer.

Do something you enjoy that's not directly related to helping the person you're caring for. Physical activity, e.g. gardening, swimming or going for a brisk walk has been shown to be a great stress reliever.

Or you could do something that allows you to relax, e.g. reading, listening to music, relaxing in a hot bath or catching up on sleep. Find something that allows you to switch off the thoughts that may be constantly whirring through your head.

The important thing is to create some 'you' time and protect it.

You should also remember to treat yourself from time to time without feeling guilty - going out for a meal, buying new clothes, watching sport, going to the pub or simply visiting friends or family.

If your loved one's care needs are such that they can't be left alone, perhaps a friend or relative would be able to stay with them for a couple of hours. You could also ask your local council whether your loved one can attend a day centre. Alternatively you may have a local carers' centre or other charity that offers this service.

They may also offer what is called a sitting service. This is where a trained volunteer will keep your loved one company for a few hours, while you have a break.

To find out about these services, see the Resources section later in this fact sheet

Longer breaks in caring

Sometimes you may feel you need a longer break - a day here and there, a few days break or a holiday of a week or two - or, over time, a combination of these.

This doesn't necessarily mean going away yourself. It could be that the person you're caring for goes on holiday and you stay home. This will give them new experiences, a change of scene and routine, and a chance to mix with other people, while you get a well-earned break too. If you go away and need to arrange alternative care, then depending on how much care your loved one needs, friends or family may be able to take over.

Your local council will have a social services department that can arrange help - usually called 'respite care'. (You'll need to have an assessment of needs and may have to pay for the respite care).

For more informaiton, see the Carer's assessment section later in this fact sheet

Some areas have GP Carers' Prescription Service, so the GP can prescribe carers a break, if the doctor feels it would benefit their health.

Alternatively, you may wish to employ a paid care worker in your home or pay for short-term residential care.

Practical support

Build yourself a support network

Identify a small network of people you can rely on for practical support. Allow yourself to accept and ask for their help.

Friends are generally more than willing to help, but are often unsure what to do and are sometimes nervous about asking. Letting people know what you need, no matter how small, can help take some of the weight from you. It also helps them know what they can do, when they may be feeling helpless.

Let others know you're a carer

In order to access support, you'll need to let others know that you're caring for someone. This includes:

Family and friends

Once they know, they can provide support, emotionally and practically. You could ask for their help with some of the following tasks:

- Housework: Ironing, cooking, vacuuming, cleaning.
- Shopping: Or you could do this online.
- Gardening: Mowing the lawn, tidying the garden.
- Helping with the children: Taking or picking them up from school, clubs or other activities.
- Other: Walking the dog, washing the car, giving lifts to and from hospital.

Sometimes family and friends don't understand, however much they want to. We've put together some resources to help them do this, that you can point them towards.

See our Friends and family webpage at: thebraintumourcharity/support-family-and-friends

Others who have been through, or are going through, something similar.

They may know instinctively how to help you.

We have a closed Facebook group specifically for carers, available 24/7. It can enable you to share experiences, find and give support and help you feel less isolated.

For information how to join, visit: thebraintumourcharity.org/facebook-support

Your GP

They will be able to take in to account your circumstances and may also be more flexible with appointment times if they know you're a carer. You can sometimes do this via the GP's website.

The Adult Services or Children's Services (Social Services) departments of your local authority

They can give you a carer's assessment to find out the practical and financial support available to you. (See the Carer's Assessment section further on in this fact sheet.)

Local carers' centre,

They are a source of information and advice for practical and emotional issues.

Your employer

They may be flexible around working hours and leave arrangements. You may also find it helpful to let colleagues you trust know that you're a carer, so they can show their support.

For help with telling your employer and your rights, see our Employment resources,

thebraintumourcharity.org/employment-support

Make a list of useful numbers

Making a list of useful numbers to contact, especially for out of hours, can make you feel more reassured that you know what to do should anything happen that causes you concern.

It can help to ask your loved one's healthcare team, as early as possible, what things are a cause for concern. That way you know when to ask for help.

Look after your physical health

As a carer, you may not be getting enough sleep - either through the person you're caring for disturbing you in the night, or through worry.

Long-term lack of sleep, as well as affecting your concentration, ability to make decisions and making you feel depressed, can increase your risk of various health conditions, such as high blood pressure, diabetes and obesity.

Talk to your GP who can give advice or medication, and try some of the following tips for a better night's sleep:

- make sure your room is the right temperature
- avoid drinking tea, coffee or alcohol in the evening
- don't eat too late
- try not to have a TV or computer in your bedroom
- have a warm bath.

If you're worrying at night, have a notepad beside your bed - many carers have found it useful to write things down and deal with them the next day.

If you still can't sleep, get up and do something relaxing, like reading or listening to quiet music.

Make sure you eat well. A balanced diet will keep your body strong and give you more energy to provide the care for your loved one.



For information about this and how to do it on a budget, see the Resources section of this fact sheet.

If you're having to do any lifting as part of your caring, make sure you protect your back. Speak to your GP about being shown how to do this properly.

Make sure you and your family are safe

If your loved one has memory difficulties, this can sometimes cause problems relating to safety, e.g. you may tell them not to touch the cooker, but they may forget that you told them that. Placing reminder notes in an appropriate place can help.

You can find lots of helpful tips in our Memory difficulties webpage and fact sheet:

thebraintumourcharity.org/memory-difficulties

If your loved one becomes violent

Some tumours can affect an individual's ability to control their behaviour and emotions.

Very occasionally this may lead to agitation or aggressive behaviour either towards you, or perhaps to your children. You may come to feel unsafe in your own home. It's important in this situation that you act.

Keep yourself and your family safe by learning to read the trigger signs and seek help from your healthcare team. You may be referred to a psychologist or psychiatrist who can help you manage these symptoms more safely.

However, carers often report that denial, guilt and fear can make them reluctant to do so. You must remember it's the disease that's doing this, not the person.

Speak to your GP or local carers' centre - they can help you with emotional and practical support either directly or by referring you to a psychologist/psychiatrist. They can also help with approaching your local social services for a carer's assessment, which looks at your needs.

It's important not to feel guilty if you're unable to care for your loved one if they get really ill. Caring is a skill and not always a natural instinct, especially with the challenges of personality changes and memory loss.

You can find out more about personality changes at: thebraintumourcharity.org/personality-changes

Carer's assessment

You're entitled to a carer's assessment by your local authority to assess your own needs.

At this assessment you can discuss any help that would maintain your own health and also balance caring with other aspects of your life. You may agree with your local authority that you need a break as part of your care plan and the local authority may agree to fund it.

Charities and benevolent funds are other sources of financial help to pay for respite care or for your break.

For information about how to find these, contact our Information and Support Line: **0808 800 0004** or **support@thebraintumourcharity.org**

Or call your local carers' centre or see the Resources section later in this fact sheet.

Financial support

If money is a concern for you, find out about the financial assistance available to you. This is an important part of looking after yourself and relieving your stress.

For example, if you, or the person you care for, is over 75, you can apply for a free TV licence. Or if they're blind, you can get a discounted licence. You can find out more at: **gov.uk/free-discount-tv-licence**

You or your loved one may be entitled to some benefits. We have a weekly telephone Benefits Clinic where you can find out if you and/or your loved one are eligible for various benefits, and get help applying for them.

For example, if the person you care for receives certain benefits, you may also be eligible for Carer's Allowance or Carer's Credit.

Our expert benefits adviser can explain various benefits to you, and advise you on filling in forms. The clinic runs every Tuesday with appointments from 9.30am to 4.00pm.

You can book an appointment online at: thebraintumourcharity.org/benefits-clinic

In the eyes of the law, people with a brain tumour (low or high grade) are likely to be considered to have a disability, even though you, and they, may not see themselves in that way. As such, there is other financial help available. You can find more at: **gov.uk/financial-help-disabled**

Your local authority, local carers' centre and local Citizens Advice Bureau can also tell you about ways of helping your financial situation and dealing with the extra costs that caring for someone can bring. For example, early redemption (ill-health commutation) of a pension or life insurance policy.

For more information and money saving tips from our Citizens Advice advisor visit:

thebraintumourcharity.org/financial-support/

It's important to be aware that some benefits can affect other benefits that both you and the person you care for get.



Emotional health and support

Emotional effects of being a carer

Being a carer isn't easy. Caring for someone with a brain tumour can be both physically and emotionally demanding. It can be a full-time 'job', with no built-in breaks, and can frequently cause anxiety, stress and feelings of isolation and loneliness.

Many carers also state that they're given little information at diagnosis about their loved one's condition. As a result, they feel in the dark, uncertain, and have to find information themselves.

Depending on your loved one's tumour and symptoms they're experiencing, your caring role can be suddenly thrown upon you, before you've come to terms with their diagnosis, giving you no time to 'prepare' for this role.

Or it may develop more gradually and you may have become a carer before you realised it. But either way, psychologically and emotionally, it can come as a shock.

The Brain Tumour Charity produces a pack of information, which is particularly useful for people who are newly diagnosed.

If you'd like a copy, please contact the Information and Support Line - **0808 800 0004** or **support@thebraintumourcharity.org** You may also work outside the home and have to juggle your job with your responsibilities as a carer, and possibly also with looking after a family.

Or you (and your loved one) may have to give up your jobs, with the resulting negative effect on household finances and the strain this can cause.

You could be a young carer looking after a parent and/or younger brothers and sisters while juggling school/ college and trying to keep in touch with your friends.

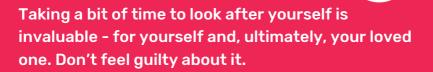
Not only do you have to process the shock and devastation that a brain tumour diagnosis has brought to your family, but you also have to deal with the change in household relationships.

Whereas once your parent was the protector, supporter and leader, now the roles may be reversed. It can be difficult to explain or tell anyone how you feel.

It is important to remember you're not alone in feeling this way.

Your wider family might be able to help, but may be only up to a point. Or it could be that you don't have an extended family you can call on. Carers often find that they lose contact with friends after the person they care for has been diagnosed. This can be because friends find the situation uncomfortable and 'don't know what to say'.

You didn't choose to be come a carer, it just happened. The effects can be wide-ranging – anxiety, frustration, isolation, your own ill-health, depression and financial difficulties.



Many carers struggle alone. The person you'd normally turn to for help may be the person who has the brain tumour - and they're going through their own emotional and physical challenges.

They may also be undergoing personality changes as a result of their brain tumour that makes this even more difficult. This could, in turn, put strain on your relationship with them.

The dynamics of your relationship may have changed - if your partner has a brain tumour and needs a lot of care, you may now be acting more in a parenting-type role than as a partner. Although you may gain much personal satisfaction from caring for your loved one and want to continue caring, all this puts an incredible amount of strain on you.

The Royal College of General Practitioners (RCGP) reported that about 40% of all carers have significant distress and depression levels.

Additionally, the charity Headway found that 59% of people caring for a person with an acquired brain injury (which includes brain tumours) show signs of clinical depression, with 21% in the severe or extremely severe range.

According to the RCGP, the risk of distress increases with the amount of time devoted to caring each week.

Tips for dealing with the emotional effects

Acknowledge your feelings

You're probably going through a wealth of emotions while caring for your loved one - anxiety, anger, frustration, fear. Carers often say they feel helpless, lacking control or even hollow. They feel like they're lurching from one crisis to another. A lack of support and/or sleep can make these worse. On top of this, many people get trapped in a cycle of resentment and guilt. Resentment towards the person you're caring for can be because:

- you feel that your life is no longer your own
- you don't want your whole life to be about the illness
- you feel that the person you're caring for doesn't appreciate what you're doing for them
- you've had to give up a career/future employment prospects and pension rights
- you've had to give up your social activities and networks.

Then you feel guilty for having these resentful feelings, or because you feel you should be 'doing more' or 'doing better' at caring.

It's important to acknowledge these very natural feelings and realise you're not alone in feeling this way

If you can, talk to the person you're caring for about this - they may also welcome the opportunity to talk about their own feelings. Many people who are cared for worry about being a burden on their loved ones and take comfort from seeing them doing something just for themselves. Naturally though, you may find it easier to speak to someone outside of the carer/patient relationship.

This could also be because it's not possible to speak to the person you're caring for. For example, if you're caring for a child, or if your partner has withdrawn from you because they don't want you to 'see them like this', or the tumour has caused cognitive or personality changes that make talking to them difficult.

Find people you can talk to

This could be a close friend or relative, a counsellor or someone else who's going through the same thing, i.e. via a support group, online discussion forum or a support line, such as those provided by The Brain Tumour Charity (see page 25.)

Friends and family are often willing to listen, but may be worried about upsetting you, so it might be helpful if you 'make the first move'.

Friends can also provide the chance to talk about/do other things not related to your caring. Maintaining and nurturing friendships can be more difficult, however, when much of your time is taken up caring for someone. This is something your friends are likely to understand. Try to stay in touch using whichever method works best for you, even if it is only for 5 minutes - phone, text messaging, Skype, Facebook and emailing. Many of these can be useful if you find it difficult talking about how you feel face-to-face.

Carers often find that friends, and sometimes family, do gradually fall away. This may be because they're dealing with their own emotions about the illness of someone who's also their friend or loved one, or because they find it difficult to know what to say.

Carers have suggested the following:

- Find out if you have a local carers' centre they often have social events carers.org/carers-services/find-your-local-service
- Twitter you can join conversations and talk about anything you like
- Local faith-based groups or communities
- Online discussion forums/Facebook groups.

The Brain Tumour Charity has an active Facebook Support Group, specifically for carers. You can access it from anywhere in the world, at any time (24/7).

You can 'meet' other carers and discuss your worries, fears and share ideas. Or, if you're not ready to speak to others directly, you can simply read about others' experiences.

thebraintumourcharity.org/facebook-support-groups

There's also our Information and Support Line that you can call for free: 0808 800 0004 or email **support@thebraintumourcharity.org**

You may be surprised who ends up forming your support network.

Be aware of depression

Depression is very different to general unhappiness, low mood or 'feeling down'. If you're experiencing depression, you may feel that:

- Your everyday activities are a real struggle
- You've very little or no motivation
- You're unable to feel enjoyment or interest in the things you used to.

Many carers experience depression. If you think you're depressed, there are a variety of sources of support available to you.

Your GP will be able to discuss options with you, including counselling, talking therapies, mindfulness courses, medication, self-help and organisations that specialise in supporting those experiencing depression.

Use the network of people you've developed for emotional support. Some people have also found writing all their thoughts and feelings down has helped them.

For more information, see our Depression and brain tumours webpage and fact sheet: **thebraintumourcharity.org/depression**

Resources for carers

As well as turning to your own network of friends and family for support, make use of organisations that provide emotional and practical support.

Disclaimer: The Brain Tumour Charity provides the details of other organisations for information only. Inclusion in this fact sheet does not constitute a recommendation or endorsement.

'Looking after me' course

This is a free course for carers of those living with a long-term health condition. The course runs for around 6 weeks and is led by tutors who have experience of caring for a friend or relative. It covers topics including relaxation, healthy eating and communicating with healthcare professionals.

For more information, contact self management uk: 0800 988 5560 or, from a mobile, 0333 344 5840 hello@self-managementuk.org selfmanagementuk.org/support-for-carers

Many local councils and NHS Trusts also run these courses.

Taking a break at home

There are organisations that can provide you with a short break by coming to look after the person you care for while you take a break. These include:

Crossroads Care scheme:

Services local to you can be found on the Carers Trust website. **carers.org/our-work-locally** or email **info@carers.org** (Charges may apply.)

Agencies found in the Yellow Pages/yell.com

under 'Home Care Services' or 'Nurses' Agencies and Care Agencies'. There will be a charge for these services.

Short breaks

Paul's Place

Offers free bed and breakfast or self-catering breaks on the Devon coast for:

- young adults who are a long-term, unpaid carer of a close relative
- parents or siblings caring for a young adults with a terminal or life-threatening illness
- adults of any age who have a life-threatening brain tumour plus their carers.

You need to be referred for a grant from Paul's Fund by a qualified professional, e.g. healthcare professional, social worker, counsellor.

pauls-fund.co.uk/pauls-place/

The following charities/funds may be able to help you, but you'll need to check their eligibility criteria.

The Margaret Champney Rest and Holiday Fund

This fund is part of Ogilvie Charities that gives grants to support respite holidays for carers.

ogilviecharities.org.uk/funding-for-holidays-forcarers/

Family Fund

A charity that provides grants towards the cost of holidays for families on a low income and who look after a severely disabled or seriously ill child aged 17 or under. familyfund.org.uk/

Family Holiday Association

A charity providing breaks or grants towards the cost of a holiday away from home for low income families, who are dealing with sever or sudden illness, disability or bereavement. You need to be referred by your social worker, GP, health visitor, school, a charity or other welfare organisation.

familyholidayassociation.org.uk/

Finance

The Brain Tumour Charity, in partnership with Rushmoor Citizens Advice

We have a **free** weekly telephone Benefits Clinic every Tuesday with appointments from 9.30am to 4.00pm. It's available to anyone living in the UK.

You can book an appointment online thebraintumourcharity.org/benefits-clinic/ Or contact our Information and Support Line: support@thebraintumourcharity.org or 0808 800 0004.

Carers Trust

It offers grants of up to £300 for items or activities that will help carers, e.g. breaks, items for the home, courses, home repairs, short-term replacement care. carers.org/article/grants-available-carers-trust

carers.org/article/grants-available-carers

Turn2us

An independent charity that can help you find sources of financial support based on your needs and circumstances.

turn2us.org.uk/

Carers' assessments

For carers in England:

Changes in the carers' assessment came into effect in April 2015.

carersuk.org/files/section/4630/factsheet-e1029-assessments-and-the-care-act-after-april-2015.pdf

For carers in Wales:

carersuk.org/images/Factsheets/ Factsheet_W1020__Assessments_guide_to_getting_help.pdf

For carers in Scotland:

carersuk.org/images/Factsheets/ Factsheet_S1020__Assessments_-_guide_to_getting_help.pdf

For carers in Northern Ireland:

carersuk.org/images/Factsheets/ Factsheet_NI1020__Assessments_-_guide_to_getting_help.pdf

Healthy eating on a budget

Information from NHS Choices:

nhs.uk/live-well/eat-well/20-tips-to-eat-well-forless/

Day care for adults

If the person you're caring for is well enough to attend, you could find out about local lunch/social clubs.

These provide them with an opportunity to meet new people and also time for you to have a short break. Contact your local council or voluntary services for information.

Your local hospice may also run similar groups. This can help you feel more at ease and relaxed knowing your loved one is safe with people around to support them if needed.

Other organisations

Citizens Advice

As a carer, you may be entitled to various forms of financial support. Contact your local Citizens Advice and ask to speak to a Benefits Advisor for more information. citizensadvice.org.uk/

Carers UK

Carers UK is an organisation led by carers for carers. They offer a wealth of support and information to carers. **carersuk.org** or **020 7378 4999** Helpline: Mon & Tue 10am-4pm **0808 808 7777**

Carers Trust

Carers Trust, formed by the merger of The Princess Royal Trust for Carers and Crossroads Care, provides access to breaks, information and advice, education, training and employment opportunities.

carers.org or 0300 772 9600

Young Carers

Young Carers, part of Carers Trust, is a website and online support service for young people aged 18 and under, who look after someone in their family who has an illness. Young carers can chat to others in a similar position, share stories and hear each others' experiences in a safe environment.

info@carers.org carers.org/about-us/about-young-carers/

Macmillan

Macmillan can refer you to trained Macmillan counsellors. **macmillan.org.uk** or **0808 808 0000**

The Brain Charity

The Brain Charity offers emotional support, practical help and social activities to anyone with a neurological condition and to their family, friends and carers. **thebraincharity.org.uk** or **0800 008 6417**

When your caring role stops

Your caring role can stop for various reasons – it could be because your loved one has recovered and no longer needs care, or it could be because they can no longer be cared for at home, or because they have died.

Whatever your situation, you may feel quite lost when your caring role stops, and it can be quite difficult and take some time to adjust to.

It might be that you suddenly have lots of time to fill and don't know how to do it. Or it could be that you suddenly find that everything catches up with you, and you feel physically and emotionally exhausted for a while.

If you're grieving, you'll have all the emotions that this brings, along with all the practical matters that need to be dealt with.

There's good information about these practical issues via the following link: carersuk.org/help-and-advice/ practical-support/when-caring-ends/bereavement

Grief doesn't always come straight away - you may not grieve until after you've sorted out all the practical things. Listen to your own feelings and do what's best for you - there's no right or wrong way. Use your support network to help you - let them know what you need. You've spent a lot of time looking after someone else, now let people look after you.

Talking about your loved one and sharing memories of them is one of the most helpful things you can do. It can also help you come to terms with their death. Local hospices often have support groups, memorial events and bereavement courses.

Look after yourself - eat properly and get enough rest (even if you can't sleep). Try not to turn to alcohol or drugs - the relief will only be temporary or may make you feel worse.

Try not to keep your feelings and emotions bottled up talk to someone or write them down. And don't feel guilty about feeling relief - this is a very natural feeling.

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"For so long, it's like I've been living in a dark tunnel that gets narrower, but now I've reached the light at the end, I feel completely blinded by it."

> Supporting Carers: An action guide for GPs and their teams 2nd ed; Royal College of General Practitioners, no date

There are many organisations who can help with grieving and bereavement.

For example, Cruse Bereavement Care: **cruse.org.uk** or **0844 477 9400**; or your local hospice may provide bereavement support.

Your GP is also an important source of support, particularly if your grief seems overwhelming. They can also put you in touch with a bereavement counsellor, if necessary.

When you're ready, you may need support to rebuild a life of your own and reconnect with education, work or a social life. Again make the most of your support network, family and friends and do it in your own time.



Notes	



About this information resource

The Brain Tumour Charity is proud to have been certified as a provider of high quality health and social care information by The Information Standard - an NHS standard that allows the public to identify reliable and trustworthy sources of information.

Written and edited by our Information and Support Team, the accuracy of medical information in this resource has been verified by leading health professionals specialising in neuro-oncology. Our information resources have been produced with the assistance of patient and carer representatives and up-to-date, reliable sources of evidence.

We hope that this information will complement the medical advice you've already been given. Please do continue to talk to your healthcare team if you're worried about any medical issues. If you'd like a list of references for any of our information resources, or would like more information about how we produce them, please contact us.

We welcome your comments on this information resource, so we can improve. Please give us your feedback via our Information and Support Team on 0808 800 0004 or **support@thebraintumourcharity.org**

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THE BRAN TUM UR CHARITY

About The Brain Tumour Charity

Going further for a cure

As the UK's leading brain tumour charity, we're here to accelerate a positive change in how people affected by brain tumours are diagnosed, supported and cured.

At The Brain Tumour Charity, we believe that no-one should have to live with a brain tumour or lose a loved one to a brain tumour. Advances in both treatments and quality of life care need to be made – and they need to be made quickly.

We know that if we put our heads together, we're more than up to the challenge. So we're building a movement of people from every walk of life – all coming together to accelerate a cure.

Find out more and get involved: thebraintumourcharity.org













thebraintumourcharity.org

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