

Carers - looking after yourself

If you give unpaid support to a member of your family or to a friend, who could not manage without your help, you are a carer.

Caring can have a huge effect on you and your life.

It is often forgotten that you can only care well if you care for yourself.

Of course, each carer's experience is unique to their own circumstances. This fact sheet contains some practical suggestions that have been shared with us by carers, which they have found helpful and may be of use to you.

In this fact sheet:

- Who is a carer?
- What can carers do to look after themselves?
- Breaks in caring
- Practical and financial support
- Emotional support
- Resources for carers
- Post-caring

Who is a carer?

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

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

However, if you are involved in looking after someone with a brain tumour, you are classed as a carer and all carers share some basic needs. One of these is the need to make sure you look after yourself.

What can carers do to look after themselves?

Carers say the following things 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, through weekly breaks of a few hours, to a short weekend break or respite breaks/holidays of one or more weeks. Or it could be a combination of these - whatever works best for you.

Daily breaks - make time for yourself

Many carers feel guilty if they take time out for themselves, but you are important too, and need to be cared for as well. It is 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 more effective.

Do something you enjoy that is not directly related to helping the person you are caring for. Physical activity e.g. gardening,

swimming or going for a brisk walk has been shown to be a great stress reliever.

Or 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.

Also allow yourself a treat from time to time without feeling guilty - going out for a meal, buying some 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 cannot be left alone, perhaps a friend or relative would be able to stay with them for a couple of hours. Or enquire with your local council about whether your loved one can attend a day centre. Alternatively you may have a local carer's centre that offers this service. *(Please see the Resources section later in this fact sheet.)*

Longer breaks

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 does not necessarily mean going away yourself. It could be that the person you are 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, whilst you get a well-earned break.

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.

Or your local council will have a social services department that can arrange for help - usually called 'respite care'. (You will need to have an assessment of needs and may have to pay for the respite care). *(Please see the Carer's assessment section later in this fact sheet.)*

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 on whom you can rely for practical support. Allow yourself to accept and even 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 to take some of the weight from you and also help them know what they can do during a time 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**, who can then provide support – emotionally and practically. You could ask for their help with some of the following tasks:
 - **Housework:** Ironing, cooking, vacuuming, cleaning
 - **Shopping:** You could also consider doing this online
 - **Gardening:** Mowing the lawn, tidying the garden
 - **Helping with the children:** School drop offs/pick ups, lifts to/from activities like swimming or other clubs etc.
 - **Other:** Walking the dog, washing the car, giving lifts to and from hospital.
- **Your GP**, who will be able to take in to account your circumstances and may also be more flexible with appointment times.
- **The Adult or Children's Services (Social Services) departments of your local authority**, who can give you a carer's assessment to ascertain the practical and financial support available to you. *(Please see the Carer's assessment section later in this fact sheet.)*
- **Local carers' centre**, who are a source of information and advice for practical (and emotional) issues
- **Your employer**, who 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 that they can show their support.

Useful numbers

Make a list of useful numbers to contact, especially for out of hours. Also ask your loved one's health team beforehand when you need to ask for help i.e. what should cause you concern.

Look after your physical health

As a carer, you may not be getting enough sleep - either through the person you are 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 are 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 are 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.

If your loved one becomes violent

Some tumours can affect an individual's ability to control their behaviour and emotions. *(See Personality changes fact sheet.)*

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 is 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 health care team.

You may be referred to a psychologist or psychiatrist who can help you and your loved one 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 is the disease that is 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.

Carer's assessment

You are 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 Support & Info Line (support@thebraintumourcharity.org or 0808 800 0004), call your local carer's 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 that is available to you. This is an important part of looking after yourself and relieving your stress.

Your local authority, local carers' centre and local Citizens' Advice Bureau can help you with this. *(See our Financial support fact sheet for information about what you may be entitled to.)*

Continued overleaf >

Emotional health and support

What are the emotional effects of being a carer?

Being a carer is not 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 frequently causes anxiety, stress and feelings of isolation and loneliness.

Depending on your loved one's tumour and the symptoms they are experiencing, your caring role can be suddenly thrown upon you, before you have even 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. Either way, psychologically and emotionally, it can come as quite a shock.

Many carers also state that they are given little information at diagnosis about their loved one's condition. As a result, they feel in the dark, uncertain, and having to find information themselves. The Brain Tumour Charity produces a pack of information, which is particularly useful for people who are newly diagnosed. If you would like a copy, please contact Support & Info 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 with school/college and trying to keep in touch with your friends.

Your wider family might be able to help, but possibly only up to a point, or it could be that you do not have an extended family that 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 did not choose to become a carer, it just happened and the effects can be wide-ranging - anxiety, frustration, isolation, your own ill-health, depression and financial difficulties.

Many carers struggle alone. The person you would normally turn to for help may be the person who has the brain tumour - and they are 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.

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

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

Additionally, 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 progressively with the amount of time devoted to caring each week.

So taking a bit of time to look after yourself is therefore invaluable - for yourself and, ultimately, your loved one. Do not feel guilty about it.

How do I deal with the emotional effects?

Acknowledge your feelings

You are probably going through a wealth of emotions whilst caring for your loved one - anxiety, anger, frustration, fear. Carers often say they feel helpless or even hollow. 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 are 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 are caring for does not appreciate what you are doing for them
- you have had to give up a career/future employment prospects and pension rights
- you have 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 are not alone in feeling this way.

If you can, talk to the person you are 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 is not possible to speak to the person you are caring for. For example, if you are 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 is 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 below)

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 are dealing with their own emotions about the illness of someone who is also *their* friend or loved one, or because they find it difficult to know what to say.

Carers have suggested the following ways of making new friends:

- find out if you have a local carers' centre - they often have social events
<http://www.carers.org/carers-services/find-your-local-service>
- Twitter - you can join conversations and talk about anything you like
- a local faith based group or community
- online discussion forums/Facebook groups.

The Brain Tumour Charity has an active Facebook support group that you can access anywhere in the world, where you can 'meet' other carers (and brain tumour patients) and discuss your worries, fears and share ideas. Or, if you are not ready to speak to others directly, you can simply read about the experiences of others.

<https://www.facebook.com/groups/114009085471466/>

We also have telephone support groups, where you can talk with others and ask some of the questions that you may feel unable to ask of your healthcare professionals, or that they may not be able, or have time, to answer.

There is also our Support & Info Line that you can call for free: 0808 800 0004 or email support@thebraintumourcharity.org

You may be surprised at 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 are experiencing depression, you may feel that:

- your everyday activities are a real struggle
- you have very little or no motivation
- you are unable to feel enjoyment or interest in the things you used to.

Many carers experience depression. If you think that you are 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 have developed for emotional support. Some people have also found writing all their thoughts and feelings down have helped them.

Resources for carers

As well as turning to your own social 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 six weeks and is led by tutors who have experience in caring for a friend or relative. It covers topics including relaxation, healthy eating and communicating with health professionals.

- For more info, contact **self management uk**:
<http://selfmanagementuk.org/our-courses/03333445840>
- Many local councils 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:** <http://www.carers.org/what-crossroads-care-scheme> / 0844 800 4361
Charges for their services may apply.
- **Agencies found in the Yellow Pages** under 'Nurses and nursing agencies'. *There will be a charge for these services.*

Short breaks

- **Paul's Place:** <http://www.pauls-fund.co.uk/pauls-place/>
Offers free bed & 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; or 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. medical staff, social worker, counsellor.

Benevolent funds and charities

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

- **Saga Respite for Carers Trust** - provides a limited number of free holidays each year for carers aged 50+ and a friend.
<http://www.saga.co.uk/saga-charitable-foundation/saga-respite-for-carers-trust.aspx>
- **The Margaret Champney Rest and Holiday Fund** - fund from the Ogilvie Charities that gives grants to support respite holidays for carers.
<http://www.ogilviecharities.org.uk/Grants/Rest-and-holiday-fund/Funding-for-Holidays-for-Carers.html>
- **The Kiloran Trust** - charity providing breaks in London for all carers.
<http://www.kilorantrust.org.uk/>

- **Family Fund** - charity that provides grants towards the cost of holidays for families on a low income who look after a severely disabled or seriously ill child aged 17 or under <http://www.familyfund.org.uk/>
- **Family Holiday Association** - charity providing breaks or grants towards the cost of a holiday away from home for low income families. You need to be referred by your social worker, GP, health visitor, a charity or other welfare agent. <http://www.familyholidayassociation.org.uk/>
- **Turn2us** - independent charity, can help you find sources of financial support based on your needs and circumstances. <http://www.turn2us.org.uk/>

Carers' assessments

- For carers in England, changes in the carers' assessment came into effect in April 2015. <http://www.carersuk.org/files/section/4630/factsheet-e1029--assessments-and-the-care-act-after-april-2015.pdf>
- For carers in Wales: https://www.carersuk.org/images/Factsheets/Factsheet_W1020_Assessments_-_guide_to_getting_help.pdf
- For carers in Scotland: https://www.carersuk.org/images/Factsheets/Factsheet_S1020_Assessments_-_guide_to_getting_help.pdf
- For carers in Northern Ireland: https://www.carersuk.org/images/Factsheets/Factsheet_NI1020_Assessments_-_guide_to_getting_help.pdf

Healthy eating on a budget

- Information from NHS Choices: <http://www.nhs.uk/Livewell/eat4cheap/Pages/cheap-food-shopping.aspx>
- Information from the British Nutrition Foundation: <http://www.nutrition.org.uk/healthyliving/healthyeating/budget?start=1>

Day care for adults

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

Other organisations

- **Citizens' Advice Bureaux (CAB)**
As a carer, you may be entitled to various forms of financial support. Contact your local CAB and ask to speak to a Macmillan Benefits Advisor for more information.
- **Carers UK**
Carers UK is an organisation led by carers for carers. They offer a wealth of support and information to carers. www.carersuk.org / 020 7378 4999 / 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. www.carers.org / 0844 800 4361
- **Macmillan**
Macmillan can refer you to trained Macmillan counsellors. www.macmillan.org.uk 0808 808 0000
- **Neurosupport**
Neurosupport offers practical and emotional support to people with neurological conditions and to their family, friends and carers. www.neurosupport.org.uk/ 0151 298 2999
- **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. www.youngcarers.net / 0844-800 4361

Post-caring

"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*

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 it can take some time to adjust.

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 are grieving, you will have all the emotions that this brings, along with all the practical matters that need to be dealt with. (There is good information about these practical issues via the following link. <http://www.carersuk.org/help-and-advice/practical-support/when-caring-ends/bereavement>)

Grief does not always come straight away - you may not grieve until after you have sorted out all the practical things. Listen to your own feelings and do what is best for you - there is no right or wrong way. Use your support network to help you - let them know what you need. You have spent much 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.

There are many organisations who can help with grieving and bereavement. For example, Cruse Bereavement Care <http://www.cruse.org.uk> / 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 are 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.

What if I have further questions?

If you require further information, any clarification of information, or wish to discuss any concerns, please contact our Support and Information Team:

Call: 0808 800 0004

(free from landlines and most mobiles:
3, O2, Orange, T-mobile, EE, Virgin and Vodafone)

Email: support@thebraintumourcharity.org

Join our closed Facebook group:
[bit.ly/supportonfacebook](https://www.facebook.com/groups/supportonfacebook)

About us

The Brain Tumour Charity makes every effort to ensure that we provide accurate, up-to-date and unbiased facts about brain tumours.

We hope that these will add to the medical advice you have already been given. Please do continue to talk to your health team if you are worried about any medical issues.

The Brain Tumour Charity is at the forefront of the fight to defeat brain tumours and is the only national charity making a difference every day to the lives of people with a brain tumour and their families.

We fund pioneering research to increase survival, raise awareness of the symptoms and effects of brain tumours and provide support for everyone affected to improve quality of life.

We rely 100% on charitable donations to fund our vital work. If you would like to make a donation, or want to find out about other ways to support us including fundraising, leaving a gift in your will or giving in memory, please visit us at thebraintumourcharity.org, call us on **01252 749043** or email fundraising@thebraintumourcharity.org

About this fact sheet

This fact sheet has been written and edited by The Brain Tumour Charity's Support and Information Team.

The accuracy of medical information has been verified by leading health professionals specialising in neuropsychology and professionals working with carers.

Our fact sheets have been produced with the assistance of patient and carer representatives and up-to-date, reliable sources of evidence.

If you would like a list of references for any of the fact sheets, or would like more information about how we produce them, please contact us.



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Your notes

Saving lives through research, information, awareness & policy



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